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Towards A Life Well-Lived With Spinal Cord Injury

A resource for affected individuals, carers, and health professionals

Professor Michelle McLean (Editor-in-Chief), Ms Elmarie Stander, Assistant Professor Jaclyn Szkwara, Associate Professor Allan Stirling, Dr Priya Iyer, Associate Professor Tanisha Jowsey, Dr Thomas Titus and Dr Dinesh Palipana

Cover by Emmy Peterson

Towards a life well-lived with spinal cord injury

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A resource for affected individuals, carers and health professionals

MICHELLE MCLEAN; ELMARIE STANDER; JACLYN SZKWARA; ALLAN STIRLING; PRIYA IYER; TANISHA JOWSEY; THOMAS TITUS; AND DINESH PALIPANA

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We thank them for sharing their cultures, spiritualities and ways of living with the land and wildlife in this place we now call home.

We pay respect to Elders past, present and emerging.

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In addition, while many individuals with lived and/or professional experience in terms of health and well-being have provided the best available evidence, the information, guidance and recommendations are of a general nature and will not apply to everyone. It is advisable to seek specialist advice, depending on your specific needs.

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About the Contributing Editorial Team

The Contributing Editorial team comprises the following Bond University academics in the Medical Program: Professor Michelle McLean (Editor-in-Chief), Ms Elmarie Stander, Assistant Professor Jaclyn Szkwara, Associate Professor Allan Stirling, Associate Professor Tanisha Jowsey, Dr Thomas Titus (Nephrology, Gold Coast University Hospital) and Dr Dinesh Palipana (Emergency Department, Gold Coast University Hospital). The final member of the editorial team is Dr Priya Iyer, a dietitian and nutritionist at The University of Sydney.

The editorial team members have also contributed to and/or reviewed chapters in this resource.

Details of the Contributing Editorial Team, other contributors and reviewers can be found at the back of this resource.

Acknowledgements

The Contributing Editors would like to thank everyone who has made this resource possible. Including the contributing editors, other chapter contributors and reviewers, about 60 individuals provided personal and professional stories, often lived and living experiences of spinal cord injury, as well as evidence-based content and/or expert feedback to create the 18 chapters of *Towards a Life Well-lived with Spinal Cord Injury: A resource for those affected, their carers and health professionals.* The resource came about through following conversations with Dr Dinesh Palipana and Dr Thomas Titus, who wanted to have 'something' useful for everyone affected by spinal cord injury, either directly (the person with the injury) or indirectly (carers, family and health professionals). We hope that the resource will be useful to the wider health community, as well as health professions educators and students.

We thank Bond University and CAUL for accepting our proposal for this resource. We would also like to acknowledge the support of the Bond Library throughout the development of this resource, particularly Antoinette Cass, Emmy Peterson and Bronwyn Linthwaite, for guiding us through the process of online publication, including accessibility, and ensuring we met copyright requirements.

As the Editor-in-Chief, I (Michelle McLean), I am extremely grateful for a supportive editorial team, particularly Elmarie Stander and Jaclyn Szkwara, who worked late into many nights and over weekends to ensure what we hope is a polished resource.

Foreword

Foreword from Dr Dinesh Palipana (OAM): Doctor, lawyer, disability advocate, researcher and son

There are no words to explain what it feels like to become paralysed with a spinal cord injury (SCI). That moment, the instant, when you realise that your life has changed forever. The thousand things that you think about in that moment, many of which you once took for granted. The fear for the future. The fear for the now. The fear of whether you will even stay alive.

In the twenty-first century, people with a SCI can live a near-normal lifespan, depending on where in the world they live and many other considerations. *Still, what is that life like?*

With a SCI, nearly every facet of life is affected. While physical paralysis is a foundation to unseen functions like the bladder and bowel, it also leads to broad socio-economic impacts, affecting employment, relationships, housing and community integration. Even the ability to thermoregulate is lost, which brings about thoughts on how the natural environment affects someone with a SCI.

Good health and well-being are the product of all of these things coming together in the whole person. That is why although the paralysis is simple in its cause, the damaged spinal cord, the impacts are complex. And, so, while people can now exist with a SCI for a long time, whether they can truly live well depends on many things. As humanity, we are not yet masters of all of those things.

This resource is an attempt to bring the science and the lived and living experiences of individuals together to inform the best care for people with sSCI, putting the person at the centre. We should not forget, however, that for a person with a SCI to live a life well-lived takes a 'community'. Besides their own motivation and resilience, a life well lived depends on the support of many, including family, friends, health professionals, employers, peers, government, the wider community and the researchers whose innovations offer hope. This resource, *Towards a Life Well-lived with Spinal Cord Injury,* is a product of passionate people from all walks of life uniting with the hope that in their combined efforts, we can continue to create a better future for people living with SCI.

Introduction: Towards a Life Well-Lived with Spinal Cord Injury

Contributors: Michelle McLean and Thomas Titus

Reviewer: Elmarie Stander

Editors: Michelle McLean and Elmarie Stander

> *"I wish for a world that views disability, mental or physical, not as a hindrance, but as unique attributes that can be seen as powerful assets if given the right opportunities."* **Oliver Sacks**, physician, best-selling author and professor of neurology (1933-2015)

Spinal cord injuries (SCIs) are more common than one might expect. Globally, over 15 million people live with SCI (World Health Organisation, 2024a). In 2024, Lu and colleagues analysed pooled results from 229 studies between 2000 and 2021 and found that globally about 24 people in every million experience SCI each year. Of those, 26 per million were injuries caused by accidents or physical trauma, referred to as ***traumatic spinal cord injuries (TSCIs),*** and about 18 per million SCIs were ***non-traumatic spinal cord injuries (NTSCIs)***, caused by disease or degeneration. The incidence of TSCI was found to increase with age, with men 3.2 times more likely to sustain a TSCI. While the incidence of TSCI has remained consistently high, NTSCI incidence has been increasing steadily since 2007, but was stable in 2021 (Lu *et al.*, 2024).

In Australia, a 2020 Spinal Cord Injury Australia report commissioned by Spinal Cure Australia and icare (prepared by AlphaBeta Australia) indicated that approximately 20,800 Australians were living with SCI, with an expected increase of 380 new incidents that year. The most common cause of the SCIs was sudden, traumatic impact to the spine, largely from falls, road accidents and sports-related injuries. Eighty-one % of TSCIs occurred in people under 65, with 23% being under 35. For the over-65 demographic, non-traumatic causes, such as tumours and degenerative disorders, were responsible for the SCIs. About one-third (approximately 7,000) of all SCIs in Australia were classified as severe, leading to debilitating consequences such as chronic pain, respiratory failure and bladder and bowel dysfunction. Mental health impacts were also considerable, with up to 40% of affected individuals likely to experience ***post-traumatic stress disorder (PTSD)*** and about 30% likely to experience depression (Spinal Cure Australia, icare, 2020).

Additional Australia statistics are available from the Australian Institute of Health and Welfare (AIHW, 2021) website. For the 2017-18 period, there were 187 newly reported cases of TSCI due to external causes in the Australian Spinal Cord Injury Register. Eighty 80% were males, with land transport crashes (46%) and falls (36%) the most often reported causes.

Why the need for this resource

Currently, the focus of healthcare in relation to SCIs is understandably the acute (hospital) phase, which is the phase immediately following the 'event' that led to the injury. This phase is then followed by transitional rehabilitation, and, after weeks, months or perhaps a year in the healthcare system, the person can eventually 'go home' (**Figure 1**).

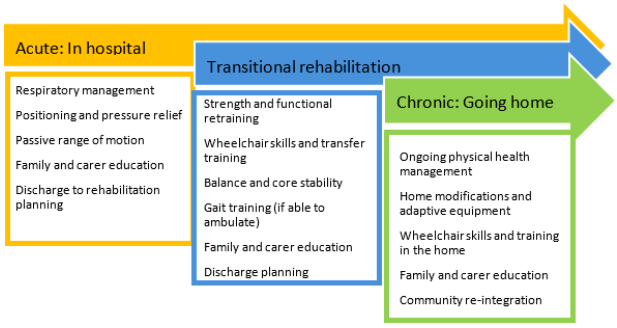


Figure 1. The three phases following SCI: Acute, transitional rehabilitation and chronic. Created by Jaclyn Szkwara using Canva.

While in the hospital and transitional rehabilitation, much is done for the person. This is appropriate as their recovery is paramount. It is, however, the 'going home' phase, either to one's own home or the family home or perhaps into *specialist disability accommodation (SDA)*, that has been neglected in terms of research and resources. Moving into one's home or the family home generally requires structural modifications to ensure accessibility. Daily living requirements are likely to differ for each individual, depending on what they can do physically upon returning home. Returning home to rural, regional or remote Australia would bring additional challenges for ongoing care. This resource therefore focuses on the 'coming home' phase and what life might be like in Australia in this new chapter in life as one reintegrates into the community.

A SCI, however, brings a range of complex physical, physiological, emotional and psychological challenges. There is a simplistic belief that disruption of nervous system control following SCI is a matter of adjusting to the loss of motor control and absent sensation. The reality is anything but simple. While the loss of sensation and motor control as a result of nervous system damage is by far the most important aspect of SCI, there are additional impacts on most of the body's organ systems, but particularly the cardiovascular, respiratory, gastrointestinal and urinary systems, as well as on psychological well-being. For individuals with high-level injuries, an *autonomic nervous system (ANS)* that is *dysreflexic* will affect blood pressure control, bowel and bladder sphincter control and sexual function. For those with the highest levels of injury, there may be loss of temperature regulation and a need to be ventilated.

Navigating these bodily changes requires ongoing education, support and access to reliable, up-to-date information. As contributing editors, we hope that this resource provides a comprehensive platform offering practical guidance, lifestyle advice, coping mechanisms and community connections in one place for individuals who now live with SCI, as well as their carers, families and teams of health professionals who accompany them on their various life journeys following SCI. We also hope that health professions educators will recommend the resource to their students to ensure that the next generation of health professionals is well-informed and empathetic in supporting individuals with SCI and their 'significant others'.

The idea of this resource, ***Towards a life well-lived with spinal cord injury: A resource for affected individuals, their carers and health professionals***, emerged following an online meeting in January 2025 between **Dr Thomas Titus** (Nephrologist, Gold Coast University Hospital, GCUH), **Dr Dinesh Palipana (OAM)** (Emergency Department, GCUH), **Professor Michelle McLean** (Medical Educator, Bond University), **Assistant Professor Jacob Thorstensen** (Physiologist, Bond University) and **Associate Professor Allan Stirling** (Surgeon and Anatomist, Bond University). Below **Dinesh**, who has lived with quadriplegia since 2010, offered the following input, which provided us with a rationale for this resource:

"I think it's really about giving people the tools to manage some of the acute complications and also making sure that they can maintain health in the long-term without getting to that point of a complication. So, I wonder if it should be a toolkit, something that the patient can give to their healthcare providers? Or is it something that the healthcare provider, whether it be a GP or an emergency department doctor or a physiotherapist, can access online?

I think the other aspect is that often the patient with the spinal cord injury will know what complications happen to them or at least have a general idea, but when they go to a hospital or to a GP the person with the SCI might not know how to express things. I think the credibility given to them [by health professionals] is quite low. So having this toolkit might give them the ability to point out "Actually, this is what's happening and this is being written by a university and doctors" *or however we frame it. It also also probably empower them to speak for themselves.*

Those are just some thoughts that I have about the problem that we're trying to address. There isn't much evidence behind what we [the healthcare sector] are doing [in terms of managing those with SCI]. I don't think we [health professionals] understand what the best practice might be or what the best evidence might be with regard to some of these things. I don't think we [doctors] really know.

The other issue that I come across and I can probably illustrate it with an example. So yesterday I was talking to a person with a spinal cord injury and he keeps getting autonomic dysreflexia because he has haemorrhoids, which could potentially become life-threatening at some point and he's bleeding every day. He has had heaps of problems with this, but he has a referral to the public system because most of these patients don't have the financial capacity to access private care. But he has been downgraded from Category 1 to Category 2 now. I think it's because whoever is looking at these referrals may not understand that actually for a person with paralysis, this is a huge problem. So, how do we empower GPs to better advocate when there is a problem like that and needs to be referred so a patient can be seen and cared for promptly?

There is another one as well to think about and probably even going back to the basics like we were taught in medical school and even in specialist training to take a history and ask "Where is the pain? Where is it moving to? How is your bowel function?"

Intended audience

This resource includes important information, first and foremost, for individuals living with SCI who are 'going home' either from the hospital or rehabilitation. While the resource focuses on the chronic phase after injury (**Figure 1**), returning home as soon as possible is critical, which, as we will see later, is supported by **Perry Cross (AM)**, who has lived with quadriplegia with ventilation following a *traumatic spinal cord injury (TSCI)* during a rugby match when he was 19. Remaining in hospital too long can lead to feeling like 'part of the hospital furniture'. In Perry's view, the clinical team should discharge a person with SCI as soon as it is feasible. This means, however, that planning for the next stage of one's journey after discharge needs to start early in the rehabilitation process, with funding and appropriate accommodation priorities. Importantly, **Chapter 1** provides information on Specialist Disability Accommodation (SDA) through the National Disability Insurance Scheme (NDIS) and other funding sources, such as My Aged Care.

This resource will also assist those who may not fully understand the implications of their SCI and how their body responds to the anatomical and physiological changes, which depend on the level of injury and whether it is complete or incomplete (**Chapter 2**). It is likely that during the period immediately following the initial injury, the individual with the SCI and their family would have been inundated with information about what had happened and what they should or should not do. For some, the delivered information may also have been too technical to be practical, with lots of medical jargon. **Chapter 2** will explain the repercussions of the level and completeness of the injury on the body's various physiological processes.

Under the current model of care in Australia, once someone with SCI is discharged home into community life, a **General Practitioner (GP)** becomes their primary healthcare provider responsible for overseeing their health and well-being as part of a multidisciplinary healthcare team. Finding an appropriate GP is discussed in **Chapter 1**, with further details about the GP's important role in **Chapters 3**, **5** and **6**.

This resource thus aims to provide information, resources, and recent research findings, as well as ***continuing professional development (CPD)*** activities for health professionals relating to various aspects of the health and well-being of individuals living with SCI after discharge into the community. Carers, family and friends, as well as health professionals and health professions educators, will hopefully find the resource helpful. We also believe that researchers, advocates and policy-and decision-makers will also find the resource useful for identifying systemic issues and understanding the special considerations required when working in this clinical space.

A range of health professionals, researchers and most importantly, individuals with ***lived and living experience (LLE)*** of SCI have contribted to this e-resource with one shared goal: *To provide practical guidance, evidence-based information and personal stories relating to SCI to empower affected individuals, carers, families, friends, health professionals and health professional educators and their students.* From understanding how the body functions after SCI to planning for independence, staying healthy and accessing community supports, this e-resource offers tools to assist with the journey towards a life well-lived. If you are living with SCI, we hope that this resource can empower you to live more independently (*or should it be interdependently?*) and confidently, while also providing carers, families and health professionals with resources to enhance emotional support and clinical care. As the resource is open source, it will be widely accessible, so that anyone transitioning home after SCI, including their carers, other family members and health professionals, has a range of resources on hand to support maintaining good health and well-being.

Lenses and frameworks used in this resource

Thorough engagement with affected individuals and their carers and various health professionals, as well as extensive research in the disability domain, specifically in relation to SCI in Australia and globally, this resource was written using several lenses and frameworks, which are described below:

- The power of storytelling involving ***lived and living experience (LLE).***
- A collaborative partnership involving embodiment, identity, voice, hand and heart.
- From disability to ableism for inclusion.
- A social lens: From disability (deficit) to functioning (strength) in the community.
- An eco-biopsychosocial approach to living well with SCI, and
- A strength-based lens of hope.

Storytelling involving lived and living experiences (LLEs)

This resource uses storytelling, which is a powerful tool in health communication. Stories can transform facts into meaningful, engaging narratives that can influence behaviour. The World Health Organization (2024b) wrote the following about the power of storytelling:

> *"In health communication, scientific evidence and data are often used to convey important information and advice about behaviours that impact health. However, facts alone may not be enough to engage and convince people. That is where the power of storytelling comes in, and why it is a core part of the Communication for Health (C4H) approach used in the World Health Organization (WHO) Western Pacific Region. Drawing upon insights from social, behavioural and communications sciences, C4H leverages the full power of communication, including storytelling, to achieve public health outcomes.*
>
> *Stories are at the heart of human existence and people are hardwired to respond to them. Stories provide meaning to facts and allow individuals to connect with the information being conveyed, both intellectually and emotionally. Evidence from neuroscience, psychology and behavioural science shows that storytelling has the power to change how people think and to influence their behaviour."*

This resource was thus intentionally developed in partnership with individuals with ***lived and living experience (LLE)*** of SCI, a term borrowed from the Royal Australian and New Zealand College of Psychiatrists (RANZCP) (2021, 2025). RANZCP uses the term ***lived and living experience (LLE)*** to describe experiences of individuals whose mental health challenges have led to such significant life changes that they must *"reimagine and redefine themselves, their place in the world, and their future plans."* These understandings are developed in partnership with affected individuals, their carers and other family members. In Pacific contexts, this partnership incorporates culturally grounded concepts such as *aiga* (in Samoan and other Pacific cultures, referring to extended family networks that emphasise collective care and responsibility) and *whānau* (in Māori culture, denoting extended family and kinship groups). Members of multidisciplinary teams also contribute to this collective, culturally informed understanding.

In this resource, we have extended the LLE concept to all aspects and experiences of an individual's life, including the physical, social and psychological. As individuals with LLE of SCI are often advocates, advisors and supporters across health and disability systems, their stories and insights can inform policy and guide service design through surveys, focus groups and representation on committees and consumer groups. Evidence consistently demonstrates that partnering with people with LLEs leads to more effective service delivery and better-informed planning for the SCI community (National Mental Health Commission (NMHC), 2018; RANZCP, 2021). These LLEs are also important in peer support or mentoring programs, such as those offered by Spinal Life Australia and Spinal Cord Injuries Australia (SCIA).

Collaborative partnership framework: Voice, hand, heart and embodiment

As contributing editors, we acknowledge that each person living with SCI is unique in terms of whether they sustained a *traumatic SCI (TSCI)* or a *non-traumatic SCI (NTSCI)*, their level of injury (thoracic, cervical, lumbar) and whether the SCI is complete or incomplete. This makes the anatomical, physiological and psychological impacts of the injury individualised. As individuals come to terms with how their injury has impacted their body's function, they are said to 'embody' these implications. *Embodiment* thus recognises that the body actively shapes thoughts, feelings and interactions with the world. Mind and body are inseparable. They work together to create meaning. This embodiment shapes a person's identity, both personally and professionally. The concept of embodiment is central to understanding LLEs and is reflected throughout this resource. The two short videos below provide some insight into the concept of embodiment.

Videos: Embodiment explained

- What is embodiment and why does it matter?
- What is embodiment?

We also acknowledge that affected individuals and their family, carers and friends are from all walks of life, with a range of education levels, different ages, genders, sexual orientations, faiths (including none) and cultural identities, amongst many other 'characteristics'. For some, SCI may have put the brakes on their career trajectories. We know, however, that once settled into life in the community, many people living with SCI go on to fulfil some, perhaps all of their goals, which may include returning to work, enrolling in further studies, getting married, becoming parents, getting involved in assisted sport and perhaps becoming advocates and peer mentors.

We have conceptualised our engagement with affected individuals and their 'significant others' as a collaborative partnership that includes recognising individual embodied identities, listening to their voices with heart and as allies (empathy) and documenting (hand) their LLEs so that others may learn from those who have gone before. We have attempted to capture these elements in **Figure 2**.

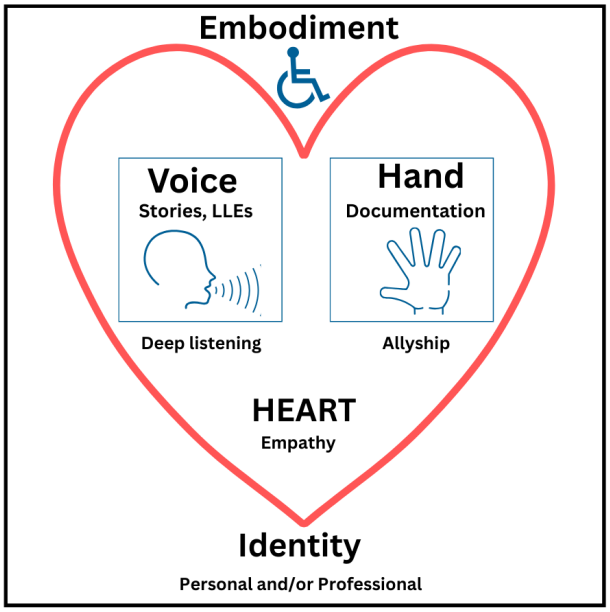


Figure 2. A collaboration partnership framework involving voice, hand and heart is used in this resource. Designed by Michelle McLean and created by Elmarie Stander using Canva, licensed under a CC BY-NC (Attribution NonCommercial).

In part, we drew on the work of Creamer and Lansbury (2022), whose original concept of the**voice** and the **hand** reflected interconnected elements in building successful research partnerships between Indigenous organisations and non-Indigenous allies. Thus:

- **Voice** refers to the stories told, the LLEs and perspectives shared by individuals and communities. It represents authentic narratives that carry embodied knowledge, identity and cultural meaning and value.
- **Hand** refers to the documentation and translation of these LLEs and stories into tangible outputs, such as resources, research reports and policies. As allies, the hand ensures that voices are not only heard but also acted upon and embedded in systems and practices.

We extended Creamer and Landsbury's (2022) framework by adding **heart***:*

- **Heart** symbolises empathy and meaning. It is not about tokenism or surface-level gestures but about genuine understanding, exploring the LLEs, listening actively and deeply as allies, respecting personal and cultural narratives and translating that understanding into meaningful action. Heart is gained through education and co-design, where empathy drives decisions and system change, ensuring inclusion is real and measurable rather than symbolic.

The hope is that the LLEs which individuals have willingly shared for this resource will provide others with context so that they can put themselves in their 'shoes'. For the most part, the information provided is practical and evidence-based, based on what is currently available in Australia and, in some instances, Aotearoa New Zealand and globally. Many chapters include links to and summaries of the best available evidence and research to guide decisions that support good health and well-being and a life well-lived in the community.

As with most aspects of maintaining good health and well-being, despite chronic illness or disability, prevention is key to a life well lived with SCI. This, of course, depends on a healthy diet, a strong support network and regular medical check-ups. For **Dr Priya Iyer**, who has contributed to several chapters in this resource, nutrition plays a crucial role in the ongoing health and well-being. SCIs often result in physiological and metabolic changes and decreased energy expenditure due to limited mobility and reduced metabolically active muscle mass. This increases the

risk of weight gain and cardio-metabolic diseases, making a balanced, high-fibre diet important.

In this resource, the LLEs have been gathered through engagement with individuals living with SCI, their carers or support workers and various health professionals, as contributors, reviewers or both. We are grateful for their shared stories:

- LLEs as individuals living with SCI include **Perry Cross, Dean Durman**, **Dr Dinesh Palipana** and **Adrienne Graham**.
- LLEs of 'significant others' were provided by **Teresa Blair**,**Jacqui Durman** and **Chithrani Palipana**.
- Support workers' LLEs were provided by **Emma Simpson**, **Dan Boardman** and pastoral care provider, **Reverend Canon Cheryl Selvage**, who also reviewed and contributed to **Chapter 14** with Adrienne Graham, and
- Chapter reviewers living with SCI include **Lindsay Nott, Dr Dinesh Palipana** and **Dr Jonathan Tang.**

Health professionals who provided input, often LLEs, included several occupational therapists, physiotherapists, exercise physiologists, GPs, surgeons, podiatrists, anatomists, physiologists, a nephrologist, a psychiatrist, an anaesthetist, a dietitian and a pharmacist, many of whom are also academics. Researchers engaged in SCI research, often responsible for clinical trials, have also provided a chapter on SCI research and innovation (**Chapter 16**). Two psychologists, a lawyer, a bioethicist and two human rights advocates with experience of working with individuals living with SCI (or disability in general) and in some instances, their families, have also shared their expertise as contributors and/or reviewers. The biographies for contributors and reviewers can be found at the end of the resource.

This resource also seeks to promote the Australian Spinal Cord Injury Register, to which all Australian spinal units contribute data. We hope that this resource serves as a clarion call for those affected by SCI, their families, friends and health professionals to strongly advocate for an SCI Clinical Registry to ensure longitudinal health information can be collected and research trials organised to inform future health decisions. A registry collects data on age (date of birth), sex/gender and remoteness area (RA), a geographic classification that indicates geographic accessibility. One of the foremost advocates for this Clinical Registry has been **Dr Jonathan Tang**, who returned to competitive sport four years after sustaining a SCI as an elite gymnast and also completed his GP training. In 2016, he stated that:

"The proposed registry would track patients throughout their lives, capturing individual treatment, complications and medicine provided. [A registry] will allow us to answer questions such as, if I had a kidney infection, what would be the best medication to use?"

When asked in December 2025 about the progress of this Registry, **Jonathan** indicated that:

> *"The Spinal Cord Injury Registry has unfortunately encountered funding issues, and I am currently not involved. Nevertheless, I believe it is a very important initiative, and I will continue to advocate for its development and support."*

From ableism to inclusion

In being the **hands** documenting the **voices** in this resource, we have tried to avoid being 'ableist'. We have focused on the strengths of being different. Through an ableist lens, being able is the 'normal' state and deviating from that is 'abnormal'. This is a deficit lens that leads to discrimination, exclusion, marginalisation, abuse and even violence.

In an article entitled *Disability bioethics and commitment to equality*, Guidry-Grims (2022) challenged the notion that disability (intellectual or physical) is viewed as a condition of weakness and neediness. For that author,

> *"When disability is viewed in this way as an inherently vulnerable state of being, the essential sociopolitical dimensions of disability receive inadequate attention, which, in turn, makes it impossible to identify injustices correctly."* (p. 209)

Ainslee Hooper, an anthropological disability inclusion consultant, with a LinkedIn forum, Making Inclusion Work, wrote in April 2025 that *"disability is not a dirty word"*, in response to the following comment someone made a few years ago: *"If we just stop using the word disability, we can get rid of the negative stereotypes."* Below is an extract from her blog, The problem with avoiding the word disability: Why changing the language won't change the exclusion:

> *"You can't address exclusion without naming it. And you can't address ableism if you're not even willing to say the word disability. Avoiding the word doesn't reduce stigma—it just makes it harder to see. It makes the work less clear, the goals less measurable, and the people most affected less visible.*
>
> *Disability isn't a bad word. It's a valid identity. It's a legal category that unlocks rights and protections. It's a key consideration in inclusive design, hiring, policy, and leadership.*
>
> *So when we erase it—intentionally or not—we risk erasing the people, too.*
>
> *If we can't name the group, we can't track outcomes. If we don't talk about disability openly, we won't build systems that work for disabled people. And if we keep replacing the word with euphemisms, we permit ourselves to stay vague when clarity is exactly what inclusion requires. Here are a few practical ways to start:*
>
> - *Use the word disability confidently and respectfully. You don't need to capitalise it or put it*

in quotes. Just say it plainly.

- *Audit your language. Look at your documents, strategies, job ads, and public statements. Is disability mentioned explicitly? Or is it lost in "diverse needs" language?*
- *Get comfortable being uncomfortable. Discomfort isn't a reason to step back—it's often a signal you're in the right place to learn.*
- *Ask, don't assume. Talk to people with disabilities about how they want to be represented. Involve them meaningfully in your inclusion efforts, and*
- *Stop waiting to "get it right" before taking action. Inclusion is an ongoing process, not a perfect outcome."*

A very public example of how an ableist system excludes disabled people is from our own backyard. Katz (2023), in *Australia, 'the most voter-friendly country in the world'?* Examining voting rights for people with physical disability highlights that although Australia is reputedly a jurisdiction with enviable voter enfranchisement and participation procedures, Federal and State and Territory electoral processes do not adequately cater for individuals with physical disabilities. Despite alternative voting structures, they are either too narrowly constructed, carry election-integrity risks or result in a voting experience lacking independence.

Media story: Voting a challenge in Australia if you have disability

The ABC's Voting with a disability can be a challenge, even in a country like Australia – ABC News reports on how individuals with disability can be excluded from exercising their democratic right, such as voting.

Article 29 of the Convention on the Rights of People with Disability (CRPD), to which Australia is a party, creates certain duties for States to ensure that people with disabilities are not discriminated against in their ability to be involved in voting and other areas of public life, saying, *inter alia*:

State Parties shall undertake:

> *"a) To ensure that persons with disabilities can effectively and fully participate in political and public life on an equal basis with others … including the right and opportunity for persons with disabilities to vote […] by:*
>
> *(i) Ensuring that voting procedures, facilities and materials are appropriate, accessible and easy to understand and use;*
>
> *(ii) Protecting the right of persons with disabilities to vote by secret ballot in elections and public referendums … [and] facilitating the use of assistive and new technologies where appropriate."*

Katz (2023) concluded that:

> *"Australia, despite its voter-friendly reputation, does not extend voting franchise to people with physical disabilities on an equal basis with others. Although there is growing awareness of the problem, and formal findings of breaches of Australia's CRPD obligations have been made, to date Australia has not taken action to amend this situation. Notwithstanding the country's undertaking to be bound both by the CRPD and its Optional Protocol, a lack of political will in Australia remains to amending systemic electoral shortcomings. By its ongoing inaction, Australia deprives an identifiable group of people the right to vote on the same terms as other Australians and compromises the right to secret and independent voting that sits at the cornerstone of Australian democracy."* (p. 220).

In Australia, **Chapter 11** explores the legal considerations relating to SCIs. Relevant Acts and Laws on the Australian Government's Anti-discrimination website, including:

- Disability Discrimination Act 1992, with links to the Disability Standards for Public Transport 2002, Disability (Access to Premises – Buildings) Standards 2010 and the Disability Standards for Education 2005, as well as the legislation in the various States and Territories and the Australian Human Rights Commission Act 1986.

A social lens: From disability (deficit) to functioning (strength) in the community

Perhaps one of the most noteworthy global advancements in terms of disability was the 2001 WHO's International Classification of Functioning, Disability and Health (ICF), which measures health and disability at the individual and population levels. The ICF uses a social lens, replacing the long-standing medical model. In the model, a person's ***functioning*** and disability are conceived as a dynamic interaction between health conditions and environmental and personal factors. Functioning and disability are both multi-dimensional concepts. Disability is the umbrella term for an impairment of body structure or function, a limitation in activities or a restriction in participation. The ICF website provides a clinical checklist and learning and education modules. **Figure 3**, redrawn from Slide 13 from an ICF learning module (WHO, 2001), depicts the interplay between functioning and disability in various domains.

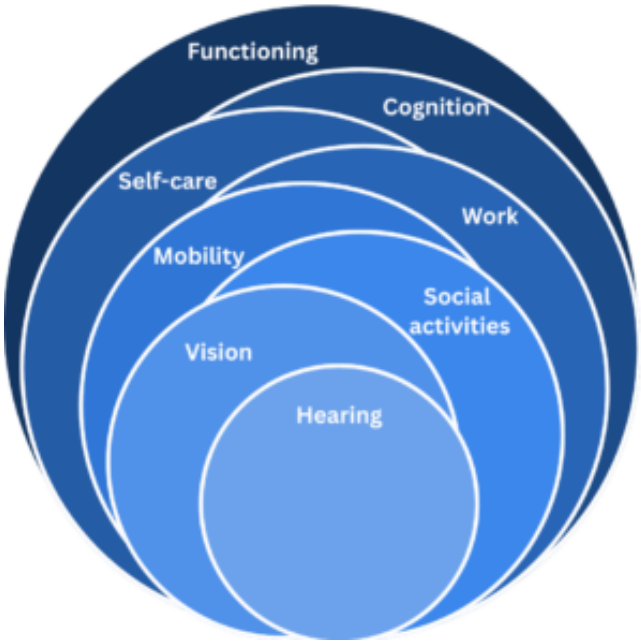


Figure 3. The multiple domains of the ICF's multi-dimensional model of functioning and disability, with the level of a person's functioning varying across domains, collectively reflect functioning. *Source:* WHO (2001), adapted by Elmarie Stander using Canva.

In 2002, the Australian Institute of Health and Welfare (AIHW) published a factsheet about the ICF model, with **Figure 4** (Figure 1, AIHW) reflecting the interactions between ICF components.

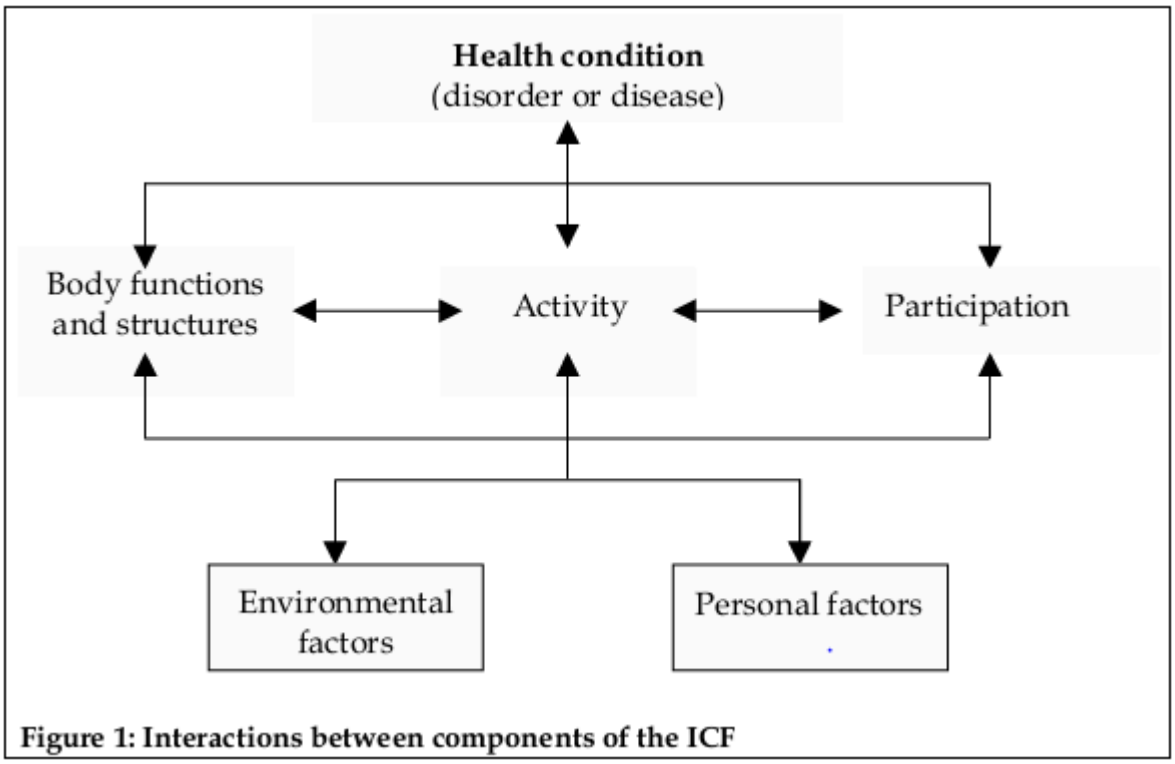


Figure 4. Interactions between the various components of the ICF model. *Source:* AIHW (2002), The International Classification of Functioning, Disability and Health (ICF), CC BY 4.0.

The AIWH factsheet also provided a table with examples of components and domains of the ICF Model, which has been recreated as **Table 1.**

Table 1. A social lens of the various body structures and functions, activities, participation and environmental factors contributing to functionality and disability. *Source:* AIHW (2002), The International Classification of Functioning, Disability and Health (ICF), CC BY 4.0

Component	Domains
Body function	• Specific mental function, such as memory function • Sensory functions and pain, including hearing, sensation of pain and smell
Body structure	• Components of the nervous system (spinal cord and related structures) • Structures involved in voice and speech (mouth structures)
Activities and participation	• Mobility, including getting around inside and outside the home • Self-care, such as showering and dressing • Major life areas, such as remunerated employment and studying • Community, social and civic life, including recreation and spirituality
Environmental (contextual) factors	• Products and technology for communication and mobility • Support and relationships, including family, friends and health professionals

Towards an eco-biopsychosocial approach to living with SCI

Drawing on the ICF's social model of functionality, which incorporates psychosocial aspects of living with a disability, Budd *et al.* (2022) explored these dimensions in Psychosocial Consequences of Spinal Cord Injury: A Narrative Review, to generate a biopsychosocial framework for SCI. Their review synthesises psychosocial outcomes and determinants across domains, such as stigma and ableism, relationships and family, finances and employment, living situation, community reintegration, mood and coping, self-harm and non-adherence, sexual health, ageing and post-traumatic growth, all of which provide foundational evidence for this framework.

Aligning with the ICF social model (functioning as the interaction of health conditions, activities and participation and environmental and personal factors), we extend Budd and colleagues' (2022) biopsychosocial model to an 'ideal' strength-based eco-biopsychosocial model to depict the ecological, biological and psychosocial factors that contribute to a life well lived with SCI, all of which are not possible without the appropriate political will in terms of laws, strategies and policies (**Figure 5**).

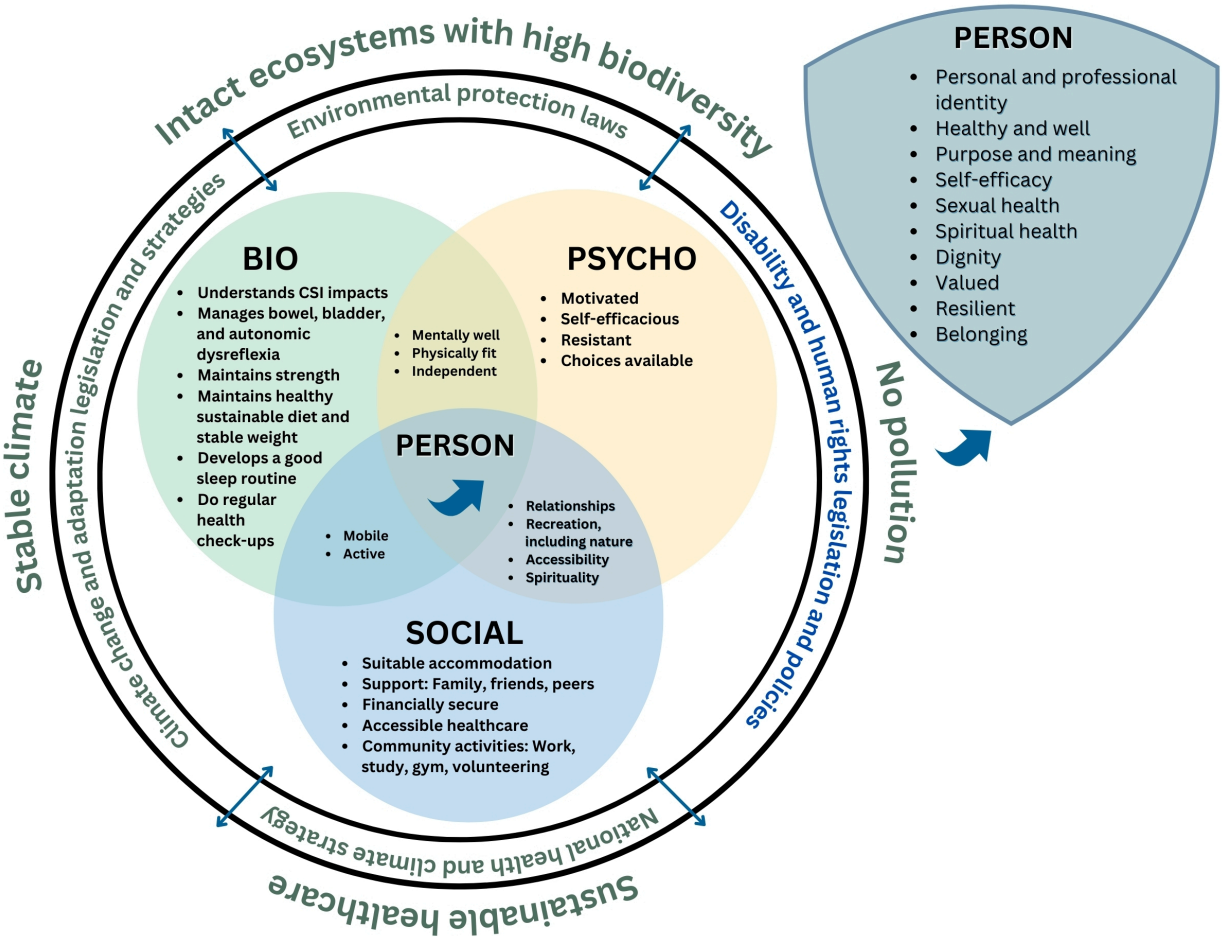


Figure 5. An eco-biopsychosocial model reflecting what is needed to live a life well-lived with SCI in Australia. Designed by Michelle McLean and created by Elmarie Stander using Canva, licensed under a CC BY-NC (Attribution NonCommercial).

This eco-biopsychosocial perspective presents an integrated conceptual framework that positions the person living with SCI at the centre of the intersection of *biological (bio)*, *psychological (psycho)* and *social* domains, depending on the *ecological (eco)* element – A healthy planet with a stable climate, biodiverse and intact ecosystems and no pollution. An ecologically sustainable healthcare system would contribute to a healthy planet (Stein *et al.*, 2024).

The eco-biopsychosocial model for a *life well-lived with SCI* addressed in this resource involves three levels (and the relevant chapters):

- ***Macro*-level (planet):** The *eco* is the overarching construct that addresses the importance of a stable climate, intact ecosystems and high biodiversity, a clean environment and an ecologically sustainable healthcare system. **Chapter 17** is the main chapter addressing the*ecological* element, with the legislation and strategies being the *meso*-level.
- ***Meso*-level (governments, organisations):** The next level represents broad categories of legislation, policies and strategies that ensure disability legislation and supports, such as the Disability Discrimination Act 1992, Disability Services and Inclusion Act 2023, the NDIS and the 2021-2031 Disability Strategy as well as a healthy planet, such as the Climate Change Act 2022, the 2023 National Health and Climate Strategy, which advocates for an environmentally sustainable healthcare system, the 2025 National Climate Resilience and Adaptation Strategy and the Vehicle Efficiency Emissions Standards Act 2024. The main chapters addressing legislation are **Chapters 10**, **11** and **17**.
- ***Micro*-level (individual):**
  - The *bio* relates to Anatomy and Physiology and to the clinical management and prevention of secondary conditions at an individual level, addressed in **Chapters 2**, **3**, **4**, **6**, **7**, **13**, **15**, **16** and **17**.
  - The *psycho* involves psychological well-being, including good spiritual and sexual health, self-efficacy, determination, motivation, resilience, informed choices and mental alertness, amongst others, in **Chapters 3**, **5**, **10** and **14**, and
  - The *social* includes support from family, friends, colleagues, and health professionals, as well as inclusion and collaboration (two-way arrows across three levels), protection from discrimination and financial support and healthcare access. Elements can be found in **Chapters 1**, **3**, **5**, **6**, **9**, **10**, **11**, **16**, **17** and **18**.

A strength-based lens of hope

Finally, this resource has been written with hope, in line with **Christopher Reeve's** words:

"Once you have chosen hope, anything's possible."

As already described above, we have used a *strength-based rather than a deficit lens*. While many living with SCI are confined to a wheelchair, motivation, tenacity, willpower and resilience have ensured that many individuals, with support from health professionals, family and friends, have gone on to live fulfilling lives as academics, doctors, lawyers, researchers, disability advo-

cates, podcasters, authors, peer supporters and mentors, significant others, parents, grandparents and even carers. You will read in the various stories how affected individuals have adapted to a very different life that has required numerous adjustments, hard work and resilience.

Before we begin **Chapter 1**, we provide examples of lives well-lived with SCI both in Australia and abroad:

- In 1980, **Barry Corbet** published 'Options', with the last copies published in the mid-1980s. The book, which interlaced his life living with SCI with those of others across Australia, was a foundational piece of writing about what it is like to live and thrive with disability. Below, his family describe why they have made '*Options*' freely available for download in 2023:

"Barry Corbet passed away in 2004, and is still missed. Much has changed in the over 40 years since Options was written; some things have improved, others have not. But the words in this book, and the people portrayed within it, are as relevant and important as they were in 1980. We are happy to make Options available once again, and hope that it can help many others to understand the options that they have."

Jennifer Corbet, Jonathan Corbet, Micheal Corbet and Muffy Moore

- **Christopher Reeve** (1952-2004) was paralysed (quadriplegia, ventilated) following an equestrian accident in 1995. He motivated neuroscientists to conquer the most complex brain and central nervous system diseases. He put a human face to SCI. Under his leadership, the Christopher and Dana Reeve Foundation grew to become a pre-eminent SCI and paralysis foundation, funding some of the earliest discoveries in basic science and debunking the centuries-old dogma that the spinal cord could never be repaired.
- In the 1990s, **Perry Cross (AM)** sustained a C2 injury while playing rugby union, leaving him with quadriplegia and needing to be ventilated. For **Perry**, research brings hope, which is why he started the Perry Cross Spiral Research Foundation. Watch **Perry Cross** describe the work of his Foundation. In October 2024, Perry delivered a special message about nerve bridging finance for a clinical trial that commenced at the end of 2025. Listen to **Dean Durman,** a contributor to many chapters, interview **Perry Cross** in April 2026 in an episode called The Fragility and Beauty of Life.
- In 2008, **Dr Olivia Lee Ong**, a 28-year-old Australian junior doctor, was struck by a car, leaving her with paraplegia. Today, she is a successful pain and rehabilitation physician. She is now a personal coach. The Heart-Centred Doctor tells her story, as well as provides advice to health professionals who frequently experience burnout in a busy Australian healthcare system. Listen to **Dr Ong's** 2023 TED Talk about *How to be your own best friend* and her 2024 interview with Dr Kevin, a leading social media MD: Hope after a spinal cord injury.

- **Dr Dinesh Palipana (Medal of the Order of Australia, OAM)**, a doctor, lawyer, disability advocate and researcher, was born in Sri Lanka. His family moved to Australia during the civil war in Sri Lanka when he was 10. While studying medicine, a 2010 car accident left him with quadriplegia. He completed his medical studies and went on to become the first quadriplegic medical intern in Queensland. He was also the Queensland Australian of the Year for 2021, and, in 2022, he was listed as #33 on the Courier Mail's top 100 power list for Queensland's most influential in health and well-being. Currently, he works in the Emergency Department at Gold Coast University Hospital, Queensland. For the record, he has flown a modified plane, parachuted from an aeroplane, climbed the Story Bridge in Brisbane (right) and published an autobiography, *Stronger*, in 2024.
- At the age of 22, **Grace Spence Green** sustained a C4 SCI. She went from supporting patients on one day on the wards in the UK to fighting for her life the next day. To Exist As I Am: A Doctor's Notes on Recovery and Radical Acceptance chronicles her journey from an idealistic medical student to SCI patient, doctor and disabled activist, ending up back on the wards and finding her 'tribe' along the way. Experiencing her journey as a young woman, daughter, girlfriend, friend, student and doctor in the UK after SCI affords valuable insights for developing empathy. Her memoir reframes disability and questions the value we place on independence, in favour of *interdependence*, the rich networks of care that bind people together and what love truly looks like. Rather than yearning to be 'fixed', Grace shows how we might fight for change while embracing a joyous life exactly as we are. James Broadbent (2025), in his review of Grace's book, wrote:

> *"As a resident doctor in the UK's National Health Service, I echo Spence Green's observation that there is a dearth of disabled role models within medicine, and this has too long propagated a powerful negative message that we belong in the patient role not the professional role. As young professionals of today we have the capacity to occupy this inspirational void and to become the leaders and role models of tomorrow."* (p. 1555).

Structure of the resource

The resource comprises two Parts, **Part A** and **Part B**. **Part A** covers 'coming home' after being discharged from the hospital or rehabilitation, staying healthy, including ageing with SCI and covers three stages, which we have chosen to depict as a flowing river, drawn by Assistant Professor, **Jaclyn Szkwara,** who created many of the interactive images in this resource:

From coming home to ageing with SCI by Jaclyn Szkwara

1. **Stage 1 (Chapters 1-2):** Coming 'home' and getting settled, supported by carers and health professionals, with access to financial assistance and a deep understanding of the implications of SCI.
2. **Stage 2 (Chapters 3-5):** Staying healthy and well, monitoring health and well-being and returning to work or study through, for example, good nutrition, quality sleep, exercise, socialising, getting back to work and studying.
3. **Stage 3 (Chapter 6):** Aging with SCI, in which natural degenerative changes overlay accelerated ageing as a result of SCI.

Part B (Chapters 7-18) comprises 12 Special Topic chapters, including travelling with SCI, participating in sport, current research and innovation, the impact of a changing climate and health professions education:

- **Chapter 1 Coming 'Home' and Getting Settled:** Returning home after SCI, adapting your environment, accessing support systems and understanding the roles of health professionals.
- **Chapter 2 Implications of Spinal Cord Injury on your Body:** Physiological and psychological impacts of SCI, injury levels, organ system effects, pain types and management strategies.
- **Chapter 3 Staying Healthy, Well and Fit:** Evidence-based advice on nutrition, exercise, sleep, social connection, sun exposure, oral and foot care, mindfulness and carer well-being.
- **Chapter 4 Keeping Track of your Health and Well-being:** Managing health records, digital tools like My Health Record, and apps for medications and well-being.
- **Chapter 5: Getting Out There:** Employment, volunteering, advocacy, driving with SCI and strategies for workplace inclusion.
- **Chapter 6: Ageing Well with Spinal Cord Injury:** Ageing with SCI, dementia research, health risks, financial considerations, ageing carers and *voluntary assisted dying (VAD)*.
- **Chapter 7: Children and Adolescents with Spinal Cord Injury:** Differences from adults, rehabilitation, mental health, education, family dynamics and transition to adulthood.
- **Chapter 8: Spinal Cord Injury in Rural, Regional and Remote Australia:** Incidence,

research, cultural safety and a GP's perspective on treating First Nations patients with secondary complications of SCI.

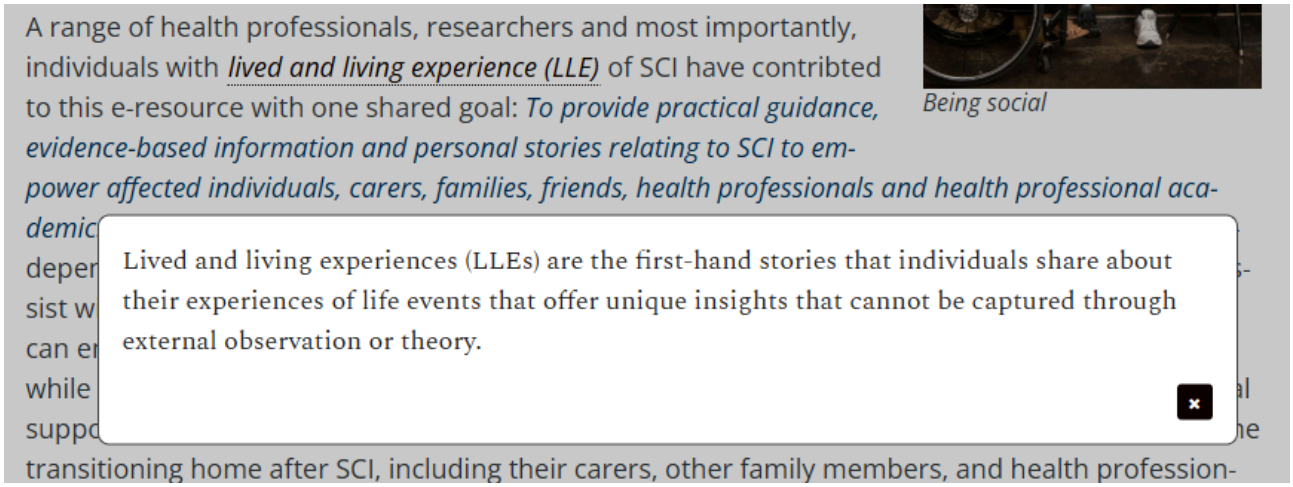
- **Chapter 9: Spinal Cord Injury and Marginalised Communities:** Impacts on individuals who identify as LGBTQIA+, people with neurodiversity, homeless populations, prisoners, migrants, refugees and asylum-seekers.
- **Chapter 10: Dignity, Discrimination, Abuse, Violence, Relationships, Intimacy and Fertility:** Sensitive issues including dignity in healthcare, abuse risks, discrimination and relationship and sexual health challenges.
- **Chapter 11: Legal Considerations Relating to Long-Term Spinal Cord Injury:** Human rights protections, consent, privacy and complaint processes, particularly in healthcare.
- **Chapter 12: Getting Around and Travelling with Spinal Cord Injury:** Local transport, driving, flying, accessible tourism and travelling with complex medical needs.
- **Chapter 13 Surgery and Anaesthesia for Individuals with Spinal Cord Injury:** Preparation, anaesthesia considerations, common surgeries, recovery and guidance for healthcare professionals.
- **Chapter 14: Spirituality and Spinal Cord Injury:** Benefits of spiritual care, meditation, prayer and humour as sources of resilience.
- **Chapter 15: Engaging in Sport with Spinal Cord Injury:** Benefits of sport, para-sport pathways, classification and risks and practical advice for carers and health professionals.
- **Chapter 16: Spinal Cord Research and Innovation:** Therapies for SCI repair, clinical trials, cell transplantation, stimulation techniques and nutritional research.
- **Chapter 17: A Changing Climate: Implications for Individuals Living with Spinal Cord Injury:** Physiological and mobility risks during extreme weather, preparedness strategies, emergency protocols and policy frameworks, and
- **Chapter 18: Health Professions Education: Curriculum and Inclusion:** Training and education of various health professionals in terms of SCI (and disability in general) and working in multidisciplinary healthcare teams, as well as what inclusion means for applicants to medicine and medical students.

How the information is presented in this resource

As this e-resource is intended for a broad audience, from individuals living with SCI to health professionals, particularly GPs, we have tried to use 'middle of the road' language, with links to an extended glossary and summaries of research in many chapters. **Part A** is largely written in the first-person, particularly **Chapter 2**, to assist individuals living with SCI in understanding what has happened to their bodies so that they can recognise when 'things' may be off kilter and seek assistance. In most Chapters, we have included '**Clinical resources**' to allow a deeper dive into some of the evidence. We hope that, regardless of readers' educational background, this resource will be useful to anyone living with SCI, as well as their carers, families, friends, health professionals and health professional students.

This resource is primarily designed as a digital platform to allow flexibility in the types of media that can be used. Wherever possible, we have incorporated interactive elements, for example, a map of Australia that enables pop-up boxes with State and Territory information when a small icon is selected. Similar interactive diagrams appear in **Chapters 1**, **3**, **5** and **6**, allowing users to explore the key health professionals they may need at different stages of their journey, from returning home to ageing with an SCI. There is a section at the start of the resource that discusses accessibility. A print-friendly PDF version is also available, but this option necessarily limits the richness of the interactive experience.

Glossary terms appear throughout the book, with many in **Chapter 2** because of the Anatomy and Physiology. **Chapter 16**, the research and innovation chapter, also has numerous glossary terms. As the image below shows, the digital version shows glossary terms, such as ***embodiment, being blue, italicised*** and *faintly underlined*. If you click on the glossary term, an explanation will appear in a pop-up box.



Icons in different coloured boxes have been used to draw attention to the range of resources and information provided in the resource. These resources range from *Personal stories (LLEs)* to*Reminders* and *Take-away messages* at the end of each chapter (**Table 2**). For example, stories (LLEs) appear in clear boxes, while reminders appear in blue-shaded boxes.

Table 2. Icons used to signpost different types of resources and information, which appear in shaded boxes of various colours to indicate different resources.

	Important resources and/or information (sand-coloured box) Includes fact sheets, guides, websites and other key resources.		**Interesting information (sand-coloured box)** Optional content for readers who want more detail. Includes websites and additional resources.
	Research (parchment-coloured box) Links to research articles.		**Clinical resource (bright blue box)** Resources mainly for health practitioners, including clinical guidelines and research articles for a deeper understanding.
	Podcast (grey box) Audio resources, such as podcasts, many of which will be stories.		**Reminder (grey-blue box, as for Key Take-aways and Key Topics at the start of each chapter)** Links to relevant and related content in other chapters.
	Key recommendation (blue-grey box, which is the same colour as Key Topics at the start of the chapter, Reminders and Key Take-aways) and links to other chapters Practical recommendations or actionable advice.		**Personal story (clear box)** Personal stories or LLEs of affected individuals, carers, support workers and health professionals, in the form of a written contribution, video, podcast or blog.
	Video (grey box) Video resources, including YouTube links. Many of these will be stories.		**Media story (grey box)** News or media articles and videos, many of which feature personal stories or relevant events.
	Key Take-aways (blue-grey box) Summary points are provided at the end of each chapter.		**Quotes** Short quotes from a range of sources, including contributors with LLEs who helped inform this e-resource.

This resource, which has been written about SCI in Australia but extended to disability more broadly in some chapters, draws on Australia's Disability Strategy 2021-2031, which sets out a national framework to improve the lives of people with disability and is jointly owned by the Australian Government and all State and Territory governments. The annual reports, the fourth published in January 2025, review progress against the Outcomes Framework, which tracks seven priority areas for people with disability:

- Employment and Financial Security
- Inclusive Homes and Communities
- Safety, Rights and Justice
- Personal and Community Support
- Education and Learning
- Health and Well-being, and

- Community Attitudes.

Important information: Australia's Disability Strategy 2021-2031 (4th annual report, Jan 2025)

The fourth annual report can be downloaded or viewed online. It can also be accessed via the Disability Gateway. The Disability Strategy Roadmap focuses on the seven key outcomes.

As will be discussed in several chapters, while some measures have improved, others have remained unchanged or regressed, highlighting the need for sustained coordinated action to achieve the Strategy's vision of an inclusive Australia.

Key recommendation: Always seek professional advice

Disclaimer: The information in the various chapters of this resource has been contributed by individuals living with SCI, their carers and support workers, a range of health professionals and academics and researchers. To the best of our ability, the chapters have been written using evidence from current medical, sociological, legal, environmental and ethical research. Notwithstanding, the information provided is not a substitute for personalised medical advice. Individuals should consult their treating health professionals for guidance specific to their circumstances.

References

Australian Institute of Health and Welfare. (2002). *The international classification of functioning, disability and health (ICF)*. Australian Government. https://www.aihw.gov.au/reports/disability/icf-disability-health/summary

Australian Institute of Health and Welfare. (2021). *Spinal cord injury, Australia 2017-18.* AIHW. Australian Government. https://www.aihw.gov.au/reports/injury/spinal-cord-injury-australia-2017-18/summary

Australian Institute of Health and Welfare. (2025) *Australia's Disability Strategy 2021–2031 Outcomes Framework: 3rd annual report, catalogue number ADS 5.* AIHW, Australian Government.

https://www.aihw.gov.au/reports/australias-disability-strategy/australias-disability-strategy-outcomes-framework/

Australian Institute of Health and Welfare. (2026) *Australia's Disability Strategy 2021–2031 Outcomes Framework: 4th annual report, catalogue number ADS 7.* AIHW, Australian Government. https://www.aihw.gov.au/reports/australias-disability-strategy/australias-disability-strategy-2021-2031-outcomes/contents/about

Broadbent, J. (2025). Disability, equity, and social justice through the eyes of a physician. *Lancet, 406*(10512), 1554-1555. https://doi.org/10.1016/S0140-6736(25)02026-4

Budd, M. A., Gater, D. R., & Channell, I. (2022). Psychosocial consequences of spinal cord injury: A narrative review. *Journal of Personalized Medicine, 12*(7), 1178. https://doi.org/10.3390/jpm12071178.

Creamer, S. & Lansbury, N. (2022), *The voice and the hands: Reflecting on what makes a successful research partnership between Indigenous organisations and non-Indigenous allies.* Native American Indigenous Studies Association Conference 2022 – Regional Gathering, Brisbane, May 30. https://espace.library.uq.edu.au/view/UQ:1b7932e

Guidry-Grimes, L. (2022). Disability bioethics and the commitment to equality.*Theoretical Medicine and Bioethics, 43*, 209-220. https://doi.org/10.1007/s11017-022-09575-2.

Hooper, A. (2025). *The problem with avoiding the word disability: Why changing the language won't change the exclusion*. https://www.linkedin.com/pulse/problem-avoiding-word-disability-ainslee-hooper-n6ntc/.

Katz, E. (2023). Australia, 'the most voter-friendly country in the world'? Examining voting rights for people with physical disabilities. *Alternative Law Journal, 48*(3), 216-220. https://doi.org/10.1177/1037969X231190481.

Lu, Y., Shang, Z., Zhang, W., Pang, M., Hu, X., Dai, Y., Shen, R., Wu, Y., Liu, C., Luo, T., Wang, X., Liu, B., Zhang, L., & Rong, L. (2024). Global incidence and characteristics of spinal cord injury since 2000–2021: a systematic review and meta-analysis. *BMC Medicine, 22*, Article 285. https://doi.org/10.1186/s12916-024-03514-9

National Mental Health Commission. (2018). *Sit beside me, not above me: Supporting safe and effective engagement and participation of people with lived experience.* https://www.mentalhealthcommission.gov.au/publications/sit-beside-me-not-above-me

Royal Australian and New Zealand College of Psychiatrists. (2021). *Partnering with people with lived experience.* Position Statement, September 2021. RANZCP. https://www.ranzcp.org/clinical-guidelines-publications/clinical-guidelines-publications-library/partnering-with-people-with-a-lived-experience

Royal Australian and New Zealand College of Psychiatrists. (2025). *Lived and living experience strategy.* 19 November 2025. RANZCP. https://www.ranzcp.org/college-committees/annual-reports-plans-and-evaluations/lived-experience-strategy

Spinal Cure Australia, Insurance and Care NSW. (2020). Spinal cord injury in Australia. *The case for investing in new treatments*. Report commissioned by SCA and icare, prepared by AlphaBeta Australia. https://treasury.gov.au/sites/default/files/2021-05/171663_the_australian_spinal_cord_injury_research_collaborative_supporting_document_3.pdf

Stein, P. J. S., Stein, M. A., Groce, N., Kett, M., Akyeampong, E. K., Alford, W. P., Chakraborty, J., Daniels-Mayes, D., Eriksen, S.H., Fracht, A., Gallegos, L., Grech, S., Gurung, P., Hans, A., Harpur, P., Jodoin, S., Lord, J. E., Macanawai, S. S., McClain-Nhlapo, C.V., Mezmur, B.D., Moore, R.J., Muñoz, Y., Patel, V., Pham, P. N., Quinn, G., Sadlier, S. A., Shachar, C., Smith, M. S. S., & van Susteren, L. (2024). Advancing disability-inclusive climate research and action, climate justice, and climate-resilient development. *Lancet Planetary Health, 8*(4), e242-e255. https://doi.org/10.1016/S2542-5196(24)00024-X

World Health Organization. (2001). *International classification of functioning, disability and health (ICF).* Geneva: World Health Organization. https://www.who.int/standards/classifications/international-classification-of-functioning-disability-and-health.

World Health Organization. (2024a). Spinal cord injury. https://www.who.int/news-room/fact-sheets/detail/spinal-cord-injury

World Health Organization. (2024b). The power of storytelling for health impact. WHO Western Pacific Region. https://www.who.int/westernpacific/newsroom/feature-stories/item/the-power-of-storytelling-for-health-impact.

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List of Abbreviations and Acronyms

ABI: Acquired brain injury

ABS: Australian Bureau of Statistics

ABT: Activity-based therapy

ACCOs: Aboriginal Community Controlled Organsiations

ACI: Agency for Clinical Innovation

AD: Autonomic dysreflexia

ADH: Anti-diuretic hormone

ADN: Australia's Disability Network

ADRD: Alzheimer's disease and related dementia

AEP: Accredited Exercise Physiologist

AFDO: Australian Federation of Disability Organisations

Ahpra: Australian Health Practitioner Regulation Agency

AIHW: Australian Institute of Health and Welfare

AMC: Australian Medical Council

AMSA: Australian Medical Students Association

ANS: Autonomic nervous system

ANZSCOS: Australia and New Zealand Spinal Cord Society

AQF: Australian Qualifications Framework

ARATA: Australian Rehabilitation Technology Association

ARF: Access Request Form

ASA: Accessible Homes Australia

ASIA: American Spinal Injury Association

ASRC: Asylum Seeker Resource Centre

ASQA: Australian Skills Quality Authority

B-cells: B-lymphocytes

BMD: Bone mineral density

BMI: Body mass index

BP: Blood pressure

BTF: Blended tube feeding

BT: Behavioural therapy

CALD: Culturally and linguistically diverse

CBT: Cognitive behavioural therapy

CBT-I: Cognitive behavioural therapy for insomnia

CDM: Medicare's Chronic Disease Management

CHSP: Commonwealth Home Support Program

CNS: Central nervous system

CPAP: Continuous Positive Airway Pressure

CPD: Continuing professional development

CPT: Compulsory Third Party

CRPD: Convention on the Rights of People with Disabilities

CVS: Cardiovascular system

CSIRO: Commonwealth Scientific and Industrial Organisation

DVA: Department of Veterans' Affairs

DVT: Deep vein thrombosis

EAF: Employment Assistance Fund

ECP: Early Childhood Partners

ED: Emergency Department

EEJ: Electroejaculation

EESS: Eye and Ear Surgical Support program

ESSA: Exercise and Sport Science Australia

FAS: Forward Ability Support

FES: Functional Electrical Stimulation

FEV: Forced expiratory volume

FODMAP: Fermentable Oligosaccharides, Disaccharides, Monosaccharides and Polyols

FNDN: First Peoples Disability Network

GCUH: Cold Coast University Hospital

GI system: Gastrointestinal system

GP: General Practitioner

HEN: Home enteral nutrition

HENS: Home Enteral Nutrition Service

HPS: High physical support

icare: Insurance and Care NSW

IBS: Irritable bowel syndrome

ICF: International Classification of Functioning, Disability and Health

IDC: Indwelling catheter

IDS: Immune depression syndrome

IMC: Intermittent catheter

ISCOS: International Spinal Cord Society

ISNCSCI: International Standards for Neurological Classification of Spinal Cord Injury

InSCI: International Spinal Cord Injury Community Survey

JLO: Justice Liaison Officer

LAC: Local Area Co-ordinator

LDL: Low-density lipoprotein

LGBTQIA+: Lesbian, Gay, Bisexual, Transgender, Queer/Questioning, Intersex, Asexual, plus other sexual and gender minorities (SGMs)

LLE: Lived and living experience

LMN: Lower motor neurone

LT: Locomotor training

LTPA: Leisure-time physical activity

MABI: Mindfulness- and acceptance-based intervention

MAIC: Motor Accident Insurance Commission

MDANZ: Medical Deans Australia and New Zealand

MMM: Modified Monash Model, referring to the MMM categories of Australia

MNC RSCIC: Mid North Coast Rural Spinal Cord Injury Coordinator

MOICDP: Medical Outreach Indigenous Chronic Diseases Program

MRI: Magnetic resonance imaging

NASA: National Aeronautics and Space Administration

NBD: Neurogenic bowel disorder

NDIA: National Disability Insurance Agency

NDIS: National Disability Insurance Scheme

NDRC: National Disability Recruitment Coordinator

NEDA: National Ethic Disability Alliance

NeuRA: Neuroscience Research Australia

NFP: Not-for-profit

NIIS: National Injury Insurance Scheme

NK cells: Natural killer cells

NLI: Neurological level of injury

NNSW LHD: Northern NSW Local Health District

NMBA: Nursing and Midwifery Board of Australia

NMES: Neuromuscular and muscular electrical stimulation

NMHC: National Mental Health Commission

NP: Nursing Practitioner

NSW: New South Wales, Australia

NSW SOS: NSW Spinal Outreach Service

NT: Neurotypical

NTSCI: Non-traumatic spinal cord injury

NZQA: New Zealand Qualifications Framework

OEC: Olfactory ensheathing cell

ONS: Oral Nutrition Support

OSA: Obstructive sleep apnoea

OT: Occupational Therapist

PBS: Pharmaceutical Benefits Scheme

PEG: Percutaneous endoscopic gastrostomy

PHR: Personal Health Record

PMN: Pain Management Network

PNS: Peripheral nervous system

PTG: Post-traumatic growth

PTSD: Post-traumatic stress disorder

PVS: Penile vibratory stimulation

PWDA: People with Disability Australia

QoL: Quality of life

QLD: Queensland, Australia

QUT: Queensland University of Technology

RACGP: Royal Australian College of General Practitioners

RANZCP: Royal Australian and New Zealand College of Psychiatrists

RAP: Rehabilitation Appliances Programme

RCT: Randomised control trial

RLS: Restless legs syndrome

RMR: Resting metabolic rate

RN: Registered Nurse

RRC: Reasonable Rent Contribution

RRR: Regional, Rural and Remote, as it applies to Australia: RRR Australia

RSCIS: Rural Spinal Cord Injury Service

RIG: Radiologically-inserted gastrostomy

RSV: Respiratory syncytial virus

RTW: Return to Work

SCI: Spinal cord injury. Also refer to **TSCI** (traumatic SCI) and **NTSCI** (non-traumatic SCI)

SCIA: Spinal Cord Injury Australia

SCI/D: Spinal cord injury/disorder

SCI-IDS: SCI-Induced Immune Deficiency Syndrome

SCIRE: Spinal Cord Injury Research Evidence

SCoRH: Spinal Cord Research Hub

SCS: Spinal cord stimulation

SDA: Specialist Disability Accommodation

SDAC: Survey of Disability, Ageing and Carers

SEWB: Social and emotional well-being, as in the SEWB framework for Aboriginal and Torres Strait Islander peoples

SGM: Sexual and gender minorities

SI: Suicide ideation

SIL: Supported independent living

SOC: Sense of Coherence

SPOT: Spinal Outreach Team (Queensland)

T-cells: T-lymphocytes

TENS: Transcutaneous electrical stimulation

TMS: Transcranial magnetic stimulation

TPD: Total and Permanent Disability

TSCI: Traumatic spinal cord injury

TTS: Text-to-speech

UMN: Upper motor neurone

UN: United Nations

UNDDR: United Nations Office for Disaster Risk Reduction

UNHCR: United Nations High Commissioner for Refugees, the UN Refugee Agency

US/USA: United States/United States of America

UTI: Urinary tract infection

UV: Ultraviolet

VAD: Voluntary assisted dying

VET: Vocational Education Training

VOS: Visiting Optometrists Scheme

VR: Virtual reality

WAT: Wheelchair-accessible taxi

WAV: Wheelchair-accessible vehicle

WBC: White blood cell

WFH: Work from home

WFOT: World Federation of Occupational Therapists

WHO: World Health Organization

WMO: World Meteorological Organization

PART A: INTRODUCTION: COMING 'HOME' AND STAYING FIT, HEALTHY AND WELL (CHAPTERS 1-6)

As discussed in the **Introduction**, **Part A** is depicted as a river flowing through a valley, with three stages:

1. **Stage 1 (Chapters 1-2, below):** Coming 'home' and getting settled, supported by a carer or support worker and health professionals, with access to financial assistance and a deep understanding of the implications of SCI.
2. **Stage 2 (Chapters 3-5):** Staying healthy and well, monitoring health and well-being and returning to work or study through the five pillars of health and well-being requires good nutrition, quality sleep, exercise, getting sun exposure, socialising, as well as getting back to work or studying.
3. **Stage 3 (Chapter 6):** Aging with SCI overlays natural age-related degenerative changes.

Below are more details about these three stages.

Stage 1: Coming 'home' and getting settled (Chapters 1 and 2)

Perhaps after weeks, months and even a year, you have the green light to go 'home'. Home is written in inverted commas as 'home' may vary, depending on the next stage of your rehabilitation and reintegration into the community. This will be determined by many factors, not least the level and severity of your injury and hence your functionality, and whether your home can be adequately modified, whether you physically have a home and whether you have the necessary support.

In this resource, our focus in **Chapter 1** is the family 'home' or your own home, but we will provide information about alternative disability accommodation in the various Australian states.

Considerable planning is required before you transition home. This planning needs to start long before you are discharged. A multidisciplinary team of health professionals will assist with many aspects of your transition, such as assistive technology and ensuring mobility at home,

depending on your individual needs, including if you require ventilation. Depending on your physical needs, you may need a full-time carer or support worker.

Returning home from the hospital or rehabilitation after SCI marks a major milestone in your recovery, but it also comes with new considerations, especially when managing your diet and nutrition. Where and how you live and the support you receive all play a vital role in your ability to maintain a healthy lifestyle. Interviews with individuals in their homes 2-10 months after discharge from the SCI unit highlighted that the transition to home is not merely a physical relocation but a complex process involving emotional, social and environmental adjustments. Maintaining and strengthening social relationships emerged as a key factor in successfully adapting to life post-SCI (Weber *et al.,* 2021). Increased psychosocial distress is reported in ~17-25% of individuals after SCI and during the transition to community life (Craig *et al.,* 2015), with particularly low quality of life in the early years post-injury (van Leeuwen *et al.,* 2011). Individuals will face challenges adjusting to home life, including modifying their environment and routines to manage new physical limitations, which are likely to cause emotional distress due to isolation and shifting social roles. This makes strong support from family, friends and healthcare professionals essential (Moran *et al.,* 2024). Below are a few ***LLEs*** from people who have made this transition 'home' following an SCI.

Ashley Treseder's story: The first few weeks at home

Ashley's story: Life changes after a spinal cord injury describes the first few weeks at home. His mom moved in to help him. He also had a support worker to assist him in adjusting to his new life. Listen to **Ash** talk about how his life as an active, young man changed forever in 2019, including breaking up with his fiancée.

Dr Dinesh Palipana's story: No NDIS, so no Specialist Disability Accommodation (SDA)

Dinesh was asked about the most difficult aspect of transitioning home after nearly eight months in the hospital. 'Home' was his family home as there was no National Disability Insurance Scheme (NDIS)

accommodation in 2010, when he had his accident and was released home. He was fortunate that no modifications were necessary to accommodate his wheelchair and new routine, as everything was on a level and fairly open and accessible. He shares his trepidation about going home below.

> *"Before my accident, I lived by myself in Gold Coast. I had my own apartment, but that wasn't going to work anymore. It was impractical to live by myself, at least at the start of this. So that left my parents. Their place was somewhat accessible. Just the way it was built. It was a single-storey home. Everything was flat. That was lucky. We managed then. It wasn't modified in any way, but it was still tricky.*
>
> *The most difficult part was the psychological readiness for it [going home]. I had spent nearly eight months in the hospital. I was scared to go home and that's probably because before I went into the hospital, I was walking. I could go to the toilet normally. I could do all these things. During those eight months, everything had been so structured and done for you. There were nurses and medical staff around if something went wrong. It was almost like a* ***Stockholm syndrome*** *type thing. You are just there, used to the routine. This is a new life. The body is so different. So, I was just really scared. The first thing, going home, I think, is the psychological readiness to do it. Also, being out in the community, it was a scary thing to think that I am now going to be wandering around and fending for myself. And the independence too, in a way. But it's more like, what if something goes wrong? I think in those eight months, I got so used to the rigid routine: In the morning, they'll do your bowel therapy with you, and then you'll have a shower, and then you'll go to physio. It's rigid. So I think I was actually really fearful to go home. My mum had to pry me away slowly. So we started with, and I think this is what most people do, they get a weekend pass home. So we went home one night, and I was like, "This is okay". It seemed to be working fine. And I went home one night a week and it just built up gradually. But I was really scared to do it."*

Personal stories: Returning home after SCI

Returning Home After a Spinal Cord Injury: Personal Experiences with Paralysis (US short videos): This website offers personal stories from people living with spinal cord injury, including interviews with 100 individuals sharing their experiences transitioning from hospital to home.

Challenges beyond physical and psychosocial factors include financial, healthcare, accessibility and lack of specialist SCI services in the area, as well as inadequate policies supporting seamless community reintegration. Barriers have also been identified during the transition home from the rehabilitation or healthcare setting. The need for comprehensive, individualised planning that addresses these multifaceted barriers to support successful community reintegration for individuals living with SCI has therefore been emphasised (Silver *et al.*, 2012).

"A 'systems' approach would have a logical flow – a holistic and whole person approach, which is what I often see missing in SCI care. There seems to be a unilateral focus on the main SCI-related goals, with the view to discharging individuals. It would be great to have a whole-of-person approach in helping adjust and live life well." **Dr Priya Iyer,** NSW nutritionist and dietitian and resource contributor

Important resource and information: icare support needs for adults with SCI

Some years ago, the New South Wales (NSW) Government, in collaboration with **icare** (Insurance and Care Services for the people of NSW), released Guidance on the support needs of adults with spinal cord injury. It is a valuable resource that supports many of the topics in this resource.

We suggest using **Figure 1** on p. 19 – **Decision-making framework for a person with spinal cord injury and their need for support workers** – which is an algorithm addressing three aspects: *Understanding the person, Understanding the person's context and Understanding the person's progress.*

A helpful section in this icare Guide is **Chapter 12 – Levels of support and assistive technology –** from p. 24 onwards. Each SCI level or range is then described, such as C1-C3 with no motor function below or C1-C5 with some motor function below, plus whether the individual is a non-walker, a household walker or a community walker. Suggestions about suitable assistive technology are then offered.

Below is the Executive Summary from the Guide:

> *"There are many factors to consider when deciding on support needs. The Guidance on the support needs of adults with spinal cord injury is a best practice tool to assist with making decisions around why assistance from support workers is needed. A working party of experts representing service users, health professions, providers, service delivery, support workers and researchers, worked with a guideline developer over a 14 month period to develop the guidance. The guidance was developed using an adapted guideline methodology in recognition of the complexity of the topic. The guidance draws on the knowledge from the limited research evidence available, but also the rich first-hand practical and contextual knowledge of the working party experts. In this guidance, there is a decision-making framework and an overview of the factors to consider, information and resources. For the different levels of spinal cord injury (no motor function below and some motor function below the level of injury), there are tables on estimates for the levels of support and lists of assistive technology. Other sections provide definitions; highlight practical matters to consider; screening tools; an information sheet for the person with a spinal cord injury and their family."*

Note: Although the Guide is due for review in 2027, the content should still be mostly current.

Part of coming home is also managing your health needs. This requires an understanding of what has happened to your body anatomically and the physiological implications for the vari-

ous organ systems. **Chapter 2** discusses the Anatomy and Physiology of SCI and how to prevent complications.

Stage 2: Staying healthy, well and fit and preventing complications (Chapters 3-5)

Stage 2 focuses on maintaining health and well-being and preventing complications after returning home. Chapters 3-5 highlight the shared responsibility between GPs and individuals living with SCI to stay physically and psychologically well. Key strategies include eating a balanced diet, exercising regularly, getting quality sleep, preventing infections and pressure injuries, building a strong social life and contributing to society, all elements for living a purposeful and fulfilling life. This is further explored in **Chapter 3** (Staying Healthy, Well and Fit), **Chapter 4** (Keeping Track of Your Health and Well-being) and **Chapter 5** (Getting Out There).

Stage 3: Ageing with spinal cord injury (Chapter 6)

Stage 3 addresses the process of ageing and how SCI might accelerate it. Ageing is inevitable, but its impact varies depending on individual health and lifestyle. For people living with SCI, normal age-related changes combine with the physiological effects of the injury, which can accelerate decline in some body systems. Muscles, joints, bones, heart and glands are most likely to experience premature ageing, while less is known about its effects on the urinary, gastrointestinal, skin and respiratory systems. This is further discussed in **Chapter 6.**

Regaining independence is an important part of coming home and being part of the community. Below are a few personal stories (LLEs) about independence.

Perry Cross' story: Reflecting on what independence means

- Before launching into the nuts and bolts of going home, it may be worth listening to this interview with Perry Cross about his sense of loss of independence when he went home after rehabilitation. In his words, *"Having a spinal cord injury is like having a job"*, and
- Years later, this podcast with Perry is On finding independence.

Jacob and Claire's stories: Independent living after rehabilitation

SCIA's Have the Nerve's Talking about first experiences after SCI (Episode 7). **Jacob** and **Claire** talk about their experiences of moving into independent living after months in rehabilitation.

Finding independence, however, depends on the *accessibility of facilities*, whether this be home, healthcare, transport, places of work and study and social venues. Below, **Shane Clifton** writes and then talks about what accessibility means, which, in this instance, is physical accessibility.

Shane's story: Advertised as accessible, but not really

Staying healthy and well also means being able to physically access health-care facilities, public transport and venues. *How accessible is Australia for wheelchair users?*

Shane Clifton, an Associate Professor at the University of Sydney, teaching ethics and dis-ability studies, and who has C4 quadriplegia, wrote this *Conversation* article in October 2024 after being unable to attend a suppos-edly "accessible" event in Sydney: When even fringe festival venues exclude people with disability, cities need to act on access.

Shane's article was followed up with a podcast, in which he talks about the events that led to the article, plus a broader conversation around whether advertised 'accessible' spaces are truly accessible: SCIA's Have the Nerve podcast, Is that... actually accessible? (Episode 48, 13 December 2024).

Below are two resources that might be useful for navigating life once discharged home.

Important resources and information: Transitioning to the community

- Agency for Clinical Innovation (ACI): 2019 Report: Improving transitions to community living for people with SCI in NSW, and
- Spinal Cord Australia: Navigating Life with a Disability.

A term often associated with getting through hardship, such as SCI and emerging stronger and determined is ***'resilience'***. On the American Psychological Association website, ***resilience*** is described as:

> *"The process and outcome of successfully adapting to difficult or challenging life experiences, especially through mental, emotional, and behavioral flexibility and adjustment to external and internal demands. A number of factors contribute to how well people adapt to adversities, predominant among them (a) the ways in which individuals view and engage with the world, (b) the availability and quality of social resources, and (c) specific coping strategies. Psychological research demonstrates that the resources and skills associated with more positive adaptation (i.e., greater resilience) can be cultivated and practiced. Also called psychological resilience."*

In *Spinal cord injury and aging: An exploration of interrelatedness between key psychological factors contributing to the process of resilience*, Jenkins and Cosco (2012) wrote:

> *"Many older adults demonstrate resiliency and they achieve this resiliency by the psychosocial contributions of self-efficacy and social supports. These two psychosocial factors are intertwined in the presence of SCI and have the potential to be synergistic in their effects upon resilience and positive psychological outcomes. Furthermore, spirituality is an underexamined component of resilience that is both a factor in SCI and the gerontological populations."* (p. 319).

For Jenkins and Cosco (2012*), "rooted in positive and developmental psychology, the concept of resilience forsakes the biomedical tradition of cataloguing adverse psychological outcomes in favour of fostering resources that enhance the capacity of individual resilience."* (p. 316). They see opportunities for circumventing maladaptive trajectories following SCI.

Although Jenkins and Cosco (2012) wrote this in the context of ageing, we have used the term 'resilience' in several chapters in the e-resource, making resilience a key consideration for a life well-lived with SCI. We have conceptualised their three elements of resilience (*self-efficacy, social supports, spirituality*) as the 'three Ss' in **Figure 5**.

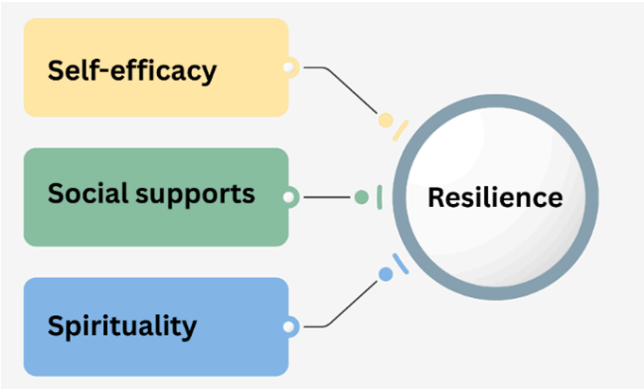

Figure 5. Based on Jenkins and Cosco's (2021) discussion about ageing with SCI, we have translated this into the **3Ss** that contribute to resilience: *Self-efficacy, social supports and spirituality.* Designed by Michelle McLean and drawn by Elmarie Stander using Canva, licensed under a CC BY-NC (Attribution NonCommercial).

Taken from the American Psychological Association website, *self-efficacy* refers to an individual's belief in their capacity to independently carry out behaviours to achieve goals. Self-efficacy Theory (SET) is widely used in research, education and clinical practice in health psychology, having been applied to behaviours such as self-management of chronic illness, smoking and alcohol cessation, eating, pain control and exercise.

Social supports include family, friends, healthcare workers and peers with SCI. They play an important role in daily coping with life.

In terms of *'spirituality'*, Jenkins and Cosco (2012) use this definition:

> *"A universal and fundamental human quality involving the search for a sense of meaning, purpose, morality, well-being, and profundity in relationships with ourselves, others, and the ultimate reality."*

Chapter 14 in **Part B** of this resource discusses spirituality, spirit and spiritual health.

Perry and Dan's story: A recent (February 2026) show of friendship and resilience

On 13 February 2026, at Kurrawa Park Boardwalk in Broadbeach, Perry Cross and Dan Boardman took on The 100 km Roll and Run (lots of photos). Between 17h00 and 03h45 (Saturday), they lapped the boardwalk in pouring rain until the 100 km had been completed. **Perry** navigated his power wheelchair using his chin control, while **Dan** ran 60 km. Dan's mum, Jane Boardman, also rode the full 100 km in support. Supporters braved the weather to run and roll with them. The event was dedicated to Cure Crusader Ambassador Kurt Drysdale, who recently passed away at 31 after a rugby injury in 2015 had left him with quadriplegia. The power team of Perry and Dan showed immense resilience to complete the event, raising at least $13,603. You can follow this story on Perry's Facebook page: https://www.facebook.com/perry.cross.18/.

Chapter 1 of *Towards a Life Well-lived with Spinal Cord Injury* follows next.

References

Craig, A., Perry, A. N., Gues, R., Tran, Y., Dezarnaulds, A., Hales, A., Ephraums, C., & Middleton, J. (2015). Prospective study of the occurrence of psychological disorders and comorbidities after spinal cord injury. *Archives of Physical Medicine and Rehabilitation, 96*(8), 1426-1434. https://doi.org/10.1016/j.apmr.2015.02.027

Jenkins, H. T., & Cosco, T. D. (2021). Spinal cord injury and aging: an exploration of the inter-relatedness between key psychosocial factors contributing to the process of resilience. *Health Psychology and Behavioral Medicine*, *9*(1), 315-321. https://doi.org/10.1080/21642850.2021.1911656

Moran, K., Barclay, L., & Lannin, N. A. (2024). Experiences of people with non-traumatic spinal cord injuries returning home after inpatient rehabilitation. *Disability and Rehabilitation*, *46*(2), 362-368. https://doi.org/10.1080/09638288.2022.2162611

Silver, J., Ljungberg, I., Libin, A., & Groah, S. (2012). *Barriers for individuals with spinal cord injury returning to the community: A preliminary classification. Disability and Health Journal, 5*(3), 190-196. https://doi.org/10.1016/j.dhjo.2012.03.005

van Leeuwen, C. C. C., Post, M., W. M., van Asbeck, F. W.A., Bongers-Janssen, H. M. H., van der Woude, L. H. V., de Groot, S., & Lindeman, E. (2011). Life satisfaction in people with spinal cord injury during the first five years after discharge from inpatient rehabilitation. *Disability and Rehabilitation, 34*(1). https://doi.org/10.3109/09638288.2011.587089

Weber, L., Voldsgaard, N.H., Holm, N.J., Schou, S. H., Biering-Sørensen, F., & Møller, T. (2021). Exploring the contextual transition from spinal cord injury rehabilitation to the home environment: a qualitative study. *Spinal Cord, 59*, 336-346. https://doi.org/10.1038/s41393-020-00608-y

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Chapter 1. Coming 'Home' and Getting Settled

Contributors: Michelle McLean, Priya Iyer, Perry Cross, Emma Simpson, Jaclyn Szkwara, Sarah McGuigan, Christian Moro, Dinesh Palipana, Teresa Blair, Genny Kohker, Daniel Boardman and Chithrani Palipana

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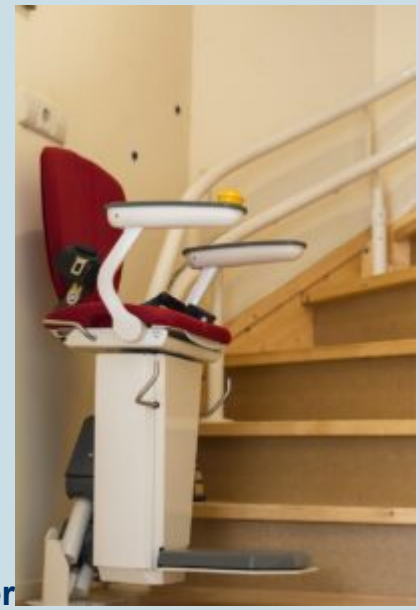
"A spinal cord injury changed my life, but persistence, support and bold action opened doors I once thought closed."

Dr Dinesh Palipana, Opening doors: Why medicine must welcome doctors with disability

As per the **Introduction,** much of the planning for transitioning home begins while you are still undergoing rehabilitation. Ideally, it would be good to have a customised mobility device, funding, support and accommodation secured and ready so that your transition home is smooth and uneventful, but there will be bumps along the way.

Recognising that the transition home can feel overwhelming, this Chapter is designed to provide individuals, their families and carers with useful information in an interactive format. It includes personal stories, media features, podcasts, videos, important information (key disability-specific and 'need-to-know' content), and interesting information (additional resources and 'nice-to-know' content). For health professionals, it also offers clinical resources to support engagement with individuals living with SCI. The information you receive on discharge and the services provided may vary across the States, so you need to be fully versed in terms of what is available in your State. If you live regionally, rurally or remotely, there may be additional information in **Chapter 8.**



Key Topics in this Chapter

- Exploring ‘what and where home’ might be after discharge, the modifications that may be required and who can help assist
- Independent living at home will vary according to the severity and nature of the injury and will be dependent on the level of function
- Navigating the complex landscape of federal and state-based supports and services, such as the *NDIS* and My Aged Care
- The difference between a carer and a support worker, including support for carers
- Health professionals and other individuals likely to be involved in the transition home and the settling-in process, and
- Getting around in your local community and accessing transport options.

1.1. Coming ‘home’, but where is ‘home’?

‘Home’ may be your family home or your original house or it may be an apartment. Circumstances may, however, dictate that you need to be accommodated elsewhere until you can move home. If you are unable to go home, you will need to find specific accommodation, which may not be easy, but there are more options today than when**Perry Cross** and **Dr Dinesh Palipana** sustained their SCIs. There was no NDIS at that time. Read their stories about ‘coming home’.

Perry's story: Accommodation

Read about Perry Cross' journey in terms of trying to find accommodation as a C2 ventilated person with quadriplegia since 1994. Although Perry initially stayed with family, he had to find specialised accommodation through the NDIS, which had only recently set up Specialist Disability Accommodation (SDA), an NDIS-funded housing option for individuals with functional impairments or very high support needs. An assigned Specialist Support Officer then helped Perry work on a Specialist Support Coordination Plan.

Dinesh's story: Home accommodation

Like Perry Cross, **Dinesh** sustained his SCI before the NDIS. This is his story about accommodation.

> *"The place I live is in Hope Island. We did that because I was living in rentals for a while, during medical school and after medical school. Then, it got to a point, maybe three years ago, four years ago, I was like, okay, I should start building place. But to build something like this, because there are so many different requirements, especially for SDA. Which is good. I mean it needs automatic doors, battery backup system, the footpaths need to be a certain width. Yeah, yeah. The entire inclination. So, we went and spoke to a heap of developers and there was one that was building something SDA in Hope Island. It was more goodwill. They said, okay, let's take this journey together. So, we built on that It's not that close to things, which has been the only problem."*

Important information: Short-term accommodation

Read about SCI and short-term accommodation in case you are not able to find accommodation, your 'home' is not ready or there has been an issue that needs repairing. Specific Disability Accommodation (SDA) dwellings are designed to enhance independence and facilitate the support that is needed. To be eli-

gible for SDA, you must have a functional impairment that requires very high support needs and you must meet the NDIS funding criteria.

Sharon's story: SDA experience

Listen to Sharon talk about her SDA experience.

It is important to be acquainted with the SDA design standards. They include:

1. **Improved liveability:** Enhanced physical access and features for sensory, intellectual or cognitive impairment
2. **Fully accessible:** High-level physical access for individuals using wheelchairs or with significant mobility challenges
3. **Robust:** Durable housing for individuals with high physical support needs or behaviours of concern, and
4. **High physical support:** Features for individuals requiring high levels of physical support.

SDA funding is provided through your NDIS plan. You are required to contribute a reasonable amount towards rent (called Reasonable Rent Contribution, RRC) and pay for other everyday living expenses, such as electricity and utility bills. You can use the SDA finder tool to locate vacancies and information about SDA dwellings. You can also contact providers directly to inquire about vacancies. More information below:

- SDA pricing and payments
- What home and living supports the NDIS funds
- Find SDA accommodation.

In addition to SDA through the NDIS, several organisations offer short- and/or long-term accommodation:

- In Sydney, Forward offers long- and short-term accommodation at Ferguson House if you are visiting Sydney for medical appointments, for respite or while home modifications are being completed.

- There is short-term accommodation in Perth and long-term in Sydney through Spinal Cord Injuries Australia (SCIA).
- If you live in Victoria, try SIL & SDA Vacancies, Available Housing Options.
- On the Gold Coast, Queensland, Accessible Homes Australia (ASA) offers three accommodation options, with Hervey Bay available in 2026.
- ParaQuad Tasmania owns and operates two accessible accommodation units in Tolosa Street, Glenorchy, just 8 km from central Hobart, 15 minutes from the Hobart waterfront and BD and 10 minutes from MONA. Named after the man whose idea it was to build them, the smoke-free Glenn Moore Units are purpose-built for wheelchair users and feature ceiling hoists (own sling required), easy-access bathrooms and reverse-cycle air conditioning. There are large open-plan living areas and free onsite parking.

Important information: NDIS Commission

Recently, the NDIS Commission completed an own motion inquiry into supported accommodation, specifically the SDA option known as 'group homes'. The inquiry examined relevant reportable incidents and complaints made to the NDIS Commission to identify:

- Trends in the issues occurring in supported accommodation
- What is causing those issues
- Models of best practice to eliminate or address these issues, and
- How the NDIS Commission can use its powers to make sure higher standards of support are delivered.

This inquiry found:

- A need for specific regulation of group home settings to enhance the quality and safety of these settings for people with disability
- Greater engagement with people living in group homes is required to support their exercise of choice and control
- The attitude and aptitude of the workforce drive a high number of the issues evident in group home settings
- The interaction of supported independent living (SIL) and specialist disability accommodation (SDA) arrangements affects the ability of people with disability in supported accommodation to make changes to their living arrangements
- The NDIS needs to better understand the supported accommodation market and how people interact with it, including by improving the collection, monitoring and analysis of relevant data, and
- The interface with health and the supported accommodation system is not effective for many people living in these settings.

To elevate the quality and safety of supported independent living services, the following actions were identified:

- **Action 1:** Enhance regulation and monitoring of supported accommodation

- **Action 2:** Educate providers and workers
- **Action 3:** Increase oversight of supported independent living services
- **Action 4:** Enhance guidance for reportable incidents.

To amplify the voices of NDIS participants living in supported accommodation:

- **Action 5:** Increase participants' understanding of their rights and capacity to exercise rights
- **Action 6:** Support the exercise of choice and control by participants living in larger sites in relation to change in their living arrangements
- **Action 7:** Embed the voice or participants in supported accommodation into the design of the audit scheme.

To improve the NDIS to maximise the choice, control and experience of participants living in supported accommodation:

- **Action 8:** Deepen understanding of the supported accommodation market
- **Action 9:** Develop our understanding of participant personal well-being and choice.

Important information: NDIS Design Standard

In 2025, the NDIS reviewed its SDA Design Standard. You can read the review consultation process, which closed in December 2025 here: Specialist Disability Accommodation Design Standard Review. At the time of publication of this resource, the outcome of the review was not yet available.

In terms of life safety and fire safety measures, it is worth noting that **Clause 22** in the SDA Design Standard requires the provision of:

- Emergency power solutions for the High Physical Support (HPS) design category to cater for a minimum 2-hour outage in no less than two double GPOs (power points) in participant bedrooms and any automated doors provided, and
- A medical-grade emergency power solution is required in the HPS category to support life safety equipment.

Clause 24 and the best practice recommendations identify fire safety measures through the provision of fire-safe design principles. This includes the following:

- Smoke alarms are required in bedrooms and living spaces, and evacuation plans are mandated, and
- Sprinklers are recommended and references are made to consider fire-resistant walls, fire compartmentation and emergency lighting.

The review considered the minimum requirements of best practice fire safety measures, such as dwellings with several NDIS participants or in high-density settings. It also considered whether there should be a stronger emphasis on tailored evacuation plans to reflect the specific needs of the participants, such as participants with high physical or cognitive impairments. Specifications for uninterrupted power solutions and backup power storage were also explored.

Additional information, if interested: National Energy Retail Amendment to improve life support

The National Energy Retail Amendment (improving life support processes) Rule 2025: This link contains the Australian Rehabilitation Technology Association's (ARATA) September 2025 submission on the National Energy Retail Amendment (Improving Life Support Processes) Rule.

1.2. Independent living at home

If you are returning to 'independent' living, your home will need to be modified to accommodate your needs. It would be advisable to have these modifications completed before you move in, but this may not always be possible.

Dr Kieran Le Plastrier's story: Where you live is important

Dr Kieran Le Plastrier, a GP with considerable experience in providing healthcare for individuals with SCI living independently, wrote the following:

> *"Where and how you live after SCI has a big impact on daily life and health. As sections above in this Chapter will highlight, many people hope to return to their original home, but that home may need modifications (like ramps, wider doorways or bathroom aids) to be wheelchair accessible. If a home cannot be adapted, some individuals and families may be able to access support to build a new accessible house or move into specialist disability accommodation (SDA), highlighted in sections above. Unfortunately, truly accessible housing is hard to find. Spinal Cord Injuries Australia notes that finding accessible homes can be very difficult, prompting advocacy for clearer information in real estate listings. Choosing a home in an accessible location is important too. For example, being near paved paths, public transport and healthcare facilities can make it easier to get to appointments. Australian data show that people living in remote areas have higher rates of SCI hospitalisations, partly because rural environments can pose more risks and accessing immediate care is harder. Living far from city centres can also mean fewer nearby health services, so if you're considering a rural or remote home, plan how you will reach doctors or how they can reach you (some GPs or nurses might do home visits*

or outreach in those areas). In the discussion to follow, some assistive technologies may be game changers for people living with SCI who choose to live more rurally in Australia."

Chapter 8 discusses rural, regional and remote (RRR) Australia and the challenges relating to disability. It also includes a section of First Nations people and disability.

We asked **Perry Cross**, who has been living with a C2 ventilated quadriplegia after a rugby accident when he was 19, and his long-standing support worker, **Daniel Boardman**, the following question:

"What are the essentials for transitioning home if 'home' is the family home or your own home?"

Below is **Perry**'s advice. Note his suggestions about the property's location and the ideal direction it should face.

Keep it simple, small and central

Perry's advice is to keep your home simple, small and central. While wide doorways and flat surfaces are essential, many other things are generally unnecessary extras. The ideal location for someone with SCI: A small, simple home or apartment in a central or inner-city location to allow easy accessibility to services. Since individuals living with SCI require frequent access to health services, including hospitals and health professionals and perhaps a gym, visitors and readily available accessible taxis or buses. Living in suburbia has challenges: Larger living spaces that need to be furnished, which drives up costs and has fewer transport options. Dan, Perry's support worker, reiterated this. Being central means a café or two within a short distance, which makes life easy for the individual and the support worker. Perry currently lives in a small apartment with a commercial area on the ground floor, including a café, a GP practice and a loading bay for taxis that can transport a wheelchair. All very convenient!

Maintain a physiologically conducive indoor temperature

Since a high-level SCI generally precludes body temperature regulation, the ambient indoor temperature needs to be heated and cooled, depending on the individual's needs. If you can, find an apartment that faces North or has open areas of natural sunlight. This is not only therapeutic and is needed for the body's Vitamin D synthesis, but it also helps to heat the room, keeping costs down, particularly in Melbourne, Canberra and Sydney winters. Natural lighting is also far healthier than artificial light.

Carer- and support worker-friendly homes

Having a routine and knowing who does what in your home is important. For example, something as simple as: Who organises the purchase of washing powder when it is about to run out? Good question! Make sure the routine is documented and a copy is easily accessible for whoever visits your home. This helps to maintain consistency from day-to-day, as support teams change. This, of course, requires open communication. Perry's advice is to set up systems and processes as soon as possible when transitioning home and ensure that everyone is on the same page. Trial and error are important at the start. Don't be afraid to change systems and adapt. As everyone is a cog in the machine, encourage people to talk through potential changes or improvements or changes to the design and organisation of the home.

Knowing where 'things' are in the home is imperative for a productive environment, not only for the individual with the SCI but also for those providing care, support and health services. They all come and go regularly from your home and so need easy access to materials, devices and other household staples to facilitate their work. Being organised is really important. Perry advises labelling every single 'thing', each stored in a specific place for easy access, and then returned to the same place. Another tip is to always maintain an uncluttered and clean workspace.

Get the exercise ball rolling early

Worth procuring early in your transition home are massage guns and some exercise equipment, such as exercise bands. You should be encouraged to exercise every day to prevent muscle tightening, reduce spasms and maintain strength. **Chapter 3** will provide more details about how to stay healthy and well. Perry's sage advice is:

> *"Don't lie in bed all day, as you will start to lose muscle and system function and mobility. Your goal should be to retain as much mobility as possible. If you can move an arm, even a small amount, keep it moving! If you don't use it, you will lose it".*

If possible, automate your home

"Home automation is life-changing", says Perry. Lights, television and air-conditioning can all be controlled by voice. Amazon's Alexa, Apple's Siri and Google's Home are examples of interfaces that enable home automation. This not only empowers Perry to take control of his home but also allows him to be independent, so he does not have to constantly ask his carer or support worker to change the TV channel, turn on a light or tweak the air-conditioning. Family and staff can focus on important duties around the home without interruption. For Perry, this automation is empowering, but also enhances the working relationship with family, support workers and carers. Dan agreed wholeheartedly. It certainly has made it easier for him.

Perry's article: Assistive technology

- Accessible Homes Australia: How assistive technology is changing lives, from automated doors to back-up battery power, and
- Also relevant is Ausmed's article on Ventilator Support: NDIS High Intensity Daily Personal Activities, intended for NDIS workers and providers.

Clinical resource: Ventilator management in the community

Ausmed's Ventilator management in the community: Provides guidance on ventilator management in community settings, including safety, monitoring and best practices.

Important information: AI-powered homes

Here are all the new AI-Powered smart home features Google just announced (Tech): Covers Google's AI-powered smart home updates, including new features in the Google Home app and enhancements to Nest devices.

We also asked **Dr Dinesh Palipana** to share his experience going home for the first time. Automation was definitely high on his agenda, but what was life-changing for **Dinesh**, who lives with quadriplegia, was a high table in the dining room.

Dinesh's story: A high table changed his life

"A high table is the ideal height for me with a high-level injury because I can lean on it and I feed myself. So, we have a table that is high and it has been awesome because I can socialise and eat dinner with my mum. For me, it was one of the most life-changing things because now when I get home, I roll up to that table and have dinner with mum. Before I just sat and ate in the corner and then went to bed."

No one said it was going to be easy transitioning home. Below, **Dan Boardman**, Perry's long-time support worker, provides advice.

Dan's story: The first few weeks and months at home

"Encourage your client's wellness by getting them to eat well, visit saunas and be positive. Don't worry about stuffing up. Have fun, try new things and adapt when things don't go according to plan. Read **Chapter 12** *on travelling by air! As a support worker, you can have a big impact on a person's abilities. While you might be told by some – "Don't encourage them to fly. Don't do this. Don't do that" – ignore it. Instead, listen to the person and what they wish to do or accomplish. Work together and allow things to go wrong – often. In some cases, it can feel to the person like they're a kid again as everything is new. While it may be uncomfortable at first, this isn't necessarily a bad thing. Learn together, make mistakes, stuff things up and work out how to do it better next time. It's ok to be wrong. Communication is, however, key. While many of the day-to-day jobs might be the same, a highly experienced support worker is less worried about things going wrong and instead is happy to adapt and work through whatever issues arise. It's ok to be wrong, and it's ok to learn together. It is often uncharted territory for the person and the support team, and this is absolutely fine.*

Not everyone has family or friends who can provide support for the person. In some cases, the clinicians and paid support team may be the closest thing the person has to a family. Understand this, and be as supportive as possible, some genuine care and attention can go a long way. Emotionally support the patient, have a laugh with them and smile."

We asked **Emma Simpson**, who worked as a support worker before becoming an OT, a similar question to the one we asked **Perry**:

As a support worker, what are the essentials for a smooth transition home for an individual with SCI?

Below is the advice she provided.

The power of routine: Consistency for confidence and calm

Establishing a reliable daily routine is one of the most effective ways to support independence, reduce uncertainty and maintain health and well-being after returning home with SCI. Routines offer structure in a world that may now feel unpredictable. They reduce the number of small decisions that can become tiring over the course of a day.

For people living with SCI, routines can help regulate:

- Bowel and bladder care
- Pressure relief schedules
- Medication times
- Skin checks and personal care
- Nutrition and hydration
- Sleep-wake cycles, and
- Participation in work, therapy or leisure.

From a support worker's perspective, routines also bring clarity and efficiency. When care tasks are completed in a consistent order, guesswork is reduced, risk is minimised and the person being supported feels more in control. New staff can follow documented routines without having to ask about every detail, which can preserve the person's energy and dignity. Examples of simple routine-based tools include:

- A visual schedule for morning or bedtime care tasks and activities
- A weekly template for meal planning, social activities or support worker duties
- A shared Google Sheet noting key times for rehabilitation, medical routines or family commitments, and
- Day-specific task lists.

When the essentials are predictable, there is more freedom to enjoy the day without worry or constant planning. This becomes especially important when you start to add in childcare duties or family and/or work commitments.

Assign a 'key worker' for oversight

In households with multiple support workers, it can be helpful to assign a *key worker*. This is a trusted and experienced team member who takes responsibility for coordinating broader, ongoing care-related tasks. While day-to-day routines may be handled by various staff, the key

worker can oversee monthly and administrative responsibilities to prevent gaps or duplication. A key worker might assist with:

- Maintaining a stock inventory of personal care items, continence products and cleaning supplies
- Ensuring batteries for hoists, electric wheelchairs or communication devices are charged or replaced regularly
- Updating a shared care calendar with upcoming appointments, service reviews or changes to support rosters
- Flagging training needs for new staff or communicating changes in routines, and
- Acting as a point of contact between the individual, family (if appropriate) and service providers.

Having a central figure who takes ownership of these background tasks helps reduce errors, keeps things running smoothly and allows the person living with SCI to focus less on admin and more on living their life.

Specifically, in terms of how you manage your food and nutrition, your living arrangements post-injury need to be tailored appropriately:

- **Returning to your own home** might require kitchen modifications, such as lowered benches or wheelchair-accessible storage and assistive devices for cooking and eating
- **Living with family** often brings emotional and practical support, but carers or support workers may need guidance on preparing suitable meals that align with your health goals, and
- **Supported or shared accommodation** may involve service providers who can assist with meal planning and preparation.

Important resources and information: Home modifications

- This American organisation provides many short personal interviews about transitioning home after SCI. Some content may not apply to Australia, but the interviews nonetheless provide insight into the challenges parents, partners and those who had sustained an SCI faced and overcame
- The University of Sydney has provided a peer-reviewed Consumer Factsheet about arranging home modifications and funding. Additional information can be found at Home modification information, and
- Home Modifications Australia is another useful website.

1.3. Navigating the maze of support

Depending on your individual personal circumstances and immediately following your injury, your various insurances and funding eligibility would have kicked in on application. For instance, you may have been eligible for funds from several sources, such as:

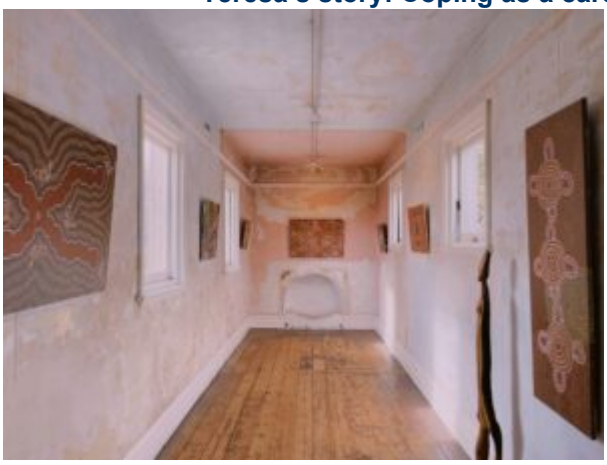
- An income protection insurance (either personal or provided by your employer), which would cover 75% of your monthly income until age 65
- A Total and Permanent Disability (TPD) insurance (personal or provided by your employer) is likely to be associated with your superannuation
- National Injury Insurance Scheme (NIIS) for catastrophic injuries caused by motor vehicle accidents, workplace accidents, medical accidents and general accidents at home and in the community
- Workman's compensation if you were injured on duty
- Private health insurance
- Medicare
- NDIS, and/or
- My Aged Care (if over 65 or over 50 if you are a First Nations person).

Now, as you transition 'home', finding the right support, whether it be funding or essential services, will be like navigating a whole new maze. While the NDIS is overseen federally, each Australian State and Territory has its own systems, providers and procedures, making the experience vastly different depending on where you live. We will provide these later as an interactive map of Australia.

Navigating Australia's healthcare maze. Tanisha Jowsey and Hugh Brocklebank.

Below, **Teresa Blair**, a First Nations Gumbayungirr woman, writes about her experiences during the COVID-19 pandemic when she and her partner, with a recent SCI, 'disappeared' in the healthcare system. Teresa describes how she drew on ancient Indigenous wisdom, such as remaining connected to Country, to care for herself. **Teresa** describes what it meant to finally get support from the Brisbane-based Spinal Outreach Team (SPOT).

Teresa's story: Coping as a carer during COVID-19



Giinagay, which is *Welcome! in my language,* Gumbayngirr.

"My name is Teresa Blair and I am a proud Gumbayngirr Saltwater Woman from Urunga, born on Gumbayngirr Country in Bellingen, New South Wales. In this reflective account, I share my lived experience as the primary carer for my partner, of Middle Eastern heritage, who sustained a life-changing SCI.

Our journey has highlighted not only the challenges of navigating health systems but also the importance of culturally grounded approaches to care and carer well-being. This experience has taught me that recovery after injury is not solely clinical. It is also emotional, cultural and deeply relational.

The injury occurred during the COVID-19 pandemic, a time when health services were under immense pressure. Although a referral for spinal care was submitted, it was never followed up. That delay had lasting consequences. Without guidance or support, we spent two years seeking help while my partner's condition progressively declined. When we finally accessed specialist care, the spinal cord damage was permanent.

He was eventually admitted to hospital for emergency surgery. During the procedure, complications caused further spinal trauma, requiring intensive care and an extended period of rehabilitation. Support from the Brisbane-based Spinal Outreach Team (SPOT) came later, helping us navigate the National Disability Insurance Scheme (NDIS) and explore treatment options to manage ongoing symptoms.

SPOT's multi-disciplinary approach was pivotal, including an Occupational Therapist, an Exercise and Sports Scientist, a Social Worker and Support Workers. Each contributed uniquely: guiding home modifications, supporting strength-building and mobility, navigating systems while respecting cultural values and providing care and emotional support. That clinical support was essential but what is often overlooked is the equally demanding role of the carer.

Becoming a full-time carer changed every aspect of my life. I had no training, no roadmap and limited support. I was suddenly responsible for daily personal care, medications, advocacy and navigating complex systems, all while being emotionally present. Carers are often invisible in health and disability settings and for First Nations carers, the challenges are even greater. We manage care responsibilities while navigating systemic barriers, cultural disconnection and limited access to culturally safe services.

I did not have extended family nearby. Like many Aboriginal women, I carried much of this burden alone, which led to exhaustion and burnout. Over time, I realised that to continue supporting someone else, I also needed to care for myself. For me, this meant returning to culture and Country.

Spending time on Country – walking, breathing, being still – helped me reconnect with my spirit and identity. These moments were not simply personal reflection; they were essential to my healing. Cultural practices, time on Country and connection to ancestors are not optional. They are central to the well-being of First Nations people. Our ways of knowing, being and healing are often overlooked in mainstream care models, yet they are powerful and necessary tools, especially for carers navigating long-term, complex situations.

Support from SPOT and the NDIS transformed our home into a safer and more accessible environment. Adjustable seating, mobility aids such as shower and toilet chairs, ankle and legs aids and walking sticks has enabled my partner to re-engage in daily routines with dignity. Despite his injury, he continues to cook, shop, fold laundry, manage rubbish and contribute to family decision-making.

In both Middle Eastern and Gumbayngirr cultures, contributing to family life is a source of pride and belonging. These seemingly small acts are powerful reminders that he remains a provider and central to our household and community.

Reflecting on this journey, I believe significant change is needed in how healthcare and disability services respond to both the person with the injury and their carers. Based on my lived experience, I recommend:

- *Timely, transparent and accountable referral processes, particularly during crisis periods*
- *Improved communication and coordination between services, families and support teams*
- *Recognition of carers as key stakeholders in health and disability planning*
- *Access to culturally safe and trauma-informed mental health and respite services for carers, and*
- *Integration of Country-based and cultural healing practices into carer and patient well-being plans.*

Living well with SCI is possible, but only when individuals and their support networks are properly equipped. For Middle Eastern and First Nations families, this means cultural values, collective responsibilities and connection to Country must be recognised as central to care. When services acknowledge the importance of culture, listen to lived experience and make space for holistic healing, they do more than support survival. They nurture strength, dignity and the possibility of a life truly well-lived."

1.3.1. What support can I expect when transitioning 'home'?

Below, we will discuss the following federally funded bodies, some of which may be run by the various States and Territories:

- National Disability Insurance Scheme (NDIS) (Federal)
- Home Enteral Nutrition (HEN) (State, but funded by the NDIS)
- My Aged Care (Federal)
- Medicare: Health and Disability (Federal)
- Commonwealth Home Support Program (CHSP) (Federal)
- Compulsory Third Party (CPT) insurance (State), and
- Department of Veterans' Affairs (DVA) (Federal).

Important resource and information: icare

icare's (Insurance & Care NSW) Guidance on the support needs of adults with spinal cord injury: Although this is an NSW guide, it is useful as it covers all aspects of SCI. Navigating the array of support services available for those living with SCI can be complex. Health professionals play a crucial role in coordinating care, advocating for patients and ensuring access to appropriate services. By leveraging Federal and State resources and fostering interdisciplinary collaboration, optimal support can be availed to live life well after SCI.

Below, we provide a list of federal support services, including the NDIS, My Aged Care and Medicare.

Important information: Disability Gateway

Disability Gateway is an Australian Government initiative designed to assist individuals living with disability, their families and carers in accessing essential information, services and support across the country. The Gateway offers resources related to Australia's Disability Strategy 2021-2031, including updates, targeted action plans and supporting documents aimed at fostering an inclusive society for people living with disability.

Operating Monday to Friday from 8 am to 8 pm AEDT/AEST, the Gateway provides a comprehensive online platform and a dedicated helpline (1800 643 787) to guide users through various areas of life, including (with videos):

- Income and finance: Access to income and financial support
- Employment: Training and assistance in finding a job
- Aids and equipment: Technology to facilitate everyday activities
- Housing: Programs and information to help find suitable accommodation
- Transport: Assistance with mobility and transportation options
- Health and well-being: Support and services for maintaining health
- Everyday living: Help with daily tasks and activities
- Education: Access to educational opportunities at all stages of life
- Leisure: Information on sports, recreation, travel and tourism, and
- Rights and Legal: Guidance on legal matters and rights protection.

1.3.1.1. National Disability Insurance Scheme (NDIS)

The best place to find out about NDIS funding is from the NDIS itself, and then listen to others' experiences.

Stories: About the NDIS

- What is the NDIS? This animated video, under five minutes, explains what the NDIS is, what it

means to be a participant, what happens if you're not eligible, and where to find more information, along with an overview of the Participant Service Guarantee and the timeframes it sets for key processes
- SCIA's Have the Nerve, How disabled do you need to be for the NDIS? (Episode 12): Listen to two people involved in advocacy for disability talk about the NDIS and some of the difficulties individuals experience in getting funded, and
- SCIA's Have the Nerve, NDIS, WTH? (Where's the Help) (Episode 21): Support Coordinator role explained.

Important information: All about the NDIS

- How to Access the NDIS. Use this map to find out more about the NDIS in your State or Territory
- The source of all truth is the NDIS website, and should be checked regularly as resources and budgets are regularly reviewed and updated, and
- Who is who in the NDIS (and what do they do)? Read about the role of the NDIA Planners, Local Area Coordinators (LAC), Early Childhood Partners (ECP), Support Coordinators (video) and Plan Managers.

To be funded by the NDIS, you need to know if you meet the disability requirements. The NDIS provides funding for individuals with permanent and significant disabilities, including those resulting from a SCI. If eligible, the NDIS process is usually started from the hospital. As already mentioned, it would be ideal to transition to a modified home. For this to happen, planning, including securing funding, needs to start before you are discharged. I (Michelle) spoke to an NDIS service provider about his advice when applying for NDIS funding. This is what he had to say:

- Start the process early (in your case, before discharge) because it will take several months, as there are many legitimacy checks to be done
- Make sure that you have all the medical evidence, functional assessments and reports
- Make sure that you are eligible. The NDIS is for under 65s and My Aged Care is for over 65s
- Complete the Access Request Form(ARF) with the help of your healthcare team or the various websites, and
- There will then be an NDIS planning meeting with an assigned Local Area Coordinator (LAC) to develop a personalised plan to meet your needs.

Important information: My Aged Care

It is important to note that the NDIS does not support anyone over 65 who sustains SCI. They need to apply to My Aged Care (see **Section 1.3.1.3**). If someone is already on the NDIS and sustains SCI, the NDIS funding will, however, not cease. What happens to my NDIS plan when I turn 65?

Before getting into the nuts and bolts of what the NDIS funds, starting with good news, can be uplifting. In terms of funding in 2025, the NDIA is changing how it pays for disability supports. What does that mean for rural communities? Each year, the National Disability Insurance Agency (NDIA) reviews its pricing rules to ensure services funded under the NDIS remain sustainable. The 2026 annual pricing review closed on 8 February 2026. NDIS review finds costs are much greater than what was publicly revealed. Among the updates are changes to therapy pricing, travel reimbursement and rural loadings. The NDIA says this will bring NDIS pricing in line with other government schemes and private health insurance. Two workshops (March and April 2025) videos are available on the SCIA site.

The NDIS offers 15 support categories:

1. Assistance with daily Life
2. Transport
3. Consumables
4. Assistance with social and community participation
5. Assistive technology
6. Home modifications
7. Coordination of supports
8. Improved living arrangements
9. Increased social and community participation
10. Finding and keeping a job
11. Improved relationships
12. Improved health and well-being
13. Improved learning
14. Improved life choices, and
15. Improved daily living.

Eligible NDIA participants can access support for:

- **Home modifications:** Support for modifications to the home environment to facilitate safe and independent living
- **Assistive technologies:** Provision of equipment such as adaptive utensils and feeding devices to aid in daily activities. To receive funding, an individual would typically need to demonstrate that the technology is necessary to meet their specific needs and goals and

that it is more cost-effective than alternative solutions. The NDIS will cover the cost of assistive technology if it is considered reasonable and necessary support for the person's disability-related needs, that aligns with the goals and aspirations of the person. Funding can be used to purchase assistive technology as well as for the installation, training and ongoing maintenance of the technology. Assistive Technology, RoboFit, is an example

- **Dietetic services:** Funding for dietitian consultations, both in-person and via telehealth, to address nutritional needs, such as creating a meal plan for you. The NDIS funds dietitian services and meal preparation supports, as well as home modifications. Do you meet the disability requirements?. Your NDIS support coordinator can help you find a dietitian with experience working with people living with SCI. Dietitians Australia is a good place to search for suitably qualified dietitians find a dietitian. Meal preparation and delivery also include tube feeds and equipment if you are not able to consume enough food or take any food through your mouth. A dietitian can discuss whether your tube feeds and equipment are funded via the NDIS or the Home Enteral Nutrition (HEN) program (see later *Section 1.3.2.2*), and
- **Meal preparation and delivery:** Assistance with meal planning and delivery services to ensure adequate nutrition. Assistance with meal planning, shopping and preparing meals or getting prepared meals delivered. NDIS only funds the meal preparation and delivery components, not the food costs of delivered meals, and this may be for a limited period. Delivered meal options may vary by State and Territory and regionally.

One of **Perry Cross**' key pieces of advice was to ***'Get the exercise ball rolling early'***. The NDIS has approved disability and neurological services that can be accessed through your plan. There are many, but below are two examples, one nationally and one on the Gold Coast.

Since 2007, Spinal Cord Injuries Australia (SCIA) has offered NeuroMoves, a specialised NDIS-approved service designed to support individuals with disabilities and neurological conditions. SCIA, founded over 50 years ago by people living with SCI, is dedicated to advocating for people with spinal and neurological conditions throughout Australia. Through expert, evidence-based care and a deep understanding rooted in lived experience, SCIA's vision, embodied by NeuroMoves, is to create a world in which individuals with spinal and neurological conditions, along with their families, can truly thrive.

NeuroMoves has 17 sites across Australia with multi-disciplinary teams of physiotherapists and exercise physiologists that work to support over 800 clients every month in reaching their health and fitness goals. NeuroMoves sets itself apart from others by not only providing industry-leading therapies for health and fitness but also a real community with a fun, social, inclusive environment where people from similar backgrounds and experiences can come together in an open space to work hard and cheer each other. NeuroMoves offers the following services:

- **Activity-based therapy (ABT):** Task-specific, functional exercises that utilise repetition and the principles of neuroplasticity to stimulate the nervous system. Exercises are performed primarily out of the wheelchair to maximise movement and weight-bearing with a wide range of accessible equipment, such as standing frames and overhead harnesses.

ABT is effective for neuromuscular re-education and strengthening

- **Strength and conditioning:** Cardio- and weights-based program designed to improve your health, strength, fitness and endurance. Depending on the level of function, this can be done in or out of a wheelchair, working one-on-one with an exercise physiologist to challenge the whole body and empower you to be your strongest self.
- **Hydrotherapy:** Water's natural buoyancy allows people with neurological conditions or physical disabilities to discover a whole new range of movement. The natural resistance of water helps improve muscular strength, postural control, trunk strength and balance
- **Functional Electrical Stimulation (FES):** Activates paralysed and weak muscles through electrical stimulation. FES can help increase movement, improve blood circulation, reduce muscle wastage and reduce the incidence of pressure injuries. FES can be used in a variety of exercises, including upper limb or lower limb cycling, stepping or while performing functional movements, such as sit-to-stand or grasping an object
- **Locomotor training (LT):** NeuroMoves gyms are the only facilities in Australia whose staff are trained under NeuroRecovery Learning to deliver LT. LT is an intensive body weight-supported treadmill program for individuals with SCI that is focused on restoring fundamental walking patterns by engaging in repetitive, intensive training designed to mimic a natural walking pattern
- **NeuroMoves Kids:** A specialised service for the youngest members of our community. Family-centred, evidence-based and fun! The principles of ABT form the foundation of our kids' program, emphasising the need for practice of purposeful everyday tasks to increase your child's participation in daily life
- **Telehealth:** Stay active and achieve your goals, anywhere, anytime. Whether you are at home or on the go, you can access expert support in both individual sessions and group classes. Sessions focus on upper body and lower body strength, cardiovascular fitness, stretching, balance and condition-specific programs. All exercises can be adapted for wheelchair or seated positions
- **Small group training:** NeuroMoves targets strength, cardio, balance, control and coordination. Groups comprise 3-5 participants with similar goals and skill levels. Condition-specific groups utilising the latest evidence and best practice are also available, such as MS Get A Head Start
- **Gym:** Group exercise physiology where individuals can take advantage of accessible gym equipment to improve their health, wellbeing and independence. These classes are not limited in size as there is small group training. The classes are aimed at building independence in a gym environment, and
- **Research:** NeuroMoves has a strong partnership with NeuRa, an independent not-for-profit medical research institute dedicated to improving the lives of people living with brain and nervous system disorders. The Project Directory provides details of research projects.

Making Strides: A rehabilitation and fitness gym servicing the Gold Coast and Brisbane. Below, **Professor Michelle McLean** describes her 2025 visit.

Michelle's story: A visit to Making Strides

While curating this resource, Michelle visited Making Strides (Burleigh Heads) to see what they offered individuals living with SCI:

> While researching the services each state offers for SCI rehabilitation upon transitioning home, I was directed to Making Strides, with rehabilitation facilities in Burleigh Heads and Ormeau. A Griffith University SCI researcher, who contributed to the SCI Research Special Topics Chapter, put me in contact with Genny at Making Strides, with whom he had collaborated on SCI research project. As Genny and Heleena showed me around the Burleigh Heads purple gym, they chatted to clients going through their paces on the various pieces of equipment. Some equipment has been designed to accommodate wheelchair users, allowing clients to work out independently. Other modalities require an exercise physiologist or physiotherapist, as programs are highly specialised and tailored for each client such as stretching and FES, which provides targeted electrical impulses to specific muscle groups in a person's legs or arms.

> Although it was a relatively quiet Friday afternoon, Genny told me that the gym is a hive of activity most of the week. *"Making Strides clients are from all walks of life, including sportsmen and women and local and international travellers,"* said Genny.

Easy access to the purple gym from the car park and plenty of fresh air in the purple gym. **Photos:** Used with permission from Making Strides.

Talking about the gym, Genny had this to say:

> *"Making Strides is a facility with over 100 years of collective experience and the peer-to-peer experience to feel supported during a vulnerable time. As an approved provider through the NDIS and state selective insurers. Everyone's diagnosis, lifestyle, goals and funding differ, so we don't copy and paste people's routines. Instead, we'll help curate a weekly, fortnightly or even monthly schedule around what works for you. Our team has experience helping clients, young and old, with a range of neurological conditions, including but not limited to SCI, transverse myelitis, MS and stroke."*
>
> What struck me was the constant friendly banter between the clients and the crew. It reminded me of the American sitcom, Cheers, 'where everybody knows your name'. An example of this

light-heartedness is the Brace Place on the wall as you walk in the first door. “Instead of a Hat Rack, we have a Brace Place, where some clients can hang up their braces”, said Genny.

Prior to visiting, I watched the video on the Making Strides website in which clients and their families spoke about the safe, supportive culture. A client spoke about her ‘family’ at Making Strides, where her SCI identity was validated. Making Strides can also refer clients to specialised health professionals, including occupational therapists (OTs), dietitians, psychologists and psychosexual therapists. Making Strides offers hydrotherapy and remedial massages (not supported by NDIS) at both the Burleigh Heads and the Ormeau facilities.

The airy, cool and easily accessible (by car) Making Strides facilities in Burleigh Heads is located in a light industrial precinct. Several supporting services are in close proximity to the Burleigh Heads gym. Holistic Nursing Solutions offers a range of services including home care, wound care, NDIS, continence, fertility services, as well as education and training services for carers, nurses, family, friends and patients. Molmike Medical provides medical consumables for continence, skin integrity, respiration, nutrition and wound care.

James from Neuromuscular Orthotics services both facilities, with premises in the vicinity, offering products such as PDE orthosis, C brace, MyoPro (myoelectric powered upper limb device) and FreeWalk exoskeleton.

Ormeau caters for the North Gold Coast, Brisbane and Sunny Coast clientele. We have the same staff and equipment across both facilities and that each offers its own charm.

Important resources and information: MyCareSpace and 2026 changes

- The MyCareSpace landing pages provide a comprehensive summary of NDIS support for SCI, including home and community support. MyCareSpace is a national online NDIS health-tech platform that helps people living with a disability find and connect with providers of disability services and supports. MyCareSpace supports participant choice and control by offering providers options that meet specific disability needs from providers who have passed the MyCareSpace verification process. The support services will depend on your level of independence, your support needs for a specific task and what you wish to achieve each day, and
- It is worth noting that from mid-2026, participants aged over 16 will have their needs assessed by an NDIA assessor. This shifts the role of gathering and interpreting information to the agency. Assessors will be allied health professionals, such as an occupational therapist or social worker, who will use an assessment tool called the Instrument for the Classification and Assessment of Support Needs Version 6 or I-CAN. I-CAN measures support needs across 12 areas of daily life, including mobility, self-care, communication, relationships and physical and mental health. Each area is scored on two scales: How often support is needed and the intensity of the support required. The assessment, based on self-reported information, is expected to take around three hours.

When **Dinesh** was asked, ***"How easy is it to access financial assistance from the NDIS?"***, this was his response:

Dinesh's story: A challenge!

"That is a little bit challenging these days because the planners don't understand what a spinal cord injury means and what the implications are either. Sometimes some of my clients have gone in front of the planner and they were asked can you stand up? So, it's that basic and there are people like one of the clients I advocated for. He only had so limited funding he could not even afford a carer. He did not have anyone, so one of his pensioner friends will come every other day from the other end of the town and will assist him with his bowel, bladder and showers, which was done on the bed because he did not have an accessible bed house."

Media stories: The NDIS is challenging!

Dealing with the NDIS is not always a smooth process. Individuals need to research and understand the services for which they are eligible. Additionally, if they are not treated with respect and dignity, they should raise this through the official channels. Below are some media stories where this did not necessarily happen:

- The ABC has provided a 30-minute history of the NDIS, including its successes and failures.
- NDIS akin to a 'Byzantine maze' for frustrated families having to go without funding for months
- They have disabilities, pensions and get little support. They're also among thousands rejected by the NDIS each year: Of note, the NDIA (National Disability Insurance Australia) says there is an increase in people being accepted to the scheme. While data shows that more people are applying and being accepted, tens of thousands of people are still being rejected each year. In the year to June 2025, it rejected 24,186 applications. Dr Yi Yang, a senior fellow at the Melbourne Disability Institute, worked with other researchers to examine NDIS applications from 485,676 people aged 7 or older made between 2016 and 2022, to determine whether they were deemed eligible. They found that three groups are more likely to be rejected from the scheme than others, including people aged 55 and older, women and girls, and those who live in disadvantaged areas
- After a major spinal injury, this renowned GP is determined to get back to work (2019): This article highlights that the NDIS does not provide support for people over 65 years of age, as shown in the case of **Professor Chris del Mar**. Friends established a GoFundMe campaign to raise $300,000 for essential home modifications. **Chapter 6** (Ageing) will address this further.

- A more recent case (2025-2026) in terms of the downside of sustaining SCI after 65, in this case, a few weeks only: Howard was left a quadriplegia after an accident in Japan. Then came another cruel twist. Howard became quadriplegic 16 days after his 65th birthday. He did not qualify for NDIS support and receives only $73,000 from My Aged Care. Had he been 64 and 10 months, he would have been eligible for NDIS funding. The age limit for NDIS eligibility was one of the topics raised in The Aged Care Royal Commission, which handed down its findings in 2021. One of the final report's recommendations was that every person receiving aged care who is living with a disability should receive supports equivalent to those available under the NDIS. This has not happened.
- In some instances, the system has let them down and this is ongoing. As recently as November 2025, it took a tribunal to get an SA 9-year-old finding from the NDIS
- *The Conversation* 2023: Taken together, the NDIS review and the Royal Commission recommendations could transform disability housing, and
- *The Conversation* 2026: A stronger focus on prevention could help governments rein in health care and social spending. A graph in this article reflects the high cost of the NDIS in terms of the Australian budget, more than defence, hospitals, medical benefits and aged care, and
- *ABC News*, 4 March 2026: NDIS ordered to fund mobility scooter in 'extremely significant' Federal Court ruling: A man with multiple disabilities won a long-running dispute with the agency that runs the NDIS over its refusal to fund a mobility scooter. The NDIA was ordered to pay the man's legal costs (much higher than the scooter).

There are plenty of good stories:

- *ABC News*, 21 November 2022: NDIS funding isn't just a one-way street – it helps participants secure work and give back to the economy
- *ABC News*, 25 March 2026: NDIS participants work more, feel better after accessing scheme, report finds: People who access the NDIS fare better in the workforce and feel healthier within four years of entering the scheme, based on data tracking the same individuals over more than a decade, and
- NDIS Stories and videos

Below are some light-hearted, humorous stories relating to the NDIS:

- Algorithms! Robots! Hubris! Is robodebt-style cruelty coming to the NDIS? *The Guardian*, 8 December 2025, and
- After opposing the Coalition's 'robo' NDIS reforms, Labor accused of going down similar path, *ABC News*, 12 December 2025.

Important resources and information: Assistance with navigating the NDIS

- Spinal Cord Injury & Accessing the NDIS, MyCareSpace

- NDIS Funding Support and Services, Spinal Life Australia
- Understanding your funding Spinal Life Australia
- Forward: A guide to the NDIS
- NDIS SCI data portal, and
- SCIA Take Action Yourself.

Clinical resource: Assisting patients with the NDIS

Health professionals can refer patients to the NDIS through the Access Request process, ensuring that all necessary documentation is provided to support the application. Health professionals can refer patients to the NDIS through the Access Request process, ensuring that all required documentation is included to support the application. Several services are available to help with finding providers; however, as we cannot endorse any specific service, we recommend conducting due diligence when exploring these options. Here are resources to help GPs support patients to access the NDIS.

Research: NDIS triumphs and challenges

In 2023, the NDIS turned 10, but it has not been plain sailing, with triumphs, challenges and controversies. In a 2023 *Medical Journal of Australia* article, Smith-Merry and colleagues wrote:

> *"The NDIS is a very significant social policy innovation and its importance for people with disability in Australia cannot be underestimated. For many people with disability, the supports provided through the NDIS have been essential to living an included life … There are over 535 000 NDIS participants compared with almost 4.4 million people with disability in Australia, including 2.4 million aged under 65 years, which means the NDIS can only ever be part of the national disability support landscape […]"*

The authors concluded with the following:

> *"Equity decisions should not be outsourced to a market where decisions of profit compete with decisions about equitable service access. In order to ensure equitable disability support, we need to consciously build a disability support system (including the NDIS) that i) ensures that decisions with equity consequences do not rely on the goodwill of service providers but are a product of market design, and ii) that provides a cohesive system structure that enables access to necessary services for people with disability sitting outside the NDIS (including people aged over 65 years). The National Disability Insurance Agency*

has significant existing powers to make decisions affecting scheme equity through scheme redesign to address under-utilisation and, at a micro-level, through decisions relating to individual participants. Key to realising equity is an adaptive approach to the design of social care markets where all parts of the market are not treated in the same way. This approach means that the areas of disability support that work best within a traditional market environment may continue to function in that way but with government directing markets in a proactive way to provide supports for people with complex or unique needs. This could include increased pricing for services for particular groups or locations or appointing providers to deliver services where markets do not emerge to provide services. We urgently need evidence for how this can be done successfully.

It is critical that issues of equity for people with disability, both within and outside the NDIS, are brought to the fore in the current NDIS review. A failure to address inequity within the operation and design of disability support means that the NDIS will continue to perpetuate the disabling and ableist structures that marginalise people with disability in the Australian society."

Reminder: NDIS changes and the: May 2026 Federal Budget

While we have provided numerous links and information about the NDIS, there have been recent changes to the NDIS Act. On 1 April 2026, the National Disability Insurance Scheme Amendment (Integrity and Safeguarding) Bill 2026 was passed. This Bill amends the National Disability Insurance Scheme Act 2013 to

- Expand the NDIS Quality and Safeguards Commission's powers to detect, prevent and respond to breaches of obligations under the Act; provide participants wishing to withdraw from the National Disability Insurance Scheme with additional safeguards and communication options
- Enable the National Disability Insurance Agency to move to an entirely electronic claiming system for providers, and
- Ensure that plan variations can include an increase or decrease of the total funding amounts.

Recent related news:

- Minister's media release: Parliament passes tough new laws to protect the NDIS from fraudsters, predators and shonks (with video and transcript)
- *ABC News*, 10 April 2026: The NDIS's 'social licence' isn't just at risk of eroding – it's close to collapse
- NDIS new way of planning: This website provides a link to the 2023 NDIS review (with video) and describes the changes from mid-2026, such as a new definition of NDIS supports, funding periods and impairment information, and
- ABC News, 8 April 2026: NDIS provider registrations in spotlight as Labor eyes options to make budget savings.

1.3.1.2. Home Enteral Nutrition (HEN)

HEN is a State-supported program of providing nutrition to individuals who cannot meet their nutritional needs through diet alone. It supports people requiring oral and/or enteral nutrition support. Individuals may require HEN for various reasons, including:

- Inability to eat or drink enough to meet nutritional needs
- Swallowing difficulties
- Physical or intellectual disabilities affecting eating or drinking, and
- Inability to absorb sufficient nutrition due to bowel disease or surgery.

Several healthcare professionals play a role in managing HEN:

- **Dietitians** assess nutritional needs and order appropriate formulas and equipment
- **Speech pathologists** evaluate swallowing function and recommend thickened fluids, if necessary, and
- **Registered nurses** assist with the care of feeding tubes and related equipment.

Additional information, if interested: HEN information, NSW and Queensland

The Home Enteral Nutrition (HEN) varies across Australian states, so it is important to consult local health guidelines for specific details. Subsidised HEN equipment and products are generally available to individuals discharged from public hospitals or supported by public hospital outpatient services, following referral by a dietitian or other public-sector healthcare professional. Clinical and consumer guides are available to support this process.

In **NSW**, HEN eligibility and access information include:

- **Eligibility criteria:** Individuals who require HEN for 12 months or more and are under the care of a dietitian or speech pathologist in an NSW public healthcare facility may be eligible for support.
- **Funding support:** Eligible persons can receive funding for tubes and equipment through EnableNSW. This includes gastrostomy tubes, giving sets, containers and extension tubes. Products are available at NSW Government contract prices and can be delivered to consumers' homes, and
- Clinical and consumer guides, including the ACI Nutrition Network Guidelines for HEN and the ESPEN guideline on home enteral nutrition (Bischoff *et al.*, 2020), are available.

In **Queensland**, information about the Home Enteral Nutrition Service (HENS) is available through state health services.

Research: HEN landscape

Recent research by Breik and colleagues (2025) maps the Australian home enteral nutrition (HEN) landscape and the growing use of blended tube feeding (BTF). Their work finds uneven access to supplies and services between jurisdictions, as well as variable program support for BTF, including explicit exclusions that can lead to out-of-pocket costs. The study identifies a clear need for coordinated, multidisciplinary pathways to support safe transition to and maintenance of HEN at home. These themes are echoed in the Agency for Clinical Innovation (ACI) evidence check, which highlights the benefits of dedicated HEN services alongside persistent gaps in community capacity, standardised models of care and equity across the system. For people with SCI who require HEN, this translates into practical priorities: structured discharge education, a named troubleshooting contact and person-centred discussions about commercial formulas versus BTF with careful attention to funding eligibility. It also requires awareness of BTF considerations such as food safety, nutritional adequacy and viscosity management amid variable clinician training and service capacity. Documenting needs and outcomes can strengthen applications to NDIS and state programs while advocacy for nationally consistent policies remains essential.

Earlier, Australian and New Zealand patients using HEN were surveyed about their health-related quality of life (Hinchcliff, 2023). Hinchcliff found that although HEN often improves nutrition and health, many participants experienced social limitations, emotional distress and physical discomfort. Family and carer support was important, highlighting that tube feeding is a lived experience requiring comprehensive, person-centred support and broader community awareness to reduce stigma and improve inclusion.

Together, these findings indicate that improving outcomes for people using HEN, especially those with SCI, requires not only robust, coordinated clinical pathways and clear, equitable funding (including fair consideration of BTF), but also targeted psychosocial supports and public awareness to address the social and emotional burdens of life with tube feeding.

1.3.1.3. My Aged Care

For individuals aged 65 and over or 50 and over for Aboriginal or Torres Strait Islander people, My Aged Care offers different types of care, such as:

- Maintaining independence and mobility
- Help at home
- Short-term care
- Respite care
- Aged care homes, and
- End-of-life care.

Health professionals can assist people in navigating the My Aged Care system by initiating referrals and providing necessary documentation.

Podcast: Being over 65

SCIA's Have the Nerve podcast, Over 65s, NDIS and Aged Care funding (Episode 6, 31 January 2024): This episode explores the challenges faced by older Australians who acquire a disability after age 65, comparing lived experiences of navigating NDIS and My Aged Care funding alongside insights from a systemic advocate.

1.3.1.4. Medicare: Health and Disability

Navigating Medicare's services and rules can be challenging. These links may help:

Important information: Medicare

- Health and Disability: This page provides more information about accessing Medicare and some health services at low or no cost, and
- GP chronic condition management plans: This page provides the rules about billing Medicare Benefits Schedule (MBS) items for chronic condition management and how to apply them.

Medicare's Chronic Disease Management (CDM) plan allows GPs to develop a care plan for individuals with chronic conditions, which may include:

- **Dietitian referrals:** Up to five allied health visits per calendar year, including dietitian services, to manage nutritional needs, and
- **Multidisciplinary care:** Coordination with other health professionals to provide comprehensive care.

The CDM option may benefit those who do not qualify for NDIS or My Aged Care services. Persons who have existing NDIS funding and My Aged Care services in place could also apply for services through CDM care plans. It is worth noting that CDM funding is limited and considerably less than that for the NDIS and My Aged Care. Health professionals can assist people in

navigating the My Aged Care system by initiating referrals and providing necessary documentation.

1.3.1.5. Commonwealth Home Support Program (CHSP)

The Commonwealth Home Support Program (CHSP) is an Australian Government initiative that funds service providers to deliver entry-level services, *assisting older individuals* to maintain their independence and stay at home.

CHSP services are designed for older people who need some help to stay at home. These services can be:

- **Short-term:** Temporary assistance to address specific needs
- **Episodic:** Intermittent support aimed at improving function or capacity, and
- **Ongoing:** Regular support to maintain independence.

Generally, CHSP services are not intended for:

- Individuals with intensive, multiple or complex needs
- Permanent residents of aged care residential facilities, and
- People whose needs are better met by other aged care programs.

Under certain circumstances, CHSP services can also be provided to individuals, including those already registered with the Disability Support for Older Australians Program and those receiving a Home Care Package. The 2025-2027 CHSP offers five categories of services, which can be accessed in this one-page document, with each sub-program offering a range of services.

Important information: CHSP services

The 2025-2027 CHSP Manual provides detailed descriptions of services that are out of scope for each CHSP service type and what CHSP funding cannot be used for.

For more detailed information, you can refer to the Manual and Catalogue from the links below:

- Commonwealth Home Support Programme (CHSP) Service Catalogue | Australian Government Department of Health, Disability and Ageing, and
- Commonwealth Home Support Programme (CHSP) Manual | Australian Government Department of Health, Disability and Ageing.

1.3.1.6. Compulsory Third Party (CPT) insurance

Although it does not receive federal support, Compulsory Third Party insurance is a state-regulated scheme that provides compensation to people injured in motor vehicle crashes caused by another driver. In Queensland (QLD), the scheme is regulated by the Motor Accident Insurance Commission (MAIC) and is paid together with vehicle registration. If an individual's SCI was caused by a motor vehicle accident in Queensland, a CTP claim may fund treatment, rehabilitation and certain home or vehicle modifications as reasonable damages through the insurer's claims process.

Important information: QLD CTP and NSW, as examples

- Use the Queensland CTP portal to lodge claims and request rehabilitation
- For more information, visit the MAIC (QLD CTP regulator) website, and
- Service NSW CTP Care.

1.3.1.7. Department of Veterans' Affairs (DVA)

The Department of Veterans' Affairs (DVA) is a federal department that supports eligible veterans and dependents, so its services receive federal support. Support for eligible individuals is available through rehabilitation programmes that address medical management, psychosocial needs and vocational goals, with person-centred plans developed to promote well-being and, where appropriate, a supported return to civilian systems or work.

DVA also provides aids, equipment and home modifications via the Rehabilitation Appliances Programme (RAP) for Gold and White Card holders with an assessed clinical need. RAP items can include home modifications, assistive technology and other prescribed supports, ordered by appropriately qualified clinicians in line with RAP schedules and clinical governance.

Important resources and information: Veterans' Affairs

DVA rehabilitation on the Social Support page. Aids, equipment and home modifications (RAP) links:

- Living independently overview
- RAP information in legislation reform resources.

1.3.2. State and Territory support and services

While there is federal support, particularly in terms of funding, rehabilitation and health and well-being maintenance is largely State-based (**Figure 1.1)**. It is important to note that the level of support in different states varies. **Dr Priya Iyer**, a dietitian who contributed extensively to this e-resource, wrote:

> *"NSW and Qld have different support systems in terms of nutrition support. From my experience discharging patients to NSW-Qld borders, I noted that Queensland is more generous with HEN (Home Enteral Nutrition) support".*

An interactive H5P element has been excluded from this version of the text. You can view it online here: https://bond.studium.pub/life-well-lived-with-spinal-cord-injuries/?p=64#h5p-1

Figure 1.1. An interactive map of Australia highlighting the various State and Territory SCI services. Created by Jaclyn Szkwara using Canva and HP5, licensed under a CC BY-NC (Attribution NonCommercial).

Important information: Wound care services

- Community nursing supports wound care at home by providing assessment, treatment, and ongoing monitoring to promote healing, prevent complications and support safe recovery in the community.

- NDIS may fund these supports when a person's disability means they cannot monitor or manage wound or pressure care on their own, or when wounds are caused by the disability; the health system remains responsible for general clinical treatment, while NDIS funding focuses on disability-related need and day-to-day management.
- Wound care through the NDIS can include private wound nurses and allied health professionals. Wound-certified nurses and podiatrists may be funded under Core Supports or Capacity Building supports in an NDIS plan (Support budgets in your plan, NDIS).
- Wound clinics are available in some LHDs and outpatient rehabilitation centres (see interactive map for links to outpatient rehabilitation centres in your state).

1.3.3. Not-for-profit (NFP) organisations

Several non-profit organisations (NFPs) support individuals with SCI and related conditions, providing resources, advocacy and research funding. Key aspects of NFP SCI organisations include:

- **Support and advocacy:** NFPs provide essential support services, including rehabilitation, therapy and emotional support to help individuals with SCI maximise their independence and quality of life. They also advocate for policy changes that benefit individuals with disabilities
- **Research funding:** NFPs play a vital role in funding research into SCI, hoping to find treatments and eventually a cure. They support both basic research and clinical trials, contributing to advancements in the field
- **Raising awareness:** NFPs raise public awareness about SCI, their impact and the importance of injury prevention. They also educate the community about available resources and support services, and
- **Community-building:** NFPs often foster community building by connecting individuals with SCI and their families through peer support groups and other initiatives.

Examples of NFP organisations focused on SCI, some of which have already been mentioned, include:

- SpinalCure Australia: A leading national NFP dedicated to advocating for and funding spinal cord injury research.
- Wings for Life: A not-for-profit foundation that supports spinal cord research worldwide.
- Spinal Life Australia: The mission to enable those living with a disability to live an accessible, equitable and empowered life. To support this mission, Spinal Life Australia developed the 'Spinal Life Way', a set of guiding principles that drive how to show up and do the work worth doing.
- estara: A South Australian charity that has been supporting people with SCI and other disabilities to live independently, safely and with choice since 1963.

- Spinal Cord Injuries Australia (SCIA): Offers peer support, advocacy and information services to individuals with SCI and their families.
- Forward Ability Support (FAS): Offers a range of services tailored to the needs of individuals with SCI: Clinical services: Specialists in delivering community-based services for SCI and related conditions, including continence and wound care product application advice, continence consults and assessments; Personal care: Assistance with daily living activities, promoting independence and dignity: Accommodation: Providing suitable living arrangements for individuals with SCI; Membership benefits: Access to the Pharmaceutical Benefits Scheme (PBS) for bowel care medicines, among other services.
- Spinal Network: Supports Australian clinical research, maintains a directory of services and provides resources and community information, and
- Sargood Foundation: A deductible gift recipient (DGR) registered charity with 25% ownership of the facility, with the others being private benefactors and icare. Actively fundraise to help support an extensive program that provides people living with SCI with opportunities to live life to the fullest.

1.4. Finding a carer or support worker

Important resources: icare guide

The icare Guidance on the support needs of adults with SCI includes many resources for carers.

Contributions to this section are from two support workers: **Daniel Broadman**, Perry's support worker for more than 15 years and **Emma Simpson**, now an OT but who worked as a support person for two clients in Brisbane.

1.4.1. What is the difference between a carer and a support worker?

It is probably worth starting this section with a definition of what a carer is *vs.* a support worker. A carer is usually a family member or a friend, while a support person is someone assigned to you through your disability funding. In many cases, carers are immediate family. In some instances, a carer is a parent; in others, a child cares for a parent. It may also be that a sibling

takes on the responsibility, or that siblings share it. Partners and spouses also often take on the role of carer. Americans tend to use 'caregiver'.

In **Dinesh Palipana**'s case, his mother, **Chithrani**, became his carer and remains so. Their story is below: From a 2022 Sydney Morning Herald article:

Dinesh's story: A dedicated mum

When **Dinesh** became a quadriplegic, people said his dream was over. It wasn't. Dinesh describes the role of his mother, his carer, **Chithrani**, in getting him to where he is after a car accident left him a quadriplegic:

"Overnight, I went from being a carefree, independent 25-year-old to having no control over anything". With a C6/7 SCI, everything below Dinesh's chest was paralysed. He was told that his dream of becoming a doctor was over, but Dinesh says that people had not banked on him having a secret weapon: His mum. When referring to her, he explains: *"Mum's a lioness: strong, resilient and persevering, yet patient and gentle. She has been through a lot, but always manages a smile."* For Chithrani, at the time of the article, *"It's 12 years since the accident and I've not had a break, but that's what mothers do. I always give him space because I can walk away: he can't."*

For those with access to LinkedIn, in early 2026, Chithrani reflected on the fateful night on 31 January 2010, when **Dinesh** sustained his SCI. Sixteen years later (January 2026), he was invited to give a keynote address in Sydney on the same night of his accident.

Listen to **Dean Durman**'s one-minute excerpt from his 2026 interview with **Dinesh:** A mother's love. In late March 2026, **Dean** also interviewed **Chithrani Palipani**. **Chithrani** talks about her life after **Dinesh's** accident (from about 13 minutes in the video).

1.4.2. How do I find a support worker and what do they do?

Finding the right support worker is a crucial step in maintaining independence, dignity, and quality of life after SCI. Options include hiring through an NDIS-approved provider, employing privately through platforms such as Mable (Find local support workers for disability and aged care) or Hireup (Your life, supported – NDIS Support Workers).

1.4.3. If my carer is a family member, can they be compensated for their work?

It is tough being a carer, and it is often unrecognised 'work'. Fortunately, Australia's Carer Recognition Act 2010 makes provision for carer compensation. This Act recognises the role carers play in providing daily care and support to a relative or friend who has a disability, a medical condition (terminal or chronic illness), a mental illness or is frail due to old age. The Act formally acknowledges this valuable social and economic contribution and complements carer recognition legislation already in place in some states and territories. The Act includes the 'Statement for Australia's Carers', with 10 key principles that describe how carers should be treated and considered in terms of policy, program and service delivery (see below).

Important information: Carer compensation

Carers can now be compensated for their services through Services Australia, which has a carer payment, carer allowance and income support payments, such as disability support pension, youth allowance for students and Australian apprentices, age pension, parenting payment, Department of Veterans' Affairs payment. There is also an annual carer supplement. There are too many to provide all the details here, as circumstances differ, so please take a look at the site to find information relevant to your situation.

Important information: Australia's Carers (Carer Recognition Act 2010)

- All carers should have the same rights, choices and opportunities as other Australians, regardless of

age, race, sex, disability, sexuality, religious or political beliefs, Aboriginal or Torres Strait Islander heritage, cultural or linguistic differences, socioeconomic status or locality
- Children and young people who are carers should have the same rights as all children and young people, and should be supported to reach their full potential
- The valuable social and economic contribution that carers make to society should be recognised and supported
- Carers should be supported to enjoy optimum health and social wellbeing and to participate in family, social and community life
- Carers should be acknowledged as individuals with their own needs within and beyond the caring role
- The relationship between carers and the persons for whom they care should be recognised and respected
- Carers should be considered as partners with other care providers in the provision of care, acknowledging the unique knowledge and experience of carers
- Carers should be treated with dignity and respect
- Carers should be supported to achieve greater economic wellbeing and sustainability, and where appropriate, should have opportunities to participate in employment and education, and
- Support for carers should be timely, responsive, appropriate and accessible.

1.4.4. Do carers and support workers need a qualification?

Generally, the answer is No, but for support workers, employers may prefer candidates with a relevant vocational qualification, such as a Certificate III in Individual Support (CHC33015). There is a range of training opportunities for carers. More information can be found in the Disability Support Guide. This site provides guidance on becoming a support worker, although the term 'carer' is used throughout.

The Australian Government, in conjunction with training.gov.au, offers an Australian Skills Quality Authority (ASQA) accredited course, 11323NAT Supporting an individual with a spinal cord injury. The course provides participants with the skills and knowledge to support an individual with SCI, such as supporting individuals' transfer location and managing a neurogenic bladder, bowel, skin care, respiratory health and ***Autonomic dysreflexia (AD)***.

TAFE Queensland offers courses that can prepare carers to support individuals with SCI. Specific course options include:

- Certificate III in Individual Support (Disability): An entry-level qualification that focuses on providing support to individuals with disabilities, including those with SCI, in home and community settings.
- Certificate IV in Allied Health Assistance: This course provides a broader understanding of the healthcare system and can include specialisation in rehabilitation and movement and mobility; and
- **Additional training:** Short courses or skill sets, focusing on specific areas, such as emer-

gency care for suspected spinal injury. Allens Training and Sports Medicine Australia offer these courses.

Key skills and knowledge gained include:

- **Understanding SCI:** Learn about the different types of spinal cord injuries, their impact on the body, and the individual needs of people living with them
- **Safe manual handling:** Gain practical skills in using equipment and implementing safe manual handling techniques to transfer individuals with spinal cord injuries
- **Neurogenic bowel and bladder care:** Learn about managing neurogenic bowel and bladder functions
- **Skin and respiratory care:** Understand the importance of managing skin conditions and respiratory issues in individuals with SCI
- **Emergency care:** Learn to identify, assess, and respond to AD, a potentially dangerous condition, and
- **First aid:** Skills in providing first aid and emergency care for suspected spinal injuries.

In NSW, there are various pathways to access qualified support, from personal recruitment to services provided under the NDIS. Carers and support workers assist with a wide range of tasks, including personal care, mobility support, domestic duties, transport and social participation. It is essential that they not only have the necessary qualifications but also a deep understanding of the needs and rights of people with SCI. Information about how to become a support worker can be found at this site.

In NSW, a support worker or carer is generally expected to hold a Certificate III in Individual Support (Disability), Aged Care or a related field. Some roles, particularly those involving complex care, such as bowel and bladder care, hoisting and pressure injury prevention, may require additional SCI-specific training. First aid certification, manual handling training and a Working With Children Check (if supporting minors) or an NDIS Worker Screening Check are usually mandatory. Some people may also prefer carers with lived experience or specialist training in spinal care or neurogenic management.

Ausmed offers a range of courses, training modules, on-demand lectures and articles to upskill carers. Short courses for carers, such as complex bowel care for NDIS support workers, chronic wounds, caring for a urinary catheter, lifestyle risk factors for those with disability, and ulcers and diabetic emergencies.

Forward offers a nationally accredited Course in Supporting an Individual with a SCI designed to develop the knowledge and skills required to provide high-quality support in residential, community-based and primary care settings. The course comprises six accredited units of competency and includes:

- Supporting individuals with safe transfers and manual handling
- Managing a neurogenic bladder and bowel
- Skin care

- Respiratory health, and
- Recognising and responding to *autonomic dysreflexia (AD)*.

1.4.6. What do carers and support workers do every day or nearly every day?

Below is **Emma Simpson's** account of her experiences as a support worker.

Emma Simpson's story: A support worker's perspective

"Supporting someone with SCI is more than a job. It is a relationship, a commitment, and an incredibly rewarding journey that is built on everyday moments. As a support worker in Queensland, Australia, I have witnessed first-hand the unique challenges and triumphs that come with life post-injury.

Support workers play a role in the daily living, rehabilitation, and long-term well-being of people with spinal cord injuries. The best outcomes happen when support workers are seen as collaborative partners who respect autonomy, promote independence, and honour the person's preferences and lifestyle. Support workers can assist in:

- *Personal care routines (e.g. hygiene, grooming, toileting)*
- *Daily living activities (e.g. meal prep, driving, errands)*
- *Exercise and rehab support (e.g. mobility programs, hydrotherapy)*
- *Social and community participation*
- *Emotional support and companionship*
- *Navigating services, such as NDIS, My Aged Care and medical appointments.*

Achieving seamless care from care support workers comes when support workers understand both the functional impacts of SCI and the individual's goals and preferences. The types of day-to-day support needs required are usually worked out with your allied health team, doctor and the provider through speaking with the person with SCI, doing assessments and understanding relevant medical information.

Having support workers trained specifically in spinal cord injury care is essential. SCI presents incredibly unique medical, physical, and functional needs that must be understood to provide safe and effective support. Key areas of specialised training include:

- ***Manual handling and transfers:** Safe use of hoists, slide sheets, and correct lifting techniques are critical for preventing injury to both the person and the worker*
- ***Pressure injury prevention:** Understanding how to identify early signs of skin breakdown and support regular pressure relief schedules.*
- ***Catheter and continence care:** Training in catheter management and hygiene practices to reduce risk of infection and promote dignity*

- *Autonomic dysreflexia awareness: Recognising the signs of this potentially life-threatening condition, such as sudden high blood pressure, pounding headache and sweating, and knowing how to respond, and*
- *Respiratory care and support for high-level injuries: Some individuals require ventilator support or assistance with coughing and secretion clearance.*

Support workers trained in these areas contribute not only to safety, but also to a person's confidence and trust in their care.

When building a support team, someone may choose to either privately source their support workers or engage workers through a registered provider or agency. Each option carries its own advantages and challenges. Privately sourcing support workers often allows for greater flexibility, control and the opportunity to build long-term relationships with hand-picked staff. It may also provide cost-savings, as overhead fees charged by agencies can be avoided. This approach, however, places administrative responsibility on the individual or their family including recruitment, rostering, payment, insurance, training and managing compliance with legal obligations. In contrast, using a registered provider offers a streamlined and often safer process, where workers are vetted, trained, insured and replaced if unavailable at the last minute. Providers manage much of the back-end work and can offer additional services like case coordination. The trade-off may, however, be less control over who is sent, less flexibility in routines and higher hourly costs. Choosing the right option depends on the individual's capacity, preferences and the complexity of their care needs."

Emma concludes with the following reflection:

"A key principle of effective support work is promoting independence, not by withdrawing support, but by offering it in a way that enables the individual to participate in their own care to the extent they choose and are able. This involves understanding the difference between doing something for someone, to someone or with someone. These distinctions matter. Doing something for someone might be appropriate when they are tired or prefer not to engage in the task. Doing something to someone without their involvement or consent can feel disempowering. Supporting someone with a task such as brushing their hair together, assisting with dressing while they direct the order, or talking through the steps of a transfer can preserve autonomy, build skills and foster dignity. Encouraging a person to reflect on what level of participation feels right for them day-to-day honours their independence while respecting their changing energy, ability and mood. It reinforces that they are in control of their own life, with the support team acting as facilitators rather than directors of care.

Through my support worker's lens, I have seen that the most fulfilling and stable care arrangements are built on mutual respect, clear and organised routines and systems and consistent communication. As support workers, we must remember that our role is not to "fix" or "rescue," but to empower. Empowerment comes through listening, learning, adapting, and showing up day after day with patience and care. The most important role as a support worker is to adjust your care to the individualised needs of the person in front of you. There is no 'cookie cutter" approach to support work.

To individuals living with SCI, and the families and workers who support them, keep building your team, refining your systems and investing in the life you want. A good life is absolutely possible and support work done well can be an important part of making it happen.

While working as a support worker, I have had the privilege of working with individuals at very different stages of life, each with unique routines, values and definitions of independence. One person I supported was in their early 40s, balancing life after SCI with a full-time job, an active social life and several personal hobbies. For them, our evening routine was a crucial anchor point in their day. My support focused on helping them wind down physically while staying prepared for the demands of the

next day whether that involved early work meetings, social events or creative pursuits. Together, we would review the next day's schedule, prepare clothing, equipment, and meals and ensure everything from wheelchairs to communication devices were charged and ready. We kept the routine efficient but flexible, making space for conversation and small rituals. My presence was not just about completing tasks, it was also about helping them protect their energy and time so they could fully participate in the parts of life that mattered most to them.

In contrast, I also supported someone in their late 70s, who valued quiet, structure and familiarity. Our mornings were slower and more methodical, often including gentle assistance with transfers, help preparing a preferred breakfast, and taking time for conversation. The priorities here were comfort, safety and routine, plus knowing exactly where everything was and doing it the same way each day. We planned for the week together, prepared for medical appointments and reflected on life stories as part of the care.

These experiences have taught me that support work is never one-size-fits-all. It is deeply relational and shaped by age, life stage, personal identity and daily rhythm. The most important thing is understanding what matters most to the person and then aligning your role to help them live their version of a good life."

Key recommendation: Meal assistance

If you require assistance with meals, your support worker plays a vital role in ensuring your nutritional needs are met. It is crucial they understand your dietary needs and restrictions, are trained in safe food handling and basic nutrition and can work collaboratively with your healthcare team, especially your dietitian.

1.4.7. Caring is time-consuming and emotionally demanding: Support for carers

For most carers, who are likely to be parents, siblings, children or partners, it will be emotional and will involve many hours a day. It may interrupt studies, careers and it may result in separation and divorce. It will likely have financial repercussions. It may also take a physical and physiological toll on the body. A quick look at this Caregiver Strain List offers some insight into the challenges carers could face.

Reminder: Finding your connection

Refer to **Teresa Blair's** story earlier on coping as a carer during COVID-19. She used her connection to Country to get her through the difficult times. In **Chapter 3**, we recommend getting out into Nature for well-being.

Chithrani Palipana's story: Becoming a Rehabilitation Counsellor

"I lost my job soon after Dinesh was injured. So, while Dinesh was going through medical school and I was sitting at Griffith Uni, I also did a Masters in Rehabilitation Counselling and then we managed [financially].

A lot of carers are not supported at all. They don't know where to go. They don't have mental support. They don't have emotional support. They have nothing. So, I think that is a good thing if someone can reach out to them and give them some support with the NDIS where you could access counselling through the participant's funding. But many of them are not aware of it and also with the newly injured as a rehabilitation counsellor.

We also do get adjustment to injury counselling and that is also not happening for someone who is getting out of a hospital with a new injury and they withdraw from society. They just think they can't go back to what they were doing. There are people who can assist them, but that is not really recognised or they don't have the awareness either."

Stories: Listen to how SCI affects more than the individual

- Listen to 40 Voices, an informative podcast for families affected by childhood SCI and dysfunction, with input from parents on how they have coped when their child sustains SCI. You will also hear the voices of adults who, as children, had sustained SCI and the role of their mother or parents.

- SCIA's Have the Nerve podcast, Something to think about – Where is the support for spouses and partners (Episode 35, 2 February 2024): **Forrest Campbell** talks about his observations about the lack of peer support for his wife when he sustained his SCI in 2015. Transitioning to a new life was not just felt by him; it became very real for his wife as well. When they looked for genuine support, they found none.

Key resources and information: Australian Carers Guide

- The Australian Carers Guide website has just been updated for 2025 (Understanding Carer Payment and Carer Allowance). Although the site is aimed largely at carers of the elderly, it has useful information such as a self-care section, with advice on sleep, loneliness and cooking tips, amongst other things. The National Carer Week website also offers lots of advice. Through this website, carers can link to the State National Carer Network Associations. This is the link to the NT Association as an example
- Each State will have carer benefits. In NSW, a good resource in terms of carer support and benefits is the NSW Carer site. In Queensland, carers can apply for a Carer Business Discount Card, with the website having both a search box and an interactive map of businesses offering discounts
- Besides the emotional strain, caring takes a physical toll on the body. The Queensland Spinal Cord Injuries Service published a Fact Sheet on back care when caring for a person with SCI in 2020, which was due to be reviewed in 2022, and
- SCIA's Peer support program: You can send a message with a query or request.

1.4.8. What does the research tell us about the impacts of caring and how carers cope and what supports they may need?

Below are a few recent publications exploring caring for a family member with SCI.

Research: Impact on carers and how they cope

- Resilience in the initial year of caregiving for a family member with a traumatic spinal cord injury: This study found that a large percentage of individuals are resilient in the initial year of caring and those who have problems adapting exhibit significant distress soon following the traumatic event. Early detection of and psychological interventions for individuals who have difficulty adjusting are indicated, as their distress is unlikely to abate if untreated over the year.
- How do family members of individuals with spinal cord and acquired brain injuries make sense of their experiences: A qualitative study of meaning-making processes: The study explored the processes that promote coping with disruptive life changes, often experienced as life before and after injury. The concept of meaning-making was used as the theoretical framework for analysis. Family members of individuals with SCI and acquired brain injury participated in two focus groups, three to 23 years post-injury. Two main themes were identified: ***Drawing upon different coping strategies and balancing family needs against personal autonomy*.** Making sense of an altered situation was by keeping a positive outlook, making comparisons to worst cases, engaging in activities and making room for one's own needs. Thus, the study illustrates that life can continue in a good way after adversities but requires flexibility and adjustments.
- A recent systematic review of the health outcomes and psychosocial implications for young carers (below 25 years of age) suggests a small-to-moderate risk of poorer mental health among young carers, with stronger effects for subgroups such as high-intensity carers. The impact on physical health was inconclusive. Social connections appear to play a key part in young carers' mental health. The authors recommend large-scale longitudinal studies to investigate the inconsistent findings. Unequal conditions of care relating to individual and situational factors could affect young carers' health.

1.5. Health professionals and others involved in your care at home

When you transition home, your rehabilitation will continue. You will also need to adjust to living outside the healthcare system. A range of health professionals will continue to support your rehabilitation and adjustment. Below, relevant health professionals provide their perspectives on how they can help you adjust to daily living and stay healthy and psychologically strong. Some HPs are involved in your longer-term adjustments, such as returning to work, which may require learning new skills, as you may not be able to undertake the same work. **Chapter 5** explores returning to work.

Upon discharge from rehabilitation, supporting your return home requires a coordinated multidisciplinary team, including a peer supporter, as is shown in **Figure 1.2.**

An interactive H5P element has been excluded from this version of the text. You can view it online here:
https://bond.studium.pub/life-well-lived-with-spinal-cord-injuries/?p=64#h5p-2

Figure 1.2. Health professionals and others who will likely be involved in getting you settled at home. Click the ⊕ symbol for an explanation of their roles for this stage of care. Created by Jaclyn Szkwara using Canva and HP5, licensed under a CC BY-NC (Attribution NonCommercial).

Important resource and information: Who is on my healthcare team?

- SCIA has provided the SCI Rookie Book – Who's who and how can they help?
- A recent *Conversation* article highlights the role of OTs in Australia in terms of support in independent living, from teaching you to cook (if you are able) to helping you navigate public transport.

The health professionals will collaborate in your care by working as one team, pooling their assessments, goals, treatment steps and progress updates to build a smooth, person-focused plan that keeps both you and your carers in the loop, safe and feeling empowered. At the very start, the team meets to figure out what you need, shares assessment findings, co-designs goals with you and identifies key priorities. For example, the physiotherapist looks at your movement, strength and breathing. The OT checks how your home environment supports you. The dietitian assesses your eating habits and bowel health, while the speech pathologist tests your swallowing and speech. The pain specialist and exercise physiologist look to identify what triggers your pain and how much activity you can handle. The social worker explores emotional or financial difficulties. Together, they select the top priority goals, whether that is getting in and out of bed on your own or eating safely and then develop a single care plan.

Next, the health professional team creates a plan that allocates who does what, when and how success will be measured. Each health professional adds step-by-step actions, timelines and expected results under the goals you all agreed on. Everyone uses the same measurements, such as how often you need to shift positions to avoid pressure sores, muscle-strength scores or pain ratings to see how you are improving. Meanwhile, the social worker supports the organisation of referrals and funding so that any equipment, home changes or community services arrive on time. Your carers get a single integrated schedule that shows therapy sessions, doctor reviews, and training workshops in a single view.

Sometimes two or more health professionals will run an integrated session, so you and your carer(s) learn consistent techniques and save time. For example:

- An OT and physiotherapist might lead a workshop on transferring safely, teaching you movement tips and how to use adaptive equipment.
- The exercise physiologist may partner with the pain specialist to tweak work-outs based on your pain-management plan, and
- The dietitian and speech pathologist may team up to design texture-modified diets that hit your nutrition targets while keeping swallowing safe.

Your team keeps in touch regularly to stay on the same page as your needs change. They hold multidisciplinary meetings where each health professional shares wins, raises concerns and provides updates on the care plan. For urgent questions, like sudden changes in bowel routines or muscle tightness, the team works with your case manager or care coordinator, who will liaise directly with your primary health carer, which will be either a Rehabilitation Specialist or a GP, so nothing slips through the cracks and is addressed promptly.

Beyond these core steps, your team might use telehealth platforms for remote check-ins, share a mobile app to log your daily progress or connect you with a peer mentor who's been through a similar journey. These extra layers mean you and your carers never face a hurdle alone and ensure optimal care is provided when you return home. This multidisciplinary approach is essential to promote independence, prevent complications, and support long-term quality of life at home.

While nutrition will be discussed in detail in **Chapter 3**, below is a list of useful dietetics-related guidelines and toolkits.

Important resources and information: Dietetics-related guidelines and toolkits

- Identification and Management of Cardiometabolic Risk after Spinal Cord Injury (PMC): A clinical practice guideline providing evidence-based recommendations for assessing and managing cardiometabolic risks in people with SCI
- Can-SCIP (Guidelines for Living): A comprehensive set of practical guidelines to support day-to-day living and long-term health for people with SCI
- SCIRE Professional: An evidence-based resource summarising research on spinal cord injury rehabilitation and best practice clinical care
- MedlinePlus SCI: A consumer-friendly overview of spinal cord injuries, including causes, symptoms, treatment and recovery information
- State Spinal Cord Injury Service – ACI Resources: A clinical guidance hub offering resources and tools for healthcare providers caring for people with SCI
- ACI Pressure Injury Toolkit: A toolkit supporting the prevention and management of pressure injuries in people with SCI and spina bifida.
- ASIA e-Learning Center: Online education modules and training materials focused on SCI classification, assessment, and care

- Actionable Nuggets (PMC): A knowledge-translation tool that provides simple, actionable insights to improve self-management for people with SCI
- WHO Package of Interventions for Rehabilitation – SCI Module: A global clinical guidance resource outlining recommended rehabilitation interventions for SCI
- Nutricia at Home: A service providing nutrition support products and home delivery for people with clinical nutrition needs
- Abbott Nutrition: A provider of nutritional products designed to support people with various health and dietary needs
- NCare (Nestlé Health Science): A home-delivered nutrition service offering medical nutrition products for people requiring specialised support
- Fresubin: A range of nutritional supplements specifically designed for people needing medical and therapeutic nutrition support
- Flavour Creations: A nutrition company offering texture-modified foods and ready-to-drink supplements to support people with dysphagia and specialised dietary needs, and
- eLearnSCI: A comprehensive online educational platform covering foundational and advanced knowledge on SCI (noting this appears as a textbox within a book).

Below, Gold Coast GP, **Dr Kieran Le Plastrier**, describes the importance of GPs in the care of individuals living with SCI.

1.5.1. Role of a General Practitioner (GP)

Having a good GP, your local family doctor, is vital after SCI. SCI is not just about paralysis. It can affect nearly every system in the body. This will be explored in detail in **Chapter 2** of this e-resource. People living with SCI are at higher risk of issues, such as *urinary tract infections (UTIs),* bowel problems, pneumonia, pressure sores and chronic pain (Mann *et al.,* 2007). Many of these secondary conditions can be prevented or managed with regular medical check-ups (Borg *et al.,* 2024). A GP helps monitor your overall health, manage medications, and catch problems early. In fact, spinal rehabilitation specialists in Australia encourage every patient to see their GP soon after leaving rehabilitation and to have regular check-ups (NSW Agency for Clinical Innovation, 2013).

Importantly, GP clinics need to be accessible. Modern Australian standards require clinics to provide wheelchair access under disability discrimination laws (Mann *et al.,* 2007). This means if you use a wheelchair, you should be able to enter the doctor's office, navigate hallways and use the exam rooms safely. Many clinics have installed ramps or widened doors to meet these standards. If your current GP's office is not accessible, you may need to find a different clinic or arrange home visits (RACGP Standards for General Practice):

> *"**Standard 5.1.3 A:** There is wheelchair access to our practice and its facilities, or if physical access is limited, our practice provides home or other visits to patients with disabilities or special needs."*

Key recommendation: Find a GP as soon as you can

Some GP practices offer home visits or telehealth if patients cannot travel (RACGP Standards for General Practice). It is wise to include your GP in your discharge planning. Let the hospital or spinal unit know who your doctor is, so they can send records and collaborate on your ongoing care.

Access to primary care can vary across Australia's states and territories. All states have specialist spinal injury units, usually in major hospitals, and often outreach services to support people once they return home. For example, Queensland, New South Wales and Western Australia have spinal outreach teams that work with local health providers, some of which are highlighted on the map of State and Territory Services in this Chapter. Whilst they provide specialist support, your GP remains the first point of contact for day-to-day health issues. In some cases, outreach staff or community nurses can visit your home to assist with specific needs, such as wound care for pressure injuries in collaboration with your GP. Different funding schemes (like state health services, the NDIS, and motor accident insurance programs) may provide various supports, but coordinating them can be complex. A GP can help coordinate referrals to specialists and other health professionals, such as physiotherapists and OTs, to ensure your health and well-being needs are part of your overall support plan (Mann *et al.*, 2007; Borg *et al.* 2024).

One challenge is that not all GPs have detailed knowledge of SCI. SCI is a relatively specialised area. Many GPs may have no SCI patients. An Australian study found that over half of people with SCI would switch to a GP who had more knowledge about their condition if they could, highlighting the importance of expertise and presumably experience (Mann *et al.*, 2007). To address this, some GPs pursue additional training or use tools like structured health assessments for SCI (Mann *et al.*, 2007). When choosing where to live, it may be beneficial to find a GP with an interest or experience in disability care. Larger communities or city areas might have GPs who work closely with rehabilitation specialists or who participate in care networks for people with disabilities (Queensland Health, 2024). If you live in a smaller town, you can still educate your GP about your needs. Specialists can provide guidelines and spinal outreach services can give your GP advice via phone or telehealth (Queensland Health, 2024). Don't be afraid to ask a prospective doctor if their practice is comfortable managing a patient with SCI. A good GP will be honest and willing to learn or collaborate. More information about what a GP does to assist with maintaining health and well-being is addressed in **Chapter 3**.

Clinical resources: RACGP SCI resources

Below are three RACGP resources that provide the foundations for working with individuals who are living with SCI:

- Fitting disability into practice: Focusing on SCI
- Management of SCI in GP – Part 1 and Management of SCI in GP – Part 2.

In addition, the RACGP College provides considerable disability and inclusion training, including how to support patients to access the NDIS, such as:

- 2022 RACGP curriculum and syllabus for Australian general practice: Disability care
- Position Statement: Care and support for people with disability, and
- Resources to help GPs support patients to access the NDIS.

1.5.2. Technology and new ways to access care

Emerging technologies are making it easier to access primary care from home. Telehealth, which means consulting doctors via phone or video call, has expanded greatly. During the COVID-19 pandemic, telehealth proved especially useful for people with mobility issues.

As an example, a woman living with a 21-year-old SCI in regional New South Wales reported that virtual care was “awesome”. It saved her long drives (sometimes whole days of travel) to see doctors. She was able to do many GP appointments by phone, have pathology forms sent directly to her local clinic, and get results shared electronically with her specialists. This kind of coordination through telehealth meant she didn’t miss important check-ups and it made her feel more independent. Telehealth is now widely offered by GPs across Australia for appropriate consultations and Medicare supports it. It can be a great option if getting to the clinic is difficult, such as for routine prescription renewals or discussing test results.

Beyond standard telehealth, other innovations are on the horizon. Some people use smartphone apps or wearable devices to monitor their health (like bladder management apps or pressure sore alerts) and share data with their healthcare providers. Remote monitoring devices can track things like heart rate, blood pressure, or sleep quality from home. While these technologies are still growing, they could help detect problems early and alert a nurse or doctor. In Australia, disability support programs (including NDIS) have started funding certain assistive technologies. In the NSW example above, the woman was able to get a video-conferencing device funded through her NDIS plan. Having the right tech at home (good Internet, a computer or tablet and any needed adaptive devices) can expand your choices for medical

care. There are even trials of telerehabilitation, with physiotherapists or occupational therapists providing guided therapy sessions over video (Irgens *et al.*, 2018), which might complement the care from your GP and local health services. It is important, however, to ensure a balance, as not everything can be done remotely. Hands-on examinations, vaccinations, or emergency treatments still require in-person visits. Technology should be seen as an addition to regular care, giving more flexibility. Remember, you will need access to high-quality, reliable Internet services to access technology-based healthcare assistance.

1.5.3. Considerations for First Nations people living with SCI

For Aboriginal and Torres Strait Islander people living with SCI, there may be additional factors when returning home. First Nations people experience spinal injuries at 1.5 times the rate of non-Indigenous Australians, often due to higher rates of accidents in some communities and limited access to preventive services. Many Indigenous patients have to recover far from home, such as a spinal unit in a city, and then face a long journey back to their community. This distance can make follow-up care challenging. Culturally safe and community-based healthcare is crucial. Aboriginal Community Controlled Health Services (local clinics run by Indigenous communities) can play a key role as a primary care provider for First Nations people living with SCI. These clinics understand local culture and language, and they employ Aboriginal Health Workers and doctors who can help bridge communication between patients and hospitals. When an Indigenous person with SCI goes home, ideally, the hospital's Aboriginal liaison officers and the person's GP or community clinic will work together to create a care plan that fits the community context.

Positive steps are being taken. For instance, the Princess Alexandra Hospital Spinal Injuries Unit in Queensland has an Aboriginal and Torres Strait Islander Health Capability Officer working on making the service more culturally welcoming. They gather feedback from patients, including those from remote Torres Strait islands, on how to make the hospital and rehab experience feel "more like home," such as incorporating yarning circles and Indigenous art. This kind of cultural respect should extend to community care as well. Simple steps like having a yarning mat at the local clinic or involving extended family in SCI education can improve comfort and outcomes. Moreover, Government programs like the Medical Outreach Indigenous Chronic Diseases Program send specialists, such as rehabilitation doctors and endocrinologists, to visit remote communities periodically, which can help support local GPs in managing complex conditions.

For First Nations people and their carers, a key message is to use all available supports, including local health services, telehealth for specialist follow-ups and community programs. It might also be beneficial to connect with Indigenous peer support groups to hear from other Aborigi-

nal or Torres Strait Islander people who have gone through spinal rehabilitation and returned to community life, which can be empowering. Every person's situation is different, but maintaining strong ties to culture and community while also getting the medical care you need is possible with planning and support.

Reminder: Chapter 8

Chapter 8 covers rural, regional and remote Australia, with a section on disability resources for First Nations people.

Returning home after SCI is a major step, so planning is key. By thinking about housing and healthcare together, people with SCI and their families can create a living situation that is safe, supportive, and empowering. The goal is a home where you can live as independently as possible and a plan so that help is never far away, whether that help comes from a local GP, a visiting nurse, an online consultation or a community elder. With the right supports in place, a new home after SCI can truly be the foundation for moving forward with life, such as Western Australia's Spinal Outreach Service.

1.6. Getting around locally

Travelling can be a challenge if you are not able to drive.

Important information: Funding package in Sydney for WATs

There have been some recent developments in Sydney in terms of wheelchair accessible taxis (WATs). To this end, a $15 million funding package for wheelchair accessible taxis begins – Spinal Cord Injuries Australia, which you can book Wheelchair Book & Ride (transportnsw.info).

It is important, however, to get out and about to socialise and do things like grocery shopping, going to the gym, and attending your medical appointments. For some, cars can be modified to enable them to drive, but this may not be possible for those with quadriplegia. Your family

and friends will often take you to appointments or social events, but there are other options, such as modified taxis, buses, personal drivers and modified cars.

We refer you to **Chapter 12,** a Special Topics chapter that discusses getting around locally and travelling with SCI in more detail, including under what circumstances you can get a driver's licence, plus the trials and tribulations of travelling locally and internationally by air.

Key Take-aways

Choosing or modifying a home after SCI is not just about installing ramps and wider doors. It is also about considering how you will access healthcare and long-term support. Here are some key points to remember:

- **Accessibility and location:** An accessible home in a well-connected location can make it easier to see your GP and other health professionals. Lack of accessible housing is a common barrier, so use advocacy and support services to find or create a suitable home. Think about transportation and distance to clinics when deciding where to live, because being in a very remote area might mean more planning for medical visits.
- **Regular GP care:** Your GP will be a central figure in your life after SCI, managing preventative health and everyday issues. SCI comes with higher health needs, so regular check-ups are essential to stay ahead of problems, such as infections or pressure injuries (Mann *et al.,* 2007; Borg *et al.,* 2024). Make sure the GP's clinic is accessible, or arrange home visits or telehealth if needed. Don't hesitate to find a GP who understands your needs. Many people with SCI say they would switch to a more knowledgeable doctor if they could (Borg *et al.,* 2024). It is okay to 'shop around' for a supportive GP.
- **State and community supports:** Australia has specialist spinal injury services and outreach teams in each state that can support you and your GP after discharge. These teams provide expert advice via phone or video, helping manage issues in collaboration with local doctors and therapists. Make sure you get contact details for such services before leaving rehab. Also, explore what the NDIS can fund, such as home modifications, equipment, such as hoists or shower chairs and even assistive technology that can indirectly help you access healthcare, such as a tablet for telehealth or funding for a support worker to drive you to appointments.
- **Technology options:** Take advantage of telehealth and other technologies. Virtual GP or specialist appointments can save you travel time and reduce stress, as shown by people like Ali, who managed much of her care from home through calls and video conferences. Remote health-monitoring devices or apps might help track your health, but always use them as a complement, not a replacement, for professional medical advice. Ensure you have a reliable phone and Internet connection in your home if you plan to use these services, and
- **Cultural and individual needs:** Everyone's situation is unique. If you are from an Indigenous community or any culturally diverse background, look for healthcare providers who respect and understand your culture. Engage with Aboriginal Medical Services or multicultural health workers (Australian Government, 2023). Likewise, younger people with SCI, older adults, veterans or people with additional medical conditions may have specific needs. Make sure your home and care plan reflect your personal circumstances. For example, a ventilator-dependent person will need a home with back-up power and close links to a hospital, while someone with a lower-level injury might priori-

tise proximity to an accessible gym or workplace. **Chapter 9** provides an intersectional lens, discussing disability, including SCI, in terms of neurodiversity, being part of the LGBTQIA+ community or being culturally and linguistically diverse (CALD), perhaps as a migrant or an asylum-seeker.

Next, in **Chapter 2,** we explore the impact of SCI on your body by explaining what happens at different injury levels, then describe the impact on the various organ systems. Also discussed are the complications (secondary issues), such as urinary or respiratory infections, pressure injuries and how to avoid these often life-threatening complications.

Reminder: Relevant chapters

- **Chapter 2:** This chapter explains what has happened to your body and the implications, which will depend on the level of the injury and whether it is complete or incomplete. Also discussed are the secondary complications, such as infections, pressure injuries and *autonomic dysreflexia (AD)* and how to prevent and manage them
- **Chapter 3:** The message in this chapter is to stay healthy, well and fit through five pillars: *Good nutrition, quality sleep, physical activity, exposure to sunlight and socialising.* We added good oral and foot health to the list.
- **Chapter 4:** Tracking health and well-being is important to manage a body that is already anatomically and physiologically different.
- **Chapter 5:** Studying, socialising, and working will soon be on your mind once you have settled.
- **Chapter 6:** Ageing with SCI would be most relevant to older individuals who have SCI.
- **Chapter 7:** Children and adolescents will probably return home to their families. Chapter 7 offers insight into some of the considerations for young people with SCI.
- **Chapter 8:** For those living rurally, regionally or remotely, this chapter is relevant. There is a section on disability amongst First Nations people.
- **Chapter 9:** We are all intersectional beings. This chapter addresses some of the groups and communities that may be marginalised for one or more reasons: Homeless, incarcerated, neurodivergent, culturally and linguistically diverse, some of whom may be migrants or asylum-seekers.
- **Chapter 10:** Coming home means being out in public spaces, which may mean being on the receiving end in terms of abuse or discrimination, such as on public transport or inaccessibility of venues. The Chapter also considers sexuality and fertility, which are relevant as you rejoin family and social life.
- **Chapter 11:** It is always good to know your legal rights, just in case...
- **Chapter 12:** This chapter looks at public transport, wheelchair-assisted taxis (WATs), the process of driving for those who can, and the challenges of flying for work or on holiday.
- **Chapter 13:** As someone who is just returning home not too long after your SCI, there may be future surgeries on the horizon. Chapter 13 describes what to expect.
- **Chapter 14:** Spiritual health is part of good health and well-being.
- **Chapter 15:** Part of getting settled at home might involve thinking about which para sports are available.

- **Chapter 16:** Knowing that there are different avenues of research for SCI offers hope. Research often involves recruiting participants for clinical trials.
- **Chapter 17:** Our climate is changing, with higher ambient temperatures and more adverse weather events. Mobility is limited during cyclones and floods, while evacuations are hampered by power outages. For those with T6 or higher SCIs, the inability to regulate body temperature poses significant health risks. One of the first things on a "To Do" when returning home is to develop an emergency plan for various weather events, including a stock of water, food, spare batteries, a torch and medication.
- **Chapter 18:** Health professions education explores how members of multidisciplinary teams are trained and educated to assist with the health and well-being of individuals with SCI. The Chapter also considers inherent requirements for professional health education programs, as well as support for students who are accepted into the program or who are injured while students.

References

Bishcoff, S. C., Austin, P., Boeykens, K., Chourdakis, M., Cuerda, C., Jonkers-Schuitema, C., Lichotra, M., Nyulasi, M., Sneider, S. M., Stanga, Z., & Pironi, L. (2020). ESPEN guideline on home enteral nutrition. *Clinical Nutrition, 39*, 5-22. https://www.espen.org/files/ESPEN-Guidelines/ESPEN_guideline_on_home_enteral_nutrition.pdf

Breik, L., Barker, L.A., Bauer, J., & Davidson, Z.E. (2025). A narrative review of home enteral nutrition in Australia with a focus on blended tube feeding. *Nutrients, 17*(6), 931. https://doi.org/10.3390/nu17060931.

Borg, S.J., Borg, D.N., Arora, M. Middleton, J. W., Marshall, R., Nunn A., & Geraghty, T. (2024). Unmet healthcare needs, access to services and experiences with health providers among persons with spinal cord injury in Australia. *Spinal Cord 62*, 396-405. https://doi.org/10.1038/s41393-024-00997-4.

Craig, A., Nicholson Perry, K., Guest, R., Tran, Y., Dezarnaulds, A., Hales, A., Ephraums, C., & Middleton, J. (2015). Prospective study of the occurrence of psychological disorders and comorbidities after spinal cord injury. *Archives of Physical Medicine and Rehabilitation*, *96*(8), 1426-1434. https://doi.org/10.1016/j.apmr.2015.02.027

Hinchcliff, M. (2023). *Health-related quality of life in patients who utilise home enteral nutrition in Australia/New Zealand: Summary of survey results*. ausEE Inc. and University of Wollongong. https://www.feedingtubeaware.com.au/__static/ead32d1871f762367e9283d9976c55fd/summary-of-survey-results.pdf?dl=1.

Irgens, I., Rekand, T., Arora, M., Marshall, R., Biering- Sørensen, F., & Alexander, M. (2018). Telehealth for people with spinal cord injury: a narrative review. *Spinal Cord 56*, 643-655. https://doi.org/10.1038/s41393-017-0033-3.

Mann, L., Middleton, J.W. & Leong, G. (2007). Fitting disability into practice. Focus on spinal cord injury. *Australian Family Physician*, *36*(12), 1039-1042. https://www.racgp.org.au/getattachment/09d01ef8-fa85-4db4-9303-49e23bb6cbe9/attachment.aspx

Moran, K., Linda, B., & and Lannin, N. A. (2024). Experiences of people with non-traumatic spinal cord injuries returning home after inpatient rehabilitation. *Disability and Rehabilitation*, *46*(2), 362-368. https://doi.org/10.1080/09638288.2022.2162611

Queensland Health. (2024) *Spinal Cord Injury Service Delivery Model for Queensland.* State of Queensland (Queensland Health). https://www.health.qld.gov.au/__data/assets/pdf_file/0029/1364591/Spinal-Cord-Injury-Service-Delivery-Model-for-Queensland_Digital.pdf#:~:text=match%20at%20L2661%20pain%20specialists%2C,pain%20clinics%20may%20provide%20regular

RACGP Standards for general practices. *AGPAL Fact Sheet*. https://swsphn.com.au/wp-content/uploads/2022/04/racgp-standards-for-general-practices-factsheet.pdf.

Silver, J., Ljungberg, I., Libin, A., & Groah, S. (2012). Barriers for individuals with spinal cord injury returning to the community: A preliminary classification. *Disability and Health Journal*, *5*(3), 190-196. https://www.sciencedirect.com/science/article/abs/pii/S1936657412000477

Smith-Merry, J., Gilroy, J. & Watharow, A. (2023). The NDIS at ten years: designing an equitable scheme for the next decade. *Medical Journal of Australia*, published online 3 April 2023. https://doi.org/10.5694/mja2.51899.

van Leeuwen, C. M. C., Post, M. W. M., van Asbeck, F. W. A., Bongers-Janssen, H. M. H., van der Woude, L. H. V., de Groot, S., & Lindeman, E. (2012). Life satisfaction in people with spinal cord injury during the first five years after discharge from inpatient rehabilitation. *Disability and Rehabilitation*, *34*(1), 76-83. https://doi.org/10.3109/09638288.2011.587089.

Weber, L., Voldsgaard, N. H., Holm, N. J., Schou, L. H., Biering-Sørensen, F., & Møller, T. (2021). Exploring the contextual transition from spinal cord injury rehabilitation to the home environment: a qualitative study. *Spinal Cord*, *59*(3), 336-346. https://doi.org/10.1038/s41393-020-00608-y.

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Chapter 2. Implications of Spinal Cord Injury on your Body

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> *"I am lucky to have the health literacy to be able to navigate these problems [with my body, such as autonomic dysreflexia]. Not everyone has that. Medical training is complex. There is a lot to learn."* (p. 120). **Dr Dinesh Palipana,** in *Stronger*

Understanding SCI and its effects on the body is essential for living well, as highlighted in the introduction of this e-resource through the concept of***embodiment***. This principle recognises that the body actively shapes thoughts, feelings and interactions with the world. Mind and body are inseparable, working together to create meaning through shared experiences.

The 2013 University of New South Wales (NSW) report, Research into Maximising Life Choices for People with a Spinal Cord Injury, reinforces this view, noting that staying healthy and living well after SCI begins with understanding how your body now functions. The report also found that access to resources is critical for enabling life choices and social inclusion. Physical and emotional well-being, along with strong family support, were identified as the most important factors for achieving goals.

These factors are particularly important because during hospitalisation and rehabilitation, most care is provided by others. Transitioning home, however, requires the individual to take responsibility for health, either independently or with support, depending on the level and extent of their injury. In the early weeks and months, health professionals likely explained the implications of the injury and how the body's needs have changed. At the time, this information may have felt overwhelming and is often difficult to recall later. Taking an active role involves making informed choices. This e-resource aims to support decision-making and access to appropriate services, both of which are key to maintaining health and well-being.

This Chapter explores how SCI affects the body, including the roles of injury level and severity, the distinction between primary and secondary damage, the impact on major organ systems, and how pain occurs and can be managed. It includes personal stories, videos, podcasts and key SCI-specific information. Up-to-date, evidence-based resources for healthcare professionals are provided throughout and marked as 'clinical resources.

Understanding the effects of different injury levels and types helps individuals with SCI, family members and support workers recognise when something may be wrong and communicate effectively with health professionals, especially GPs. In his autobiography, *Stronger*, **Dr Dinesh Palipana** explains that his medical training helped him understand what was happening in his body, which enabled him to identify issues early and prevent serious complications. Drawing on his insights and those of others, this Chapter aims to support individuals, their immediate family members and support workers by using plain language to explain what is happening in the individual's body, especially immediately or soon after the incident.

Key Topics in this Chapter

- The level of an injury (cervical, thoracic or lumbar)
- The extent of an injury (complete or incomplete)
- The impact on the various organ systems of the body, such as the respiratory, renal and reproductive systems, but particularly the nervous system and the musculoskeletal system
- Secondary injuries due to the body's various responses to the primary injury
- How to prevent complications, some of which can be life-threatening, and
- How pain is felt, different forms of pain and how they can be managed.

2.1. Exploring what has happened to your body

Globally, over 15 million people are living with SCI (World Health Organisation, 2024). In Australia, one new case occurs every day, adding to the more than 20,800 people already affected. With so many lives impacted, there is a clear need for easy-to-read references so that those with SCI, as well as their families and carers, understand the implications. This Chapter presents this information in plain language to make complex concepts easier to grasp. Understanding how the spinal cord normally functions provides essential context for interpreting the extent and effects of the injury. This knowledge supports more accurate diagnosis, better and informed treatment planning and helps prevent further complications.

As illustrated in the iceberg diagram below (**Figure 2.1**), the inability to move following SCI is merely the tip of the iceberg. Depending on the level and extent of the lesion or injury, many additional bodily functions may be impacted, often in ways that are not immediately considered.

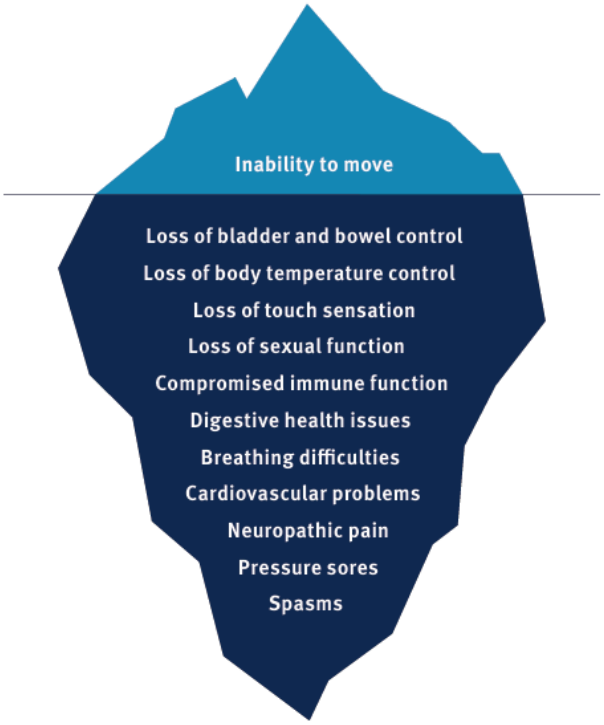


Figure 2.1. The iceberg model: The inability to move is the tip of the SCI iceberg. *Source:* Queensland Health (2024), CC BY 3.0

To understand the implications of SCI, it is important to become familiar with the normal yet complex anatomy of the spinal cord, the main pathway transmitting information between the brain and the rest of the body. The spinal cord contains various tracts that carry *sensory signals* and *motor signals* and is supplied by a network of blood vessels that ensure its proper functioning.

It is also helpful to consider the spinal cord's position within the broader nervous system, one of the body's key coordinating systems. With this background in place, the following sections outline the different levels of spinal injury (*Anatomy*) and explain how, depending on the injury level, different organ systems are affected (*Physiology*). The direct impact of a spinal injury is damage to the nervous system.

Video: Structure and function of the nervous system

Spinal Cord Injury, Animation (Alila Medical Media, 27 Sept 2022): This is a useful video as an overview of the nervous system before you read the information below about the anatomy.

2.2. Nervous system overview

Anatomically, the nervous system has two main parts:

- The *central nervous system (CNS)* comprises the brain and spinal cord, which control most body functions and information processing, and
- The *peripheral nervous system (PNS),* which comprises nerves that branch from the CNS to the rest of the body, allowing the brain to communicate with muscles, *glands* and organs.

An additional division of the PNS is the *autonomic nervous system (ANS),* which controls automatic functions such as heart rate, breathing, and digestion. These actions occur without conscious effort. Together, the CNS and PNS (including the ANS) allow the body to sense, move and respond to the environment. SCI can affect one or several components of the nervous system, leading to a wide range of symptoms and complications.

2.2.1. The spinal cord

The spinal cord is a long, tube-shaped bundle of nerves that runs down the centre of your back, enclosed and protected by the vertebral bones (*vertebrae*). In adult men, the length is about 45 cm, and in women, about 43 cm. The spinal cord begins at the base of the brain and extends to the lower back, ending around the level of the hips. The spinal cord is protected by three thin layers of supporting tissue called the *meninges*.

The spinal cord comprises four main regions, more or less in line with the vertebrae:

- Cervical (neck): C1-C7
- Thoracic (chest): T1-T12
- Lumbar (lower back): L1-L5
- Sacral (pelvis): S1-S5, and
- Coccygeal (tailbone): Co1.

The spinal cord is thickest in the neck and lower back because these areas give rise to the nerves that supply the arms and legs. In the cross-section shown in **Figure 2.2,** you can see that the centre of the spinal cord contains grey matter, shaped like a butterfly or the letter 'H'. This grey matter houses the 'bodies' of *nerve cells (neurones),* the structure of which is described in **Section 2.4.1**. below. Outside the grey matter is the *white matter*, which comprises *axons* (nerve fibres) that carry messages up and down the spinal cord. These white matter fibres can be thought of as bundles of telephone wires, each carrying a specific message either from the brain to the body or from the body back to the brain.

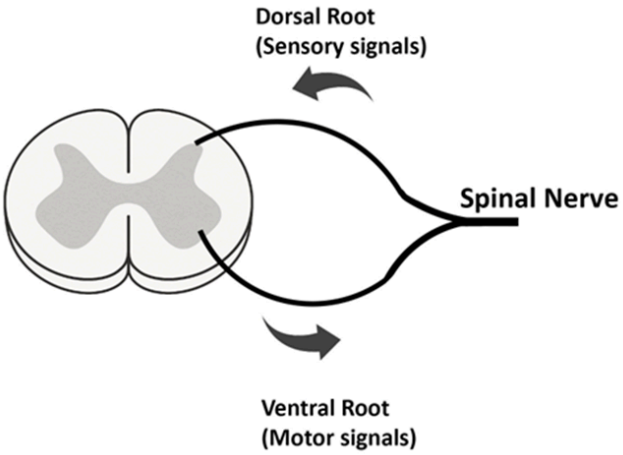


Figure 2.2. Normal spinal cord in cross-section showing the incoming (*sensory*) and outgoing (*motor*) signals. Image generated by Allan Stirling using DALL·E using OpenAI (2025).

2.2.2. Spinal nerves

These are nerves that exit the spinal cord in a specific region to travel to an area of your body, like the hand or the foot (**Figure 2.2**). Thirty-one (31) pairs of spinal nerves branch out from the spinal cord along the length of your back **(Figure 2.3)**. Each exiting spinal nerve has two roots:

- A *dorsal root* (closest to your back) brings messages from your body or the external environment to the spinal cord (or brain) and contains*sensory nerves,* and
- A *ventral root* (closest to the front of your body) sends messages to the body, such as muscles, glands and organs and has *motor nerves.*

At the end, the spinal cord becomes a bundle of nerves called the *cauda equina,* which looks like a horse's (*equina* L.) tail (*cauda* L.), hence the name.

Figure 2.3. Spinal nerves (dark yellow in the diagram) exit at each level of the vertebrae. Image generated by Allan Stirling using Adobe Firefly, Adobe Inc. (2025).

Health professionals will talk about the 'level' of your injury. This can refer to the spinal cord or the nerve level and/or the vertebral level. These are often linked to numbers, referring to either the nerve number that has been injured or the bone (vertebra) in your spine that has been damaged. This can be confusing as they are slightly different.

In terms of the vertebrae, there are:

- Seven (7) bones in your neck (cervical vertebrae), named C1, C2, C3...C7
- Twelve (12) bones in your chest (thoracic vertebrae), named T1, T2...T12
- Five (5) ones in your lower back (lumbar vertebrae) named L1, L2...L5
- Five (5) bones fused to form one sacrum, and
- Four (4) bones fuse to form a coccyx.

The nerves follow a similar naming and numbering pattern, but there is also a C8 nerve. Different medical providers may refer to SCI in different ways, but they should typically refer to the nerve level when discussing SCIs. **Table 2.1** shows the common usage of these often-confusing terms.

Table 2.1. Nerve and vertebral reference terminology used in clinical practice.

Reference used	Based on	Use in clinical practice
Spinal cord or nerve level	Neurological segment	Standard for SCI diagnosis and rehabilitation planning
Vertebral level	Bony injury location	Often used in radiology or trauma contexts

2.2.3. Functions of the spinal cord

The spinal cord is like a superhighway for messages between your brain and your body. It has three main jobs:

- **Carrying sensory information:** It brings information from your skin, muscles, and organs up to your brain. For example, if you touch something hot, the message travels up your spinal cord to your brain so you feel pain
- **Carrying motor commands:** It sends instructions from your brain to your muscles, allowing you to move your arms, legs and other body parts, and
- **Providing reflexes:** The spinal cord can also make quick decisions without the brain. For example, if you touch something sharp, your hand pulls away before you even realise it. This is called a *reflex*. Other reflexes that may be affected by SCI are the swallowing and cough reflexes.

2.3. Classification of SCIs

When the spinal cord is damaged, it is referred to as a spinal cord injury (SCI). Such injuries can occur in different ways, depending on what caused the injury and the severity of the injury. The injury can be caused traumatically through a motor vehicle accident, fall, sporting injury or a suicide attempt, often abbreviated to *TSCI* or non-traumatically as the result of a pathological disease such as a tumour or cyst or during surgery and referred to as *NTSCI*.

Any damage to the spinal cord interrupts messages to the brain and the body. The extent of this disruption will depend on whether the injury is *complete* (all feeling and movement below

the injury are lost) or *incomplete injury* (some feeling or movement remains below the injury). *Incomplete injury* subtypes include:

- *Central cord syndrome:* Most common incomplete SCI resulting from *hyperextension* injuries due to falls or motor vehicle accidents. Often features more motor (movement) impairment in the arms than in the legs, and
- *Anterior cord syndrome:* Often associated with *flexion* injuries or injuries that affect the blood supply to the spinal cord. In this circumstance, individuals have a combination of motor and sensory loss but can often still feel vibration and are aware of where their limbs are in three-dimensional (3D) space. This is called *proprioception*.

Important resources: Getting to grips with the terminology associated with SCI

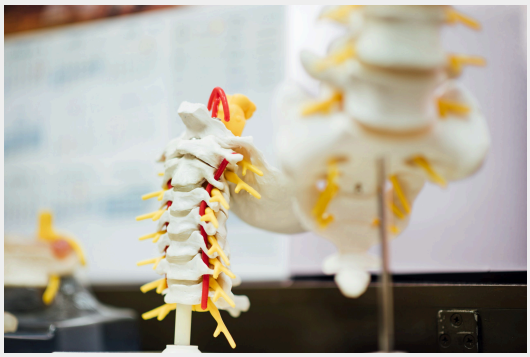
- SCIA Rookie Book for SCI Basics for SCI Supporters: The SCI Rookie Book is a beginner-friendly guide designed to help family members and new supporters understand the basics of spinal cord injury and how to find the right supports during the early stages after injury. It also provides a useful introduction to SCI anatomy.
- Understanding Spinal Cord Injury: Part 1— The Body Before and After Injury: This fact sheet provides an accessible overview of how the spinal cord and body function before and after spinal cord injury, offering foundational knowledge to help individuals understand the physical changes that occur following SCI. It also explains key terminology, such as the difference between complete and incomplete injuries.
- What is a Spinal Cord Level of Injury? This webpage explains how the level of a spinal cord injury affects movement, sensation and overall function by outlining the different spinal regions and the typical impairments associated with injuries at each level.
- A guide to common SCI terms (Shirley Ryan AbilityLab, 28 May 2025): This article provides a plain-language overview of common spinal cord injury terminology to help patients and families better understand SCI diagnoses, injury types and related medical language.

2.3.1. Location of the injury impacts function

A key consideration with SCI is where along the spine the injury or lesion has occurred. As a rule, the higher the injury (nearer the head), the more nerves will be affected and the more complications there will be. **Table 2.2** provides an overview of the symptoms, based on the injury location.

Table 2.2. Common implications based on the location of the SCI.

Location	Effects
Neck (cervical)	Can cause paralysis in both arms and legs (called quadriplegia or tetraplegia) and sometimes problems with breathing or controlling the heart.
Chest (thoracic)	Usually affects the legs and lower body, but the arms are not affected, leading to paraplegia.
Lower back (lumbar and sacral)	Mostly affects the legs, bladder, bowel and sometimes sexual function.



Video: Impact of the injury level

Spinal Cord Injury: Levels of injury (Dr Matt & Dr Mike, 29 September 2020): In this video, **Dr Matt** explains why spinal cord injuries at different levels cause different symptoms, highlighting how the injury's location affects the functions controlled below that level.

2.3.2. Why are the spinal cord tracts important in understanding the implications of SCI?

The arrangement of the spinal cord is unique. As mentioned previously, the outer part of the spinal cord, called the ***white matter,*** is where the nerves travel up and down. These nerves are bundled together in groups that share similar roles. The main pathways are shown in **Table 2.3**, which have implications following SCI.

Table 2.3. Major ascending and descending spinal cord tracts.

Name	Main function
Cortico-spinal tract	This is a major pathway from the brain to the muscles. It is responsible for voluntary motor control. Injury to this tract leads to weakness or paralysis below the level of the injury, meaning you can't move your muscles anymore.
Dorsal columns	These are bundles of nerves (or tracts) that run from your body back towards your brain. They transmit a variety of different sensations like fine touch, vibration, and proprioception. This last word refers to your body's ability to sense its position, movement, and balance without looking.
Spino-thalamic tract	This pathway transmits pain and temperature from the various nerves around your body back to the brain. If it is damaged, patients may not be able to recognise cuts, burns or pressure injuries, putting them at risk of injuries going unnoticed.

2.3.3. Common problems following SCI

When the spinal cord is injured, there is immediate damage, which is called the ***primary injury***. At first, the injury might crush or cut the nerves. A ***secondary injury*** arises from the body's response to the primary injury, which is usually the infiltration of the injured tissue by cells of the immune-inflammatory system. A primary injury is generally irreversible. The secondary injury is sometimes delayed.

From a clinical perspective, it is possible to establish acute (minutes to hours), subacute (hours to 3-4 months) and chronic (months to years) phases of the secondary injury**.** In these phases, SCI patients may suffer so-called 'spinal shock' lasting 8-12 weeks, ***neurogenic shock*** lasting 3-4 months and ***immuno-inflammatory shock*** lasting 1-4 months. Therefore, many researchers have focused on understanding the pathophysiology of secondary damage, also known as the 'secondary injury cascade', to prevent further damage due to swelling, bleeding and inflammation (Ortega *et al.,* 2023). Recovery depends on the extent of the damage and where the injury is. In some instances, it is possible to regain some movement or feeling, especially if the injury is incomplete. In other instances, the loss of function and feeling is permanent, in the case of a complete severing of the nerve. Early treatment and physical therapy can help improve recovery.

If a part or the whole spinal cord is damaged, then, depending on which nerves are damaged, problems with moving the body and feeling sensations may be experienced. As the iceberg model showed (**Figure 2.1**), SCI impacts many different organ systems in the body, resulting in a range of other issues with spasms or cramps, breathing and sexual function and, for some, regulating body temperature (**Figure 2.4**). Generally, the higher the level of injury, the more complex the 'issues'.

Interactive H5P Content:

An interactive H5P element has been excluded from this version of the text. You can view it online here:
https://bond.studium.pub/life-well-lived-with-spinal-cord-injuries/?p=87#h5p-3

Figure 2.4. An interactive diagram that highlights the main impacts of SCI on different body systems. Image generated by Allan Stirling using Adobe Firefly (Adobe Inc., 2025) and interactivity with H5P.

In summary, the spinal cord is a vital part of your body that connects your brain to everything else. It helps you move, feel, and react quickly to danger. Depending on the level (cervical, thorax or lumbar) and severity (complete or incomplete) of the damage, you may experience difficulty or an inability to move your muscles (paralysis), feel normal sensations, such as pain and your body may not be able to regulate many of its automatic functions, particularly in high-level SCIs, such as temperature and heart rate or it may affect your reflexes such as swallowing, coughing and bladder control.

The next section will describe how the nervous system works (***neurophysiology***) and will draw on the Anatomy just described above. It will also translate these effects on the body, in terms of how nerve damage impacts the muscles and reflexes.

Clinical resources: Complexities of SCIs

The following are useful resources for health professionals:

- Chopra, M., & Kumar, H. (2025). Navigating the complexities of spinal cord injury: An overview of pathology, treatment strategies and clinical trials. *Drug Discovery Today, 30*(6), 104387.

  This article explains how a TSCI begins with an initial mechanical impact on the spinal cord, which then triggers a chain reaction of biological changes that worsen the damage over time. After the first injury, a secondary process unfolds in stages: Acute (2–24 hours), subacute (2–14 days), intermediate (14 days–6 months) and chronic (after 6 months). Each stage involves distinct harmful changes in the spinal cord, including inflammation, chemical imbalances, myelin loss, oxidative stress and cell death. These ongoing processes contribute to continued neurological decline and make treatment complex.

- Molinares, D. M., Gater, D. R., Daniel, S., & Pontee, N. L. (2022). Nontraumatic Spinal Cord Injury: Epidemiology, Etiology and Management. *Journal of Personalized Medicine, 12*(11), 1872.

  Most SCIs are caused by trauma, such as accidents or falls, which is why most research focuses on traumatic injuries. But not all SCIs are traumatic and it is important to understand the difference because the causes and treatments can vary. NTSCIs are due to, for example, congenital conditions,

tumours and infections. This article summarises these causes and explains why recognising them is important for care.

2.4. Introduction to how the nervous system works (Physiology)

Physiology is the study of how the human body functions and can relate to the function of whole organs or systems, such as the cardiovascular system, right down to the individual cellular level. Neurophysiology describes how the nervous system works to keep your heart beating, your breathing, your muscles working, your glands secreting, your temperature regulated, your gut digesting, your kidneys and bladder getting rid of waste products, to mention just a few bodily functions.

2.4.1. Neurones

Before we discuss organ system level function, such as cardiovascular, respiratory and urinary concepts, we first need to describe the cell that is the functional unit of the nervous system, the *neurone* (**Figure 2.5**). Neurones are said to be 'excitable' as they change their electrical properties to cause many effects within the nervous system and body. We call these electrical signals 'action potentials', which are electrical messages that are passed along the length of neurones and allow one part of the brain or spinal cord to talk to another part or to an organ, such as the heart or bladder or tissue like muscle or *glands*, such as the *adrenal glands.*

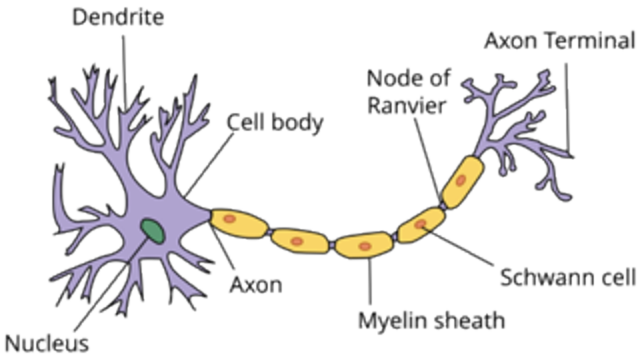


Figure 2.5. The structure of a single neurone, which has a cell body that contains numerous dendrites to receive messages and a single axon to transmit the impulse. *Source:* Wikimedia Commons, Neurone, CC BY-SA 4.0

2.4.1.1. What are the different parts of the neurone and how do they work?

Apart from the cell body, a neurone has three functional components:

- *Dendrites*, which look like a big tree with lots of branches that receive signals from other

neurones or from receptors in the different parts of the body, such as the skin and muscle
- A single *axon*, which is like a long electrical cable (and it operates like one), and
- *Axon terminals* , which end on another neurone, organ, muscle or gland and bring about a response, such as muscle contraction or a gland releases its secretion.

It is important to note that neurones are not just electrical cells (**Figure 2.6**). They respond to chemicals. At the dendrites, receptors respond to chemicals called *neurotransmitters* that are produced at the axon terminal. So, when neurotransmitter molecules bind to these receptors, the neurone changes its electrical properties. Sometimes, these chemical signals cause the neurone to fire, leading to an action potential that passes along the axon. Finally, axons eventually form axon terminals, which store and release neurotransmitters. If an action potential arrives at the axon terminal, this causes neurotransmitters to be released from the neurone.

Picture of action potential moving along neurone

Figure 2.6. Animation of an action potential. *Source:* Wikimedia Commons, Action potential, CC BY-SA 3.0

Neurones connect via *synapses.* A synapse is a single connection point between an axon terminal of one neurone, and a part of the dendrites of another neurone. Note that single neurones can form many synapses. Thus, if one neurone has an action potential that causes a neurotransmitter to be released into the synapse, this can cause another neurone to fire by activating receptors on the dendrites of the other neurone. Neurotransmitters can also have inhibitory effects and can stop neurones from firing.

Synapses allow neurones in the nervous system to form complex circuits. There can be circuits for muscle control, for the sensation of limb position, pain and bodily sensations and the control of involuntary organs involved in breathing, heart rate and blood pressure regulation. These circuits typically involve electrical action potentials being passed through the spinal cord.

2.4.1.2. How do neurones relate to SCI?

In the spinal cord, the *axons* of many neurones are bundled together into spinal tracts. Think of the spinal cord as a handful of uncooked spaghetti. The whole bundle represents the spinal cord, with each spaghetti strand the axon of a single neurone. With this in mind, one can see that the spinal cord contains the axons of many neurones. It has been estimated that there may be more than 1 million axons in the human spinal cord.

Axons can be very long. To this end, some axons start in the brain and travel all the way down to the bottom of the spinal cord. On the other hand, some axons are short, only a few millimetres. Some axons send action potentials away from the brain, which is important for muscle control and autonomic functions like heart rate control and blood pressure regulation. Axons also send action potentials towards the brain, which is important for sensory functions like balance and to feel pain. If there is an injury to the spinal cord, this can damage the axons of many neurones in the spinal cord. The affected neurones then cannot send action potentials along their length, compromising neurone-to-neurone signalling.

Neurones that send signals towards the brain can be affected by the injury (*sensory pathways*). Neurones that send signals away from the brain can also be affected (*motor pathways*). Sometimes both types of neurones are affected. Considering that there are many different types of spinal cord injury, there are also many types of neurones in the spinal cord affected by the injury. It is important to note, however, that the rest of the nervous system above and below the SCI remains intact. Yet, there are sometimes changes to the interactions between neurones above and below the injury that may lead to *secondary symptoms* in the months or years after injury.

2.4.2. Control of motor function

When considering motor function, this relates to the ability of the nervous system to activate and control the many muscles in our body. Whenever the nervous system signals to the muscles to contract, this causes muscles to shorten, which pulls on bones in our skeleton to help us move, which is why we call the muscles that move the body's skeletal muscles. This is not to be confused with the other muscle types in the body: *Smooth muscle*, which lines hollow organs like our blood vessels or airways and *cardiac muscle* in our heart. Some skeletal muscles are involved in walking (locomotion), allowing us to control our fingers to write or pick up a coffee cup, or bench press very strong weights in the gym. All these actions first require a neural command signal to be sent from the nervous system to the muscles.

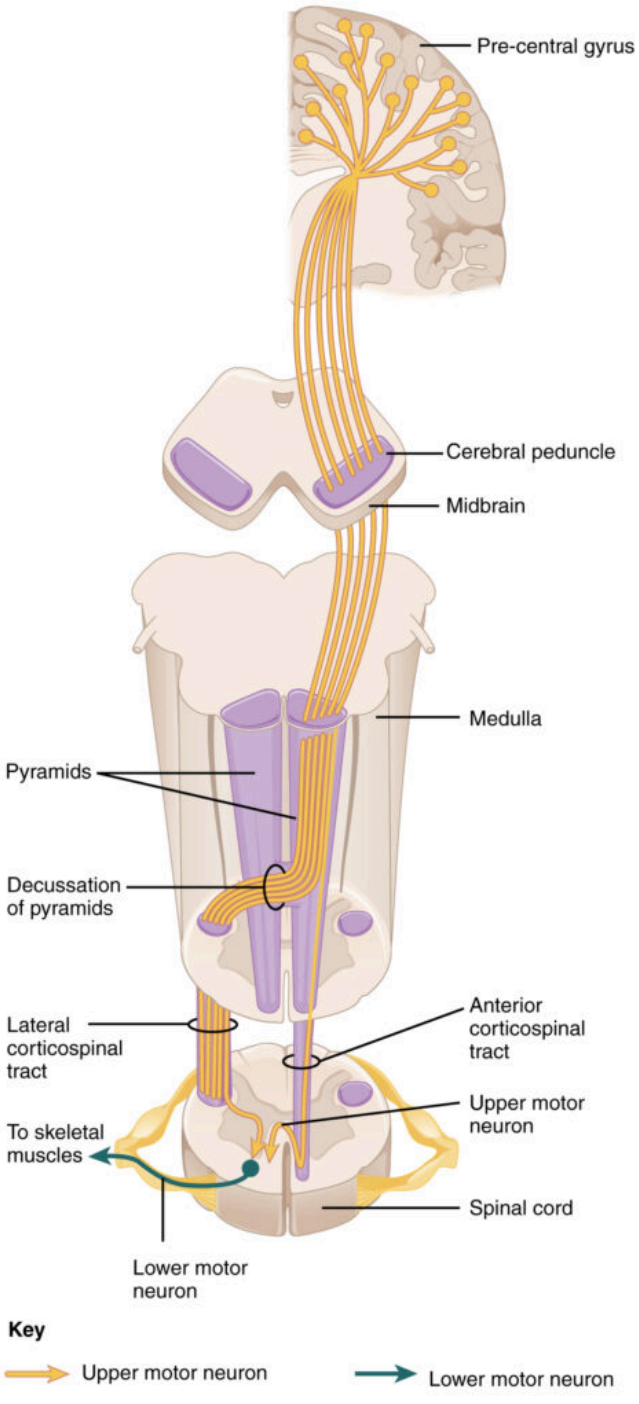
2.4.2.1. How does the brain communicate with muscles?

Movement of the body, which requires contraction of muscles, can be voluntary or reflexive (reflexes will be discussed later). The voluntary control of muscle contraction requires a command signal from the brain to be sent to the spinal cord. Put simply, every conscious or voluntary movement we make starts with a thought, which is sent down the spinal cord in the form of electrical messages. In the spinal cord, some neurones allow this command signal to be relayed to muscles.

Specifically, as detailed in the **Anatomy section** above, several motor pathways descend the spinal cord. For the control of limb muscles, the chief pathway is the *cortico-spinal pathway* (**Fig-**

ure 2.7; **Table 2.3**). As the name suggests, the cortico-spinal pathway starts in the top layer of the brain (which we call the cortex) and ends in the spinal cord. In the spinal cord, neurones in the cortico-spinal pathway connect directly with other neurones. These may include ***motor neurones***, which send messages from the spinal cord to the muscles or ***interneurones***, which link different parts of the spinal cord and help coordinate movement.

Figure 2.7. The cortico-spinal pathway. *Source:* Wikimedia Commons, Corticospinal pathway, CC BY 3.0



Notably, cortico-spinal neurones are labelled ***upper motor neurones***, while the motor neurones that originate in the spinal cord are called ***lower motor neurones***. The latter are sometimes labelled ***alpha-motor neurones*** or spinal motor neurones. If we link this to the structure of neurones, the cell bodies and dendrites of upper motor neurones in the ***motor cortex***, while their axons travel down through the spinal cord, where their axon terminals release ***neurotransmitters***. Lower motor neurones are in the spinal cord. Their axons extend to the muscles, forming the ***peripheral nerves***. At the point where the nerve meets the muscle, called the ***neuromuscular junction***, they release chemical messengers that trigger the muscle to contract. This is an important distinction functionally, as injuries to upper and lower motor neurones result in different effects. In the case of SCI, the damage typically involves the upper motor neuron*es*, while lower motor neurones remain intact. As far as our current understanding goes, the axons of damaged upper motor neurones do not regenerate or re-sprout after injury, but the axons of lower motor neurones can. This is the reason SCI is usually lifelong.

2.4.2.2. Why can I no longer control some or all my muscles?

If we draw this information together, for voluntary muscle activation and contraction to occur, cortico-spinal neurones need to send action potentials towards the spinal cord. This causes an

excitatory neurotransmitter to be released to lower motor neurones through one or several synapses. This neurotransmitter excites lower motor neurones which pass action potentials to the muscle. Lower motor neurones hence signal to muscles to contract, allowing us to move. If the spinal cord is injured, then cortico-spinal neurones cannot 'talk' to lower motor neurones. This causes paralysis, as lower motor neurones are no longer 'excited' and muscles are not activated by the lower motor neurones.

2.4.2.3. Are there any other motor pathways affected by SCI?

Although the cortico-spinal pathway is important for voluntary control of muscles, particularly the fine control of muscles for the upper limbs (arms), it is important to note that other descending motor pathways activate lower motor neurones to control or initiate muscle activation. Therefore, SCI does not just affect the cortico-spinal pathway. It also affects many other motor pathways. These alternative pathways are important for other parts of our movement control, such as walking, balance, posture, head and neck stability and other reflexes, which we deem gross functions. We call these pathways the ***extra-pyramidal pathways***, because they do not travel down the spinal cord in the same way as the ***pyramidal tracts,*** such as the cortico-spinal pathway. For completeness, the 'pyramids' are a part of the brainstem that the corticospinal tract passes through.

Importantly, because these extra-pyramidal pathways also synapse with lower motor neurones, damage to these pathways in SCI can disrupt the ability to effectively coordinate the many muscles involved in whole-body movements described above as gross motor functions. This is why some individuals with SCI cannot walk, stand upright and maintain their balance.

Video: Motor neurone damage

Neurone motor injury (Dr Matt & Dr Mike, 28 September 2020): In this video, **Dr Mike** clearly explains the differences between upper motor neuron and lower motor neuron damage, including how each type presents in the body.

2.4.2.4. What happens to muscles to allow movement?

Muscles are made of many very long cells, the *muscle fibres.*. Muscle fibres are directly innervated by *lower motor neurones* through a specialised connection called the *neuromuscular junction* (**Figure 2.8)**.

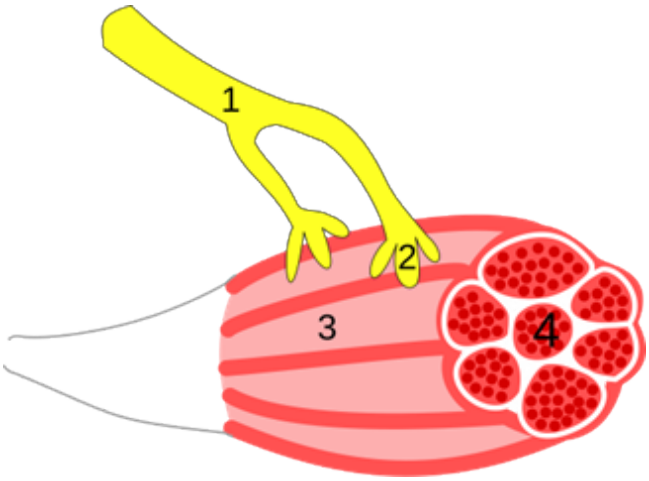


Figure 2.8. A neuromuscular junction. #1 is the axon of a motor neurone ending on your muscle (#3), which comprises numerous bundles (#4) of muscle cells. The chemical (neurotransmitter released at #2) will 'excite' the muscle, causing it to contract. *Source:* Wikimedia Commons, Neuromuscular, CC BY-SA 3.0

When the lower motor neurone signals for muscle contraction to occur, this causes the neurotransmitter, *acetylcholine*, to be released onto the muscle fibres at the neuromuscular junction. Consequently, muscle cells become electrically excited. This electrical signal eventually causes small proteins in the muscle cells to change shape and slide past one another. Individual muscle cells then shorten, which eventually causes the whole muscle to shorten. These interactions can also cause muscles to lengthen or stay the same length. It is the changing of the length of whole muscles and muscle groups, such as shortening and lengthening of muscles that pull on bones to move the skeleton, allowing us to move.

Because the nervous system cannot send a signal to some muscles to contract after SCI, this leads to muscle wasting (*atrophy*). Think of muscle atrophy as the opposite of what happens when we go to the gym, where our muscles get bigger from lifting weights. This is called muscle *hypertrophy* and occurs when we safely overload our muscles with resistance, which triggers structural changes that make them stronger and larger in appearance. After SCI, because muscles are no longer contracting due to the loss of stimulation from lower motor neurones, they become smaller and weaker (post-injury inflammation and hormonal changes may also contribute). In addition, because muscles are no longer 'pulling' on the bones, those with SCI can be prone to fractures (bone breaks), as it is the mechanical interaction between muscle and bone that causes bone adaptations that make them strong and durable.

2.4.3. Control of sensory function

In the control of motor function section, we discussed how the brain sends signals down the spinal cord to the lower motor neurones, allowing muscles to contract and produce movement. This section will cover how signals are sent in the opposite direction, such as from the

body to the brain. Understanding this pathway is important because SCI affects not only movement but also sensation. This can include changes in your ability to feel where your limbs are in space (a sense called *proprioception*) or to detect sensations such as pain, temperature or touch.

2.4.3.1. How does the body communicate with the brain?

The brain is very good at taking in information from the world, processing this information, and using it to generate an output or modify something in the brain or body. It starts with something called a *sensory receptor.* There are receptors in the eyes that respond to light, helping with vision. There are also receptors on the tongue that allow for taste. Similarly, there are receptors in the ear that pick up vibrations and allow hearing. These receptors interact with neural circuits above the spinal cord, such as those for vision, taste, smell, sight and hearing (which are all intact after SCI).

We also have sensory receptors in our muscles, our joints and our skin that help us feel touch, vibration, movement of our skin, pressure, pain and temperature, amongst other things. These receptors are either a specialised part of *sensory neurones* or are closely associated with sensory neurones. Unlike lower motor neurones, sensory neurones send signals towards the spinal cord.

2.4.3.2. How do sensory signals get from the body to the brain?

For *sensory signals* to get from the body to the brain, there are three neurones involved and many synapses. These are called first-, second- and third-order neurones. *First-order neurones* send information from the receptors to the spinal cord or brainstem, *second-order neurones* send information from the spinal cord or brainstem to deep parts of the brain (*thalamus*) and*third-order neurones* send information from deep in the brain to the brain's outer layer (cortex). Keep in mind that sensory signals from one side of the body end up travelling to the opposite side's cortex. For example, painful stimuli on the right side of the body will be processed and recognised by the left cortex. To simplify the complex interplay that is sensory physiology, the receptors first sense the signal and activate a sensory neurone, the spinal cord transmits this signal, the sensory physiology decides where to send the signal and the cortex perceives the signal. SCI disrupts the transmission of sensory signals to the brain. After SCI, signals from receptors cannot be perceived by the cortex.

Video: First-, second- and third-order neurones

1st, 2nd & 3rd Order Neurons EXPLAINED in 90 Seconds! (The Artful Medic, 8 April 2024): This quick video shows how first-, second- and third-order neurones relay a sensation from the skin all the way to the brain.

Many types of sensory signals are sent to the brain. The specific pathways they travel, including where they cross over in the spinal cord to the opposite side of the nervous system, differ for these signals. Sensory modalities like fine touch, *proprioception* and vibration travel via a different pathway compared with *nociceptive (pain)* and temperature signals. Specifically, the '*dorsal columns*' transmit fine touch, proprioception and vibration and are located towards the back (posterior) of the spinal cord and cross to the opposite side of the nervous system at the brainstem level (**Table 2.3**). The '*spino-thalamic tract*' transmits pain and temperature signals and is located towards the front (anterior part) and sides (lateral parts) of the cord and crosses to the opposite side of the nervous system at the spinal cord level (**Figure 2.9**).

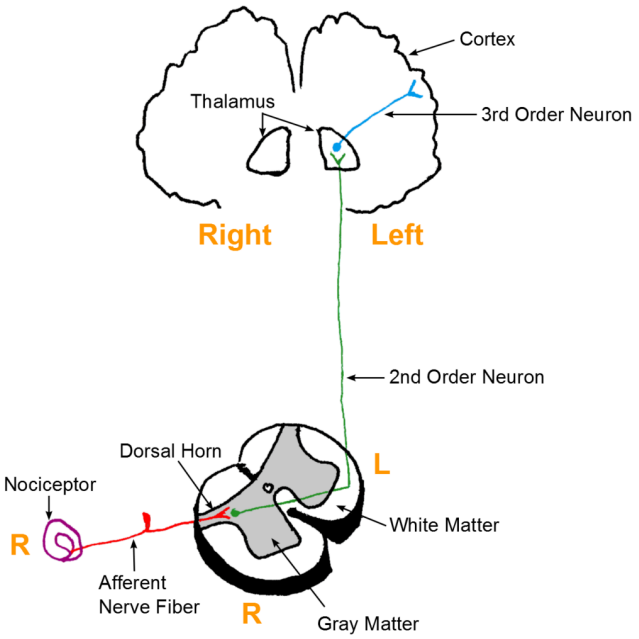


Figure 2.9. The neural pathway that sends pain to the brain. *Source:* Wikimedia Commons, Afferents, CC BY-SA 4.0

2.4.3.3. Why are sensory issues so variable between different people with SCI?

The uniqueness of each SCI often results in many different sensory consequences because:

- Numerous sensory pathways travel through different locations of the spinal cord
- A portion of, or the entirety of, a given sensory pathway may be damaged and
- SCIs affect different spinal levels.

After SCI, there are also changes to the rest of the nervous system that are not affected by the

injury, which can cause exaggerated pain or feelings of pain from stimuli that are usually not painful, in addition to the usual numbness or lack of sensation below the injury level.

Video: Sensory neurones

Sensory Pathways: Touch/Proprioception vs Pain/Temperature (Dr Matt & Dr Mike, 28 September 2020): In this video, Dr Mike explains how sensory information travels to the brain through the spinal cord, highlighting the differences between how touch and proprioception signals are carried compared with pain and temperature signals. He also discusses how we perceive different sensations and the role of sensory neurones in these pathways.

2.4.3.4. Why do people living with SCI get pressure sores?

Pressure sores relate to the sensory pathways we discussed above. After SCI, the axons of spinal cord neurones that form sensory pathways and ascend to the brain are affected. *Sensory signals* cannot get from some parts of the body to the brain anymore, including information regarding pain and pressure. Normally, when lying down for prolonged periods, excessive discomfort in the skin due to stretching, pulling, squashing or rubbing will activate receptors and tell the brain that a given body part needs to be moved or 'readjusted'. SCIs often reduce or eliminate sensation and mobility below the level of injury due to damage to both sensory and motor pathways. Thus, an individual with SCI may not feel discomfort and painful signals, such as pressure, heat, or moisture and is unable to shift positions naturally, leading to prolonged pressure on certain high-risk pressure areas. Consequently, thinning and deprivation of blood supply can happen, resulting in pressure sores in high-risk areas like on the heels, tailbone and the sacrum ischial tuberosities (sitting bones), elbows, shoulders, the back and the back of the head.

2.4.4. Reflexes

Reflexes are involuntary, but rapid, responses of the body to a stimulus. Reflexes play an important role in everyday functions, helping us maintain posture and balance, regulate vital functions, such as heart rate and blood pressure, and protect the body by triggering quick movements in response to potential dangers or threats.

Importantly, reflexes are rapid and involuntary because they do not require the brain to operate and often involve simple spinal cord circuits involving only two or three neurones. Because reflexes do not require input from the brain to occur, many are still functional after SCI. After an injury, however, reflexes that were once normal and previously helped maintain control of the body's physiology have the potential to become problematic. This happens because the brain can no longer communicate with the neurones controlling these reflexes and therefore cannot regulate them.

Two main reflex types involve different components of the nervous system:

- *Somatic reflexes* involve lower motor neurones and muscle contraction, and
- *Autonomic reflexes* involve circuits that regulate automatic physiological functions that cannot be voluntarily controlled by the brain, such as heart rate control, blood pressure regulation and sweating. This section will briefly touch on somatic reflexes, followed by a section on autonomic control of the body and its associated reflexes as they relate to SCI.

2.4.4.1. How can my muscles contract without input from the brain?

As discussed in the motor function section (**Section 2.4.2)**, to move our body, we need our muscles to contract. Muscle contraction occurs because lower motor neurones excite muscle fibres, causing the fibres to shorten, which causes muscles to produce force. Although lower motor neurones are activated by motor pathways that travel down the spinal cord, this is not the only way to activate motor neurones to cause muscle contraction. *Sensory neurones* travel from muscle, skin and joints and can also excite lower motor neurones to cause muscle contraction, without input from the brain. Therefore, we have somatic 'reflexes'. For example, when stretch receptors are activated in muscle, action potentials are sent via sensory neurones towards the spinal cord. This causes motor neurones to fire and muscles to contract without any conscious control by the brain. Muscle contraction in this example is involuntary.

2.4.4.2. Why do I get muscle spasticity and involuntary contractions?

Muscle spasticity occurs when muscles involuntarily contract or stiffen at unwanted times and sometimes for extended periods, which can be painful. After SCI, this occurs because the *reflex circuits (arcs)* in the spinal cord below the level of injury are no longer properly controlled by the brain. Without this regulation, the reflexes become overactive, leading to the uncontrolled muscle contractions known as spasticity.

Let's consider *stretch reflexes* as an example and the associated spinal cord circuits that cause the muscles to contract in response to muscle stretch (**Figure 2.10**). Stretch reflexes involve

some types of neurones that we have described in the neurones section of this Chapter (refer to motor and sensory neurones, **Section 2.4.1.2**). In muscles, the sensory neurones which respond to stretch are called ***muscle spindles***. When muscles are involuntarily stretched, this causes the muscle spindles to signal ***sensory neurones*** to send action potentials away from the muscle and towards the spinal cord. The sensory neurones that fire in response to muscle stretch form synapses with lower motor neurones. Hence, these sensory neurones cause motor neurones to reflexively fire in response to the muscle stretching. Of course, motor neurones tell skeletal muscles to contract, so the muscles reflexively produce a muscle contraction (muscle twitch).

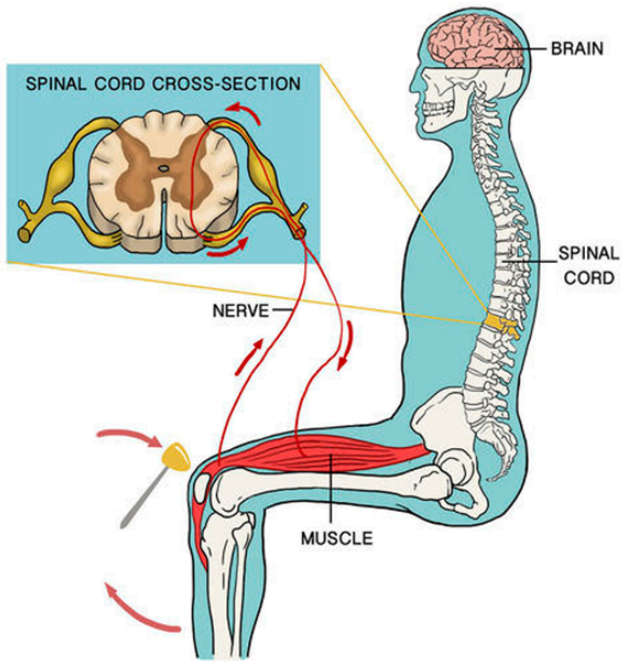


Figure 2.10. The spinal cord stretch reflex occurs when the tendon is tapped with a rubber mallet. *Source:* Wikimedia Commons, Hammer taps knee, CC BY 3.0

Health professionals test for reflexes by using a rubber mallet. They 'tap' the tendon attached to the muscle, which causes it to stretch a little. They watch to see how much the muscle twitches. In those without spinal cord damage, these reflexes are noticeable, but somewhat small. After a chronic (long-term) SCI, these reflexes can be quite large. Specifically, after the tendon tap, the muscles can contract very strongly and for long periods. This suggests that motor neurones are ***hyperexcitable*** and are more easily activated by sensory inputs (amongst other things). This contrasts with the ***'spinal shock'*** seen immediately after injury, when reflexes are absent or greatly diminished in the days to weeks after injury. During spinal shock, the motor neurones are ***hypoexcitable***, or less responsive to stimulation, until reflex activity gradually returns as the ***spinal circuits*** adapt.

Although stretch reflexes were discussed above, please note that there are many other ***somatic reflexes*** affected by SCI, such as ***muscle reflexes*** initiated by stimulating the skin. Normally, descending pathways from the brain and brainstem act to modulate or control spinal cord ***sensorimotor loops.*** After longer-term spinal injury, however, these pathways cannot communicate with neurones in the spinal cord, so the ***reflex circuits (arcs)*** change their properties and activity. From what we understand, there is a loss of ***inhibitory synaptic input*** to motor neurones, and/or the ***motor neurones*** change their biophysical properties, so they are more likely to send action potentials to muscles and fire for longer durations when activated by sensory neurones projecting from, for example muscles, joints and the skin. This contrasts with motor neurone hypoexcitability seen at the initial stages of SCI, which results in the motor neurones becoming less likely to fire because of a loss of excitatory or facilitatory input from ***descending motor pathways***.

Video: SCI, motor neurones and reflexes

Spinal Cord Injury, Motor Neurons, and Reflexes (Dr Matt & Dr Mike, 28 September 2020): In this video, **Dr Mike** explains how motor pathways travel from the brain and down the spinal cord to the muscles. He explains how reflexes work and what happens in upper motor neurone and lower motor neurone injuries.

2.4.5. Autonomic control

As was discussed in **Section 2.2**, the *autonomic nervous system (ANS)* is the part of our nervous system that controls all the involuntary processes in the body. It talks directly to the organs, blood vessels and *glands* in our body. Things like heart rate, blood pressure, sweating, metabolism, sexual function and more are controlled by the ANS (**Table 2.4**). There are two main components of the autonomic nervous system, which differ in their structure and function. They are the sympathetic and parasympathetic components:

- When we are relaxed, *parasympathetic activity* increases, which is why we call this the 'rest and digest' division of the ANS, and
- When we are stressed or highly aroused, activity of the *sympathetic nervous system* increases, which is why we call this the 'fight or flight' division of the ANS.

Consequently, the sympathetic and parasympathetic divisions can be thought of as 'constantly competing' to control the physiology of our body and maintain homeostasis. One system helps with general housekeeping activities in the body (parasympathetic activity), while the other ramps up physiological processes to keep us safe when the body is 'threatened' (sympathetic activity).

Table 2.4. The two 'arms' of the ANS and their functions.

Parasympathetic nervous system functions	Sympathetic nervous system functions
• Increases urinary activity • Increases digestive activity • Stores energy (causes insulin secretion to store glucose) • Stimulates mucus production in airways	• Increases cardiac output by increasing heart rate and the force of heart muscle contraction (stroke volume) • Increases constriction (narrowing) of blood vessels throughout the body (which increases blood pressure) • Causes dilation of blood vessels (widening) supplying skeletal muscles • Dilates the airways • Dilates the pupils in our eyes • Mobilises stored energy (like glucose) • Increases sweating

Although functionally distinct, the sympathetic and parasympathetic nervous divisions of the ANS are also anatomically distinct. The sympathetic nervous system involves nerves that start in the spinal cord at the thoracic and lumbar levels and terminate on organs, *smooth muscle* and *glands* throughout the body. It also causes the *adrenal glands* to release adrenaline into the blood. On the other hand, the parasympathetic nervous system involves nerves that start in the brainstem (*cranial nerves*) and the sacral spinal cord. Depending on the level, SCI can affect the sympathetic and parasympathetic nervous divisions of the ANS in many ways. Consequently, this can result in impairments across the body's autonomic processes. In the next section, *autonomic dysreflexia (AD)* is described, which usually occurs with SCI above T6.

Clinical resource: Managing spasticity guidelines (2024)

Department of Physical Medicine and Rehabilitation/UAMS IDHI Brain Injury Program's Spinal Cord Injury Guidelines (2024): Comprehensive guidelines for the medical management of spasticity in individuals with SCI and traumatic brain injury.

2.4.5.1. Impaired temperature regulation (mainly T6 and above injury)

The *hypothalamus* in the brain acts as your body's thermostat. It relies on signals from the spinal cord to regulate temperature. SCI disrupts this communication, leading to poor temperature control. This manifests as dangerously low (*hypothermia*) or high (*hyperthermia*) body temperatures when exposed to extreme cold or heat.

This inability to control body temperature is primarily due to disruption of the ***autonomic nervous system (ANS)*** pathways that control sweating and regulate the diameter (dilated when trying to cool) of blood vessels, which are two ways the body loses heat. Injury at the cervical (neck) or upper thoracic (upper back) levels (T6 and above) tends to have more severe temperature-regulation issues than lower-level injuries.

Mason Ellis' story: Temperature issues after a cervical injury

Body Temperature Regulation After Spinal Cord Injury, Quadriplegic (C5,C6,C7) (27 January 2025): Mason Ellis, who has C5-C7 quadriplegia, talks about body temperature after SCI.

If you have a higher-level injury and regulation of your body temperature is disrupted, below are suggestions for helping your body stay within a safe physiological temperature range, which is about 36.1-37.2 °C for adults under 65, depending on where it is taken, which may be orally, rectally or in the ear or armpit:

- **Monitor the ambient temperature:** Carefully monitor the surrounding temperature and humidity to avoid extreme conditions. Individuals with high-level SCIs are cautioned to avoid exposure to temperature extremes
- **Adjust clothing:** Wear appropriate clothing layers, based on the weather, including cooling garments when needed
- **Remain hydrated:** Stay well-hydrated to support thermoregulation
- **Stay cool or warm:** Use fans, air conditioning or heating devices as necessary, and
- **Regularly check your temperature:** Monitor body temperature frequently, especially in situations where temperature dysregulation is likely.

In **Chapter 1, Perry Cross** emphasised the importance of home location, particularly in cities such as Canberra, Sydney and Melbourne, which experience very cold winters. His advice was to choose a location that receives afternoon sun.

Important resources: Queensland's medical and heating electrical concessions

Queensland Spinal Cord Injuries Service's (QSCIS) Fact Sheet for GPs about temperature regulation after SCI:

Interestingly, the Queensland Government has a Medical and Cooling and Heating Electricity Concession Scheme. To be eligible, you must be a Queensland resident and have a qualifying medical condition and need cooling or heating to stop your symptoms from becoming significantly worse. Qualifying medical conditions that are relevant to someone living with SCI include:

- Autonomic system dysfunction (as discussed above)
- Loss of skin integrity or sweating capacity (also relevant)
- Severe compromise of functioning, such as mobility at extremes of environmental temperature
- Hypersensitivity to extremes of environmental temperature leading to increased pain or other discomfort or an increased risk of complications, and
- Live at your principal place of residence, which has an air-conditioning or heating unit.

Clinical resources: Temperature regulation after SCI

The following are useful resources for health practitioners:

- Queensland Health's Factsheet: Information for GPs: Temperature regulation after SCI: This factsheet provides guidance for GPs in terms of recognising, assessing and managing temperature-regulation problems in people living with SCI
- Price, M. J., & Trbovich, M. (2018). Thermoregulation following spinal cord injury. In A. A. Romanovsky (Ed.), Handbook of Clinical Neurology (Vol. 157, pp. 799-820). Elsevier. This ScienceDirect chapter provides an overview of spinal cord structure, biomechanics and injury mechanisms, outlining how the spine and spinal cord respond to external forces that lead to the TSCI, and
- Schmidt, K. D., & Chan, C. W. (1992). Thermoregulation and fever in normal persons and in those with spinal cord injuries. *Mayo Clinic Proceedings, 67*(5), 469–475. This article explains how SCI alters the body's ability to regulate temperature and outlines how clinicians can distinguish these thermoregulatory changes from fever caused by infection.

2.4.5.2. Autonomic dysreflexia (usually at and above T6)

Autonomic dysreflexia (AD) is a sudden rise in blood pressure if one has a T6 and above lesion. It is more likely to occur if the lesion is complete. The higher the level of the SCI, the greater the risk, with up to 90% of patients with cervical or high-thoracic SCI being susceptible. Susceptible individuals can experience AD up to 40 times per day (Badur *et al.,* 2025).

AD leads to an uncoordinated sympathetic response that may result in a potentially life-threatening *hypertensive episode* when there is a noxious stimulus, such as an infection or constipation below the level of the SCI. Earlier, we discussed how reflexes are important for maintaining *homeostatic mechanisms* and controlling what happens inside the nervous system and body. We also discussed how reflexes are affected in SCI, as parts of the nervous system above the injury cannot effectively control the function of reflex-related circuits below the injury. Normally, sympathetic reflexes would be controlled by the nervous system, but after injury, this does not happen very well. Stimuli such as pain, bladder distension, skin irritation and constipation all trigger sympathetic neurones. This causes blood pressure to increase. Because the nervous system cannot control sympathetic neurones below the injury site and so cannot switch them off, effectively, sympathetic activity remains high. It can lead to stroke and cardiac arrest if not managed. In about 85% of cases, the stimulus originates from a urological source, such as a UTI, a distended bladder or a blocked catheter (Badur *et al.,* 2025).

Video: Autonomic dysreflexia (AD)

Autonomic Dysreflexia (Dr Matt & Dr Mike, 9 September 2020): If you want to delve deeper into AD physiology, listen to **Dr Mike** describing the impact of AD across the body, which can be life-threatening.

The available AD resources are mainly for clinical management, as AD is life-threatening. Below is some information from the US that clearly explains AD so that everyone can understand.

Important information: AD triggers

- SpinalCord.com offers this information for affected individuals. This extract is particularly useful:

"Researchers encourage medical students to remember the main potential AD triggers using 'the 6 Bs'- bladder, bowels, boils, bones, babies and back passage. Although this may sound a bit crude, these encompass and summarize potential triggers and can be helpful for individuals to recognize symptoms in themselves."

- A US medical update resource, Autonomic Dysreflexia, provides an extensive list of triggers for AD. The following events or conditions can all cause episodes of AD:
    - Bladder distention
    - Urinary tract infection
    - Calculus
    - Cystoscopy or instrumentation
    - Urodynamic study (test to evaluate how the bladder and urethra function, using computerised equipment to measure pressure as the bladder fills and empties)
    - Epididymitis or scrotal compression
    - Bowel distention
    - Faecal impaction
    - Bowel instrumentation or colonoscopy
    - Reflux or gastritis
    - Gallstones
    - Gastric ulcers
    - Invasive testing
    - Haemorrhoids
    - Gastro-colic irritation
    - Appendicitis or other intra-abdominal pathology or trauma
    - Anal fissure
    - Menstruation
    - Pregnancy, especially labour and delivery
    - Vaginitis
    - Sexual intercourse
    - Ejaculation
    - Deep vein thrombosis
    - Pulmonary emboli
    - Pressure ulcers
    - Ingrown toenail
    - Burns or sunburn
    - Blisters
    - Insect bites
    - Contact with hard or sharp objects
    - Temperature fluctuations
    - Constrictive clothing, shoes or appliances
    - Heterotopic bone (formation of bone in soft tissues where it doesn't normally exist, often after trauma, surgery or neurological injury), and
    - Fractures or other skeletal trauma.

Clinical resources: Practical, evidence-based AD management

The following are useful resources for health practitioners:

- ACI's Treatment of autonomic dysreflexia for adults and adolescents with SCIs: This is an excellent resource for managing AD. The website includes:
    - An algorithm that health professionals can use to guide assessment and treatment
    - Clinical practice guidelines outlining best-practice management strategies
    - Educational resources for clinicians, individuals with SCI and carers, and
    - Emergency management protocols for responding to AD episodes quickly and effectively.
- Queensland's Metro South Management of AD: This Queensland Health factsheet provides practical guidance for recognising, assessing and managing AD, a dangerous spike in blood pressure that can occur in people with SCI at or above T6.
- Badur N. B., Winkle MJ, Leslie SW. (2025). Autonomic Dysreflexia. In: *StatPearls.* Treasure Island (FL): StatPearls Publishing: This is a ***Continuing professional development (CPD)*** activity that explains AD, why it occurs after SCI and how to recognise, manage and prevent this potentially life-threatening condition.

Videos: Preventing AD and an AD first aid kit

Below are a few videos describing how to present AD as well as the importance of an AD first aid kit:

- What is AD? (Agency of Clinical Intervention, 26 May 2025): This short video (about six minutes) explains what AD is by outlining how it occurs, the underlying mechanisms and the key signs and symptoms that individuals with SCI need to recognise
- How to manage AD (Agency of Clinical Intervention, 26 May 2025): This short video (about 10 minutes) explains how to manage AD by guiding viewers step-by-step through the clinical algorithm for recognising, treating and resolving an episode safely, and
- Prevention of AD (Agency of Clinical Intervention, 26 May 2025): This short video (about three minutes) on preventing AD explains common triggers such as bladder, bowel and skin issues and emphasises the importance of keeping a prevention kit that includes an AD medical emergency card (**Figures 2.11a and b**). It appears you can order such a card here.

Figure 2.11a. Autonomic dysreflexia (AD) emergency kit: Spare catheter, lignocaine gel, surgical gloves and prescription medication. Created by Elmarie Stander using Canva, based on information provided by ACI, NSW, CC BY-ND.

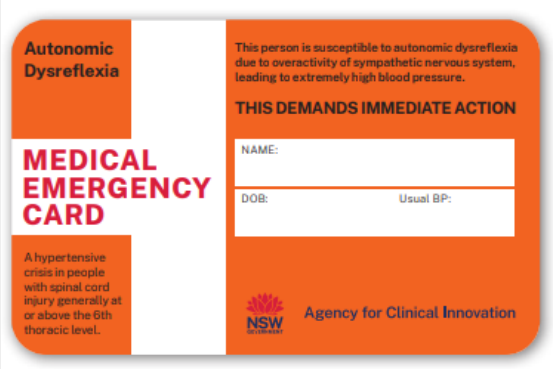


Figure 2.11b. An example of an AD Medical Emergency Card. Source: ACI, NDS, CC BY-ND.

2.5. Impacts of SCI on your body

The impacts will vary depending on where your SCI is (level) and the severity of the injury (*complete injury* or *incomplete injury*). The simplest way to understand what is happening to your body is to describe what is happening to the various organ systems of your body. The body functions as a whole, so an injury or malfunction in one tissue or organ will have repercussions elsewhere in the body. There are two systems considered to be 'overarching' systems that control most of the other organ systems. These are the nervous system and the *Endocrine (hormone) system,* so you might read about the neuroendocrine system.

We also need to remember that injury to your spinal cord can be primary (at the time of the initial injury) and secondary (the body's response to the damage).

Video: Primary and secondary injury

Spinal Cord Injury: What happens in the spinal cord after injury? (Dr Matt & Dr Mike, 2 October 2020): Listen to **Dr Mike's** explanation of primary and secondary injury after damage to the spinal cord.

The American Spinal Injury Association's (ASIA)-International Spinal Cord Society (ISCOS) developed the International SCI Worksheet

in 2019. This is a standardised assessment tool based on the International Standards for Neurological Classification of Spinal Cord Injury (ISNCSCI) and used by health professionals to assess the extent of movement and sensation after SCI. It considers muscle strength and sensation in different parts of the body to determine the extent of the injury and its severity. **Table 2.5.** indicates the ASIA Impairment Scale Classification according to ISNCSCI. This helps doctors plan treatment, track recovery and prevent complications.

Table 2.5. ASIA Impairment Scale Classification according to the International Standards for Neurological Classification of Spinal Cord Injury (ISNCSCI) (Valdez-Resendiz *et al.*, 2025).

Grade	ASIA Impairment Scale Classification	Muscle motor function	Secondary function
A	Complete	None below the level of the injury and sacral segments S4-5	None below the level of injury of the sacral segments S4-5.
B	Sensory incomplete	None below the level of the injury and sacral segments S4-5	Preserved below the neurological level, with some sensitivity preserved in the sacral segments S4 and S5
C	Motor incomplete	Motor function is preserved at the most caudal sacral segments for voluntary anal contraction. Less than half of the key muscles that function below the neurological level of injury (NLI) have a muscle grade ≥ 3	Sensory incomplete status (sensory function preserved at the most caudal sacral segments S4-S5)
D	Motor incomplete	Motor incomplete status as defined above, with at least half (or more) of key muscle functions below the single NLI having a muscle grade ≥ 3	Preserved
E	Normal	Functions are normal. All motor functions preserved	All sensory functions preserved

Clinical resource: ASIA-ICOS Assessment Sheet

ASIA–ISCOS International Spinal Cord Injury Worksheet (2019): This standardised assessment tool is based on the International Standards for Neurological Classification of Spinal Cord Injury (ISNCSCI). It provides a structured evaluation of sensory and motor function to determine the neurological level of injury and impairment severity. Key components include:

- **Muscle function grading:** Scores range from 0 (total paralysis) to 5 (normal strength), with "NT" for not testable and "*" for non-SCI-related conditions
- **Sensory evaluation:** Light touch and pinprick at key dermatomes graded as 0 (absent), 1 (altered) or 2 (normal)
- **Neurological level of injury (NLI):** The most caudal segment with intact sensory and motor function on both sides, and
- **Zone of Partial Preservation (ZPP):** Segments below the injury level with some preserved function, applicable when sacral sparing is absent.

This worksheet supports consistent, reproducible SCI assessments to guide diagnosis, rehabilitation planning and monitoring of neurological recovery.

This is important because understanding how SCI affects the body goes beyond knowing medical terms or classifications. It explains why certain changes occur, such as altered breathing, muscle weakness or changes in sensation and why these can lead to complications if not man-

aged properly. This knowledge enables individuals with SCI, as well as their families and carers, to recognise problems early, communicate effectively with health professionals and make informed decisions about care and lifestyle.

Before we discuss the impact of SCI on the body's organ systems, the video below will provide **Dinesh's** lived experience of a higher-level SCI on the physiology of different parts of his body.

Dinesh's story: Experiences of what happened to his body

It is worth listening to Dr Matt and Dr Mike's Medical Podcast (1h22), from 2020, in which they speak with **Dr Dinesh Palipana,** who sustained a C6/C7 injury in a car accident.

Dinesh talks about why he can feel some sensations below the injury on one side. He also talks about his compromised respiratory function, leading to sleep apnoea and low saturated oxygen. To compensate, Dinesh sleeps upright and uses a *Continuous Positive Airway Pressure (CPAP)* machine. His coughing and sneezing are also affected. If Dinesh gets the flu, he presses his belly to help him cough. He advises getting an annual flu vaccination, as those with SCI are more likely to develop pneumonia as a complication of influenza. It is also important for carers to be vaccinated and practice good infection control. As the podcast was recorded in 2020, Dinesh talks about COVID-19. The team discusses AD in considerable detail, with Dinesh sharing how he can trigger his blood pressure to increase. From the video, it is evident how some of the main organ systems are affected by nerve damage.

2.5.1. Cardiovascular system (heart and blood vessels)

The cardiovascular system (CVS) comprises the heart and the blood vessels. The heart pumps oxygenated blood from the lungs to the heart, which then distributes it to the various organs and glands. Deoxygenated blood is then returned to the heart and pumped to the lungs for reoxygenation. Through the sympathetic arm of the ANS, blood pressure in the circulatory system is maintained by changing the diameter of muscular vessels to redirect blood to where it is most needed, such as the brain. Blood vessel diameter can also be altered in response to fluctuations in core temperature and to sensory information from the skin. Peripheral blood vessels will constrict during cold weather and will dilate when the central body temperature rises. In the latter, sweat glands may be stimulated so that the body can cool through evaporation of sweat on the skin surface.

Video: Heart and circulatory system

The Heart and Circulatory System – How They Work (Mayo Clinic, 20 June 2013): This animation features the heart and circulatory system and how they work.

With SCI, the cardiovascular control centres in the brainstem cannot normally control sympathetic neurones, so the body with SCI cannot adequately control blood pressure when body position and posture change suddenly. As SCI affects the sympathetic nervous system, which controls the heart and blood vessels, SCI can affect all the things the sympathetic nervous system does to control the CVS. Typically, the higher the SCI, the more the cardiovascular system is affected. A disrupted sympathetic control of the CVS system can cause dizziness, fainting and abnormal changes in blood pressure. Specifically, SCI can cause:

- **AD:** Already been described in **Section 2.4.5.2** above.
- **Orthostatic hypotension:** When a person with SCI stands up, the CVS counteracts the effects of gravity, which causes the pooling of blood in the legs. If this does not happen, less blood reaches the brain, causing dizziness, lightheadedness, and sometimes fainting. There are specialised receptors in blood vessels called baroreceptors that detect a decrease in blood pressure when standing. This triggers the sympathetic nervous system to constrict blood vessels, including those to and from the legs, to maintain blood pressure. This prevents blood pooling in the legs by reducing blood flow to the legs and allowing more blood to return to the heart (increasing venous return).
- **Higher risk of *venous thromboembolism* (or DVT, deep vein thrombosis):** Because muscle contractions and the sympathetic nervous system promote blood return to the heart (venous return), yet muscle control and sympathetic activity are impaired after injury, blood can pool in the legs. This increases the risk of blood clotting in the veins. This can disrupt blood flow throughout the body, particularly in the legs or lungs. There is a significantly increased risk of stroke by 300-400% (Badur *et al.*, 2025).

Video: DVT resource

The Christopher & Dana Reeves Foundation provides an easy-to-read resource about deep vein thrombosis (DVT).

- **Reduced capacity to exercise:** Because of a lack of sympathetic control, people with SCI tend to have lower cardiac output during exercise. During physical activity, the sympathetic nervous system increases heart rate (beats per minute) and the force of contraction (stroke volume), allowing more blood, oxygen and nutrients to be pumped to exercising skeletal muscles. SCI impairs the cardiovascular control centres in the brainstem's ability to drive the increase in sympathetic tone required to raise cardiac output. Hence, because cardiac output is compromised, people with SCI have a greatly diminished exercise capacity. As cardiovascular fitness is compromised, this may increase the risk of cardiovascular disease, diabetes, and obesity, especially if cardiovascular limitations prevent an individual from engaging in any form of physical activity; the inability to contract muscles voluntarily also contributes to this lack of exercise. In **Chapter 3**, we explore the physiological and psychological benefits of engaging in exercise. In **Chapter 15**, we discuss different forms of sport available for people living with SCI, and
- **Muscle atrophy (wasting)** is another significant concern following SCI. Substantial muscle loss can occur below the level of injury due to loss of innervation, particularly within the first 12 weeks after the event, with ongoing changes to muscle bulk throughout life. *Areflexic injuries* at or below L1 are at greater risk of muscle wasting due to flaccid paralysis, which results in the loss of tone and increased susceptibility to pressure injuries. A chronic SCI can also lead to reduced testosterone levels, contributing to further muscle atrophy.

Clinical resource: SCI and heart disease risk

The following is a useful resource for health professionals:

Yoo, J. E., Kim, M., Kim, B., Lee, H., Chang, W. H., Yoo, J., Han, K., & Shin, D. W. (2024). Increased risk of myocardial infarction, heart failure, and atrial fibrillation after spinal cord injury. *Journal of the American College of Cardiology, 83*(7).

This study investigates how much more likely people with SCI are to develop major heart conditions, including heart attack, heart failure and atrial fibrillation, compared with people without SCI. It shows that SCI survivors have significantly higher risks across all levels of injury, particularly those with more severe disability, highlighting the need for careful cardiovascular monitoring and prevention in this population. This research from Korea further reinforces that SCI is linked to a greater risk of heart disease.

2.5.2. Respiratory system (mainly trachea and lungs)

The respiratory system comprises the trachea, the bronchi, bronchioles and the lungs (**Figure 2.12**). Air is taken in with each breath, oxygen is extracted, and carbon dioxide is exhaled. Although breathing is regulated by the ANS via the brain stem, we can voluntarily control our breathing by holding our breath or when we cough. SCI impacts the respiratory system. It not only affects breathing control, but also the ability to cough and clear mucus from the airways. The magnitude and type of functional impairments relating to the respiratory system depend on the level of injury.

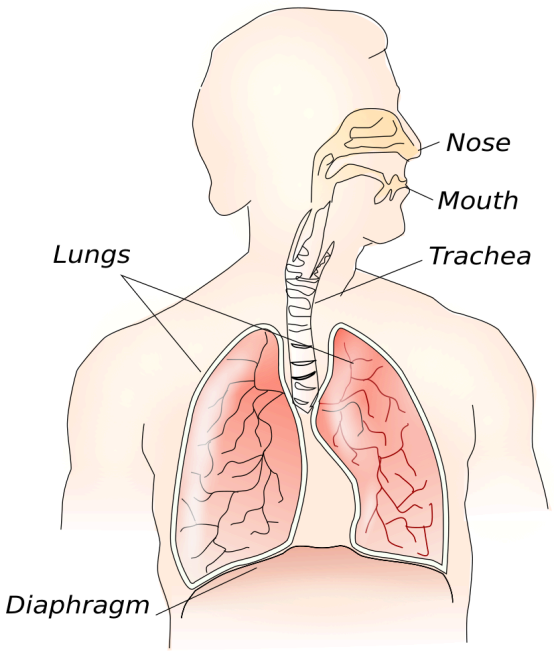


Figure 2.12. Components of the respiratory system, showing the location of the diaphragm, which is required for the mechanics of breathing. *Source:* Wikimedia Commons, Respiratory system, CC BY-SA 2.5

SCI can result in:

- **Weakness or complete paralysis of the respiratory muscles:** Breathing is both an automatic and voluntary process. There is a baseline respiratory rate, which is controlled by the brainstem, but we can also consciously control the speed and frequency of inhales and exhales by activating some motor parts of the cortex. Regardless, breathing requires the neural control of several respiratory muscles, mainly the diaphragm, the intercostal muscles and abdominal muscles. These muscles are activated by lower motor neurones originating from several parts of the spinal cord. The diaphragm is innervated by the phrenic nerve (C3-C5), intercostal muscles are innervated by spinal nerves at T1-T11 levels and abdominals are innervated by nerves from T6-L1 levels of the cord. Because of the above anatomy, a high-level

SCI (C1-C2) results in complete paralysis of the diaphragm and other respiratory muscles. The brain and brainstem cannot synapse with the lower motor neurones innervating the diaphragm, intercostals or abdominal muscles, so these muscles cannot contract at all. This means that a ventilator is needed to replace the neural control of breathing, ensuring that air can enter and exit the lungs. If an injury is between C3 and C5, there may be partial paralysis to the diaphragm and complete paralysis to the intercostal and abdominal muscles. Lower SCIs, such as those affecting the thoracic spinal cord, do not require a ventilator because the diaphragm can still be controlled by the nervous system. Regardless, even minor injuries still affect the intercostal and abdominal muscles, reducing lung capacity because the chest wall cannot move optimally.

- **Impaired ability to cough and expel mucus from the lungs, leading to an increased risk of infection:** The ability to cough requires the ability of the intercostal and abdominal muscles to contract, causing a forceful expiration (pushing air and substances out of the lungs). When these muscles are weakened or paralysed, as is seen after SCI, mucus and other respiratory secretions remain in the airways as they cannot be 'coughed out'. In addition, SCI makes it difficult to breathe in enough air to forcefully expire. Therefore, those with SCI have a higher risk of pneumonia and respiratory infections because bacteria and other harmful pathogens can accumulate in the airways. In addition, because those with SCI have an already reduced lung capacity, their lung function is particularly compromised by respiratory illness when compared with those without SCI and typical respiratory function.
- **Abnormal breathing patterns during sleep:** Our patterns of breathing change when we sleep. With SCI, the respiratory centre in the brainstem cannot effectively communicate with the lower motor neurones that control respiratory muscles. Consequently, people with SCI can *hypoventilate* (not breathe enough) during sleep. This causes carbon dioxide to build up in the body, which triggers the brain to wake them up often during the night. This can lead to *sleep apnoea.* Sleep apnoea is discussed in considerable detail in **Chapter 3**, and
- **Inability of the autonomic nervous system to control breathing:** Because the sympathetic nervous system regulates smooth muscle contraction of the lungs and the amount of blood delivered to them, this may also affect respiratory function during exercise, further contributing to the dysfunction caused by respiratory muscle weakness.

2.5.2.1. Respiratory infections

Respiratory chest infections following SCI depend on the injury level. It is severe in high cervical injuries, characterised by low lung volumes and a weak cough reflex due to respiratory muscle weakness. AD and early-onset sleep disordered breathing add to this respiratory impairment. The mainstays of management following acute high cervical SCI are *tracheostomy* (opening in the trachea to bypass a non-functional nasopharyngeal passage due to high SCI) and *non-invasive ventilation,* such as assisted coughing techniques by a physiotherapist or humidification, help with lower cervical and thoracic level injuries. Prompt investigation to determine the

extent of the SCI and associated injuries is key to improving outcomes in subsequent management. The most common respiratory complications in the first year following SCI are fluid in the lungs (pulmonary oedema) and blood clots in the lungs (pulmonary emboli). After this, pneumonia is the most life-threatening illness and a cause for recurrent hospital admissions. Fluid in the lungs is due to excessive fluid administration in the post-acute injury phase, aspiration of gut contents and poor cough reflexes due to high SCI, causing respiratory infections (pneumonia), weak respiratory muscles compromising the ability to clear the infection and compromise the lung function, invasive lung procedures, compromised immunity and sleep disordered breathing. Community-acquired viral infections and infective exacerbations of pre-existing asthma, and hospital-acquired bacterial chest infections, are the most common respiratory infections.

2.5.2.2. Prevention

Prevention of respiratory tract infections by improving breathing techniques through yoga, by strengthening respiratory muscles through exercises, improving cough reflexes by humidification and physiotherapy, avoiding pollution and allergic environment to avoid precipitation of allergic respiratory infections, taking routine respiratory medications, throat gurgles, preventing aspiration of gut contents into trachea by avoiding going to bed soon after meals and checking on sleep postures or sleep apnoea conditions. For repeated episodes or respiratory conditions, consult the need for a ***tracheostomy*** by a respiratory physician, and, if admitted to intensive care for severe respiratory infections, follow ***ventilation-associated pneumonia care bundles.*** Following robust respiratory etiquette, such as using a facemask in public places and staying away from people who are coughing or have a respiratory infection, is effective in preventing being compromised.

Consulting a GP to rule out a viral or bacterial respiratory infection (nasal swabs or sputum) at the earliest onset of symptoms can be a proactive way of preventing a serious infection and hospital admission.

2.5.2.3 Management

If a respiratory condition persists or worsens, please seek medical advice from a health professional. Prompt assessment and treatment are important for preventing complications.

Important resource: Respiratory infections after SCI

SpinalCord.com's Respiratory infections after SCI: This resource explains why respiratory infections are common after SCI and provides practical tips for prevention and management.

Clinical resource: Management of respiratory issues in SCI

The following is a useful resource for health professionals:

Berlowitz, D. J., Wadsworth, B., & Ross, J. (2016). Respiratory problems and management in people with spinal cord injury. *Breathe, 12*(4), 328-340.

This review outlines how SCI affects respiratory function, explains why respiratory impairment is more severe with higher-level injuries and summarises current management strategies to support breathing and reduce complications.

2.5.3. Urinary system (mainly kidneys and bladder)

Everyone knows the importance of passing urine normally, but we seldom think about its vital role in keeping us alive and functioning normally. Below, we have provided a simplified version of a very complex system that we are still working to understand.

Conventionally, when talking about the urinary system, we start with the kidneys, which is where the formation of urine begins (**Figure 2.13**). The kidneys are two 'fist-sized' organs located towards the back of the abdomen, behind the intestines, just below the rib cage. They filter 5 litres of blood in our body several times a day and generate approximately 140 litres of filtrate. Of this, 139 litres are reabsorbed into the bloodstream, with only 1.0-1.5 litres passing down the ureter (draining each kidney). Ureters drain into the muscular urinary bladder. Normally, each kidney produces about 25 ml of urine per minute, which is temporarily stored in the bladder.

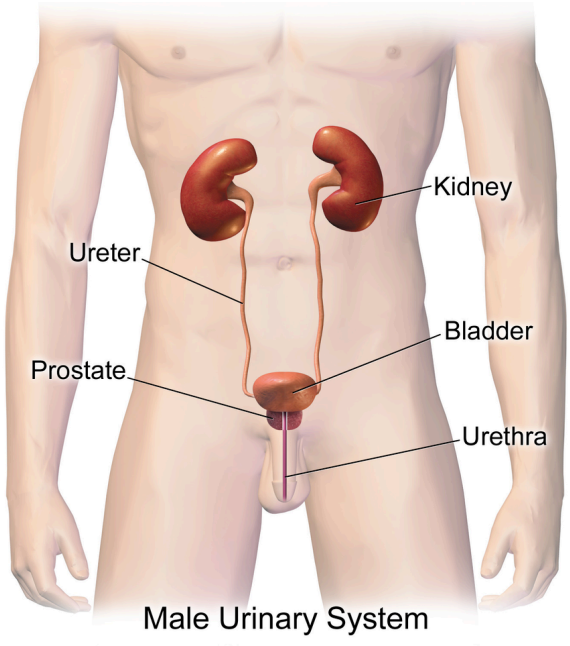


Figure 2.13. Components of the male urinary system. *Source:* Wikimedia Commons, Urinary system, CC BY-SA 4.0

Your urinary bladder is a simple muscular storage 'bag', with an opening at the base that is controlled by a set of muscles called the ***urinary sphincter***. The ANS controls the storage and emptying of the bladder. It is called autonomic because it is not under complete voluntary control (and as such, it is independent), even though we do have some control through our conscious mind, so that we pass urine at socially appropriate places and times. Urine passes from the bladder to the outside through a tube called the urethra, which is longer in men.

The kidneys generate urine to void waste products from the body. They are also responsble for maintaining blood pressure, keeping the volume of fluid in our body appropriate, removing medications and other artificial substances, secreting a hormone called erythropoietin that acts on bone marrow to produce red blood cells (so not to become ***anaemic***), as well as activating vitamin D so that we absorb enough calcium from our gut to maintain healthy bones. Calcium is also required for muscle contraction, nerve function, and blood clotting. In addition, the kidneys play an important role in maintaining the acid-alkali balance in our blood. It goes without saying that when our kidneys do not work well, many bodily functions can become deranged.

2.5.3.1. Role of the nervous system in normal urinary function

As already mentioned in an earlier section, the ANS comprises two arms: the sympathetic and parasympathetic nervous systems. They affect the bladder differently. The parasympathetic nerves are responsible for the contraction of the bladder muscle (detrusor muscle) and the relaxation of the internal urethral sphincter, allowing the passage of urine out of the body. The sacral segments of the spinal cord control this, and the nerves exit through holes in the sacral bone (second, third and fourth sacral segments). The external urethral sphincter, which is under our conscious control, however, needs to relax as well, for urine to pass from the bladder. The voluntary control of passing urine comes from the frontal lobe of the brain to a separate part of the same sacral segments and then to the muscles in the external urethral sphincter.

The sympathetic nervous system relaxes the bladder muscle, allowing the bladder to fill with urine and contracts the internal urethral sphincter to prevent leakage. The control centre is located in the last three thoracic and first two lumbar segments of the spinal cord. It can be seen that the sympathetic and parasympathetic nervous systems have opposing functions. They must be kept in balance for the urinary bladder to function normally.

The kidneys also have nerves. Their role in health is still being worked out. They seem to have an important role in blood pressure control.

2.5.3.2. Impact of SCI on your urinary system

There are various types of neurogenic bladder, based on the injury level:

- **Overactive bladder (spastic, hyperreflexic):** Lesions at or above the T12 vertebral level with intact sacral nerves typically result in detrusor overactivity and reflex voiding, and
- **Underactive bladder (flaccid, areflexic):** Lesions below the T12 vertebral level, with damage to the sacral nerves, typically result in poor detrusor contraction and incomplete or absent voiding.

Bladder dysfunction is one of the earliest and most common urinary disturbances after SCI.

When *supraspinal control* over the sacral spinal cord is lost, voluntary control of bladder emptying is impaired. If sympathetic and parasympathetic nervous control of the bladder is preserved, the bladder may fill and empty reflexively, often leading to incontinence once a threshold volume is reached. Bladder filling is driven by renal urine production and is largely passive, whereas bladder emptying may be uncoordinated and incomplete.

Incomplete emptying leaves residual urine in the bladder, which can increase the risk of a *urinary tract infection (UTI)*. When parasympathetic nervous control is impaired, detrusor contraction is inadequate, leading to urinary retention as the bladder continues to fill without effective emptying. In other cases, the bladder remains flaccid and fails to store appropriately, resulting in continuous dribbling.

2.5.3.3. Managing bladder dysfunction

Developments in bladder management have allowed a dramatic improvement in morbidity and mortality of people with SCI, with a significant decrease in lower UTIs. The goal of the SCI bladder program is to preserve kidney function while removing urine at regular, socially acceptable times, avoiding high bladder pressures, urinary retention, incontinence and infection. A bladder urine volume of less than 500 ml is a useful guide to avoid bladder distention, excessive pressure and urinary reflux, as well as to reduce the incidence of infections. A fluid intake restriction of two litres per day is common for people living with SCI, and the use of adult incon-

tinence pads for inadvertent leakage. In male patients, if the incontinence is intermittent, there may be an option to consider using a 'convene', a condom-like drainage bag.

If a large volume of urine remains after bladder emptying, an intermittent catheter (IMC) can be inserted by the SCI person or carer temporarily to remove the retained urine. IMC is removed shortly after complete bladder evacuation. In situations where intermittent catheterisation is possible due to physical or social factors, or there have been complications of IMC such as severe and recurrent UTIs, one will have to consider an indwelling catheter (IDC). An indwelling catheter (IDC) is inserted by health staff and remains in the bladder for an extended period. IDC increases the risk of catheter-associated UTI, as it is a plastic tube (a foreign body) that predisposes to biofilm formation inside and outside the IDC by common perineal organisms, leading to resistant UTIs that require intravenous or broad-spectrum antimicrobials. Best evidence-based practice for catheter use by people with SCI involves training them how to use an IMC aseptically and avoid IDC when they are self-reliant to use after the acute injury.

Important resources: Bladders and catheters

- SCIA's Bladder Management Options Following SCI (20 November 2021): This resource provides a clear overview of bladder management options after SCI, explaining common challenges and outlining practical methods to help people manage bladder function safely and effectively.
- Queensland Spinal Cord Injuries Service's (QSCIS) Indwelling catheters: This resource explains the use of indwelling catheters, outlining when urethral and suprapubic catheters are used, how they work, recommended catheter types, potential complications and essential day-to-day care and maintenance for people with SCI.
- QSCIS's Preventing catheter blockage: This factsheet explains why catheter blockages occur and provides practical guidance for preventing, identifying and managing blockages in people who use long-term indwelling catheters, particularly those with spinal cord injury.

Clinical resources: Bladder management in SCI

Spinal cord injury bladder management – a guide for clinicians in non-specialist units (PDF) (Agency for Clinical Innovation, NSW, June 2023): This clinical guide provides practical, evidence-informed advice for healthcare professionals in non-specialist settings on how to assess, manage and support bladder care for people with SCI, beginning in acute care and continuing through routine management.

Bladder complications can also be managed pharmacologically (**Table 2.6**). Most issues are managed with a combination of intermittent self-catheterisation and oral anti-cholinergic medications.

Table 2.6. Medication used to assist in bladder dysfunction.

Medication class	Examples	Action
Anti-cholinergic (muscarinic acetylcholine receptor antagonist)	Oxybutynin (Ditropan, Oxytrol), darafenacin (Enablex) solifenacin (Vesicare), tolterodine (Detrusitol)	Decreases bladder tone, reduces bladder muscle contractions, and may reduce urinary frequency and incontinence.
Anti-cholinergic (tricyclic anti-depressant)	Imipramine (Tofranil)	Increases urethral resistance tone, decreases bladder tone, suppresses bladder contractions, may reduce urinary frequency and incontinence.
Cholinergic (muscarinic acetylcholine receptor agonist)	Bethanechol (Urocarb)	Helps complete bladder emptying when the bladder has low tone.
Alpha-adrenergic agonist	Ephedrine	Helps increase bladder storage when the sphincter is permanently relaxed.
Alpha1-adrenergic receptor blocker	Prazosin, terazosin	Helps relax the sphincter and lower bladder pressures during contraction, but may lower blood pressure.
Beta3-adrenergic-receptor agonist	Mirabegron (Betmiga)	Relaxes the bladder muscle during the storage phase of urination, increasing bladder capacity.
Botulinum toxin	Botulinum toxin A	Injected into the bladder wall to reduce excessive detrusor activity for individuals who can self-catheterise.

Despite proactive management of bladder dysfunction, urinary tract infections (UTIs) are common in individuals with SCI. Asymptomatic UTIs are not usually treated, and antibiotics are not routinely used to prevent infection and reduce the development of drug-resistant bacteria. If a symptomatic UTI is confirmed, appropriate antibiotic therapy may be prescribed in patients at higher risk of an *upper UTI (pyelonephritis)*. Regular monitoring of kidney function and prompt treatment of complications as they arise can prevent progressive deterioration.

2.5.4.4. Urinary tract infections (*UTIs*)

Ideally, the urinary tract is sterile (free of microbes) due to normal defence mechanisms of the urinary tract. Predisposition to UTIs is the consequence of loss of bladder-bowel sphincter control, contaminated perineal areas, and urinary catheterisation. This is the most common infection in people with SCI and needs a detailed discussion on educating how this infection occurs and practising strategies to avoid it. Hand hygiene, perineal care and clean toilets are preventative strategies.

Important resource: UTI causes

Cystitis (Utis) Factsheet (Janette Williams, CNC Continence, Private Practice): This factsheet provides an easy-to-understand explanation of cystitis and includes a detailed list of common causes of urinary tract infections (UTIs), particularly relevant for people with SCI.

Several protective factors prevent bacteria from entering the urinary tract:

- The first is the physical distance between the bladder and the outside. The further the distance, the lower the risk of infection, which is why males are less prone to bladder infections than females
- The internal and external urethral sphincters also prevent bacteria from entering the urinary tract, and
- The third protective factor is complete bladder emptying. When urine remains in the bladder due to incomplete emptying, it becomes a breeding ground for bacteria, which can cause infection.

If a catheter is required to empty the bladder, either due to retention or due to continuous dribbling, the natural protection against infection is lost. UTIs are a common reason for emergency hospital visits and admissions. With IMC, the risk of infection is minimised by meticulously following aseptic technique during catheter insertion. If, however, you need to use a catheter continuously to drain the bladder, these natural barriers are permanently bypassed. Sometimes a biofilm can form on the inside of the catheter, allowing bacteria to ascend the urinary tract, evade antibiotics, and form permanent colonies. From this site, they can occasionally enter the bloodstream, causing severe infection needing hospitalisation. Fortunately, the lining of the urinary tract secretes chemicals to prevent bacteria from ascending the urethra from the surrounding perineal contamination with faeces. The immune system also steps up to fight bacteria within the urinary tract. This co-existence of bacteria within the urinary tract without causing active infection is common in catheterised patients and is called asymptomatic bacteriuria. But the balance is easily upset. Such individuals often become ill when bacteria breach these barriers. Unfortunately, there are no foolproof solutions to preventing these infections. It is a constant battle.

2.5.4.5. Renal stones

Urine carries waste products out of the body, but some of these substances do not dissolve easily in water. It is often called a 'supersaturated' solution. When the balance that keeps them

dissolved is disturbed, they can form crystals. These crystals may stick to substances such as cell debris, bacteria or inflammation in the urinary tract. Over time, they can grow bigger and harden into stones. If stones are not found and treated early, they can block the urinary tract and cause serious kidney problems.

Most stones are made of calcium oxalate or calcium phosphate. The best way to manage this is early detection with regular ultrasound scans and removing stones before they cause damage. Drinking plenty of fluids, eating a healthy diet and preventing urinary infections are important steps to reduce the risk of stones forming.

2.5.4.6. Hypertension (high blood pressure)

As previously mentioned, the kidneys play an important role in keeping our blood pressure within a safe range. When their function is disturbed, blood pressure control is defective. Often, blood pressure rises (called hypertension), and if it is not picked up early and treated, the high pressure can damage blood vessels supplying the brain and the heart, causing strokes and heart attacks. The blood vessels in the kidney itself are not spared, and damage to the kidney becomes progressive. This could lead to a vicious downward spiral toward permanent damage and death.

The nervous system also controls blood pressure through the kidneys, and an unregulated autonomic system can cause a sudden, severe rise in blood pressure, which, if undetected, can have catastrophic consequences such as stroke or heart attack and even death. As discussed earlier, this situation is called AD and can be precipitated by even simple things like constipation. Regular blood pressure monitoring and prompt treatment are the only solutions. Recognising AD and preventing precipitating factors (**Section 2.4.5.2**), such as urinary retention, urinary infection, constipation or using an irritant laxative, will help.

2.5.4.7. Chronic kidney disease and progressive renal failure

Recurrent damage to the kidney from blockage of the urinary system, recurrent infections, stones and untreated hypertension can lead to scarring within the kidney. Once scarring sets in, it is progressive and can lead to complete loss of kidney function, such as severe kidney failure. Dialysis treatment is needed to keep the individual alive.

2.5.5. Gastrointestinal system (mouth to anus, with accessory glands)

The gastrointestinal (GI) system plays a crucial role in digestion, nutrient and water absorption and waste elimination. It begins with the mouth, where food and liquids enter and ends with the anus, through which waste in the form of faeces is eliminated (**Figure 2.14**). Numerous accessory structures, such as the salivary glands, liver and pancreas, assist with mechanical and chemical digestion and nutrient absorption.

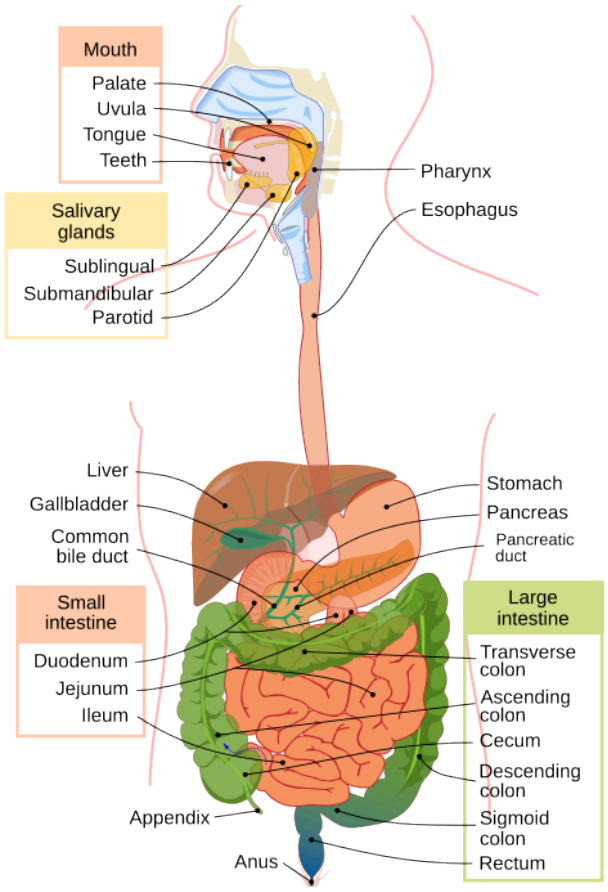


Figure 2.14. The various components of the GI system, with accessory glands such as salivary glands, liver and pancreas. *Source:* Wikimedia Commons, Gastrointestinal system, Public Domain

In individuals with SCI, this complex system can be severely disrupted, leading to ***neurogenic bowel dysfunction (NBD)***, a condition marked by impaired bowel motility, defaecation control and reduced quality of life. The term, ***neurogenic bowel***, is used to describe the loss of normal bowel function. This typically manifests as faecal incontinence, chronic constipation or both and can significantly affect quality of life and independence (Ethans *et al.*, 2024). *NBD* is not merely a functional inconvenience. It carries a substantial physical, emotional, and social burden. Understanding how SCI affects the GI tract is essential for people with SCI, their carers, support workers and clinicians.

Normal bowel function relies on a finely tuned balance between *ANS* innervation (sympathetic and parasympathetic), the enteric nervous system (intrinsic to the gut wall) and somatic pathways (notably the pudendal nerve controlling the external anal sphincter). These work together to ensure that the bowel is controlled by a finely tuned ensemble of nerves.

The ANS plays two key roles: The sympathetic nerves act like brakes, slowing bowel movement, while the parasympathetic nerves act like the accelerator, helping the bowel push stool forward. Alongside them, the ***enteric nervous system***, built into the gut wall itself, acts like the conductor of the ensemble. It keeps local movements and secretions in rhythm, ensuring stool moves smoothly through the colon. Finally, the somatic pathways, especially the pudendal nerve, give us conscious control over the external anal sphincter, the muscle we tighten or relax when deciding to go to the toilet. Together, these systems create harmony through

wave-like muscular contractions (peristalsis), resulting in stool moving at the right pace (colonic transit). When the rectum fills, the sphincter opens at the right time. This is called *ano-rectal coordination*.

With SCI, the interruption of supraspinal and spinal reflex pathways alters peristalsis, colonic transit, and anorectal coordination (Hakim *et al.*, 2021). So, the harmony we referred to earlier is disrupted. The brain can no longer send clear signals down the spinal cord to coordinate the orchestra. The reflex pathways that normally balance peristalsis, colonic transit, and sphincter control are interrupted. The result is a bowel that no longer follows the usual rhythm. Peristalsis may slow, stool may linger too long in the colon, and the rectum and sphincter may fail to work together. What was once a smooth, coordinated process becomes disjointed, leading to constipation, leakage or difficulty emptying, the hallmarks of NBD.

Following SCI, bowel dysfunction develops in three phases:

1. **Spinal shock phase:** Temporary loss of all reflex activity, including gut motility
2. **Recovery phase:** Reflex arcs may resume, revealing either *upper motor neurone (UMN)* or *lower motor neurone (LMN)* patterns, and
3. **Chronic phase:** Bowel patterns stabilise but often require lifelong management.

2.5.5.1. Types of NBD

NBD after SCI presents in two principal patterns, depending on the level and completeness of the SCI (Durney *et al.*, 2020). Both severely affect quality of life, although the clinical presentations and management strategies differ:

- **Reflexic bowel (or UMN bowel):** When the SCI is at or above T12, the reflex pathways that control the bowel are still intact, but the person loses voluntary control. This means the brain cannot send signals to relax the anal sphincter when it is time to pass stool. The anal sphincter stays tight and closed most of the time, making it difficult for stool to pass naturally. As a result, stool often accumulates, leading to constipation. Because the reflex arc is still working, bowel movements can be triggered in other ways. For example, digital stimulation (gently touching inside the rectum) or using suppositories can activate the reflex and cause the bowel to empty. Think of it like a locked door. You can't open it with the usual key (voluntary control), but you can still press a hidden button (reflex stimulation) to open it.

- **Areflexic bowel (or LMN bowel):** When the SCI is below T12, the reflex pathways are damaged or lost. This means the bowel no longer responds to stimulation in the same way. The anal sphincter becomes loose and floppy because it has lost its normal tone. Without the reflex to trigger emptying, stool may leak unexpectedly, causing incontinence. At the same time, the bowel does not empty effectively, so stool can remain in the bowel, leading to ineffective clearance.

In this scenario, it is like the door is broken; it does not stay shut. It also does not open fully when needed. This causes both leakage and incomplete emptying.

Reminder: Difference between a reflexic and an areflexic bowel

- **Reflexic bowel (UMN)** = tight sphincter, constipation, bowel emptying possible with stimulation.
- **Areflexic bowel (LMN)** = loose sphincter, leakage, poor emptying because the reflex is gone.

Can SCI affect the upper GI tract?

Although NBD primarily affects the lower bowel, SCI can also disturb the upper GI tract. This includes delayed gastric emptying, gastro-oesophageal reflux and impaired swallowing. These changes are partly due to disrupted autonomic regulation and changes in abdominal muscle tone (Emmanuel, 2019). This can result in constipation, faecal incontinence, prolonged time to evacuate bowels and abdominal pain or bloating.

Additional physiological changes include impaired colonic transit time, loss of defaecation sensation, dysregulation of the anorectal co-ordination reflex, and intestinal fluid dysregulation. These changes result in NBD symptoms manifested differently depending on the type and level of SCI. Effective bowel management is a cornerstone of comprehensive SCI care and nutrition plays a vital role in this process (Yeung *et al.,* 2021). **Chapter 3** provides extensive information on what a healthy, mindful diet should look like to minimise bowel issues, including the right amount of fibre, plant proteins, water intake and healthy eating habits.

Both reflexic bowel (UMN type) and areflexic bowel (LMN type) can trigger AD (Furusawa *et al.,* 2011). This is explained below:

- **Constipation and stool retention:** Hard stools stretch the rectum and the bowel wall. This stretching acts as a strong stimulus below the injury level, and the body can interpret it as 'painful' or 'irritating', triggering the autonomic nervous system to respond with AD
- **Manual evacuation or digital stimulation:** Even routine bowel care, such as using a suppository or digital stimulation, can irritate the rectum. This irritation can trigger AD episodes
- **Impaction (blockage):** A large stool mass can cause prolonged rectal distension and is one of the most common bowel-related causes of AD, and
- **Haemorrhoids:** This can also act as a stimulus, worsening the risk of AD during bowel care.

2.5.5.2. Managing bowel dysfunction

Constipation and/or faecal incontinence are initially managed with an integrated lifestyle approach, as early as feasible after SCI, using the individual's pre-injury bowel pattern as a guide. Adequate hydration and increasing dietary fibre and digital stimulation at regular daily time points are key. Laxatives (oral and/or rectal) may be needed initially to establish a regular bowel pattern. There are four broad classes of laxatives:

- Bulk-forming laxatives, for example, psyllium (Metamucil), ispaghula (Fybogel)
- Stool softeners, such as docusate, poloxamer (Coloxyl), liquid paraffin, and
- Osmotic laxatives, which are poorly absorbed, mix and draw fluid into the stool to soften the stool mass and stimulate bowel motility. These include:
    - Lactulose and sorbitol, which are non-absorbable sugars
    - Macrogols, polyethylene glycols, which are large non-absorbed polymers
    - Glycerol suppositories, and
    - Saline laxatives, such as powders or enemas
- Stimulant laxatives directly stimulate nerve endings in colonic mucosa to increase intestinal motility, such as bisacodyl, senna and sodium picosulfate.

Prucalopride is a recently marketed, selective 5-hydroxytryptamine-4 (5-HT4) receptor agonist that enhances gastrointestinal motility. It is indicated for chronic idiopathic constipation when standard laxatives are insufficient, so its use in the spinal cord injury (SCI) population may arise occasionally. However, it is contraindicated in individuals with intestinal obstruction or constipation secondary to other causes, such as medication effects or certain neurological disorders, because it has not been studied in these groups. While some people living with SCI can gradually reduce their use of laxatives and reserve them for episodes of impaction, others will require long-term therapy, particularly stimulant laxatives. Non-pharmacological options include ***transanal irrigation***

, ***antegrade colonic irrigation***, ***neurostimulation*** and, as a last option, ***colostomy.***

Podcast: A specialist talks about managing your bowel after SCI

SCIA's Have the Nerve podcast, What you should know about SCI and bowel management (Episode 4, 31 January 2024): Listen to a specialist nurse talking about how to manage your bowel after SCI.

2.5.5.3. Other GI issues with SCI

If one is taking medication to reduce muscle spasms or assist with bladder control, this may result in dry mouth (xerostomia), which is caused by decreased saliva production. This can affect one's ability to speak as well as make chewing and swallowing uncomfortable and challenging. Complications with mastication and swallowing can result in the individual's diet consisting only of soft foods. A reduction in saliva may also result in food debris remaining on the teeth longer, as well as the individual not receiving the antibacterial and anti-fungal effects of saliva (Rogers, 2014). **Chapter 3** discusses *xerostomia* in relation to the impact on dental health.

2.5.6. Skin (Integumentary system)

Skin is probably the largest organ of the body, with a surface area equivalent to one and a half to two square metres and it has the largest nerve supply in the human body. As shown in **Figure 2.15**, skin comprises three layers. The *epidermis* is in contact with the external environment, supported by *dermis and hypodermis*. The functions of skin include:

- **Protection:** Acts as a physical barrier against external environment- trauma, chemicals, ultraviolet (UV) radiation and pathogens. Skin has *antigen*-presenting cells, such as *dendritic cells*, *Langerhans cells* and *phagocytic cells*, which interact with the immune system to destroy micro-organisms and harmful stimuli. Any breach in the skin continuity predisposes one to infection that can spread.
- **Homeostasis:** Preventing excessive loss of water and electrolytes from body cells, removing waste through sweating and producing Vitamin D when exposed to sunlight.
- **Thermoregulation:** Regulating body temperature, such as *sweat glands* producing sweat (cooling effect), blood vessels dilating to allow the loss of heat and constricting blood vessels to retain heat and fat tissue providing support and insulation, and
- **Sensation:** Skin has sensory receptors which relay touch, pressure, pain and temperature signals to the brain and respond to the environment.

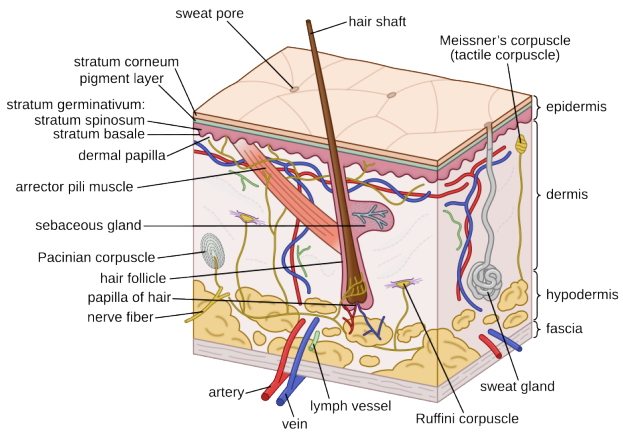


Figure 2.15.

Skin structure, layers and various accessory structures (glands, sensory receptors and hairs). *Source:* Wikimedia Commons, Skin, CC BY-SA 4.0

With SCI, the *hypothalamus* (the body's thermostat in the brain) loses communication, leading to poor response of the body to tem-

perature changes. Due to AD, the inability of the body to control blood vessel diameter impairs temperature regulation.

In addition, SCI disrupts sensory and motor pathways below the injury level, leading to loss of sensation. The person cannot feel pain or discomfort caused by prolonged pressure when sitting or lying in a particular position for an extended period. This means one may not instinctively move to relieve the pressure predisposing to pressure sores. Muscle paralysis or weakness in SCI patients restricts mobility, limiting one's ability to shift weight independently and change position frequently, thus predisposing one to pressure injuries at specific pressure points, such as the back, sacrum, buttocks, thighs, calves, and ankles. More than 85% of people living with SCI will develop a pressure injury, which can have a long-lasting, detrimental impact on the person, their family and the community.

Muscle loss reduces padding over the bony prominences. Being immobile could also contribute to pressure injuries. Loss of bladder and anal sphincter control leads to urinary and faecal incontinence, causing skin softening and damage due to excessive moisture in the sacral area. Increased risk of nutritional deficiencies, including macronutrients such as protein, which is important for collagen production in wound healing and micronutrients like vitamin C to strengthen fragile blood vessels and support collagen formation, as well as minerals like iron, copper, zinc, calcium, manganese and magnesium, which are crucial co-factors in the healing. Additionally, compromised defence mechanisms that one is born with (***innate immunity***) or learns over time (***acquired or adaptive immunity***) against micro-organisms increase their susceptibility to repeated infections, especially of the pressure injuries and catheter-associated UTIs.

2.5.6.2. Common skin conditions after SCI

The most common skin changes reported are thinning of the skin, making it susceptible to pressure injuries (85%), skin infections (37%), followed by ***eczematous changes*** (32%). An injury to the skin and underlying tissues caused by pressure is called a pressure injury (PI). The lifetime risk of developing pressure injuries in people living with SCI is 20-85%, of which 20-50% develop during acute hospitalisation. The chance of getting a pressure injury is 4.5 times greater in people with complete SCI compared with incomplete SCI (ACI, n.d.).

The second most common skin condition is fungal infections (62%), followed by bacterial (22%). ***Seborrheic dermatitis*** is common within 12 months of injury. Ingrowing toenails are more common in people with quadriplegia, while vascular skin changes are more common with paraplegia. Skin changes can affect quality of life and become life-threatening if septic.

Maintaining skin integrity is important, but numerous risk factors compromise integrity. Most common sites of pressure injuries are bony prominences that are constantly in contact with bed sheets, such as the back, buttocks, hip girdle, back of the thighs and ankles, heels and feet, shoulders, the scapula (shoulder blade) and ***perineum***.

2.5.6.3. Intrinsic risk factors

Out of several intrinsic factors that increase the risk of pressure injuries mentioned below, impaired mobility and sensory loss are the two key risk factors for PI:

- **Age:** Skin becomes thinner, less elastic, and more fragile with advancing age
- **Body weight:** Underweight (bony prominences) or overweight (stretch) place the skin at risk
- **Skin colour:** Darker skin colour can mask the early skin changes
- **Mental health:** Psychosocial factors can affect self-care
- **Smoking:** Impairs tissue oxygenation, which delays wound healing
- **Nutrition:** Protein, vitamins and minerals deficiencies impair skin integrity and repair, and
- **Co-morbidities:** Diabetes and sleep apnoea affect oxygenation and tissue health.

2.5.6.4. Extrinsic risk factors

Below are some of the extrinsic (external or environmental) risk factors for pressure injuries:

- **Pressure:** High, prolonged downward force applied to the tissue over an underlying bony prominence can obstruct circulation and reduce tissue bulk, thereby increasing the risk of pressure injuries
- **Shear:** When forces in opposite directions are applied to the underlying tissue. Tissue is 'pulled up' as the person slides down, and the bed causes compression on blood vessels
- **Friction:** Constant rubbing of skin against a surface can bruise the skin, such as a heel rubbing on sheets; and
- **Skin microclimate:** The interaction between skin temperature and moisture predisposes to tears.

In October 2025, the NSW Spinal Cord Injury Service (ACI) provided a guide for clinicians in non-SCI settings: Prevention and management of skin and pressure injuries in spinal cord injury patients. The guide provides the following 'Basic Principles' on how to prevent and manage pressure injuries for each risk factor in detail:

- **Equipment:** Individuals with SCI use a range of equipment and assistive technologies to support daily living and functional independence, such as pressure-relieving cushions, wheelchairs, mattresses, adjustable beds, slings, showering, and hygiene aids, as well as medical devices such as cervical collars, abdominal binders, compression garments and other orthoses. Equipment should be properly fitted, regularly maintained and selected with pressure care needs in mind to minimise the risk of skin breakdown.
- **Personal care:** Education for the person with SCI and their support network is essential to promote proactive skin management. Education should include performing skin

checks, recognising early skin changes and seeking advice or assistance to manage skin care.

- **Moisture and microclimate:** Thermoregulatory dysfunction, sensory impairment, and wheelchair dependence can make it challenging to manage moisture and maintain an optimal skin microclimate, particularly during Queensland's humid summers. Prolonged sitting with limited airflow, contact with synthetic fabrics, and incontinence can elevate skin moisture and temperature, increasing the risk of pressure injuries and skin breakdown.
- **Lifestyle:** Work, travel, recreational and cultural activities can influence equipment choices for people with SCI. These factors may affect the type of equipment used, such as sports wheelchairs, as well as sitting duration, postural changes and the range of surfaces encountered, such as car seats or ground-level seating.
- **Funding:** Access to appropriate funding impacts the ability to obtain, maintain, and service necessary equipment. Limited funding may delay equipment replacement or repairs, increasing the risk of secondary complications, and
- **Geographic location:** Living in regional or remote areas may limit access to equipment trials, hire services and ongoing maintenance. This can restrict equipment options and may result in devices that are not suited to the individual's clinical or functional needs.

Important resources: Skin health and predisposing factors of skin conditions

- The Cleveland Clinic's Skin Health page (13 October 2021) provides an easy-to-understand overview of the skin, describing it as the body's largest organ and explaining its structure, layers and major functions, including protection from germs, temperature regulation and sensing touch.
- The Queensland Spinal Cord Injury Service (QSCIS) provides a comprehensive list of intrinsic and extrinsic risk factors that predispose to skin conditions. Multiple comorbidities associated with autonomic, cardiovascular, pulmonary, endocrine, gastrointestinal, genitourinary, neurological and musculoskeletal dysfunction make it even more likely that pressure injuries will occur.

Video: Pressure injury prevention

This Educational Video: Pressure Injury Prevention – Craig Hospital addresses some of the risk factors above, offering suggestions about prevention and providing excellent tips about how to avoid these risk factors.

Media story: Shortage of neurosurgeons delaying surgery for pressure injuries

Pressure injuries may also be socially isolating in the event of a shortage of specialist services: WA neurosurgeon shortage delaying surgery for vulnerable patients.

Clinical resource: Dermatological findings during rehabilitation

Dermatological findings following acute traumatic spinal cord injury: About 30% of patients in rehabilitation following SCI developed a skin disorder. Of the disorders, 50% were fungal infections, all of which occurred below the injury level.

2.5.6.5. Being vigilant and checking your skin regularly

The ACI recommends twice-daily skin checks and provides a skin monitoring routine factsheet on how to do this. It is important to stage the pressure injury to know what action to take (**Table 2.7).**

Important information: Stages of pressure injuries

Royal Children's Hospital has a one-page staging infographic showing the various stages, with photographs and diagrams.

Table 2.7. Staging of a pressure injury and the response of the care team.

Stage	Description	Response of the care team
1	Intact skin with persistent redness that does not blanch on pressure.	**Early stage** • Relieve pressure immediately. • Optimise nutrition and hydration. • Maintain a moist environment with topical dressings. • Manage infection if present.
2	Partial thickness loss, including epidermis and dermis. Shallow ulcer or blister	
3	Full-thickness loss extending to subcutaneous tissue but sparing muscle or bone.	**Advanced stage** • Debridement: Removal of dead tissue (surgical, enzymatic, mechanical) • Advanced wound care dressings (hydrocolloid, foam, alginate) • Antibiotics • Graft for skin loss (flap reconstruction)
4	Full-thickness tissue loss with exposed bone, tendon, or muscle	
Unstageable	Covered by slough (dead skin), so depth cannot be determined	Debride the slough and act as per the depth of loss underneath the slough
Deep tissue injury	Deep red or purple coloured PI with full-thickness skin loss extending to deeper and surrounding tissues	Debride the purple discolouration and act as per the depth of loss

Key recommendations: Advice to prevent pressure injuries

To help prevent pressure injuries while sitting, redistribute pressure on your limbs and buttocks by:

- Shifting your weight every 15-30 minutes, such as push-ups or leaning

- Changing position every two hours, and
- Using pressure-relieving cushions (foam or air-filled) and mattresses.

Perform regular skin checks and be hygienic by:

- Keeping your skin clean and dry but moisturised
- Using gentle cleansing agents and avoiding harsh soaps
- Inspecting daily for early signs of sores and infection, and
- Managing incontinence with appropriate products to prevent skin softening from leaked urine.

2.5.6.6. Nutrition in the prevention and treatment of pressure injuries

Adequate energy, high protein intake (especially in severe injuries), and targeted micronutrient support are essential for pressure injury prevention and healing in persons with SCI (Can-Scip guidelines 2025). A recent systematic review of clinical practice guidelines for nutrition care in pressure injuries in SCI (Wang *et al.*, 2026), however, identified substantial limitations in the evidence underpinning these nutrition recommendations. The review highlighted a lack of high-quality SCI-specific research, inconsistencies across guidelines, and limited practical guidance on the monitoring and evaluation of nutrition care. Furthermore, two recent empirical studies from Queensland, Australia, demonstrated that individuals with SCI and pressure injuries do not exhibit hypermetabolism, as seen in people living with SCI who have pressure injuries, and that overfeeding may be associated with poorer wound-healing outcomes (Nevin *et al.*, 2025). It is therefore important to consult an accredited practising dietitian for a personalised healthy, nutritious diet that is high in protein and adequate in key macronutrients, vitamins and minerals, such as zinc, as well as adequate hydration.

2.5.6.7. Complications arising from pressure injuries

Below are some of the complications arising from pressure injuries, followed by important resources:

- Infection of skin (cellulitis), bone and blood (sepsis)
- Chronic wounds, causing pain and disability
- Extended hospital stays
- Increased healthcare costs, and
- Impact on mental health (depression, anxiety).

Important resources: Pressure injury guidance

- ACI: Pressure Injury Toolkit for SCI and Spina Bifida: Comprehensive guidelines and practical tools for managing pressure injuries in individuals with spinal cord injury or spina bifida
- SCIRE Professional's Pressure Ulcers: Evidence-based research and clinical recommendations for pressure ulcer management in SCI
- SCIRE Community Resource: Patient-friendly guide on preventing and treating pressure injuries for people living with SCI, and
- SCIRE Professional's Impact of Pressure Injuries: Explores the physical, psychological and social consequences of pressure injuries in individuals with SCI, highlighting the significant impact on health and quality of life.

Clinical resources: Pressure injuries

The following are useful resources for health practitioners:

- Australian Commission on Safety and Quality in Health Care's Pressure injuries: Standardised system for identifying and staging pressure injuries, essential for accurate assessment and documentation
- Clinical Practice Guidelines: Prevention and Treatment of Pressure Ulcers/Injuries: Global best-practice clinical guidelines for prevention and treatment strategies
- Wounds Australia: Chronic Wounds Factsheets: Evidence-based information and practical guidance for clinicians on the prevention, assessment and management of chronic wounds, and
- SCI Pressure Injury Toolkit – Clinician Checklist: A practical checklist designed for clinicians to guide the prevention and management of pressure injuries in individuals with SCI (NSW). Due for review in 2027.

2.5.6.8. Sepsis

In the previous sections, we emphasised the prompt recognition of infection and seeking appropriate help to treat it. It is important to understand that when infection is ignored, it can lead to an extreme form, called sepsis, in which parts of the body start to shut down, causing low blood pressure, severe breathlessness with an inability to absorb oxygen from the air, kidney failure, liver failure and brain dysfunction in the form of confusion (delirium). In extreme situations, spontaneous bleeding occurs when blood fails to clot. It can lead to death. Children under 5 years of age, elderly people over the age of 65, whose immune system is suppressed,

as well as individuals with poor diabetes control, kidney failure and liver failure, are at high risk for dying from sepsis. People with SCI are vulnerable to developing sepsis due to a combination of factors, such as immobility, pressure injuries, neurogenic bladder dysfunction, respiratory complications, such as weak respiratory muscles and poor cough reflex, and the need for frequent invasive medical procedures. Altered pain perception and need for pain medications can delay the recognition of sepsis.

Sepsis can occur in individuals living with SCI due to a combination of factors, including but not limited to:

1. **Immobility:** Individuals living with SCI often experience varying degrees of immobility, leading to reduced blood circulation and pooling in the lower extremities. This stagnant environment makes it easier for blood clots to form and infections to proliferate in the body
2. **Pressure ulcers (bedsores):** Due to limited mobility and altered sensation, SCI patients are at a higher risk of developing pressure ulcers. These open wounds provide an entry point for bacteria, potentially leading to localised infections that can progress to sepsis if not managed promptly
3. **Neurogenic bladder dysfunction:** Many SCI patients experience neurogenic bladder, which can result in incomplete bladder emptying, urinary retention, and the need for catheterisation. A plastic catheter can promote biofilm formation, increasing the risk of UTIs. If left untreated, the infection can spread to the bloodstream, leading to sepsis
4. **Respiratory complications:** Respiratory muscle weakness and impaired cough reflexes are common with SCI, making individuals vulnerable to pneumonia and other respiratory infections. These infections can spread throughout the body and contribute to sepsis
5. **Weakened immune function:** SCI can weaken the immune system, diminishing its ability to combat infections, thereby increasing the risk of harmful microorganisms thriving and sepsis.
6. **Invasive medical procedures:** Individuals living with SCI often require invasive procedures such as surgery, catheterisation and ventilator support. Without proper infection control measures, these interventions may introduce harmful germs into the body, heightening the risk of infections and sepsis, and
7. **Delayed symptom recognition:** Altered sensory perception and pain medication can delay symptom recognition in individuals with SCI, masking symptoms of sepsis. This can prolong diagnosis and treatment.

Key recommendation: Treat sepsis as a medical emergency

Given these factors, carers and healthcare providers must remain vigilant in assessing individuals for signs of sepsis. If you think someone has sepsis, **call 000**. If in the hospital, bring it to the attention of the health-care workers and physicians. Early recognition, prompt intervention and preventive measures, such as proper wound care, infection control practices and catheter management, are essential in mitigating the risk of sepsis in people living with SCI.

2.5.6.9. How can sepsis be managed?

Sepsis is the consequence of unrecognised or neglected infection. The infection can occur anywhere in the body, including the skin, respiratory tract, abdomen or the urinary tract. Once the uncontrolled infection reaches the stage of organ failure, intense treatment in a hospital is needed, without which there is a high risk of death. Even if patients survive, they could be left with long-term physical, cognitive and psychological complications. Prompt recognition and treatment of infection is vital in preventing sepsis.

Clinical resources: Sepsis

The following are important clinical resources for health practitioners:

- Australian Commission on Safety and Quality in Healthcare's Sepsis in Australia: A growing burden but signs of progress
- Australian Commission on Safety and Quality in Health Care's Co-ordination of care and post-sepsis support (updated September 2025)
- Queensland Health's Sepsis kills more Australians than road traffic accidents
- NSW Health's Sepsis fact sheet
- Australian Sepsis Network's Sepsis Data Confirms What We Knew: Time for Mandated National Standards, and
- van der Slikke, E. C., Beumeler, L. F. E., Holmqvist, M., Linder, A., Mankowski, R. T., & Bouma, H. R. (2023). Understanding post-sepsis syndrome: How can clinicians help? *Infection and Drug Resistance, 16,* 6493-6511.

2.5.7. Endocrine system

The video below explains the structure and function of the endocrine system, which produces hormones that affect different cells and tissues in the body.

Video: The endocrine system

This video explains the body's endocrine system, which produces hormones.

There are too many hormones to describe, but you would be familiar with hormones such as insulin, which is produced by the pancreas and tells cells to take up glucose and testosterone, produced by male testes, which causes masculinisation such as skeletal muscle mass increase, a deep voice, facial and body hair and sperm development. Just like the nervous system described earlier, the endocrine system can be considered another regulating system of the body (**Figure 2.16**).

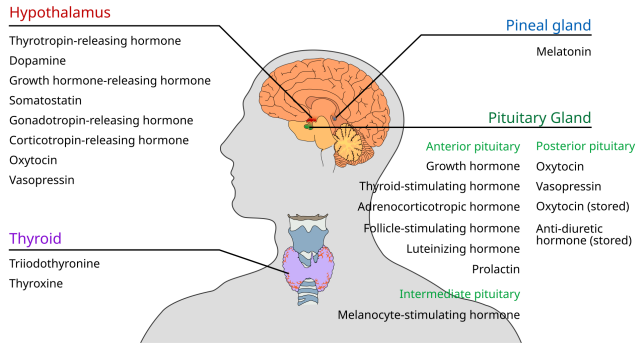


Figure 2.16. The pineal gland is an endocrine gland in the brain impacted by SCI. *Source:* Wikimedia Commons, Endocrine glands, Public Domain

As described above, SCI damages several structures at the site of the damage, including nerves that ascend and descend the spinal cord, disrupting the transfer of information. Depending on the level of the SCI, autonomic (sympathetic and parasympathetic nervous system) function can be greatly impacted by the trauma, resulting in dysfunction of various organs. We already know about the dysregulation of the heart and blood vessels, the lungs, kidneys and bladder.

One of the endocrine organs that can be affected by SCI (with implications on your body) is the pineal gland, which helps to control our *circadian rhythm*, which is the body's natural 24-hour clock and sleep-wake cycle that coordinates the physical and mental systems in the body. This cycle regulates our endocrine system in terms of, for example, when the adrenal gland produces cortisol and when our digestive enzymes are made to coincide with when we eat.

Darkness is the primary stimulus of the ***pineal gland***. In response, it synthesises and releases melatonin that prepares us for sleep. Light received through our eyes and through the nervous system inhibits melatonin production.

Primary sleep disorders, such as *circadian rhythm sleep–wake disorders* and insomnia, are commonly encountered in SCI, especially those with quadriplegia. It would appear that individuals with injuries below T4 maintain their melatonin rhythm.

Chapter 3, a chapter on maintaining good health and well-being, discusses sleep disorders relating to SCI and the non-pharmacological and pharmacological interventions that you can try. Quality sleep is discussed as one of the five pillars of good health and well-being.

Clinical resource: Melatonin and SCI

The following is an important clinical resource for health practitioners: Melatonin, a natural antioxidant therapy in spinal cord injury.

2.5.8. Immune system

The various parts of the body that are considered part of the human immune system are shown in **Figure 2.17**. The main function of the immune system is to protect one from various microbes, such as bacteria, viruses and fungi. When tissues are damaged, our immune system kicks in to protect us from infections (viruses, bacteria, fungi) and from abnormal cells (like cancer cells). If it doesn't work properly, it can lead to problems. If it is too weak, one gets frequent infections. If it is too strong, it damages one's own cells (allergies, autoimmunity).

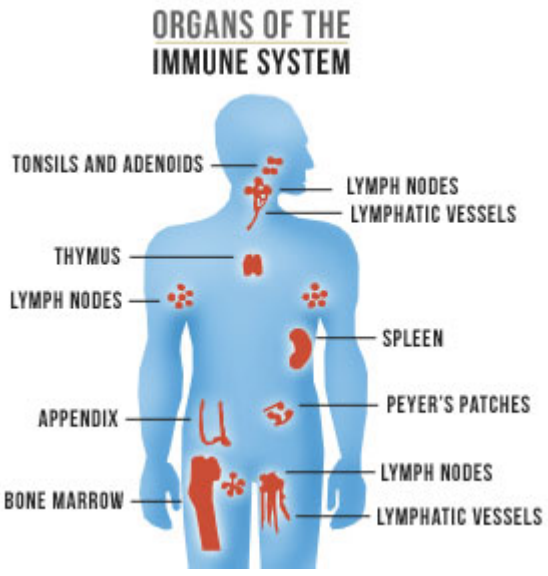


Figure 2.17. The various organs of the human immune system. *Source:* Wikimedia Commons, Organs of the Immune System, CC BY 4.0

Below is a brief description of the various sites in the body that are considered part of the immune system:

- **Bone marrow:** The 'factory' inside our bones, which produces stem cells that become ***white blood cells (WBCs)*** (immune cells)
- **Thymus:** A small organ in your chest where *T-lymphocytes* (a type of white blood cell) learn to recognise what's 'self' (your own body*) vs*. what is 'foreign' (*antigens*).

- **Lymph nodes:** 'Checkpoint' structures scattered around your body, such as in your neck, armpits and that filter all tissue fluid before it is returned to blood vessels. Any foreign antigens travelling through them will activate different immune cells
- **Spleen:** Filters blood so that if there are any antigens, such as bacteria, the appropriate immune cells will respond
- **Mucosal tissue:** Lines most of your 'tracts', such as your gastrointestinal, respiratory and urinary tracts. As they are in contact with the external environment, such as when we eat food or when we excrete waste, they have collections of immune cells to respond to any breaches of the lining of these tracts, and
- **Skin:** A physical barrier that helps keep germs out, hence it is part of immune defence.

2.5.8.2. Important cells of the immune system

There are many types of immune cells, which form part of two types of immunity: *Innate immunity* (general defence with which we are born) and *adaptive immunity* (more specific defence we acquire over time as we encounter different *antigens*).

- **Innate immune cells** ('first responders'): These act quickly and generally don't need to have seen a germ before to respond:
  - *Neutrophils:* Very common white blood cells that rush to infection sites, eat (phagocytose) the germ (mainly bacteria) and help form "swarms" to trap invaders
  - *Macrophages:* Big "eat-and-clean-up" cells. They engulf germs or dead cells and break them down. This sends out chemical signals to alert other immune cells
  - *Dendritic cells:* They are like scouts that grab germ bits (antigens), then travel to lymph nodes to present them to *T-lymphocytes* so the adaptive response can start
  - *Natural killer (NK) cells:* They are like assassins, able to kill virus-infected or abnormal (potentially cancerous) cells without prior training, and
  - *Mast cells:* Located in tissues near blood vessels, which, upon activation, release chemicals (like histamine) that initiate inflammation, an important early response.
- **Adaptive immune cells** ('smart defenders'): These are more specific cells that adapt and 'remember' past invaders so they can respond faster next time.
  - *B-lymphocytes (B-cells):* Made in the bone marrow, which turn into plasma cells that produce *antibodies*. These are like targeted missiles that stick to invaders, such as a virus, and destroy or neutralise them. Some B cells become memory B-cells, which enable our body to remember a germ it has seen before, and
  - *T-lymphocytes (T-cells):* They start in bone marrow but mature in the thymus. There are two main kinds:
    - *Helper T-cells (CD4+)*: Help other immune cells through chemical signals
    - *Cytotoxic (killer) T-cells (CD8+)*: Kill infected cells directly. They are very specific as they recognise particular antigens presented to them by dendritic cells or other 'presenting' cells.

Figure 2.18 summarises the main cells involved in an immune response when an antigen is first encountered (the primary immune response), including cells of the innate immune system (macrophages) and the adaptive immune system (B-cells and T-cells).

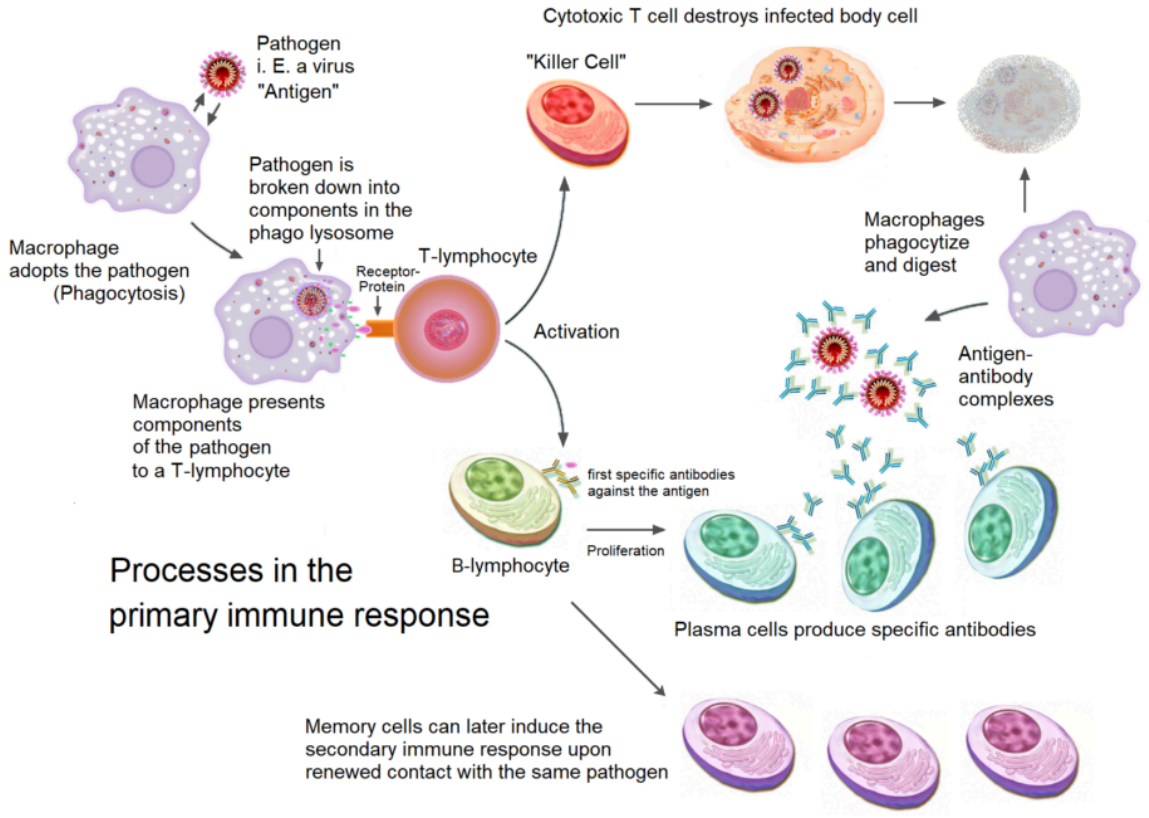


Figure 2.18.

Immune cells are involved in a primary immune response. *Source:* Wikimedia Commons, Primary immune response, CC BY-SA 4.0

2.5.8.3. Functions of the immune system

The immune system performs numerous functions:

- **Guard:** The skin and mucous membranes act like walls and gates, stopping or catching many invaders early
- **Alarm:** If a pathogen (germ) gets past the innate cells, such as macrophages, neutrophils and dendritic cells, they detect it quickly
- **Clean-up and call for back-up:** Macrophages eat the germ, dendritic cells pick up fragments (antigens) and travel to lymph nodes

- **Activating:** In lymph nodes, *T-cells* are activated by antigens presented by dendritic cells. B-cells may also be activated
- **Attack:** *B-cells* (as plasma cells) release antibodies into the blood, which stick to germs and mark them for destruction
    - *Killer T-cells* kill infected cells directly
    - Other immune cells help with inflammation, signalling and clean-up, and
- **Memory:** After the threat has gone, some B-cells and T-cells stick around as 'memory' cells, ready to respond even faster if the same germ comes back.

2.5.8.4. Immune dysfunction after SCI

The sympathetic nervous system, the 'fight-or-flight' system, is involved in controlling the immune system. It does this through nerves that run down the spinal cord and send signals to organs, such as the spleen, lymph nodes, bone marrow and gut. Normally, the brain keeps these sympathetic nerves under control, but with a high-level SCI, especially above T6 level, the brain can no longer send signals to these nerves. Because most immune-related organs are controlled by nerves located at or below T6, injuries at or above T6 interrupt this control. As a result, high-level SCIs are more likely to lead to immune problems than lower-level injuries (Rodgers *et al.,* 2022).

Regarding respiratory problems in people living with SCI, Berlowitz *et al.* (2016) suggest that individuals living with SCI at or above T3 are prone to severe infections such as pneumonia, lymph node shrinkage and weaker immune responses compared with injuries below T9. Those with incomplete SCIs, with some nerve pathways intact, tend to have better autonomic function and a lower risk of infection than those with complete injuries, especially when the injury is at or above T4.

This disruption of nerve and hormone control of key *immuno-endocrine organs* such as the spleen, adrenal glands, the lymphatic system and bone marrow leads to ***SCI-Induced Immune Deficiency Syndrome (SCI-IDS)***. Individuals with SCI are at greater risk of respiratory and urinary tract infections than those without SCI, primarily due to what is referred to as ***injury-induced immune depression syndrome (IDS),*** which is characterised by a chronic low-grade systemic inflammation. Although mature leukocyte (white blood cells) dysfunction is the main feature of SCI-IDS, ***post-injury 'bone marrow failure syndrome'*** may be the earliest manifestation of SCI-IDS, leading to impaired development and mobilisation of immune cell precursors in bone marrow. A large systematic review with meta-analysis of 54 studies (Valido *et al.,* 2023) summarises that the immune status of individuals with SCI differs from that of individuals without SCI and is clinically influenced by the phase of injury, completeness of injury, sympathetic innervation impairment, age and sex. Immune cells exhibited reduced functional capacity in individuals with SCI compared with those without SCI.

As noted above, immune problems start soon after SCI, with SCI-induced immune deficiency syndrome (SCI-IDS) persisting. Many signs of immune weakness often worsen over time as

one lives with SCI. Research suggests that this long-term immune suppression happens partly because the sympathetic nerves in the injured spinal cord rewire themselves. New, abnormal nerve connections form and these altered networks end up poorly controlling the immune organs and the adrenal glands, leading to ongoing immune problems.

The ***adrenal glands*** are located at the top of each kidney and comprise two distinct anatomical regions, the cortex and medulla. The adrenal cortex produces steroid hormones, including glucocorticoids, while the adrenal medulla releases catecholamines, such as adrenaline, dopamine and noradrenaline. These glands are essential for maintaining the body's balance and managing stress. When one experiences stress, both hormonal and neural signals activate the adrenal glands to release stress hormones. The adrenal glands are also controlled by the ANS (both sympathetic and parasympathetic nerves). After SCI, the sympathetic control of the adrenal glands is most affected, disrupting ***homeostasis*** with profound effects on immune function. Excess or sustained elevation of glucocorticoids can impair inflammatory signalling in immune cells. In mice with SCIs, blocking the effects of noradrenaline and glucocorticoids on immune cells helps them survive and function normally again. This suggests that similar treatments might one day help people with SCI by preventing or reducing the immune problems that develop after the injury.

Normally, the release of mature WBCs from the bone marrow into the blood is regulated by the noradrenaline from sympathetic nerves. We know that SCI adversely affects autonomic and neuro-endocrine control over lymphoid tissues, adrenal glands and bone marrow, thus impairing the development and mobilisation of leucocyte precursors from their primary site of production in bone marrow into blood and impairs the maturation of leucocytes (WBCs), leading to the onset and persistence of SCI-IDS.

Clinical resources: Immune system and SCI

For health professionals seeking more information on immune changes after SCI, the following peer-reviewed resources provide useful overviews of immune status, mechanisms of dysfunction and clinical implications:

- Valido, E., Boehl, G., Krebs, J., Pannek, J., Stojic, S., Atanasov, A. G., Glisic, M., & Stoyanov, J. (2023). Immune status of individuals with traumatic spinal cord injury: A systematic review and meta-analysis. *International Journal of Molecular Sciences, 24*(22), 16385. This systematic review and meta-analysis summarises current evidence on immune alterations following traumatic SCI, including changes in immune cell populations and functional deficits
- Rodgers, K. A., Kigerl, K. A., Schwab, J. M., & Popovich, P. G. (2022). Immune dysfunction after spinal cord injury: A review of autonomic and neuroendocrine mechanisms. *Current Opinion in Pharmacology, 64,* 102230. https://doi.org/10.1016/j.coph.2022.102230: This review discusses how autonomic and neuroendocrine disruption after SCI contributes to immune suppression and altered inflamma-

tory responses, and

- Ortega, M. A., Fraile-Martínez, O., García-Montero, C., Haro, S., Álvarez-Mon, M. Á., De Leon-Oliva, D., Gomez-Lahoz, A. M., Monserrat, J., Atienza-Pérez, M., Díaz, D., Lopez-Dolado, E., & Álvarez-Mon, M. (2023). A comprehensive look at the psychoneuroimmunoendocrinology of spinal cord injury and its progression: Mechanisms and clinical opportunities. *Military Medical Research, 10,* 26. https://doi.org/10.1186/s40779-023-00461-z: This article provides an integrated overview of psychological, neurological, endocrine and immune interactions after SCI and highlights potential clinical strategies for managing immune-related complications.

2.5.9. Male and female reproductive systems

With SCI, it goes without saying that both the male and female reproductive systems are impacted. This section will briefly describe the impact on the functioning of the male and female reproductive systems at different injury levels (**Table 2.8**). **Chapter 10** will provide additional details in the section on sexuality, intimacy and fertility, where recent research is explored, and resources are provided.

2.5.9.1. Level of injury and the implications on male and female sexual responses

Table 2.8 summarises the impact of nerve injury at different levels on the male and female reproductive systems and functions.

Table 2.8. Impacts of SCI level on male and female reproductive organs and their functions.

Function	Injury level	Nerve pathways	Impact: Male	Impact: Female
Parasympathetic	S2-S4	Pelvic splanchnic nerves	*Erection:* Mediated by parasympathetic fibres (S2-S4) via pelvic splanchnic nerves → vasodilation of penile arteries.	*Arousal:* Parasympathetic fibres (S2-S4) stimulate clitoral erection and vaginal lubrication.
Sympathetic	T11-L2	Hypogastric nerves	*Ejaculation: Emission phase:* Sympathetic fibres (T11-L2) stimulate contraction of the vas deferens, seminal vesicles and prostate.	*Orgasm:* Sympathetic fibres (T11-L2) cause uterine and vaginal contractions.
Somatic	S2-S4	Pudendal nerve	*Sensory input, voluntary muscle contractions during orgasm:* • *Sensation:* Pudendal nerve (S2-S4) carries sensory input from the penis. • *Ejaculation:* Expulsion phase: Somatic fibres (S2-S4) via the pudendal nerve cause rhythmic contraction of the pelvic floor muscles.	*Sensory input, voluntary muscle contractions during orgasm:* • *Sensation:* Pudendal nerve (S2-S4) transmits sensory input from the vulva and clitoris. • *Orgasm:* Somatic fibres (S2-4) via the pudendal nerve control pelvic floor muscle contractions.

Thus, complete injuries above S2 may preserve reflexogenic responses, such as reflex erection or lubrication, but impair psychogenic responses. Injuries at or below S2-S4 may impair both reflex and psychogenic responses, leading to flaccid dysfunction. Depending on the level, severity and completeness of the injury, the following functions can be affected to varying degrees. In a complete injury above the T11 level, for example, all the functions listed below would be affected.

For men, an erection may be impaired depending on the level and completeness of the injury. Reflex erections (from physical touch) may still occur if the sacral spinal cord is intact. The ability to ejaculate is often affected, with many men experiencing anejaculation (inability to ejaculate) or retrograde ejaculation (ejaculum flowing backwards into the bladder). The ability to have an orgasm may be diminished or absent, especially in complete injuries. Libido is influenced by psychological factors, medications and hormonal changes.

In women, lubrication may be reduced and it may be more difficult to experience an orgasm. Some women can retain the ability, depending on the injury. The female libido is like that of men and is influenced by psychological and physiological factors.

2.5.9.2. Male and female fertility

Sperm quality is often due to increased scrotal temperature, infection and *AD*. Assisted reproduction techniques, such as ***penile vibratory stimulation (PVS)***, ***electroejaculation (EEJ)*** or surgical sperm retrieval, may be used. For women, fertility will return following the first menstrual cycle post-injury. Women with SCI can conceive, carry, and deliver babies, but may require high-risk obstetric care due to risks like *AD*, urinary tract infections and pressure sores.

Chapter 10 provides additional information and research findings in terms of male and female sexual function and fertility.

2.5.10. Skeletal system: Osteoporosis

An inevitable complication of SCI is the associated ***osteoporosis*** that occurs predominantly in the pelvis and the lower extremities. Bone loss as a consequence of SCI has been of secondary concern historically. Jiang and colleagues' (2024) research into bone loss in patients with SCI found that ***bone mineral density (BMD)*** loss was 66.3% in SCI patients, particularly in the hips. Their results showed that weight (being heavier rather than lighter) was protective in terms of bone loss after SCI. To this end, the risk of bone loss was decreased by 8.5% for every one kilogram increase in weight. Being male may, however, had a four times higher risk factor compared with women. To summarise, individuals who were male, of low height, lightweight and had lived with long-term SCI were more likely to have bone loss. Osteoporosis is discussed in more detail in **Chapter 6**.

2.5.10.1. Management of osteoporosis

As rapid bone loss begins early in SCI, prevention of osteoporosis in the traditional sense is limited to non-pharmacological strategies, where feasible. These may include passive standing, neuromuscular electrical stimulation and functional electrical stimulation. Vitamin D deficiency is common in people with SCI (prevalence ranging from 24.9% to 83.3%). To optimise bone health in SCI, the Paralyzed Veterans of America Clinical Practice Guidelines (2022) recommend monitoring 25-hydroxy vitamin D levels and supplementation when levels are lower than 32 ng/mL, which is higher than that recommended for non-SCI individuals. While the risk versus benefit of supplementing with calcium in addition to vitamin D remains controversial, increased calcium in the diet should be encouraged and calcium levels should be monitored.

Pharmacological treatments are commonly used early in SCI to reduce fracture risk. Most effective options in SCI include ***bisphosphonates***, such as alendronate, risedronate and zoledronic acid, which inhibit bone resorption and denosumab (a monoclonal antibody administered by subcutaneous injection every six months). Caution should, however, be taken with long-term

use due to the increasing potential risk of osteonecrosis of the jaw and atypical femoral fractures (Wang *et al.*, 2023).

Clinical resources: Osteoporosis and SCI

The following are important clinical resources for health practitioners:

- University of Washington's SCI Forum Report & Video on Osteoporosis and fractures in persons with SCI: What, why, and how to manage
- Bone health and Osteoporosis Management in Individuals with Spinal Cord Injury (CPG Spinal Cord Medicine, 2022) (US Veteran guidelines)
- Porter JL, Varacallo MA. Osteoporosis (Archived) (2023). In: *StatPearls*. Treasure Island (FL): StatPearls Publishing, and
- ***Neurogenic heterotropic ossification (NHO)***: Queensland scientists unlock cause of debilitating spinal injury condition – Mater Research.

2.6. Pain and spinal cord injury

Pain following SCI warrants an in-depth exploration. About 70% of people with SCI will experience pain. Pain can be *acute* (often described as ***nociceptive***) or chronic (***neuropathic***). A large group of patients with chronic pain, however, remained without a valid pathophysiological identification for their experience of pain. In 2023, this led the International Association for the Study of Pain to recognise ***nociplastic*** pain as a third pain type, frequently described as dysfunctional, persistent and psychogenic.

Video: Difference between nociceptive, neuropathic and nociplastic pain

Nociceptive, neuropathic and nociplastic pain (Dr Andrea Furlan, 23 January 2022): In this video, **Dr Andrea Furlan** explains that there are three types of pain: Nociceptive, neuropathic and nociplastic. *Nociceptive pain* includes acute injuries and inflammatory pain, such as arthritis and fractures. *Neuropathic pain* includes pain from neuropathy, neuralgia, radiculopathy, stroke, SCI, multiple sclerosis and shingles. *Nociplastic pain* includes fibromyalgia, complex regional pain syndrome (CRPS) and migraines.

The extent to which you feel pain will depend on a range of biological, psychological and social factors, including age, genetics, existing medical conditions, experience of pain, cultural beliefs and social support. A physiotherapist may be able to provide support to help manage pain more easily and reduce its impact on day-to-day life. Chronic pain lasts for months or years and can be difficult to treat. Chronic pain can manifest in several ways: It is more likely that individuals with SCI will experience chronic pain. Chronic pain manifests in several ways:

- **Nociceptive pain:** The most common pain felt after an injury that causes tissue damage. Nerve endings called nociceptors activate after an injury and send signals to the brain to alert it when something is wrong. When the brain receives a nociceptor signal, you feel the sensation of pain
- **Neuropathic pain:** This is often described as a tight band at the level of injury and can result from nerve root compression. Below the level of injury where feeling is absent or impaired, pain can be felt at a distance from the body part generating it, such as burning buttock pain
- **Nociplastic pain:** Frequently described as dysfunctional, persistent, psychogenic pain. It appears to arise from abnormal processing and amplification of pain signals despite no clear evidence of actual or threatened tissue damage, meaning that there is no obvious pathology
- **Musculoskeletal pain:** A dull or aching pain following damage to bones, ligaments, muscles and joints that is usually felt above the level of injury or in areas where feeling is preserved below the level of injury. Examples include spinal fractures, muscular injury, shoulder spins or shoulder overuse syndrome
- **Visceral pain:** This pain arises from internal organs, typically in the thorax and abdomen. It is described as dull, aching or cramping. Visceral pain can be felt during a UTI or bowel impaction
- **Nerve root pain:** Originates from nerves that have been damaged or are compressed in the spine. Nerves carry information that controls body movements and sensations to the brain. When a nerve in the spine is damaged, it can cause pain, increased sensitivity, numbness and muscle weakness. Pain can originate from multiple nerve roots. Radicular pain refers to pain that comes from one single nerve root, and
- **Aches and pains:** Often occur around your level of impairment. Often, these pains are caused by the original damage to your spinal cord and the resulting surgeries. Aches and pains can also result from stiffness or spasticity in joints and limbs, as well as general wear and tear or arthritis in your joints.

In Hunt and colleagues' (2021) systematic review and meta-analysis of pain amongst individuals living with SCI, the overall pooled prevalence of pain was 68% of individuals. Of those experiencing pain:

- 58% identified neuropathic pain
- 56% indicated musculoskeletal pain
- 45% indicated nociceptive pain, and
- 20% identified visceral pain.

There are several options for pain relief, including non-pharmacological interventions and pharmacological strategies.

Important resource: Pain management

SCIA's A crash course in pain management (18 February 2024): This resource provides a clear, beginner-friendly overview of different types of pain and practical strategies for understanding and managing pain after SCI.

2.6.1. Non-pharmacological strategies

You could first try these strategies for relieving the impact of activities on your body that could be causing pain:

- **Prioritising:** Deciding what is important and delegating activities that are not crucial
- **Avoiding 'Boom and Bust':** Having too much activity on one day, which may exacerbate pain, requires day/s of rest to compensate, and
- **Pacing:** Breaking down activities into components or sections with allocated rest periods interspersed in the activity.

There are several approaches beyond medication, such as behavioural changes, acupuncture, and dietary management. Here are a few:

- **Exercise:** Based on the available evidence, Zhang and colleagues (2021) concluded in their systematic review and expert consensus that exercise is helpful to alleviate neuropathic pain (NP) intensity. Therefore, there is consensus that proper exercise programs can be considered as an effective alternative treatment or complementary therapy for most patients with NP. The expert consensus provided medical staff and policymakers with applicable recommendations for formulating exercise prescriptions for NP. This consensus statement will require regular updates after 5-10 years. The exercise recommended in the expert consensus involved, but was not limited to, muscle stretching, strengthening/resistance exercise, aerobic exercise, motor control/stabilisation training and mind-body exercise (Tai Chi and yoga)
- **Dietary strategies for managing neuropathic pain:** Emerging evidence suggests that diet may play a meaningful adjunctive role in the management of neuropathic pain following SCI, although findings remain preliminary and sometimes mixed. A randomised controlled trial demonstrated that a 12-week anti-inflammatory dietary intervention sig-

nificantly reduced neuropathic pain severity in individuals with SCI, with improvements associated with reductions in pro-inflammatory cytokines and eicosanoids, supporting a mechanistic link between systemic inflammation and pain modulation (Allison *et al.,* 2016). Observational research further indicates that poorer overall diet quality is associated with greater neuropathic pain severity, suggesting that dietary patterns high in ultra-processed, pro-inflammatory foods may exacerbate symptoms (Sneij *et al.,* 2025). Vitamin D deficiency is also shown to be highly prevalent in chronic SCI and independently associated with increased odds of neuropathic pain (Shi *et al.,* 2025). A recent supplementation trial in chronic SCI, however, found that while vitamin D status improved, supplementation alone did not significantly affect pain or related secondary outcomes (Hertig-Godeschalk *et al.,* 2025). This evidence suggests that overall dietary pattern and inflammatory modulation may be more influential than single-nutrient supplementation. While causality cannot yet be firmly established, adopting an anti-inflammatory, nutrient-dense dietary approach may represent a potential adjunct strategy for neuropathic pain management in SCI, warranting rigorous interventional trials. Useful resources can be accessed via these links: Pain: Lifestyle and Nutrition (Pain Management Network) has a pain screening form and a goal-setting plan

- **Psychological therapies:** Williams and colleagues' (2020) Cochrane Review found that cognitive behavioural therapy (CBT) has the largest evidence base of all the psychological therapies for persistent pain that they reviewed. The evidence indicates that on average, when compared with no treatment or a non-psychological treatment, CBT probably reduces pain and distress by small or very small amounts, may reduce levels of disability at the end of the treatment by a small amount, probably reduces disability at the end of the treatment by a very small amount on average, may make a small difference to disability 6-12 months after the treatment compared with non-psychological treatment, however, it may make little to no difference on average. There is insufficient evidence to conclude the risks of CBT and psychological therapies in general for treating persistent pain. Evidence from trials of behavioural therapy (BT) and acceptance and cognitive therapy (ACT) was of moderate to very low quality, so we are very uncertain about the benefits or lack of benefits of these treatments for adults with chronic pain; other treatments were not analysed
- **Acupuncture:** A Spinal Cord Research Evidence (SCIRE) Community resource (a bit dated) that explains the origins of acupuncture and how it works
- **Nerve stimulation:** Nerve stimulation treatments follow a similar principle to acupuncture, but instead use small electrical 'shocks' to interrupt the pain signals. This form of treatment is commonly applied externally using electrodes on the skin. More advanced procedures will use an implant to deliver stimulation directly to the nerve. This treatment could be considered if you have poor outcomes with medication, and
- **Massage:** Therapeutic massage may assist with rehabilitation and pain management in SCI. In Deetz and Petrie's (2022) case study, a 26-year-old man received eight one-hour massage sessions over five months, incorporating craniosacral therapy, Swedish massage, myofascial release, trigger-point therapy and passive stretching. Over the course of treatment, he reported a slight but consistent reduction in left-arm and back numbness, as well as improvements in neck and upper-body stiffness, and viewed massage as a

helpful component of his recovery. The authors suggest that massage therapy may be a useful adjunct to rehabilitation plans for managing stiffness and numbness after SCI, while highlighting the need for larger, more rigorous studies to further establish its effectiveness.

Important resources: Massage

The following are important resources, highlighting the importance of massages in patients living with SCI:

- Is deep tissue massage good for spinal injury patients?
- Making Strides: Therapeutic massage in SCI rehabilitation.

- **Heat:** Heat therapy can be used as part of pain management strategies.

Important resources: Heat therapy

- Queensland's Metro South Health's Pain Management following SCI for Health Professionals (includes heat and massage recommendations)
- Uhlig-Reche, H., Hoekstra, S., Wu, Y., Kellogg, D. L., Jr., Romo, T., Leicht, C. A., & Trbovich, M. B. (2025). The effect of eight weeks of passive heat therapy on mental health, sleep, and chronic pain in persons with spinal cord injury: A pilot study. *Journal of Clinical Medicine, 14*(10), 3566. Their research suggests that passive heat therapy may help relieve chronic pain. Additional studies highlighted in the next section further support this approach.

Below are a few research studies (oldest to most recent) involving non-pharmacological interventions for pain associated with SCI.

Research: Non-pharmacological interventions

- Norrbrink Budh and Lundeberg (2004) explored the patient perspective of non-pharmacological pain-

relieving therapies by asking 101 Swedish individuals living with SCI about interventions they had tried for pain relief. Ninety were still experiencing pain at the time of the study. Just over 63% had tried non-pharmacological treatments, with acupuncture, massage and ***transcutaneous electrical nerve stimulation (TENS)*** the most common. Those most likely to try non-pharmacological interventions rated their pain intensity as high or were individuals experiencing aching pain or a cutting or stabbing pain. Massage and heat were deemed to be the best for pain alleviation.

- Findings from a ***randomised control trial (RCT)*** highlight the potential of anti-inflammatory diets to reduce neuropathic pain in individuals with SCI. A 12-week intervention showed significant reductions in sensory pain and inflammatory markers (Allison *et al.,* 2016), while follow-up results one year later indicated that some pain relief persisted despite reduced diet adherence (Allison& Ditor, 2018). Overall, the findings suggest that targeting inflammation through diet may be an effective, non-pharmacologic approach to managing neuropathic pain in SCI patients.
- Two recent systematic reviews (Frediani *et al.,* 2024; Klowak *et al.,* 2024) explored non-pharmacological approaches to managing neuropathic pain, emphasising the potential benefits of dietary and lifestyle interventions. These highlight how nutrition, dietary supplements and anti-inflammatory diets may help reduce pain, improve gut health and support overall neurological function. Together, they suggest that integrating these alternative strategies can enhance outcomes and offer a more holistic approach to neuropathic pain management.
- Uhlig-Reche and colleagues (2025) investigated the effect of eight weeks of passive heat therapy on mental health, sleep and chronic pain in veterans with SCI. A time-controlled pre–post intervention pilot study in which ten veterans with chronic SCI underwent an eight-week supervised PHT intervention to raise oral temperature by one degree Celsius each session was undertaken. Outcome measures were the 5-item Mental Health Inventory, Epworth Sleepiness Scale and International Spinal Cord Injury Pain Extended Data Sets version 1.0. Results: There were no adverse events related to the intervention and 90% of the participants completed their intervention sessions. There was a reduction in pain intensity on completion of the intervention. There were, however, no improvements in self-reported mental health or sleep outcomes. To conclude, the pilot study suggests that supervised repeated passive heat therapy may help with pain in SCI. Follow-up studies with larger sample sizes and more extensive sets of chronic pain outcomes are needed to confirm these findings.

- **Surgical interventions:** Surgical procedures are sometimes used to 'clean up' damaged areas in the body to relieve pressure on damaged nerves. This procedure is considered 'riskier' and needs to be carefully assessed with your doctor.

Clinical resources: Managing neuropathic pain

The following are important clinical resources for health practitioners:

- NSW ACI provides comprehensive resources on managing SCI neuropathic pain, acknowledging that up to 70% of individuals with SCI experience chronic pain for more than six months. In particular, their SCI Pain Quick Steps resource provides a structured approach to assessing and managing pain

in individuals with SCI. This tool is designed for health professionals to develop personalised pain management plans. It covers these key areas:

1. **Comprehensive assessment:** The first step involves determining the level and completeness of SCI, classifying it as paraplegia or tetraplegia, and identifying whether the injury is complete or incomplete. This classification aids in understanding the potential impact on pain perception and management
2. **Pain type identification:** It is crucial to identify the specific type of pain experienced, such as nociceptive, neuropathic, or musculoskeletal pain. Recognising the pain type guides appropriate treatment strategies
3. **Individualised pain management plan:** Based on the assessment, healthcare professionals can develop a tailored pain management plan that may include pharmacological interventions, physical therapy, psychological support and lifestyle modifications, and
4. **Monitoring and adjustment:** Regular monitoring of the patient's response to the pain management plan is essential. Adjustments should be made as necessary to ensure optimal pain control and improve the person's quality of life.

- For a more detailed understanding and practical application, healthcare professionals are encouraged to utilise the interactive SCI Pain Navigator, with a video, Adapting assessment for chronic pain and spinal cord injury and the SCI Pain Questionnaire, which are available through the ACI's Pain Management Network. The Pain Management Network (PMN) has a OurMob chronic pain resource, with links to videos, stories and fact sheets, such as Aunty Lindy's story of her silent and body pain, and
- Evidence-based Australian and New Zealand Physiotherapy Guidelines provide a range of considerations, such as swelling, cardiorespiratory fitness and health, postural hypotension and pain. There is a Consumer version and a version for health professionals.

Taken together, the research relating to non-pharmacological interventions is encouraging, with some evidence for approaches such as massage, heat, acupuncture, TENS and anti-inflammatory dietary strategies to reduce neuropathic and chronic pain. These findings emphasise that pain is influenced by a range of factors, including inflammation, lifestyle and overall well-being, which means that several avenues for relief are available. For people experiencing pain, a range of accessible options exists that can help restore a sense of control. Each person will need to try different options to find the best form of pain relief. For families and carers, it provides hopeful ways to support comfort and quality of life. For clinicians, it encourages a more holistic and personalised approach to care that integrates physical therapies, nutritional strategies and daily routines. Together, these insights show that small and sustainable changes can make a real difference in living well with SCI.

2.6.2. Pharmacological intervention: Analgesics and nerve pain medication

Pain remains one of the most prevalent secondary complications of SCI. The exact prevalence of pain in SCI populations remains under debate, due to differences in study design and defin-

itions of pain types and severity. Most studies indicate, however, that about two-thirds of people with SCI experience chronic pain, with one-third reporting severe pain (Hunt *et al.,* 2021; Siddall *et al.,* 1999; Siddall *et al,.* 2003; Störmer *et al.,* 1997).

Despite the common term 'painkillers', no analgesic medicine can consistently eliminate pain without causing other side-effects. Instead, the goal of pain management is to provide a tolerable level of pain relief that enables the individual to maintain functionality and a reasonable quality of life.

Traditional ***analgesics***, such as paracetamol (acetaminophen), ***non-steroidal anti-inflammatory NSAIDs*** and opioids have different mechanisms of action and are often used in combination to manage short-term acute pain with good effect to prevent upregulation of pain receptors and development of chronic pain syndromes. Long-term, the use of opioids may be problematic, with a need to increase the dose to achieve the same effect (tolerance) and the potential development of dependence, addiction, and withdrawal symptoms when abruptly discontinued. Also, many types of pain, including chronic or neuropathic pain in SCI, do not respond as well to these medications.

Clinical resource: Common analgesic classes for pain relief

Non-opioid medications with the greatest evidence for efficacy in the treatment of chronic SCI-related pain are medicines that stabilise nerve membranes from the anti-epileptic class, such as carbamazepine, the gabapentinoids (gabapentin and pregabalin) and the anti-depressant class, such as amitriptyline. Specific selection, however, must be tailored to the individual. **Table 2.9** lists the common analgesic classes and the predominant types of pain they act on.

Table 2.9. Common analgesic classes and the type of pain on which they act.

Analgesic class	Type of pain	Examples
Paracetamol	Mostly nociceptive	
Non-steroidal anti-inflammatory drugs (NSAIDs)	Nociceptive	Ibuprofen, celecoxib, (plus aspirin)
'Weak' opioids (narcotic)	Nociceptive	Codeine, Tapentadol, buprenorphine Naloxone (antagonist)
'Potent' opioids (narcotic)	Nociceptive (some neuropathic activity)	Morphine, Oxycodone, Fentanyl
Anti-depressants	Neuropathic	TCAs, for example, amitriptyline SNRIs, for example, duloxetine
Anti-convulsants (membrane and mood stabilisers, anti-epileptics)	Neuropathic	Pregabalin, carbamazepine, (valproate, gabapentin)
Counter-irritants	Neuropathic, Nociceptive	Capsaicin
Local anaesthetics	Nociceptive, Neuropathic	Bupivacaine, (plus lignocaine) Benzocaine, (plus cocaine)
N-methyl-D-aspartate NMDA antagonists	Nociceptive (Neuropathic)	Ketamine, Methadone, Dextromethorphan

Below is a recent research article on treating neuropathic pain, followed by several pain resources.

Research: Neuropathic pain

Ferraro and Soliman (2025), in their article, Neuropathic pain: our best treatments still fall short, describe their systematic review findings on the management of neuropathic pain, which included 89 pharmacological interventions and nine neuromodulation interventions such as spinal cord stimulation. In terms of their findings:

- Three drug classes, α-2-delta ligands (e.g. pregabalin, gabapentin), serotonin noradrenaline reuptake inhibitors and tricyclic anti-depressants, remain strongly recommended for first-line use, notwithstanding important caveats.
- New data showed that the effects of these classes are smaller than previous estimates, and benefits

are accompanied by substantial risks and adverse effects, such as α-2-delta ligands have been linked with misuse and overdose and tricyclic anti-depressants, which are contraindicated for older adults because of the risk of sedation and falls. Prescribers are advised to balance these risks against potential benefits when proposing first-line treatments.

- Capsaicin creams and patches, previously supported by inconclusive evidence, now have a weak recommendation for second-line use. The small benefits of these treatments are offset by favourable safety and tolerability, making them appropriate for older adults who have co-morbidities or are taking multiple medicines.
- In light of the ongoing impacts of the opioid crisis, opioids (whether weak or strong) are now proposed as third-line options supported by a weak recommendation. This recommendation is specific to patients with worsening pain that has not been adequately relieved by other treatments. Opioid therapy should involve the shortest possible duration of use and early and ongoing review.
- There is a need to recalibrate expectations as current treatments are not curative. Clinicians and patients might explore other non-pharmacological approaches, such as exercise and psychology) interventions despite limited evidence of effectiveness, considering their favourable safety profiles. Shared decision-making and honest discussions about likely benefits and harms must remain central to care.

Important resources and information: Pain management

- Pain Management Network: SCI pain, with extensive resources, including videos and different sections for individuals living with SCI and health professionals.
- Understanding pain after SCI (Episode 2): Also from the Pain Management Network website, you can hear directly from individuals about useful strategies and tools to help you develop pain management skills. There is also a SCI Pain Navigator. For health professionals, there is an SCI Pain Quick Steps tool for investigating an individual's pain.
- Spinal Life Australia: Understanding and managing pain
- MSKTC (Model Systems Knowledge Translation Center): Pain after SCI: Factsheets
- A recent NZ animated e-book on chronic pain, Supporting you through your Chronic Pain Journey by Debbie Bean – Flipsnack. The cover is on the right, copied with kind permission from Jannisa Seck and Debbie Bean.

2.6.2.1. Pain medication abuse

Post-injury pain is a debilitating complication of SCI, often resulting in long-term, high-dose opioid use with the potential for dependence.

Research: Pain medication misuse

- Wilkinson and colleagues (2023) evaluated the association of SCI with post-injury opioid use and dependence to determine the effect of opioid dependence on post-injury health care utilisation. They used the US MarketScan Database of healthcare utilisation claims to extract 7187 adults with traumatic SCI from 2000-2019. Factors associated with post-SCI opioid use and dependence, post-injury healthcare use, and payments were analysed. They found that after SCI, individuals were more likely to become opioid users or transition from nondependent to dependent users (negative change: 31%) than become non-users or transition from dependent to non-dependent users (positive change: 14%). Individuals who were opioid-dependent users pre-SCI had more than 30 times greater risk of becoming dependent. Dependent users after SCI (regardless of prior use status) had 1.2-6 times more healthcare utilisation than non-users.
- In South Africa, Mashola and colleagues (2024) investigated pain medication misuse (PMM) amongst 122 community-dwelling individuals living with SCI and using manual wheelchairs. They completed the Pain Medication Questionnaire (PMQ). Eighty-five % of participants reported the presence of pain, and 48.1% used pain medication. Forty-four % who used pain medication scored ≥ 30, indicative of serious aberrant drug-taking behaviours. Opioids were mainly used for neuropathic pain and in combination with other types of medications such as anti-convulsants and non-steroidal anti-inflammatories (44.0%). Pain severity and the type of pain medication were found to be predictors of PMM. The authors concluded that Pain relief after SCI remains difficult to achieve, with a high risk of PMM, which may lead to long-lasting side-effects, dependency or overdose.
- Borg *et al.* (2024) undertook a systematic review and meta-analysis to determine the prevalence, reported harms and factors associated with opioid use among adults living with SCI in the community:
    - Unfortunately, the heterogeneity and imprecision of the various studies made it difficult to make clinical inferences about opioid use among SCI populations. The pooled prevalence for self-reported opioid use (28%) was, however, such as a recent meta-analysis on opioid use among chronic non-cancer pain (27%). In the current review, two-thirds of included studies had cohorts with mixed aetiology of SCI, yet opioid use was rarely contextualised to injury aetiology. It is well-known that TSCI is historically more common among younger and male populations, while those with NTSCI are often older and frequently considered medically complex, irrespective of their SCI. Such differences are likely to have an impact on the prevalence of opioids dispensed to or used by these subgroups. The lack of reporting by aetiology type and a reduced focus on non-traumatic cohorts make such comparisons unfeasible based on currently available studies.
    - Perceived effectiveness of opioids: Despite different measures used for measuring opioid effectiveness, opioids were often perceived to be the most effective method for pain relief among the pharmaceutical and non-pharmaceutical approaches investigated. Only four medications were rated by participants as contributing to being pain-free, where opioids had the highest pain-free rating.

To conclude, the results should be interpreted with caution based on the high heterogeneity and imprecise pooled prevalence of opioids. Contextual details, including pain, cohort-specific injury characteristics and opioid dosage,

were inconsistently reported, indicating a clear need for additional studies in a population at greater risk of experiencing opioid-related adverse effects.

The evidence highlights a critical concern. Pain management after SCI often relies heavily on opioids, creating a substantial risk of misuse, dependence and associated health complications. High rates of aberrant drug-taking behaviours, combined with inconsistent reporting and limited contextual data, underscore the urgent need for safer, more effective pain management strategies.

Clinicians must prioritise comprehensive assessment, patient education, and multimodal approaches to reduce reliance on opioids and mitigate long-term harms. Future research should address gaps in understanding opioid use patterns, particularly across different SCI subgroups, to inform targeted interventions.

2.6.3. Cannabis: A suitable pain remedy?

Over the last decade, cannabinoids have garnered international interest as an adjunct in the management of SCI pain and spasticity. Tsai and colleagues' (2022) meta-analysis retrieved five RCTs with 417 SCI patients. Unfortunately, all the included studies had a high risk of bias, with no significant difference in pain relief between the cannabinoids and placebo in SCI patients found. More rigorous research, using standardised dose forms and dose regimens, is needed to determine the role of cannabinoids in SCI. The authors concluded that the current best evidence suggests that cannabinoids may not be beneficial for pain relief in SCI patients, but they do increase the risks of adverse events, including dizziness, drowsiness and taste disorders compared with the placebo. Cannabinoids should not be regularly suggested for pain reduction in SCI patients.

Although not specifically about pain associated with SCI, Johnson and colleagues (2025) reviewed the history, efficacy, application and risks of cannabinoids in chronic pain management. Their review found evidence to suggest that cannabinoids provide moderate efficacy in managing neuropathic pain, fibromyalgia, cancer-related pain and multiple sclerosis-related spasticity. Patient-reported outcomes also further indicated widespread perceptions of cannabinoids as a safer alternative to opioids, with potential opioid-sparing effects. The quality of existing evidence was, however, limited by small sample sizes and methodological inconsistencies. The risks associated with cannabinoids, such as psychiatric effects, addiction potential and drug interactions, necessitate cautious application. They concluded that cannabinoids represent a promising, albeit complex, alternative for chronic pain management, particularly given the limitations and risks of traditional therapies such as opioids, but deficiencies remain in the research. Large-scale, randomised controlled trials with long-term follow-up are urgently needed to confirm efficacy and safety across diverse patient populations and pain aetiologies. Regulatory barriers, including the classification of cannabis as a *S*chedule I substance in the US (high potential for abuse) hinder robust research and clinical integration.

Podcast: Cannabis for pain

SCIA's Have the Nerve Podcast, Pain management and medical cannabis (Episode 5, 31 January 2024): This podcast discusses how medicinal cannabis may help people with SCI manage pain, featuring insights from clinicians and lived experience, and includes the following content warning: *This episode discusses suicidal ideation and addiction. Listener discretion is advised. If you are struggling with similar feelings, please call the 24-hour crisis support service Lifeline on 13 11 14.*

Clinical resources: Cannabis for pain

The following are important clinical resources for health practitioners:

- University of Sydney's New trial uses cannabis for spinal cord injury-induced chronic pain (2023)
- Australian Therapeutic Goods Administration's Guidance for the use of medical cannabis in the treatment of chronic non-cancer pain in Australia, and
- Cannadoc's doctors are available to assess patients' suitability for access to alternative therapies and to conduct pre-screening services in a completely private and confidential manner for all Australians who qualify.

2.6.4. Slowing the damage caused by secondary injuries to reduce pain

Most of the medication discussed thus far has been for symptom management and to improve the quality of life for individuals with SCI. Early intervention (surgical and pharmacological) is, however, critical to improving outcomes for acute SCI. Surgical decompression within the first 24 hours of trauma has been shown to as been shown to improve neurological recovery, reduce complications, and shorten hospital stays in acute SCI patients. Emerging therapies have, however, evolved from an increasing understanding of SCI pathophysiology and have an increasing role in offsetting secondary injury processes, such as ***ischaemia*** and inflammation, which exacerbate initial trauma and can lead to permanent disability (Grasso *et al.*, 2025).

Therapies focus on:

- Managing ischaemia by rapid correction of hypotension with vasoactive drugs and use of hyperbaric oxygen
- Minimising inflammation-induced secondary damage using NSAIDs, minocycline and corticosteroids to inhibit inflammatory cytokines
- Controlling the cytotoxic response with antioxidants, such as cyclosporin, vitamins C, D, E and ion channel antagonists, such as calcium channel blockers
- Modulating the immune response through the use of monoclonal antibodies that target specific cytokines, and
- Nerve regeneration techniques.

Clinical resources: Advances in therapies for SCI

The following are important clinical resources for health practitioners:

- Advances and therapies in traumatic SCI
- Navigating the complexities of SCI: An overview of pathology, treatment strategies and clinical trials, and
- Current and emergent therapies targeting spinal cord injury.

Reminder: SCI clinical trials

Chapter 16 provides a summary of the different types of SCI clinical trials.

2.6.5. Medication side-effects and risks

Individuals with SCI often have multiple health complications and so may be prescribed several concurrent medications. It is therefore important to be aware of possible drug-drug interactions (DDIs). Gupta and colleagues (2024) reviewed the regular medication of 108 individuals with SCI, with 20 potential DDIs selected for the analysis based on the most common prescribed drugs for SCI. The top three DDIs were:

- **Opioids and skeletal muscle relaxant (baclofen):** Increases the risk of opioid overdose and CNS depression
- **Opioids and gabapentinoids:** Increase the risk of respiratory depression, and
- **Benzodiazepines, plus two or more other CNS-active drugs:** Increase the risk of falls from sedation, dizziness and cognitive impairment.

Of the 108 SCI individuals, 31 participants (29%) were identified as having at least one potential DDI, with the risk highly associated with polypharmacy (being prescribed multiple medications).

While certain medication classes can be helpful in SCI for specific indications, such as urinary incontinence, pain or infection, they may also need to be used with caution due to their pharmacological actions outside the intended indication, altered physiology, risk of side-effects or interaction with the injury itself. Risk will vary depending on the level and completeness of the injury and associated complications. **Table 2.10.** outlines potential risks from medication used in SCI that would require additional monitoring.

Table 2.10. Medication to be used with caution in people living with SCI.

Medication class	Examples	Reason for caution
Anti-cholinergics	Atropine, Hyoscine butyl-bromide diphenhydramine	Can exacerbate urinary retention and constipation c autonomic dysfunction.
Antibiotics – aminoglycosides	Gentamicin	Can cause neuromuscular blockade, worsening mot
Anti-coagulants	Enoxaparin, Heparin, Warfarin,	Needed for DVT prophylaxis but increases bleeding close monitoring.
Beta-blockers	Propranolol, Atenolol, Metoprolol	May worsen hypotension or mask AD symptoms in l (above T6).
Calcium channel blockers	Verapamil, Diltiazem	Causes constipation. May worsen neurogenic bowel
Corticosteroids	Prednisone, Dexamethasone, Methylprednisolone	Long-term use increases infection risk, impairs wou causes muscle wasting.
Direct vasodilators or anti-hypertensives	Hydralazine, Minoxidil	Risk of severe hypotension due to impaired autonor SCI.
Diuretics and electrolyte-altering drugs	Furosemide, Amphotericin B	Can worsen electrolyte imbalance and orthostatic hy SCI.
Muscle relaxants	Baclofen, Diazepam	May cause sedation, dizziness, and hypotension; Ca polypharmacy.
NSAIDs	Ibuprofen, Naproxen, Aspirin	It can cause GI bleeding, renal injury, and delay bon is important in post-SCI recovery.
Opioid analgesics	Morphine, Oxycodone, Fentanyl	High prescription rates in chronic SCI with elevated and adverse effects: • Risk of respiratory depression, especially with c • May worsen constipation and neurogenic bowe and • Can mask symptoms of AD.
Sedative: Benzodiazepines	Diazepam, Lorazepam, Alprazolam	May cause respiratory depression, excessive sedatio increased fall risk.
Tricyclic anti-depressants (TCAs)	Amitriptyline, Imipramine	Cause sedation, orthostatic hypotension and worse dysfunction.

2.7. Co-ordinating care and managing chronic conditions

As this Chapter highlights, numerous health challenges and risks follow SCI, requiring a multi-disciplinary team, from inpatient acute hospital care, through to rehabilitation and the transi-

tion home. GPs play an important role as the central point of care for people living with SCI in the community (RACGP, 2024).

GPs provide continuity, monitor overall health, and coordinate with specialists, such as rehabilitation physicians, urologists and neurologists and services, such as spinal injury units, physiotherapists and NDIS support. Many SCI-related complications take time to develop, including UTIs, pressure injuries, spasticity, cardiovascular issues and osteoporosis. A GP's early detection and management of these issues is crucial. Prompt recognition and treatment of secondary conditions by the GP helps to avoid long-term morbidity and even mortality, while improving a person's independence and quality of life (Middleton et al., 2008a). For example, GPs help manage neurogenic bladder problems by monitoring for UTIs and kidney issues through annual kidney function tests and periodic bladder ultrasounds (Middleton *et al.,* 2008b).

GPs also support skin health, educating patients and carers on daily pressure relief, good hygiene and regular skin checks to prevent pressure sores. If a pressure injury develops, the GP can coordinate wound care with community nurses and refer to specialist pressure clinics if needed. Similarly, GPs assist in managing chronic pain through non-pharmacological as well as pharmacological means, with referrals to pain clinics. In short, the GP serves as the 'hub' of care, keeping track of the person's numerous health needs and ensuring nothing is overlooked. GPs are thus well placed to recognise issues associated with SCI, and by systematically addressing each problem, they can also promote health improvements and prevent further complications (Middleton *et al.,* 2008a). This is only possible, however, if individuals living with SCI are fastidious about keeping health records and see their GPs regularly.

We close Chapter 2 with links to two evidence-based resources to ensure best practice in terms of managing patients living with SCI, which is only possible through research.

Clinical resources: Practice guidelines for SCI

The following are important clinical resources for health practitioners:

- The Can-SCIP Guideline (Canadian Spinal Cord Injury Practice Guideline) is the first comprehensive living guideline designed to provide evidence-based recommendations for adults 18 years and older with SCI across all phases of care (from pre-hospital emergency care through acute and rehabilitation care, and on to community care) throughout an individual's lifetime. The Guideline was developed with over 70 experts from across Canada, and
- The SCIRE Project is an international collaboration of scientists, health professionals and the community. SCIRE provides systematic reviews of SCI research, enabling researchers and health professionals to guide their practice based on current best evidence.

Key Take-aways

- SCI affects multiple body systems beyond movement, including autonomic functions
- Nervous system disruption impacts communication between the brain, spinal cord and peripheral nerves
- Injury classification and level matter: Whether the SCI is traumatic (TSCI) or non-traumatic (NTSCI), complete or incomplete, as well as the neurological level (cervical, thoracic, lumbar) determines the pattern of impairment and complications
- SCI impacts multiple systems: Beyond movement loss, SCI affects cardiovascular, respiratory, urinary, gastrointestinal, skin, musculoskeletal and autonomic functions, leading to a risk of pressure injuries, infections, chronic pain and osteoporosis
- SCI interrupts motor and sensory pathways, causing paralysis, sensory loss and spasticity
- Reflexes and autonomic control become dysregulated, leading to temperature regulation issues and AD for those with higher-level injuries
- Higher risk of clots and stroke due to impaired circulation
- Weak or paralysed breathing muscles reduce lung capacity and impair coughing. Increasing the risk of pneumonia and respiratory infections
- Neurogenic bladder causes incontinence, retention, UTIs, kidney damage and risk of stones
- Neurogenic bowel dysfunction leads to constipation, incontinence and impaction
- Loss of sensation and mobility increases the risk of pressure injuries and infections
- Muscle atrophy and bone fragility increase fracture risk
- Secondary complications include sepsis, chronic kidney disease and systemic infections
- Rapid bone loss occurs early, with prevention including passive standing and electrical stimulation
- Monitor and supplement Vitamin D and encourage dietary calcium
- Pharmacological options for bone health include bisphosphonates and denosumab
- Pain affects ~70% of people with SCI: Nociceptive, neuropathic, nociplastic, musculoskeletal, visceral and nerve root pain
- Non-pharmacological interventions include pacing, exercise, diet, *CBT*, acupuncture, nerve stimulation, massage and heat therapy
- Pharmacological options include gabapentinoids, TCAs and SNRIs for neuropathic pain, with opioids only the third-line intervention due to dependence risk
- Opioid misuse and dependence cause significant concerns; multimodal approaches and patient education are essential
- Cannabinoids show limited evidence for SCI pain relief, with side-effects, such as dizziness and psychiatric effects, and
- Minimising secondary injury processes, such as inflammation and ischaemia, can reduce long-term pain and disability.

The next chapter, **Chapter 3**, is probably the most important chapter in the resource, as it deals with staying physiologically healthy and fit as well as psychologically well. We have proposed that this requires ensuring the five pillars of good health and well-being (healthy diet,

quality sleep, physical activity, sunlight, social interaction), as well as ensuring good oral and foot health.

Reminder: Relevant chapters

- **Chapter 3:** Now that we know what happens to the body after SCI, Chapter 3, through the five pillars of good health and well-being: Physical activity. The other four pillars of health and well-being will support sportspeople: Good nutrition, quality sleep, exposure to sunlight and socialising
- **Chapter 4:** Tracking health and well-being is important to be able to manage a body that is already anatomically and physiologically different
- **Chapter 5:** Once you start socialising, working or studying, you may need to change your routine, so you need to understand what that might mean. For example, working in an air-conditioned office all day may require adjustments if you are unable to regulate your body temperature
- **Chapter 6:** Ageing affects all bodies. Age adds another layer to the complications described in this Chapter
- **Chapter 7:** Chapter 2 describes the adult body, while Chapter 7 describes some of the complexities of developing bodies and SCI
- **Chapter 12:** If you play sport, you are likely to be flying locally and perhaps internationally. Chapter 12 offers numerous resources and LLEs
- **Chapter 16:** There may be opportunities to engage in research related to sport as well as clinical trials
- **Chapter 17:** The impact of a changing climate is important for those engaged in sport, particularly if they are unable to regulate their body temperature. There could be mobility issues during a call to evacuate if there is a bushfire or a flood. This may also happen while abroad for a sporting event. Having a suitable emergency plan is crucial, and
- **Chapter 18:** Health professions education explores how members of multidisciplinary teams are trained and educated to help with the health and well-being of individuals with SCI, and Exercise physiologists (training), OTs (equipment), physiotherapists (remediation, pain) and GPs (regular check-ups) are likely to be the key health professionals involved.

References

Agency for Clinical Innovation (ACI). (2022). *Management of the neurogenic bowel for adults with spinal cord injuries.* https://aci.health.nsw.gov.au/publications/neurogenic-bowel.

Allison, D. J., & Ditor, D. S. (2018). Maintenance of diet participation in individuals with spinal cord injury: effect on mood and neuropathic pain. *Spinal Cord Series Cases, 4*, 97. https://doi.org/10.1038/s41394-018-0131-2.

Allison, D. J., Thomas, A., Beaudry, K., & Ditor, D. S. (2016). Targeting inflammation as a treatment modality for neuropathic pain in spinal cord injury: a randomized clinical trial. *Journal of Neuroinflammation, 13,* 1-10. https://link.springer.com/article/10.1186/s12974-016-0625-4.

Australian Centre for Innovation. (n.d.). *Pressure injury toolkit for spinal cord injury and spina bidifa.* New South Wales Government. https://aci.health.nsw.gov.au/networks/spinal-cord-injury/pi-toolkit/pressure-injury-in-spinal-cord-injury#:~:text=More%20than%2085%25%20of%20people,term%20physical%20and%20psychological%20consequences.

Budh, C., N. & Lundeberg, T. (2004). Non-pharmacological pain-relieving therapies in individuals with spinal cord injury: A patient perspective. *Complementary Therapies in Medicine, 12*(4), 189-197. https://doi.org/10.1016/j.ctim.2004.10.003

Badur N. B., Winkle MJ, Leslie SW. (2025). Autonomic Dysreflexia. In: *StatPearls.* Treasure Island (FL): StatPearls Publishing. https://www.ncbi.nlm.nih.gov/books/NBK482434/:

Berlowitz, D. J., Wasworth, B., & Ross, J. (2016). Respiratory problems and management in people with spinal cord injury. *Breathe, 12*(4), 328-340. https://publications.ersnet.org/content/breathe/12/4/328

Borg, S. J., Cameron, C. M., Luetsch, K., Rolley, A., Geraghty, T., McPhail, S., & McCreanor, V. (2024). Prevalence of opioid use in adults with spinal cord injury: A systematic review and meta-analysis. *The Journal of Spinal Cord Medicine, 48*(2), 170-188. https://doi.org/10.1080/10790268.2024.2319384.

Canadian Spinal Cord Injury Practice (Can-SCIP). (2025). *Aims of neurogenic bowel management.* Can-SCIP Guidelines. https://kite-uhn.com/can-scip/en/recommendations/aims-of-neurogenic-bowel-management

Chopra, M. & Kumar, H. (2025). Navigating the complexities of spinal cord injury: an overview of pathology, treatment strategies and clinical trials. *Drug Discovery Today, June:* 104387. https://doi.org/10.1016/j.drudis.2025.104387.

Deetz, D., & Petrie, B. K. (2022). Massage therapy as a complementary treatment for stiffness and numbness post cervical spinal cord injury: A case study. *International Journal of Therapeutic Massage & Bodywork, 15*(4), 3-8. https://doi.org/10.3822/ijtmb.v15i4.745

Durney, P., Stillman, M., Montero, W., & Goetz, L. (2020). A primary care provider's guide to neurogenic bowel dysfunction in spinal cord injury. *Topics in Spinal Cord Injury Rehabilitation, 26*(3), 172-176. https://doi.org/10.46292/sci2603-172y

Emmanuel A. (2019). Neurogenic bowel dysfunction. Neurogenic bowel dysfunction. *F1000Research, 8*, F1000 Faculty Rev-1800.https://f1000research.com/articles/8-1800.

Ethans, K., Smith, K., Casay, A., Christie, C., Chu, T., Querée, M., Willms, R., & Eng, J. (2024). Bowel dysfunction and management following spinal cord injury. In J. J. Eng, R. W. Teasell, W. C. Miller,

A. F. Townson, W. B. Mortenson, J. T. C. Hsieh, V. K. Noonan, E. Loh, S. Sproule, & M. Querée (Eds.), *Spinal Cord Injury Research Evidence*, 1-160. SCIRE Project. https://scireproject.com/evidence/bowel-dysfunction-and-management/introduction/

Ferraro, M., & Soliman, N. (2025). Neuropathic pain: Our best treatments still fall short. *Insight+*. https://insightplus.mja.com.au/2025/28/neuropathic-pain-our-best-treatments-still-fall-short/

Frediani, J. K., Lal, A. A., Kim, E., Leslie, S. L., Boorman, D. W., & Singh, V. (2024). The role of diet and non-pharmacologic supplements in the treatment of chronic neuropathic pain: A systematic review. *Pain Practice, 24*(1), 186-210. https://doi.org/10.1016/j.ctim.2004.10.003.

Furusawa, K., Tokuhiro, A., Sugiyama, H., Ikeda, A., Tajima, F., Genda, E., Uchida, R., Tominaga, T., Tanaka, H., Magara, A., & Sumida, M. (2011). Incidence of symptomatic autonomic dysreflexia varies according to the bowel and bladder management techniques in patients with spinal cord injury. *Spinal Cord, 49*(1), 49-54. https://doi.org/10.1038/sc.2010.94.

Grasso, G., Cusimano, L., Noto, M., Maugeri, R., & Iacopino, D. G. (2025). Current and emerging therapies targeting spinal cord injury. *Brain and Spine, 5*, 104242. https://doi.org/10.1016/j.bas.2025.104243

Gupta, S., Dhawan, A., Dhawan, J., McColl, M. A., Smith, K. M., & McColl, A. (2024). Potentially harmful drug-drug interactions in the therapeutic regimens of persons with spinal cord injury. *Journal of Spinal Cord Medicine, 47*(5), 692-700. https://doi.org/10.1080/10790268.2023.2185399

Hakim, S., Gaglani, T., & Cash, B. D. (2022). Neurogenic bowel dysfunction: The impact of the central nervous system in constipation and fecal incontinence. *Gastroenterology Clinics of North America, 51*(1), 93-105. https://doi.org/10.1016/j.gtc.2021.10.006

Hertig-Godeschalk, A., Brinkhof, M. W. G., Perret, C., Scheel-Sailer, A., & Flueck, J. L. (2025). Efficacy of vitamin D3 supplementation in elevating circulating 25(OH)D concentration in individuals with chronic spinal cord injury (VitD-SCI): Evidence from a randomized, double-blind, placebo-controlled trial. *Topics in Spinal Cord Injury Rehabilitation, 31*(4), 61-73. https://doi.org/10.46292/sci24-00077

Hsieh, J., Benton, B., Titus, L., Gabison, S., McIntyre, A., Wolfe, D., & Teasell, R. (2022). Pressure ulcers following spinal cord injury. In J. J. Eng, R. W. Teasell, W. C. Miller, D. L. Wolfe, A. F. Townson, J. T. C. Hsieh, S. J. Connolly, V. K. Noonan, E. Loh, & A. McIntyre (Eds.), *Spinal Cord Injury Rehabilitation Evidence* (Version 7.0, pp. 1–90). SCIRE Project. https://scireproject.com/evidence/pressure-ulcers/

Hunt, C., Moman, R., Peterson, A., Wilson, R., Covington, S., Mustafa, R., Murad, M. H., & Hooten, W. M. (2021). Prevalence of chronic pain after spinal cord injury: A systematic review and meta-analysis. *Regional Anesthesia & Pain Medicine, 46*(4), 328-336. https://doi.org/10.1136/rapm-2020-101960

International Association for the Study of Pain. (2023). What's in a name? Chronic pain and nociplastic pain. https://www.iasp-pain.org/publications/pain-research-forum/prf-news/92059-whats-name-chronic-pain/.

Jiang, M., Zhang, J-W., Tang, H-H., Meng, Y-F., Zhang, Z-R., Wang, F-Y., Bai, J-Z. Liu, S-J., Lyu, Z., Chen, S-Z., Liu, J-S., & Fu, J-X. (2025). Bone loss in patients with spinal cord injury: Incidence and influencing factors, *Chinese Journal of Traumatology, 28*(6), 477-484. https://doi.org/10.1016/j.cjtee.2024.05.003

Johnson, B. W., Strand, N. H., Raynak, J. C., Jara, C., Habtegiorgis, K., Hand, B. A., Hong, S., & Maloney, J. A. (2025). Cannabinoids in chronic pain management: A review of the history, efficacy, applications, and risks. *Biomedicines, 13*(3), 530. https://doi.org/10.3390/biomedicines13030530

Klowak, M., Lau, R., Mohammed, M. N., Birago, A., Samson, B., Ahmed, L., Renee, C., Meconnen, M., Sam, M., & Boggild, A. K. (2024). A systematic review of dietary lifestyle interventions for neuropathic pain. *Journal of Clinical Medicine, 13*(22), 6766. https://www.mdpi.com/2077-0383/13/22/6766

Mashola, M. K., Korkie, E., & Mothabeng, D. J. (2024). Pain medication misuse in the South African spinal cord injury context. *Health SA, 29*, 2377. https://doi.org/10.4102/hsag.v29i0.2377

Middleton, J W., Leong, G., Mann, L. (2008). Management of spinal cord injury in general practice – Part 2. *Australian Family Physician, 37*(4); 229-233. https://www.racgp.org.au/getattachment/e63810b3-9897-498c-99b2-fe9a8995ebe0/attachment.aspx.

Nevin, A. N., Dwyer, K., Atresh, S. S., Vivanti, A., Hickman, I. J., & Banks, M. (2025). Nutritional intakes of people with spinal cord injury who have pressure injuries in hospital: A secondary analysis of a randomized controlled trial. *Topics in Spinal Cord Injury Rehabilitation, 31*(1), 17-29. https://doi.org/10.46292/sci24-00003

Ortega, M. A., Fraile-Martinez, O., García-Montero, C., Haro, S., Álvarez-Mon, M. Á., De Leon-Oliva, D., Gomez-Lahoz, A. M., Monserrat, J., Atienza-Pérez, M., Díaz, D., Lopez-Dolado, E., & Álvarez-Mon, M. (2023). A comprehensive look at the psychoneuroimmunoendocrinology of spinal cord injury and its progression: mechanisms and clinical opportunities. *Military Medical Research, 10*(26). https://mmrjournal.biomedcentral.com/articles/10.1186/s40779-023-00461-z.

Paralyzed Veterans of America, Consortium for Spinal Cord Medicine. (2022). *Bone health and osteoporosis management in individuals with spinal cord injury: Spinal cord medicine*. Washington D.C. https://pva.org/wp-content/uploads/2022/05/CPG_Spinal-Cord-Medicine_2022_FINAL.pdf

Porter JL, Varacallo MA. (2023). Osteoporosis. In: *StatPearls*. Treasure Island (FL): StatPearls Publishing. https://www.ncbi.nlm.nih.gov/books/NBK441901/

Rodgers, K. A., Kigerl, K. A., Schwab, J. M., & Popovich, P. G. (2022). Immune dysfunction after spinal cord injury – A review of autonomic and neuroendocrine mechanisms. *Current Opinion in Pharmacology, 64*, 102230. https://doi.org/10.1016/j.coph.2022.102230

Rogers, C. (2014). Treating patients with spinal cord injuries. *Dimensions of Dental Hygiene*, 17 Nov, https://dimensionsofdentalhygiene.com/article/treating-patients-with-spinal-cord-injuries/

Royal Australian College of General Practitioners. (2024). *Care and support for people with disability: Position Statement.* https://www.racgp.org.au/advocacy/position-statements/view-all-position-statements/health-systems-and-environmental/care-and-support-for-people-with-disability.

Price, M. J., & Trbovich, M. (2018). Thermoregulation following spinal cord injury. In A. A. Romanovsky (Ed.), Handbook of Clinical Neurology (Vol. 157, pp. 799-820). Elsevier.

Schmidt, K. D., & Chan, C. W. (1992). Thermoregulation and fever in normal persons and in those with spinal cord injuries. *Mayo Clinic Proceedings, 67*(5), 469-475. https://www.mayoclinicproceedings.org/article/S0025-6196%2812%2960394-2/fulltext

Shi, T., He, Y., Yu, Z., & Li, J. (2025). Vitamin D deficiency and neuropathic pain in chronic spinal cord injury: a cross-sectional study. *Frontiers in Nutrition, 12,* 1706735. https://doi.org/10.3389/fnut.2025.1706735

Siddall, P. J., McClelland, J. M., Rutkowski, S. B., & Cousins, M. J. (2003). A longitudinal study of the prevalence and characteristics of pain in the first five years following spinal cord injury. *Pain, 103*(3), 249–257. https://doi.org/10.1016/S0304-3959(02)00452-9.

Siddall, P. J., Taylor, D. A., McClelland, J. M., Rutkowski, S. B., & Cousins, M. J. (1999). Pain report and the relationship of pain to physical factors in the first six months following spinal cord injury. *Pain, 81*(1–2), 187-197. https://doi.org/10.1016/S0304-3959(99)00023-8.

Sneij, A., Farkas, G., Felix, E., Gater, D., Tiozzo, E. (2025). Poor diet quality is associated with greater neuropathic pain among people with spinal cord injury. *Current Developments in Nutrition, 9*. 10.1016/j.cdnut.2025.106936

Störmer, S., Gerner, H. J., Grüninger, W., Metzmacher, K., Föllinger, S., Wienke, C., Aldinger, W., Walker, N., Zimmermann, M., & Paeslack, V. (1997). Chronic pain/dysaesthesiae in spinal cord injury patients: Results of a multicentre study. Spinal Cord, 35(7), 446-455. https://doi.org/10.1038/sj.sc.3100411.

Tsai SHL, Lin CR, Shao SC, Fang CH, Fu TS, Lin TY, Hung YC. (2022). Cannabinoid use for pain reduction in spinal cord injuries: a meta-analysis of randomized controlled trials. *Frontiers in Pharmacology, 13,* 866235. https://www.frontiersin.org/journals/pharmacology/articles/10.3389/fphar.2022.866235/full.

Uhlig-Reche, H., Hoekstra, S., Wu, Y., Kellogg, D. L., Romo, T., Leicht, C. A., & Trbovich, M. B. (2025). The effect of eight weeks of passive heat therapy on mental health, sleep, and chronic pain in persons with spinal cord injury: A pilot study. *Journal of Clinical Medicine, 14*(10), 3566. https://www.mdpi.com/2077-0383/14/10/3566.

Valdez-Resendiz, I., Salgado-Camarillo, E. N., Hernández-Morales, F., Martínez-de los Santos, C. A., & Robba, C. (2025). Perioperative management in acute and chronic spinal cord injury, narrative review. *Journal of Anesthesia, Analgesia and Critical Care, 5*, 33. https://link.springer.com/content/pdf/10.1186/s44158-025-00252-z

Valido, E., Boehl, G., Krebs, J., Pannek, J., Stojic, S., Atanasov, A. G., Glisic, M., & Stoyanov, J. (2023). Immune status of individuals with traumatic spinal cord injury: A systematic review and meta-analysis. *International Journal of Molecular Sciences, 24*, 16385. https://doi.org/10.3390/ijms241916385.

van der Slikke, E. C., Beumeler, L. F. E., Holmqvist, M., Linder, A., Mankowski, R. T., & Bouma, H. R. (2023). Understanding post-sepsis syndrome: How can clinicians help? *Infection and Drug Resistance, 16,* 6493-6511. https://doi.org/10.2147/IDR.S390947

Wang, L., Gan, J., Wu, J., Zhou, Y., & Lei, D. (2023). Impact of vitamin D on the prognosis after spinal cord injury: A systematic review. *Frontiers in Nutrition, 10,* 920998. https://doi.org/10.3389/fnut.2023.920998.

Wang, Y., Lo, M. C., Fisher, M., Desneves, K., Nevi, A., & Iyer, P. (2026). Nutrition care in adults with spinal cord injuries and disorders with pressure injuries: A systematic review of clinical practice guidelines. *Clinical Nutrition, 58*, 106580. https://doi.org/10.1016/j.clnu.2026.106580

Wilkinson, R. L., Castillo, C., Herrity, A., Wang, D., Sharma, M., Dietz, N., Adams, S., Khattar, N., Nuno, M., Drazin, D., Boakye, M., & Ugiliweneza, B. (2023). Opioid dependence and associated health care utilization and cost in traumatic spinal cord injury population: Analysis using Marketscan Database. *Topics in Spinal Cord Injury Rehabilitation, 29*(1), 118-130. https://doi.org/10.46292/sci22-00026.

Williams, A. C. de C., Fisher, E., Hearn, L., & Eccleston, C. (2020). Psychological therapies for the management of chronic pain (excluding headache) in adults. *Cochrane Database of Systematic Reviews, 8,* Article CD007407. https://doi.org/10.1002/14651858.CD007407.pub4.

World Health Organization (WHO). (2024). Spinal cord injury. World Health Organization. https://www.who.int/news-room/fact-sheets/detail/spinal-cord-injury.

Yeung, H. Y., Iyer, P., Pryor, J., & Nicholson, M. (2021). Dietary management of neurogenic bowel in adults with spinal cord injury: an integrative review of literature. *Disability and Rehabilitation, 43*(9), 1208-1219. https://doi.org/10.1080/09638288.2019.1652702.

Zhang, Y.-H., Hi, H.-Y., Xiong, Y.-C., Peng, C., et al. (2021). Exercise for neuropathic pain: A systematic review and expert consensus. *Frontiers in Medicine, 8*, 756940. https://doi.org/10.3389/fmed.2021.756940.

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PART A: COMING 'HOME' AND STAYING FIT, HEALTHY AND WELL: STAGE 2 (CHAPTERS 3-5)

Stage 2: Staying Healthy, Well and Fit and Preventing Complications

Chapter 1 in **Stage 1** focused on coming home and **Chapter 2** explored what happens to your body after SCI. Now, in**Stage 2**, **Chapters 3-5** explore broader health and well-being considerations once you are home and in the community. In **Chapter 3**, we describe the five pillars to good health and well-being, which include good nutrition, quality sleep, exercise, sun exposure and socialising. Sometimes, however, things do go wrong and become emergencies. A *urinary tract infection (UTI)* may trigger *autonomic dysreflexia (AD)* or the start of a pressure injury may go unnoticed. These situations require prompt attention to prevent escalation.

Chapter 4 provides a range of apps for tracking your health and well-being and **Chapter 5** explores getting back to work, which may involve studying, as well as becoming more social and perhaps volunteering.

Podcast: Dinesh on defying the odds

In Double degrees, defying the odds and Doctors with Disabilities, **Dinesh** talks about what he has overcome to live a life well-lived.

Common Health Risks and Challenges After Spinal Cord Injury

It is important to acknowledge that having a *TSCI* or an *NTSCI* can shorten life expectancy. In their systematic review of studies relating to TSCI between 2000 and 2023, Zadra and colleagues (2024) found that the main factors negatively influencing survival and life expectancy included higher neurological level of injury, completeness of the lesion, the need for mechanical ventilation, increasing age and being male. They also concluded that the development of SCI-related co-morbidities, such as respiratory diseases and ischaemic heart disease, also negatively impacted survival, as does the lack of specialised care, especially in low-income countries. Additionally, factors that might also positively impact the outcome include pre-injury health status, such as athletic condition, while pre-injury habits, such as smoking and substance abuse, could negatively impact outcomes. Social determinants such as personal income and education level are also factors.

In a Swiss cohort study exploring mortality following an NTSCI, Buzzell *et al.* (2020) found a mortality rate 1.6 times that of the general population, with death most commonly due to cardiovascular disease (39.8%), neoplasms (cancer) (22%) and infection (9.9%). The researchers concluded that these findings supported the need for targeted clinical care and follow-up.

When **Dr Dinesh Palipana** was asked in his role in the Emergency Department (ED) what most often brings people with SCI to ED, he explained:

"It is a variety of things. But I think the most common issue is bladder management or catheter issues. The catheter popped out, and they can't get it back in. Also, urinary tract infections. Occasionally, bowel management, but it's less so. And then, autonomic dysreflexia, as a result of some kind of insult, such as an infection. There have also been occasions when I've seen someone attempting suicide."

When asked what had taken him to the ED after leaving rehabilitation and returning home, **Dinesh** replied:

"Exactly those things, like a blocked catheter and autonomic dysreflexia."

These are among the most frequent clinical presentations for individuals living with SCI. Timely access to healthcare is therefore important. Below, we explore the findings of the International Spinal Cord Injury Community Survey (InSCI) to research the global challenges many face in terms of SCI complications and healthcare access.

Research: Common health problems associated with SCI

The International Spinal Cord Injury Community Survey (InSCI) is a large global study that surveys individuals living with SCI about their health, daily life and access to services. The survey is a core activity of the Learning Health System for Spinal Cord Injury (LHS-SCI), which is coordinated internationally with the support of the International Spinal Cord Society (ISCoS) and the International Society for Physical and Rehabilitation Medicine (ISPRM), hosted by Swiss Paraplegic Research.

The first InSCI survey (2017-2019) across 22 countries collected more than 12,000 responses. The goal was to describe common health problems and the barriers people living with SCI face so that health systems can improve care. The second community survey (2022-2024) grew to 32 countries with more than 15,000 participants, covering all six WHO regions. Australia was included in both surveys. The Queensland arm of the Australian research can be found at The Hopkins Centre.

The infographic for the first InSCI Community Survey indicates that the most frequently reported health issues after SCI were:

- Pain (77.3% of respondents)

- Spasticity (73.5%)
- Sexual dysfunction (71.3%), and
- Bowel dysfunction (70.8%).

Additionally, the following were noted:

- The 'extreme health problems' for which treatment was being received were pain (66% of respondents), spasticity (61%), bowel dysfunction (58%) and sexual dysfunction (14%).
- The top five environmental barriers to accessing healthcare were *inaccessible buildings and places, unfavourable climatic conditions such as heat, as well as lack of transport, financial constraints and unavailability of or inappropriate state services.*
- The most common reasons for unmet healthcare needs were *healthcare costs, unavailability of services and transport problems* (Gross-Hemmi *et al.,* 2019).

In the first Australian study, Middleton and colleagues (2022) sought to identify common problems across key domains of ***functioning***, health and well-being, as well as evaluate self-reported quality of life by individuals (>18 years, at least 12 months post-injury) living with SCI. Using the Australian version of the InSCI survey, the researchers found:

- Participants (mean age 57 years, range 19-94 years) with tetraplegia (quadriplegia) and/or complete injuries had more health problems, activity or participation problems and experienced more ***environmental barriers.***
- The top two environmental barriers are frequently related to accessing public places or homes and unfavourable climatic conditions, such as heat, which is discussed in **Chapter 17**.
- Self-rated overall quality of life did not differ for injury level or completeness.
- Participants with a more recent SCI exhibited lower independence levels, more mental health problems and poorer satisfaction with self and their living conditions.
- Major activity and participation problems related to intimate relationships and accessing public transport.
- Less than half of the working-age population was engaged in paid work.

In the second follow-up in Australia, Borg *et al*. (2024) explored:

- Healthcare provider utilisation in the past year, unmet care needs and satisfaction with healthcare services
- The association between experiences with healthcare providers and unmet healthcare needs, and
- The association between healthcare provider utilisation and participant characteristics, including unmet healthcare needs.

That study found that:

- 17% of participants reported unmet healthcare needs.
- Being female, having greater functional capacity and several severe secondary conditions were associated with unmet healthcare needs.
- The most common barriers to meeting their healthcare needs were service costs (30% of respondents), inadequate provider skills (19%) and service unavailability (19%).
- **GPs were the most frequently accessed healthcare provider (80%), followed by pharmacists (54%) and physiotherapists (43%).**
- **GPs were the main point of contact for SCI-specific problems (58%), followed by specialist spinal physicians (31%).**
- Older individuals and those with several severe secondary conditions were more likely to be hospitalised in the past 12 months, while those with a greater functional status and incomplete quadriple-

gia were less likely to have been hospitalised.

- While **most participants (81%) were satisfied or very satisfied with their GPs**, fewer were satisfied with statewide SCI services (67%) and local general hospital services (62%).
- Those who felt that they had not been treated respectfully had 2.1 times higher odds of reporting unmet healthcare needs.

Some of the findings of these surveys are also mentioned in **Chapter 6**.

Based on the findings outlined above, the next section is designed to support individuals living with SCIs in setting themselves up for success by staying healthy, well and fit, including by preventing complications. The key to staying healthy and living well is working with your multidisciplinary team, which will change as you progress on your journey. As this resource will highlight is the central role of the GP in the overall care of individuals living with SCI in the community.

After understanding what has happened to your body (**Chapter 2**), **health literacy** is key to maintaining good health and well-being. Health literacy *is the ability to access, understand, appraise and use health information and services to support health and well-being. This includes understanding how your body works, recognising what it needs and using reliable information to make decisions about your health* (WHO, 2025).

Health literacy is key to recognising early changes in your health, following daily care routines and accessing healthcare services when you need them. It builds confidence in managing essential tasks such as skin care, bladder and bowel routines and monitoring for early warning signs. While health literacy is widely recognised as an important determinant of health, it remains less well understood in some groups, including people living with SCI.

As **Dinesh Palipana** wrote in his autobiography, *Stronger*, understanding how his body works helps him stay well and prevent complications before they occur. Research supports this need for stronger health literacy for those affected by SCI. We hope that this resource serves this need.

Research: High health literacy with SCI

A systematic review by Edwards *et al.* (2025) found that many people living with SCI have sufficient health literacy. A higher level of health literacy appears to be associated with socio-economic advantage and better physical and mental health outcomes. The review also concluded that *health literacy is under-researched in the SCI population and more work is needed to understand how it influences health behaviours and overall health and well-being.*

Clinical resource: ACI's Health maintenance for adults with SCI guide

Clinical guidance reinforces the importance of this capability. Agency for Clinical Innovation's (ACI) 2024 guide on Health maintenance for adults with spinal cord injuries provides a framework for structured and proactive health monitoring and encourages clinicians to support people living with SCI to understand their bodies, participate in decisions and manage their ongoing health needs. The guide is due for review in 2027.

Health literacy enables people to understand their bodies, follow daily care routines and navigate the healthcare system confidently. Three interconnected themes guide the focus of Chapters 3-5 in Stage 2 (**Figure 7**).

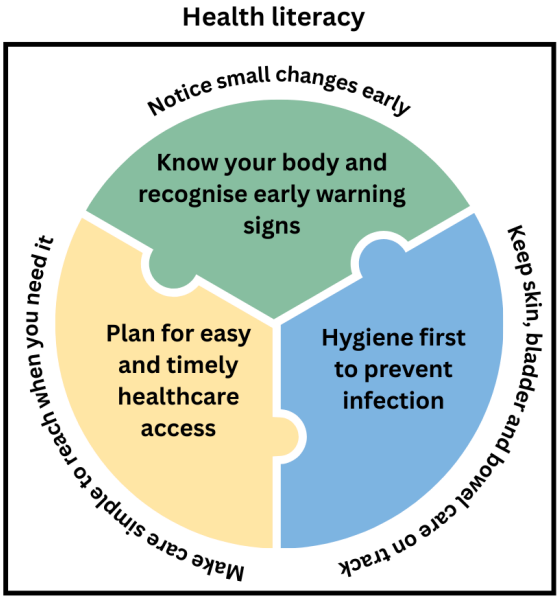

Figure 7. Summary of research themes: Supporting individuals living with SCI to stay healthy, well and fit and prevent complications. Created by Elmarie Stander using Canva, licensed under a CC BY-NC (Attribution NonCommercial).

1. **Know your body and recognise early warning signs:** Notice small changes early
2. **Hygiene first to prevent infection:** To keep skin, bladder and bowel care on track, and
3. **Plan for easy and timely healthcare access:** Ensure you can access the right care when you need it.

Next, these three themes will be explored in more detail.

1. Know your body and recognise early warning signs

Individuals who have been living with SCI for several years get to know their bodies well. They will probably offer this advice: If something feels wrong, tell someone and act early, as *'a stitch in time saves nine'*. Small changes can signal bigger problems. Trust what your body tells you.

The problems described in the InSCI survey are what commonly take an individual living with SCI to their GP or to the ED, which is why early recognition is important.

In medicine, ***red-flag symptoms*** are warning signs that indicate a more serious underlying pathology. The ACI's Health Maintenance for Adults with Spinal Cord Injuries provides a helpful list of 'red flags' (p. 10) for SCI. The following are symptoms (subjective experiences reported by someone, such as pain or nausea) and signs (objective, so can be measured, usually by a clinician, such as blood pressure or temperature, or can be observed, such as a rash) associated with SCI and which need attention:

- **Nervous system:** Autonomic dysreflexia (AD), such as a pounding headache, sweating, rash or raised blood pressure, or sudden onset of or worsening pain
- **Renal system:** Altered bladder drainage, urinary incontinence, frequent UTIs, 'gravel' (like sand) or calcified material in the urine and blood in the urine
- **Gastrointestinal system:** Changes in bowel function, such as constipation, faecal incontinence, increased laxative requirements, abdominal pain or bloating, heartburn and weight loss
- **Skin:** Breakdown, delayed healing or recurrent pressure injuries
- **Respiratory system:** Coughing, fever, shortness of breath and/or chest pain
- **Muscular system:** Unexplained increase in muscle spasms or tightness, increasing muscle weakness, loss of coordination, altered balance, galls or changes in sitting posture, fatigue not associated with activity
- **Psychological:** Signs of depression
- **General:** Excessive daytime sleepiness, memory disturbance and snoring at night, and
- **Assistive device issues:** Problems with the wheelchair, mobility or pain related to functional activities, seating or postural changes in the wheelchair, requiring review of seating and wheelchair setup by an experienced OT or physiotherapist.

2 . Hygiene first to prevent infection

Protect your skin, bladder and bowel health every day. Good hygiene is a key part of preventing infections, which are a common reason many people living with SCI present to the ED. In various conversations with **Dinesh Palipana**, he emphasised repeatedly how essential good hygiene practices are for maintaining health and avoiding complications.

Below is **Dinesh Palipana's** advice.

Dinesh's story: Good hygiene

"Since I've had this suprapubic catheter, infections were an issue for a while, but it has been a matter of making sure that our team has a really good process. Someone is helping me drain it most of the time. They have good hand hygiene and even when we drain the catheter, that has made a difference. Again, I'm lucky to have my mum and our team, so they roll me twice a day generally and check the skin. Even after a shower, we do things like use a hair dryer to make sure that skin creases are dry. We found that some of the skin creases were developing problems, and the skin was breaking down…We try to avoid places like public toilets… Just to decrease the possibility of introducing an infection."

Important resources and information: Hand hygiene

- Coloplast Care's Hand hygiene for people with spinal cord injury webpage, and
- Australian Commission on Safety and Quality in Health Care's Hand hygiene for patients and carers fact sheet.

3. Plan for easy and timely healthcare access

Know who to contact, how to get there and what supports you need. For people confined to a wheelchair, staying healthy and well also depends on accessible and timely screening. Many people do not always fully understand whether or how common screening procedures in Australia can accommodate individuals with a physical disability.

Video: What is accessible healthcare?

CODA 2022: What is accessible healthcare?

In this 12-minute video, **Nas Campenella**, the ABC's Disability Affairs reporter,**Jonathan Tang**, now a GP and a researcher with a C5 SCI and **Jean-Frédéric Levesque**, a physician and member of the HealthShare NSW Board, talk about what accessible healthcare means. Particularly pertinent to **Chapter 3** (and **Chapter 4**) is towards the end of the video when **Jean-Frédéric** talks about lack of movement not being the primary reason an individual living with SCI accesses the healthcare system, which Jonathan follows up with a message for clinicians about holistic care of patients. Virtual healthcare is discussed as a way of making healthcare more accessible. The transcript is also available on the website.

How 'accessible' are common screening procedures in Australia for those with SCI?

Below, based on conversations with **Dinesh**, we provide information and research evidence relating to three important screening and hence preventative procedures: *Colonoscopy*, *breast screening* and *cardiac stress testing*. They are essential preventative measures that support long-term health and early detection.

Dinesh's story: Screening procedures with SCI?

"Some of the screening tests that are recommended are just the practicalities of the test itself. Well, most of these people just troubleshoot it with you. I had to get a colonoscopy two or three years ago. It was interesting. My friend was the gastroenterologist and he said, "I'm not sure how we do this". So, some of this stuff is just not there.

[Then, what about] cardiac testing... How do you do an exercise stress test? What about breast screening? So, some of these simple tests, I think, become challenging for people... So, it's really a person-centred thing."

Colonoscopy

This procedure allows a ***gastroenterologist*** to look inside the large bowel (colon) to check for problems such as ***polyps*** or early signs of cancer. A thin, flexible tube with a camera on the end is gently guided through the bowel, usually through the anus, so the doctor can see what is happening inside. Medication is usually given to keep the patient relaxed and comfortable during the procedure. This test is an important screening tool that helps identify issues early, especially for individuals living with SCI who may not experience typical symptoms.

While information specific to Australia was difficult to locate, below is a useful US resource.

Important resource and information: Colonoscopy preparation with SCI

This US resource was written by a person living with a T12 injury and offers practical guidance: Tips for preparing for a colonoscopy with a spinal cord injury.

A 2015 study provides valuable insight into the challenges individuals living with SCI face when undergoing a colonoscopy.

Research: How effective is a colonoscopy with SCI?

Morris and colleagues (2015) conducted a ***matched case-control study*** comparing colonoscopy outcomes between individuals with SCI and those without. The researchers examined indications for the procedure, including bowel preparation, technical success and disease detection. Their key findings included:

- Colonoscopies in the SCI group were more often performed to investigate abnormalities (85.1% *vs.* 58.2%) rather than for screening or surveillance (18.2% *vs.* 40.8%).
- Unsatisfactory bowel preparation occurred more frequently in the SCI group (36.0% *vs.* 13.0%), and completion rates were lower (75.7% *vs.* 93.1%).
- Overall disease detection was lower for the SCI group (45.3% *vs.* 59.6%) and, notably, lower polyp detection (11.4% *vs.* 25.3%).
- The rate of malignancy diagnosis was similar between groups (2.7% *vs.* 3.0%).

Conclusions: Individuals living with SCI appear to have a similar risk of malignancy as the general population, but are less likely to undergo screening colonoscopy. When a colonoscopy is performed, it is often limited by poor bowel preparation and lower completion rates, which in turn reduces the likelihood of detecting polyps. This raises the risk of 'missed diagnoses' if one lives with SCI.

These findings highlight the importance of tailored preparation, accessible clinical environments and proactive communication with healthcare providers. Effective bowel preparation, staff familiar with SCI-related needs and appropriate positioning or support during procedures can improve both comfort and diagnostic accuracy. Understanding these challenges empowers individuals with SCI to ask informed questions, plan and advocate for the adjustments required to ensure safe and effective screening.

Breast screening

This is a routine check, usually biannually in Australia, used to look for early signs of breast cancer, perhaps before any noticeable symptoms appear. It typically involves taking low-dose X-ray images of the breast, known as a mammogram, to identify any unusual changes or lumps. Detecting issues early improves the chances of successful treatment and better long-term outcomes.

Breast screening can be harder for individuals living with SCI because most mammogram machines are designed for people who can stand and move easily. Many women living with SCI need to have the scan while sitting in their wheelchairs. This can make it difficult to position the body sufficiently close to the machine or lean in the way the staff need for clear images. If one has a limited balance and reduced arm movement, one might need to be supported during the scan, which requires an additional person. Not all screening centres have equipment that can be lowered or adjusted and not all staff are trained how to assist someone with SCI safely.

Asha's story: Breast screening not successful

Read **Asha Prasad**'s blog about the challenges with her mammogram after discovering a lump in her breast. I just need a mammogram (SCIA).

Breast screening is still possible, but it often requires extra time, careful planning and a clinic that understands how to adapt the procedure for accessibility. Below is a resource for women with disability from BreastScreen Queensland.

Important resource and information: Accommodating women with SCI

BreastScreen Queensland, for example, supports Women with disability by:

- Providing access for most types of wheelchairs at most service locations, including mobile vans
- Providing access to Australian Sign Language interpreters
- Changing the breast screening procedure for women who have difficulties with movement
- Allowing a support person to come with you into the breast screening room
- Allowing a guide or assistance dog to come with you into the breast screening room
- Providing easy-to-read information about breast screening
- Having videos available in Auslan about breast screening, and
- Providing a Factsheet.

Cardiac stress testing

Normally, during this test, a treadmill is used to progressively increase the workload of the body while monitoring heart rate, breathing, blood pressure and sometimes oxygen levels to evaluate cardiac performance, symptoms and fitness. For individuals with SCI, testing typically uses upper body protocols, most commonly the arm crank cardiopulmonary exercise testing or wheelchair propulsion, because standard treadmill tests depend on leg movement. Research shows these arm-based approaches are feasible and valid for assessing aerobic capacity, in which the maximum rate of oxygen the body can consume and use during intense exercise is an indicator of cardiovascular fitness and endurance. Testing and interpretation should, however, take into account autonomic cardiovascular changes at higher lesion levels, such as blunted maximal heart rate or altered blood pressure control, which can modify typical exercise responses and underline the need for clinicians experienced in SCI physiology to conduct cardiac stress tests (Barton *et al.*, 2026; Hodgkiss *et al.*, 2023; Lee *et al.*, 2023).

Higher-level injuries may limit heart rate and blood pressure responses during upper body exercise, so protocols and safety oversight are typically individualised, with tailored workloads and close supervision. In practice, arm-based formats, such as the arm crank cardiopulmonary exercise test (CPET) or standardised wheelchair tests, are preferred. Trials and reviews show

improvements in aerobic capacity with these modalities (Barton *et al.*, 2026; Hodgkiss *et al.*, 2023).

Information specific to Australia is difficult to find. The US resources below provide practical information.

Important resources and information: Cardiac stress testing with SCI

- Cardiovascular Training in Spinal Cord Injury (Physiopedia): This US resource provides practical guidance on ways to assess cardiovascular fitness in individuals living with SCI. Of note, it appears an ergometer, arm crank or wheelchair treadmill can be used for stress testing, along with more specialised options, such as peak oxygen consumption tests and submaximal exercise tests. These approaches are explained in more detail on the website, and
- Six Minute Arm Test (Shirley Ryan Abilitylab): Provides details on how the test is conducted.

Having explored the importance of health literacy if one lives with SCI and the difficulties one may experience with some of the routine screening procedures to ensure good health, **Chapter 3** considers the five pillars to good health and well-being before **Chapter 4** provides a range of digital resources for keeping a *personal health record (PHR)*. **Chapter 5** then discusses reintegrating into the community after discharge through socialising, work, studying and volunteering.

References

Barton, T. J., Low, D. A., & Thijssen, D. H. J. (2016). Cardiovascular responses to exercise in spinal cord injury. In: J. A. Taylor (ed) The Physiology of Exercise in Spinal Cord Injury. Physiology in Health and Disease. Springer, Boston, MA. https://doi.org/10.1007/978-1-4939-6664-6_6

Borg, S. J., Borg, D. N., Arora, M., Middleton, J. W., Marshall, R., Nunn, A., & Geraghty, T. (2024). Unmet healthcare needs, access to services and experiences with health providers among persons with spinal cord injury in Australia. *Spinal Cord, 62,* 396-405. https://doi.org/10.1038/s41393-024-00997-4

Buzzell, A., Chamberlain, J.D., Eriks-Hoogland, I., Hig, K., Jordan, X., Schubert, M., Zwahlen, M., & Brinkhof, M. W. G. (2020). All-cause and cause-specific mortality following non-traumatic spinal

cord injury: evidence from a population-based cohort study in Switzerland. *Spinal Cord 58*, 157-164. https://doi.org/10.1038/s41393-019-0361-6

Edwards, G., Dorstyn, D., & Oxlad, M. (2025). Health literacy in adults with a spinal cord injury or disorder: An updated and expanded systematic review. *Disability and Health Journal, 18*(3), 101821. https://doi.org/10.1016/j.dhjo.2025.101821.

Gross-Hemmi, M. H., Fekete, C., Post, M. W. M., Reinhardt, J. D., Pacheco, D., Ehrmann, C., Bickenbach, J., & the InSCI Group. (2019). First results from the International Spinal Cord Injury (InSCI) Survey. Swiss Paraplegic Research. https://www.swisci.ch/images/InSCI/News/InSCI_posterA0_17Oct2019_final.pdf

Hodgkiss, D. D., Bhangu, G. S., Lunny, C., Jutzeler, C. R., Chiou, S.-Y., Walter, M., Lucas, S. J. E., Krassioukov, A. V., & Nightingale, T. E. (2023). Exercise and aerobic capacity in individuals with spinal cord injury: A systematic review with meta-analysis and meta-regression. *PLOS Medicine, 20*(11), e1004082. https://doi.org/10.1371/journal.pmed.1004082

International Spinal Cord Injury Survey (InSCI). (2024a). *International Spinal Cord Injury Survey*. Swiss Paraplegic Research. https://insci.network/

International Spinal Cord Injury Survey (InSCI). (2024b). *International Spinal Cord Injury Survey Infographics.* Swiss Paraplegic Research. https://insci.network/ and https://insci.network/info-graphics

Lee, B.-S., Bae, J.-H., Choi, Y.-J., & Lee, J.-A. (2023). Predicting maximum oxygen uptake from non-exercise and submaximal exercise tests in paraplegic men with spinal cord injury. *Healthcare, 11*(5), 763. https://doi.org/10.3390/healthcare11050763

Middleton, J. W., Arora, M., Kifley, A., Clark, J., Borg, S. J., Tran, Y., Atresh, S., Kaur, J., Shetty, S., Nunn, A., Marshall, R., & Geraghty, T. (2022). Australian arm of the International Spinal Cord Injury (Aus-InSCI) Community Survey: 2. Understanding the lived experience in people with spinal cord injury. *Spinal Cord, 60*, 1069-1079. https://doi.org/10.1038/s41393-022-00817-7

Morris, B., Kucchal, T. & Burgess, A. (2015). Colonoscopy after spinal cord injury: a case–control study. *Spinal Cord 53*, 32-35. https://doi.org/10.1038/sc.2014.164

World Health Organization. (2025). *Health literacy*. https://www.who.int/news-room/fact-sheets/detail/health-literacy

Zadra, A., Bruni, S., DE Tanti, A., Saviola, D., Ciavarella, M., Cannavò, G., & Bonavita, J. (2024). Life expectancy and long-term survival after traumatic spinal cord injury: a systematic review. *European Journal of Physical and Rehabilitation Medicine, 60*(5), 822-831. https://doi.org/10.23736/S1973-9087.24.08462-4

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Chapter 3. Staying Healthy, Well and Fit

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"The first wealth is health."

Ralph Waldo Emerson, 1803-1882, American philosopher and poet:

The Conduct of Life (1860)

Good health is the foundation for purpose, participation and connection in everyday life, regardless of disability status. After SCI, sustaining well-being involves more than medical management. It requires rebuilding a relationship with the body, establishing supportive routines and applying practical strategies to maintain energy, mood and overall function.

This Chapter draws on lived experience and clinical perspectives to outline the core building blocks of well-being: nutrition, restorative sleep, safe sun exposure, meaningful physical activity and strong social ties. It also considers complementary approaches such as mindfulness, adaptive movement and creative therapies, as well as ***preventative care*** and coordinated input from healthcare teams.

Attention is given to accessible services, culturally safe care and the well-being of carers and families. The aim is to offer a holistic, adaptable framework that supports individuals, whether living with SCI or not, to cultivate a routine, thereby reducing preventable health risks and pursuing a life grounded in autonomy, connection and meaning.

Important resource: Reconnecting with your body after SCI

The article 10 Ways to Reconnect with Your Body After a Spinal Cord Injury, by SpinalCord.com, outlines a range of positive strategies that support well-being, grounding and holistic health following SCI. In fact, several themes and practices from this resource will be used in various chapters.

In relation to maintaining health and well-being after SCI, the following perspectives from individuals with *LLEs* offer practical guidance, drawing on both personal insight and frontline support and complement preventive care and everyday health management.

Key recommendation: Dr Dinesh Palipana's advice on preventative care

In his blog on preventative care, Preventive care is critical for good health and SCI, **Dinesh** emphasises the importance of proactive, long-term health planning. He advises the following:

> *"One key to staying healthy with a spinal cord injury is having a general practitioner who is comfortable in thinking a bit differently about what is necessary for long-term good health. On top of that, staying linked with a rehabilitation physician and allied health team, either in the public or private sector, helps with some nuanced challenges that may arise."*

Key recommendation: Emma's advice for good health and well-being

Drawing on her experience as a support worker for individuals living with SCI, **Emma Simpson** observed that routine played a central role in supporting her clients' health and well-being. She identified five pillars that contribute to physical recovery, emotional resilience and overall quality of life:

1. **Proper nutrition** helps manage inflammation and supports tissue repair
2. **Sleep quality** is essential for healing and cognitive function, and exposure to natural light helps regulate circadian rhythms and mood
3. **Physical activity** benefits both physical and emotional well-being, particularly when incorporating nature-based or social elements
4. **Exposure to sunlight** supports overall well-being, enhances vitamin D synthesis and helps prevent osteoporosis, and
5. **Maintaining meaningful social connections** reduces isolation and fosters a sense of belonging and purpose.

This Chapter will explore these pillars in greater detail, including the importance of oral and foot health and will offer practical strategies to help individuals living with SCI cultivate a holistic approach to health and well-being.

Key Topics in this Chapter

- The status of progress in terms of the Health and Well-being Outcomes in the 2026 Disability Strategy Report (Fourth report)
- Health professionals who can assist with the five pillars of your general health and well-being
- The five pillars of good health and well-being: Nutrition, sleep quality, exposure to sunlight, physical activity, social connection and beyond, including good oral and foot health
- Looking after your psychological well-being
- The value of connecting with Nature
- Other interventions, such as mindfulness, adaptive yoga, art and music therapy and resilience programs, and
- The health and well-being of carers and family.

3.1. How is Australia progressing in terms of the 'Health and Well-being Outcome' in Australia's Disability Strategy 2021-2031?

In terms of the Fourth report (2026) of Australia's Disability Strategy 2021-2031: Health and Well-being Outcome, the answer is probably *"OK, but not really progressing"*. **Figure 3.2** below and left shows that while 89% of people living with a disability were happy with the healthcare services they received (good news), avoidable deaths remained unchanged (not such good news). Additionally, only 68% of people living with a disability reported good health, compared with 98% of the general population.

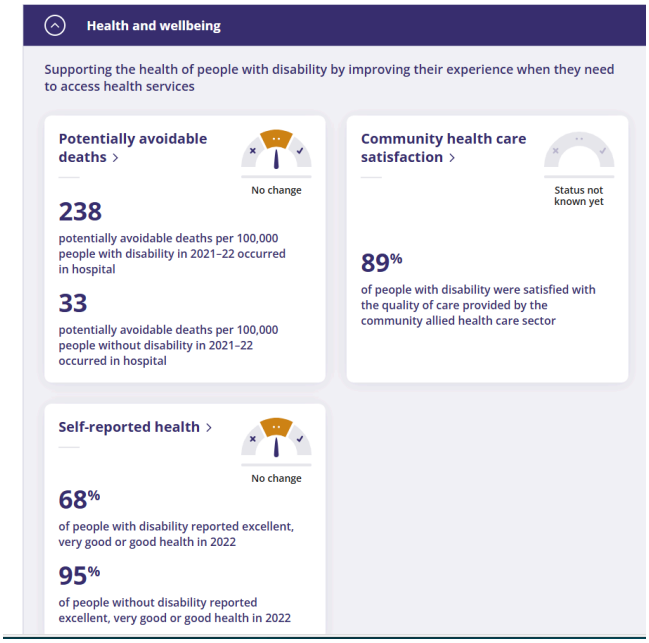


Figure 3.2. Support is available for people living with disability when they need it, despite reporting poorer health than the general population. *Source:* AIHW (2026), Health and Wellbeing, CC BY 4.0

In terms of psychological well-being, **Figure 3.3** below and right suggests that only 47% of NDIS participants were satisfied with their lives now and in the future. This % had increased from the previous survey. Notwithstanding this progress, psychological stress remained high for those living with disability.

Figure 3.3. Psychological distress remains high in the disability community, with less than 50% satisfied with life currently and in the future. *Source:* AIHW (2026), Mental Health, CC BY 4.0.

Figure 3.4. below and left, suggests that for 66% of individuals living with a disability (vs. 82% for those with no disability), healthcare accessibility was not an issue. Only 11% had experienced difficulty accessing health facilities, reinforcing that healthcare is mostly accessible for people with disability.

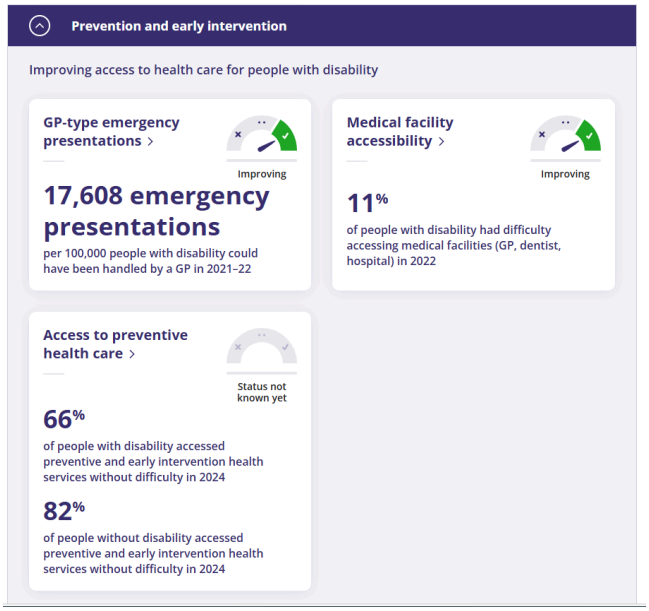


Figure 3.4. Prevention and early intervention, presumably through access to healthcare, seem to be improving for people living with disability. *Source:* AIHW (2026), Prevention and Early Intervention, CC BY 4.0

3.2. General advice for good health and well-being

Maintaining health and wellbeing after SCI benefits from insights from individuals with lived experience and frontline practitioners, whose perspectives highlight the value of structured day- and nighttime routines. Their guidance illustrates how consistent habits, thoughtful preparation and attuned support can enhance physical comfort, emotional resilience and overall quality of life. The next part draws on the LLEs of SCI (**Emily Bray**), a former support worker and now an occupational therapist (**Emma Simpson**) and a positive psychology academic (**Dr Megan Lee**), each offering practical approaches to everyday health management.

Emily's story: Finding confidence after SCI

SCIA's Have a Nerve, Finding your confidence on the days when you really feel disabled (Episode 22) (13 January 2024): The episode explores how people with SCI can rebuild confidence, meaning and purpose on days when disability feels especially confronting, including moments that trigger the thought, *"Holy crap, I'm actually disabled."* It features **Emily Bray**'s story about developing resilience, managing everyday anxieties and finding community support to navigate the added challenges of daily life.

Below are some tips from **Emma Simpson**, a former support worker who is now an OT, and **Dr Megan Lee**, a positive psychology academic, to help you stay healthy and well.

Key recommendation: Emma and Megan's advice: Establish a morning routine and start the day well

Start the day well: The importance of a consistent morning routine

For people living with SCI, a well-supported and consistent morning routine is essential. It is not just about physical care. It is about setting up for the rest of the day. Mornings often involve several care tasks in a limited window of time. A rushed or disorganised start can affect mood, physical comfort and the ability to participate in daily life.

A good morning routine might include:

- Assistance with transfers from bed to the bathroom or commode
- Continence or catheter management

- Skin checks and dressing for the day
- Grooming and personal care, such as shaving, hair brushing and general skincare
- Medication administration
- Meal preparation and assisted eating if required
- Wheelchair checks and equipment readiness, and
- Access to 10 minutes of unfiltered sunlight.

Support workers are crucial in this routine, so they should be punctual, organised and attuned to the person's pace and preferences. Using checklists or visual prompts can help streamline tasks while maintaining dignity and autonomy. It is also important to communicate early, asking *"What's your priority this morning?"* or *"Do you have somewhere to be today?"* to shape the flow of support around the person's goals. Working backwards from the departure time for an appointment can be a useful tool and allows an extra 30 minutes as a 'just in case'. This morning support is not just about attending to clinical needs. A calm, respectful start to the day provides reassurance, predictability and a sense of control. Below are **Emma's** nighttime routine suggestions.

3.2.1. End the day with intention: The nighttime routine

Nighttime care routines are just as important as mornings, both for physical well-being and mental peace. They are not simply a 'wind down' but a transition point that helps the person prepare for rest, recover from the day and set up success for the next morning. A typical night routine might include:

- Toileting or catheter management
- Medication administration
- Transfer to bed and final position adjustments
- Assistance with dressing and skincare
- Setting up pressure-relief cushions or positioning equipment
- Setting up a sleep environment for perfect sleep hygiene, and
- Preparing items for the next day, such as clothing, care products and assistive technology.

3.2.2. Preparation for the night is key

An experienced support worker uses foresight, anticipating needs before they become problems. For example:

- Refilling water bottles, charging equipment and placing the call bell within reach
- Checking continence supply levels and restocking without being asked, and

- Taking note of items that are running low or tasks that need to be followed up on the next day.

A peaceful night routine can significantly reduce the risk of overnight disruptions and help the person rest fully. For people with SCI, restful sleep also supports pressure injury prevention, emotional regulation and recovery from fatigue or muscle spasms.

Key recommendation: Megan, on creating a sleep environment that supports healthy sleep hygiene

Dr Megan Lee suggests setting up the sleeping environment with proper sleep hygiene, as it is equally important for ***circadian rhythms***. This would include:

- Nightly routine is the same every day
- Ensuring a cool, dark room
- A hot shower before bed
- Comfy sleepwear
- Luxurious linen and throws
- Orange light in living areas after 5 pm, and
- No white or blue light before bed.

Additional information, if interested: Blue light and circadian rhythm

Lights should support circadian rhythms (Frontiers in Photonics, 04 October 2023): Blue-light-emitting diode (LED) lighting can interfere with ***circadian rhythms***. Evidence-based scientific consensus supports the use of circadian-friendly lighting and recommends warning labels on blue-enriched LED lights, as they may be harmful if used at night.

3.3. The multidisciplinary team promoting your health and well-being

Just as a range of health professionals helped you transition home, so too will a team of health professionals support you to stay healthy and well. Some may be required on an ongoing basis, while others may be needed only as needed (**Figure 3.5**). A GP will be central to helping you maintain good health and well-being.

An interactive H5P element has been excluded from this version of the text. You can view it online here:
https://bond.studium.pub/life-well-lived-with-spinal-cord-injuries/?p=119#h5p-4

Figure 3.5. The multidisciplinary team members likely to be involved in the maintenance of your general health and well-being now that you have settled at home. The image is interactive. If you click on the ⊕ symbol, an explanation of the person's professional role at this stage of your care will appear. A GP will be responsible for coordinating your care and referring to others as necessary. Created by Jaclyn Szkwara using Canva and HP5, licensed under a CC BY-NC (Attribution NonCommercial).

Staying healthy and well for someone living with SCI is not straightforward. There is still much that is unknown physiologically, even for doctors. **Dinesh Palipana** alludes to this below.

Dinesh's story: *Preventative care* and long-term health risks after SCI

"What kind of vaccinations should we be aiming for? How best do we [doctors] prevent urinary tract infections?

I think it [prevention] should probably be a bit more aggressive because I had a lung function test just last week. The **FEV [Forced Expiratory Volume]** *was about 35% of predicted, which means reduced lung function. I have osteoporosis too. So, do we [doctors] need to be proactive with managing their bone health?*

I had the spinal cord injury when I was 25, and understandably, my physical activity levels dropped significantly. I only have the upper limbs now or half the upper limbs, really, and so the cholesterol level started to increase, hence I had to manage my diet. But it kept going up. I wanted to stay on top of it so I ended up seeing a cardiologist who said, "Well, we don't really know. Should we give you a statin? How do we stay on top of this, so you don't have a heart attack in your 40s?"

I answered that I have been taking statins since I was 28 or 29 years old. I don't think anyone really knows if that's the best way to go about it. I wouldn't be able to feel any myalgia that might happen as a side-effect of the statin. So, I think we need evidence to guide some of this stuff that is unknown."

3.3.1. GP care: Coordinating health and well-being

Coordinated primary care plays a central role in maintaining health and well-being after spinal cord injury, with effective general practice reducing the risk of complications and unplanned hospital readmissions (Borg *et al.*, 2024).

In this Chapter, Gold Coast GP, **Dr Kieran Le Plastrier**, outlines the essential responsibilities of general practitioners in supporting long-term health, including preventive care, routine health monitoring and strategies that promote overall well-being for people living with SCI.

Reminder: Chapter 1 and the role of a GP

Chapter 1 outlined the central GP role in the care of people living with SCI when they come home.

Important information: Difference between prevention and health promotion

This Australian Health and Welfare (AIHW) site on health promotion and health protection provides the answer, while the National Preventive Health Monitoring Dashboard adds further insight. Essentially, prevention is about preventing ill-health, which often means intervention from governments or public health agencies, such as reducing tobacco and alcohol use through campaigns. Sometimes, laws are introduced to compel compliance, such as mandating seatbelt use and, more recently, the under-16 social media ban.

Health promotion is a broad term that is based on enabling people to take control of and improve their health. Health promotion activities seek to enhance the social, educational, environmental, political and economic conditions needed to promote health, while recognising the wider determinants of health, which are social, environmental, commercial and systemic. Health promotion is thus about an individual's change

in behaviour, such as quitting smoking or adopting a diet rich in fresh fruit and vegetables and high in fibre rather than processed foods.

Beyond treating problems as they arise, GPs thus help people living with SCI stay healthy through regular *preventative care*. This includes routine health maintenance checks and evidence-based interventions to catch potential issues early. Scheduled reviews are important.

Important resource: Individuals with SCI, their carers, family and health professionals

In **Chapter 2**, we introduced you to Your Health – SCI Health Maintenance Tool, an evidence-based tool for consumers developed by consumers in 2020. It is a 'must-have' resource for anyone who lives with SCI or is involved with individuals who do. It is well illustrated, with statistics and preventative strategies for self-management of common SCI complications (bladder, bowel, skin, pain and autonomic dysreflexia). The next chapter, **Chapter 4** in this resource, explores the Health Maintenance Tool in more detail, as it has an app for tracking health and well-being.

Below are some key recommendations for GPs to support well-being from **Dr Kieran Le Plastrier.**

- **Arrange regular bloodwork** to monitor general health, such as checking renal function for those using catheters and screening for diabetes or high cholesterol, since reduced mobility may increase metabolic risk.
- **Offer guidance on nutrition and bowel care**, emphasising adequate fluid and fibre intake to prevent constipation and maintain a healthy weight. GPs should encourage physical activity suited to a person's abilities, such as wheelchair sports, exercise physiology programs or stretches to support cardiovascular health and prevent deconditioning.
- **Maintain skin integrity by conducting skin examinations during visits and reinforcing habits, such as daily skin inspections and pressure relief techniques** (Middleton *et al.*, 2008)
- This should include referral to podiatry services to maintain foot and lower limb health and reduce the risk of secondary complications, including skin ulceration due to reduced sensation, which may make individuals less aware of developing other injuries. This is particularly important given that joint contractures are also common following SCI, with at least one contracture reported in approximately two-thirds of patients within the first year, 40% of which affect the foot and ankle region (Nas *et al.*, 2015). In addition, muscle weakness can result in secondary conditions such as foot drop, while altered foot function may change pressure distribution across the foot, contributing to the development of

calluses, corns and other skin and nail complications. These are all issues that a podiatrist can assess, manage and suggest preventative strategies.

- **Do a mental health check**, as about 40% of people living with SCI may experience anxiety or depression (Middleton *et al.*, 2008). GPs should regularly screen for mood changes and can provide counselling, mental health care plans or referrals to psychologists or psychiatrists.

Below, **Dr Dinesh Palipana** explains the importance of monitoring psychological well-being in individuals living with SCI.

Dinesh's story: Experience of poor psychological well-being

"Initially, it [SCI] is about a drastic change to life and not doing the things that you used to do. But I know depression and suicide tend to be one of the leading causes of death for people with spinal cord injury, supported by published statistical data. It used to be renal tract complications, but now I think at the top it's depression and suicide. Actually, there are a couple of stories online where some prominent people who had spinal cord injuries have gone to Switzerland to seek voluntary assisted dying. Again, how do we manage depression and suicide ideation?

Depression in people with spinal cord injury is multi-factorial. I don't know if it's as simple as throwing an anti-depressant at it or cognitive behavioural therapy (CBT) because people are socially isolated. I'm so lucky to have mom and a team of dedicated carer guys and everyone around me and even in our conversation today, it's fulfilling and rewarding, but most people are isolated. They are out of work, education and socialisation. They are broke. So, in summary, there are several factors that lead to a terrible psychological state for some."

- **Encourage getting the appropriate vaccinations**, such as annual flu shots and pneumococcal vaccines, especially if respiratory function is impaired, as well as COVID-19 vaccines to reduce infection risk. As SCI can be considered a specific medical risk, additional vaccines may be required.

Clinical resource: Immunisation schedule for medically at-risk individuals

Australian Government, Department of Health, Disability and Ageing's webpage on Immunisation for people with medical risk conditions offers recommendations about vaccines for people with specific medical conditions.

- **Review medications** annually and at each visit, in case an additional medication is added. including contraindications, as some individuals may be on several medications, such as those regulating bowel function or pain or an antibiotic may need to be prescribed. A medication review is also required before surgery, as is outlined in **Chapter 13**.

Important resource: Managing medications

Factsheet on the management of medications (Vanessa Brown, CNC Aged Care BrightSky Australia): This factsheet is written through an aged-care lens, where many people take multiple medications to manage age-related physiological and skeletal changes, such as chronic pain or arthritis. Similarly, some people living with SCI may also be prescribed five or more medications, a situation known as polypharmacy. While ***polypharmacy*** is common in older adults due to multiple co-existing health conditions, it can also occur in people with SCI, particularly as they age. This topic is explored further in **Chapter 6.**

For individuals living with SCI, below is sage advice from someone (not sure who) about not having to repeat your story every time you see a health professional.

Key recommendation: Keep records of your health and well-being

It gets tiring explaining your condition repeatedly to new health professionals. It will be helpful to provide the background conditions in advance, so you do not have to discuss them on the day. SCIA has developed a template (scroll down to '*Need Additional Support? Telling your Story',* then download the template) that will

help you prepare your key information before seeing any mental health professional. Adapt it as you like or design your own. You can send this in advance or take it to your appointment.

In the next chapter, **Chapter 4**, we provide information on using the Australian Government's My Health Record to ensure continuity of care across health professionals. As mentioned earlier, **Chapter 4** will also provide information on the Health Maintenance Tool (app), which allows you to track your health and well-being daily.

3.3.2. GPs also support carers and family

Living with SCI often involves a team, including carers and other family members. GPs often develop strong, ongoing relationships not just with patients but also with their families and carers (RACGP Care and support for people with disability). A good GP understands that when someone lives with SCI, their carers may experience physical, emotional and mental stress. In routine appointments, the GP can check in with the carer by asking how they are coping and encouraging them to attend to their own health needs. Carers sometimes neglect their own medical appointments or burnout while focusing on the person with SCI, so the GP might gently remind a spouse or parent carer to have regular check-ups, get adequate rest and address any health concerns.

Emotional support is crucial. GPs can watch for signs of carer stress or depression and arrange appropriate support, such as counselling or prescribing a mental health care plan. They can also connect carers with external support services. For instance, Carer Gateway is an Australian government program that provides free counselling, peer support, respite coordination and skills courses for unpaid carers.

Clinical resource: GP assistance for carers

GPs are well placed to inform carers about these resources and refer them, as many carers are unaware that help is available. GPs can help carers access respite services, counselling and peer support to prevent burnout. Care and support for people with disability 10, NewsGP (RACGP), 2023 is an RACGP position statement on care and support for people with disability.

Practical assistance includes completing medical documentation that carers may need, such as reports for carer allowance applications or NDIS support evidence. In essence, the GP looks after the whole family's well-being, not only managing the patient's health, but also helping ensure the carers stay healthy and supported in their role. A supportive GP considers the needs of both the person living with SCI and their carers.

Reminder: Carer resources

Chapter 1 provides several carer resources. Additional links for First Nations carers can be found in **Chapter 8**, while **Chapter 9** has a section on carers who identify as LGBTQIA+.

3.3.3. Choosing a suitable GP, which includes an accessible clinic

As outlined in **Chapter 1**, selecting an appropriate GP is an important step after leaving the hospital or rehabilitation. Establishing a long-term relationship with a GP who understands the needs of individuals living with SCI is beneficial, and, where relevant, collaboration with a support worker or carer can strengthen continuity of care. For some, personal networks may help identify GPs experienced in SCI management, with home-visiting GPs offering an added advantage. The information below guides individuals who may not have such networks and need to identify a suitable GP through other means.

Important information: Finding an appropriate GP

You are entitled to a healthcare provider who respects you and is willing to partner with you in the long-term. Taking the time to choose a suitable GP and clinic will set the foundation for better ongoing care and a healthier life living with SCI.

To locate GPs in your area, can use the Healthdirect Service Finder. Services Australia also lets you search for local general practices and filter by features such as bulk billing and accessibility.

Reading online reviews or asking peers for recommendations can also be helpful. Organisations, such as Spinal Cord Injuries Australia (SCIA) or local spinal injury support groups, might know of disability-friendly GP clinics. It may also help to involve your hospital's spinal outreach or rehabilitation team in the search. Generally, they can suggest GPs who have shown interest in caring for people with SCI.

Building on the advice provided in **Chapter 1,** below are some practical tips for choosing a GP and clinic for long-term SCI care:

- **Interest and experience:** Look for a GP who is understanding and, ideally, has experience with disability or complex chronic conditions. They should be willing to learn about SCI-specific issues if they are not already familiar with them. You might ask if the GP has other patients with spinal injuries or chronic mobility impairments or simply gauge their openness and attitude in the initial consultation. A good GP will listen, be respectful, and not rush through appointments. They should demonstrate a collaborative approach by being ready to work with your specialists, therapists and support services by communicating with your spinal unit doctor or considering information from your physiotherapist or NDIS support co-ordinator.
- **Accessibility of the practice:** Before committing, consider the clinic's physical accessibility. Is there wheelchair access, such as ramp entry or ground-floor access, wide doorways and an accessible toilet? Under Australian standards and the Disability Discrimination Act, GP clinics are expected to provide reasonable access for people with disabilities (Mann *et al.*, 2007). You can often find this information on clinic websites or by calling ahead. Some clinics even have height-adjustable examination tables or portable hoists, features that can make examination easier if you have limited mobility. The reception staff's responsiveness to disability needs, such as allowing extra time for appointments or offering a quieter waiting area if needed, can also indicate whether the practice is disability-friendly.
- **Willingness to collaborate:** Managing SCI often requires input from multiple providers. A suitable GP should be willing to coordinate care, for instance, by developing a GP Management Plan and Team Care Arrangements (part of Medicare's chronic disease management) to involve allied health professionals, such as physiotherapists, dietitians or occupational therapists (Mann *et al.*, 2007). They should be open to referrals and consultations with specialists and comfortable handling the paperwork that may accompany complex care (writing referrals, prescribing equipment, or preparing reports for the NDIS, if required). A collaborative GP will also value input from you and your carers, recognising that you are an expert in your own condition.
- **Personal fit:** Ultimately, you should feel comfortable with your GP. Trust your instincts after a first visit: Did the GP address your concerns and communicate clearly? Did they show empathy and patience? It is perfectly acceptable to 'shop around' for a doctor who meets your needs. You can request a longer initial appointment to discuss your situation in detail. A supportive GP will welcome the opportunity to understand your history and goals. If you use a wheelchair or have attendant care, observe how the practice accommodates that during your visit.

3.4. The five pillars of good health and well-being

This section introduces **Emma Simpson's** *five pillars of good health and well-being*, illustrated in **Figure 3.5,** which form the foundation for the guidance explored throughout this chapter. These pillars are good nutrition, quality sleep, physical activity, morning and afternoon sunlight exposure and social connection.

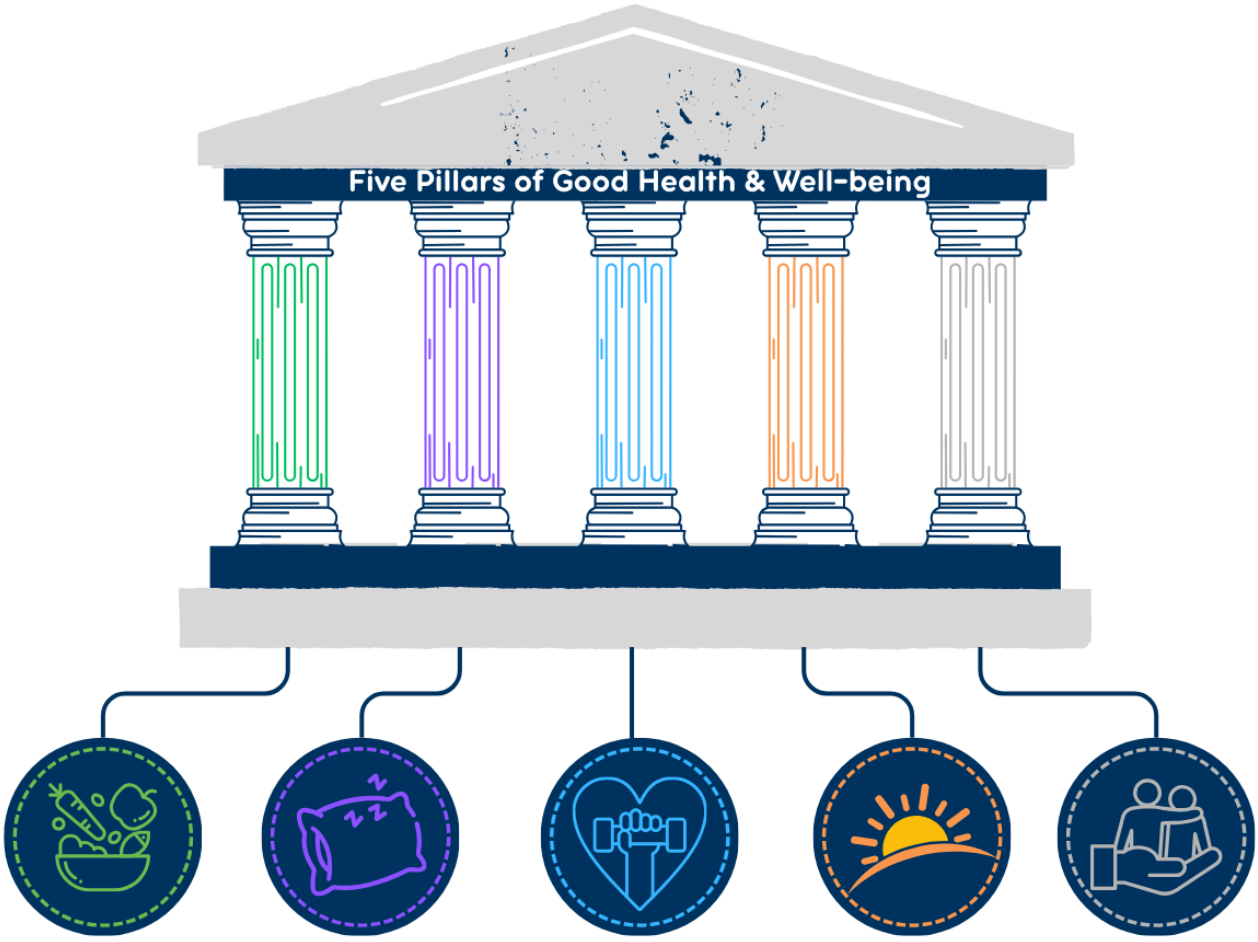


Figure 3.5. Five pillars of good health and well-being. Drawn by Jaclyn Szkwara using Canva.

3.4.1. Pillar 1: Good nutrition

Good nutrition plays a vital role in health following SCI. After an injury, the body undergoes significant and lasting changes to metabolism, muscle mass and fat distribution. These shifts are not limited to the acute stage. They persist across the lifespan. As people age, additional changes, such as reduced metabolic rate, hormonal shifts and age-related muscle loss (*sarcopaenia*), further influence body composition. Understanding how injury-related and age-related changes interact, as will be discussed in **Chapter 6**, and adjusting dietary patterns and lifestyle accordingly can support weight management, reduce secondary complications,

and promote overall health and well-being. As discussed in **Chapter 1,** depending on your specific needs and age, your NDIS or My Aged Care plan covers a dietitian.

Important information: Finding a dietitian

You can find a dietitian via your GP, NDIS co-ordinator, Case Manager or by seeking one via Dietitians Australia Find a Dietitian or HealthShare, Empowering Australians to make better health choices.

3.4.1.1. Weight changes after SCI

In the early weeks after SCI, many people experience unintentional weight loss (Castro *et al.*, 1999; Laven *et al.*, 1989). As reasons for this weight loss are multi-factorial and include a range of metabolic and biochemical derangements, interventions should be targeted and monitored accurately to prevent overfeeding (Laven *et al.*, 1989; Thibault-Halman *et al.*, 2011). After the initial recovery phase, many individuals begin to gain weight in the first 12 months following the injury (Crane *et al.*, 2011). Early adoption of healthy eating patterns in rehabilitation may therefore help prevent unwanted weight gain. There are several reasons for this initial weight gain, including:

- **Reduced mobility**, lowering daily energy expended
- **Slower metabolism**, linked to the loss of muscle mass, which lowers *resting metabolic rate (RMR)*, and
- **Changes in body composition**, with increased fat mass and reduced muscle mass.

3.4.1.2. Energy requirements following SCI

Energy is measured as kilojoules (kJ) per kg per day, but in nutrition, kilocalories (kcal) are still used. To convert kcals into kJs, multiply kcal x 4.184: 1 kcal = 4.184 kJs). Energy requirements after SCI are lower than in the general population due to changes in body composition and nervous system activity. Individuals with SCI have a 14-27% lower*resting metabolic rate (RMR)* due to reduced muscle mass and altered nervous system activity (Buchholz & Pencharz, 2004; Buchholz *et al.*, 2003; Farkas *et al.*, 2019).

Based on limited research (Cox *et al.*, 1985) using *indirect calorimetry* and a 20% activity factor, it has been suggested that for medically stable individuals in rehabilitation, those living with

tetraplegia (quadriplegia) require about 22.7 kcal/kg/day, while those living with paraplegia require about 27.9 kcal/kg/day. Individual requirements vary considerably (Buchholz & Pencharz, 2004; Pellicane *et al.*, 2013; Sabour *et al.*, 2012). More research is needed to ascertain energy requirement predictions.

Research: Consensus framework for SCI nutrition

In a recent ***Delphi study*** (expert opinion), Zengul *et al.* (2025) provide a consensus framework for nutrition in community-dwelling persons living with SCI, bridging the current evidence gap with practical guidance while acknowledging the limitations of consensus-based guidance. They emphasise a tailored energy assessment, recommending Chun *et al.'s* (2017) fat-free mass-based equation with an activity correction factor of × 1.15, which reflects lower metabolic demands in persons with SCI compared with those in able-bodied populations. Their body composition guidance also highlights a ***body mass index (BMI)*** cut-off of ≥ 22 kg/m² and waist circumference measures to better capture ***neurogenic obesity*** and its metabolic risks. This is supported by Laughton *et al.'s* (2009) *'Lowering body mass index cutoffs better identifies obese persons with spinal cord injury',* which also highlights that traditional BMI thresholds used to define obesity are not accurate for people with SCI due to their altered body composition, such as reduced muscle mass (Gorgey *et al.*, 2014). As a result, standard BMI cut-offs tend to underestimate obesity in the SCI population. These researchers suggest lowering these BMI cut-offs to improve the identification of obesity and related health risks in individuals with SCI. Further, based on limited evidence, the healthy weight range is also generally lower than that of the general population. It is noted that people with paraplegia should weigh about 5-10% (4.5-7.0 kg) less, while those with quadriplegia about 10-15% (7-9 kg) less than average matched individuals (Cox *et al.*, 1985). While adjusting BMI thresholds for persons living with SCI can improve clinical assessment, management and prevention of obesity-related complications, further studies are needed to validate the adjusted cut-offs.

After SCI, multiple interacting mechanisms alter appetite control, thereby impacting weight changes. Loss of lean mass and reduced physical activity lower resting energy expenditure (Cox *et al.*, 1985; Gorgey *et al.*, 2014), shifting the energy balance toward weight gain (Crane *et al.*, 2011) unless intake is adjusted. Adipose tissue (body fat) changes also affect circulating ***adipokines*** (Unamuno *et al.*, 2018). Studies report higher ***leptin*** concentrations relative to lean mass in people with chronic SCI (Latifi *et al.*, 2013; Maruyama *et al.*, 2008; Park *et al.*, 2018; Wang *et al.*, 2005), which may reflect altered leptin signalling and a disrupted feedback loop between fat stores and hypothalamic appetite centres (Figlewicz, 2003). Gut-derived hormones and short-term appetite signals, such as ***ghrelin*** and ***peptide YY,*** may also be dysregulated, although evidence is still emerging (Farkas *et al.*, 2025; Li *et al.*, 2025). Clinically, these physiological shifts can produce variable eating behaviours. Ongoing research on the impact of hormonal changes should inform personalised nutrition and weight-management strategies for this population. There is therefore an urgent need for SCI-specific guidelines to enable the timely evaluation of body weight and health.

3.4.1.3. General weight management strategies after SCI

Below, **Dr Priya Iyer**, a dietitian with more than two decades of clinical experience working with people living with SCI, offers some practical suggestions. This is a general guide only.

Actual serves, food choices and plate sizes should be customised individually in consultation with a dietitian.

- **Monitor weight regularly:** Record weight using accessible clinical scales at the GP or outpatient clinic, wheelchair or hoist scales and support from OTs to obtain equipment, such as hoist scales at home. Note the date and time to monitor trends.
- **Assess body composition when possible:** Access body composition measurements via assessments, such as *BIA*,*DEXA* or *MRI* (if available and accessible). Record results and trends.
- **Adjust intake to your personalised energy needs:** Prioritise nutrient-dense foods over energy-dense foods. Update intake with your dietitian as needs change.
- **Focus on food quality, not just quantity:** Prioritise vegetables, fruit, whole grains, lean proteins and healthy fats and minimise processed foods high in sugar, salt and unhealthy fats.
- **Discuss supplements only if indicated:** Follow dietitian or medical advice. Most supplements are unnecessary unless there is a clinical or medical reason.
- **Include safe, appropriate physical activity:** Follow your physiotherapist's guidance on activities that support metabolism, circulation and function.
- **Track progress and review:** Keep a simple log of weight, body composition, food intake and activity and review with your dietitian at agreed intervals.
- **Personalise plate size and serves:** Work with your dietitian to define portion sizes and sample plates that align with your goals, preferences and lifestyle.

Key recommendation: Weight management

The goal is not simply a target number on a scale, but to enhance health, independence and quality of life. Bring your measurement log and any questions to your dietitian and physiotherapist appointments to adjust more quickly and accurately.

Important resources: Nutrition websites

- Get Healthy NSW: The Get Healthy NSW website provides free phone and online health-coaching pro-

grams that support NSW adults to improve their lifestyle through healthy eating, increased physical activity, reduced alcohol use and healthy weight management.

- Healthy Eating Active Living – Getting healthy starts with small steps: The NSW Healthy Living web-page offers simple guidance, programs, and tools to help people eat well, stay active and enhance overall well-being.
- EatRight Weight Management Program – Spinal Cord Injury Model System: The UAB EatRight® Weight Management Program is a 12-week nutrition and lifestyle program designed specifically for individuals with spinal cord impairments, providing structured weekly lessons on healthy food choices, calorie balance, shopping, cooking, and long-term weight management.
- Nutrition for Individuals with Spinal Cord Injury: The SCI Forum, Everyday Nutrition for Individuals with Spinal Cord Injury page, provides tailored guidance on calorie requirements, weight management and overall nutrition considerations for people living with SCI.
- Nutrition – Living With Spinal Cord Injury: The LivingWithSCI.ca Nutrition page explains how dietary needs, energy use, and nutrient requirements change after SCI, offering practical advice on weight management, bowel health, wound prevention and general well-being.
- Nutrition & Spinal Cord Injury – General guidance and useful recipes: This PDF outlines practical dietary guidelines for people with SCI, including meal-planning tips, weight-management strategies, bowel and bladder health considerations and essential nutrients such as fibre, calcium, protein and vitamin D.

3.4.1.4. *Mindful eating*: A practical approach to sustainable weight and nutrition management

Nutrition, in combination with physical activity, is important for weight management and for reducing the risk of complications, pain and inflammation (Alison & Ditor, 2016; Brochetti *et al.*, 2018; Gorgey *et al.*, 2012).

Micronutrient recommendations balance protein needs in individuals without wounds against higher requirements in those with pressure injuries. Recent evidence in SCI highlights the absence of a***hypermetabolic state*** in pressure injuries (Nevin *et al.*, 2023) and excessive energy intake adversely affects wounds (Nevin *et al.*, 2025), underscoring the importance of individualised planning.

Macronutrient guidance refers to general population recommendations, and combining these to make a ***mindful plate*** requires a high level of planning, given the challenges of meeting low energy needs with low fibre targets. Hence, guidance from an accredited practising dietitian is paramount to remove the complexities of meal planning and translate the available evidence

(and its lack) in combination with consensus guidelines and customised preferences into an individualised plan.

3.4.1.5. Nutrition and organ systems

Drawing on **Chapter 2, Table 3.1** below summarises common impacts of SCI by organ system and offers concise, practical nutrition and dietetic actions to support health. Each row includes clear actions, safety flags and referral prompts so clinicians and readers can use the table at a glance.

Table 3.1. An organ-systems approach to nutritional considerations for individuals living with SCI.

Organ system	Common impacts of SCI	Nutrition and dietetics considerations
Musculoskeletal	Muscle atrophy; reduced mobility; increased osteoporosis risk	• Adequate protein distributed across meals • Adequate calcium and vitamin D intake • Weight management to reduce joint strain * The Calcium Calculator by Osteoporosis Canada allows an estimation of dietary intake
Respiratory	Reduced lung capacity, especially in cervical SCI, and aspiration risk	• Screen for dysphagia; refer to a speech pathologist for a swallowing assessment • Use texture-modified diets or enteral nutrition support when indicated • Monitor and maintain hydration for mucus clearance
Urinary	Neurogenic bladder; recurrent UTIs; catheter use	• Maintain hydration • Adjust diet if renal impairment is seen, in consultation with your renal team
Gastrointestinal	Neurogenic bowel: constipation, bowel accidents, delayed gastric emptying	• Adequate fibre (individualise based on SCI level and bowel presentation) • Adequate fluid intake (individualised) • Scheduled meal timing to support bowel routines • Monitor for constipation and adjust medications and diet in liaison with your treating team
Reproductive	Sexual dysfunction; potential fertility changes	• Support healthy body weight and optimise fertility nutrition, such as folate, vitamin B12, and healthy diet patterns like the Mediterranean diet
Cardiovascular	Orthostatic hypotension; increased risk of metabolic syndrome	• Adopt cardio-protective dietary patterns, such as the Mediterranean diet • Monitor BP, lipids, glucose and body weight or waist circumference • Tailor energy intake to reduce energy expenditure • Tailored physical activity guided by a physiotherapist
Integumentary (skin)	High risk of pressure injuries; impaired wound healing	• Ensure adequate wound-prevention/support nutrition as directed by a dietitian • Refer to the wound clinic for complex pressure injuries

Neuropathic pain and mood	Chronic pain may alter appetite, sleep and mood	• Screen for appetite changes and nutrient-drug interactions • Emphasise anti-inflammatory food choices, such as the Mediterranean diet • Support strategies for appetite regulation • Refer to the multidisciplinary team as indicated
Metabolic	Reduced energy expenditure, insulin resistance, and altered body composition	• Prioritise nutrient-dense foods and regular review with a dietitian • Know your energy needs and monitor body weight/body composition trends • Monitor biochemical markers with your medical team or GP periodically, such as glucose and lipids

An organ-systems approach helps translate clinical changes into practical nutrition actions. SCI affects several systems simultaneously, so nutrition care must be holistic, prioritised and personalised. Use **Table 3.1** to identify immediate safety needs (such as dysphagia or active wounds), set short-term goals (hydration, bowel routine and wound nutrition) and plan longer-term strategies (weight management, bone health and metabolic risk reduction). Always discuss serves, portion sizes and supplements with a dietitian who will tailor recommendations to your medical history, medications, personal preferences and lifestyle.

Key recommendation: Glycaemic index (GI) and mindful eating

The GI is a system that ranks foods based on how quickly they raise one's blood sugar (glucose) levels after eating. Low-GI, nutrient-dense foods are a smart choice because they provide steady energy, keep us full, support long-term health and are especially important for managing or preventing diabetes and maintaining a healthy weight. To learn about the GI of your foods, visit Glycemic Index – Glycemic Index Research and GI News.

3.4.1.6. Neurogenic bowel and diet

While general dietary advice often includes increasing fibre and fluid intake, research specific to SCI populations suggests this may not always yield the same benefits seen in able-bodied individuals (Yeung *et al.*, 2021). In fact,

a recent recommendation notes that adhering to fibre and fluid guidelines for the general population may have little to no effect on bowel function in adults with SCI, due to the altered gut

physiology following injury. Nevertheless, dietary strategies are still a valuable component of individualised bowel care plans, particularly when implemented alongside other multifaceted bowel management approaches (Bernardi *et al.*, 2020).

Dietary fibre: Systematic reviews evaluating dietary components for ***neurogenic bowel dysfunction (NBD)*** after SCI (Yeung *et al.*, 2021; Bernardi *et al.*, 2020) found that high-fibre diets may worsen constipation in some people by increasing ***colonic transit time (CTT),*** evacuation time and NBD scores. Both reviews suggested that a fibre intake of around 15 g/day could be more effective for managing NBD in SCI, based on the available evidence at the time. No new high-quality evidence has established definitive fibre targets for NBD in SCI.

Clinical practice guidelines vary, recommending daily fibre intakes in the 15-30 g range (ACI, 2022; Can-SCIP Guideline, 2025; Johns *et al.*, 2021; Kurze *et al.*, 2022). Importantly, however, the PVA-NBD Guideline emphasises the need to individualise recommendations and warns against treating a high-fibre diet as a one-size-fits-all solution. The Multidisciplinary Association of Spinal Cord Injured Professionals (Johns *et al.*, 2021) offers fibre recommendations tailored to bowel presentation. In addition, the Zengul *et al.* (2025) consensus suggests ~15-20g of dietary fibre a day, increased gradually and adjusted to bowel function. Overall, evidence specific to SCI remains limited, so fibre recommendations must be individualised and reviewed regularly with the clinical team.

Fluid intake: Adequate hydration supports the beneficial effects of fibre and helps stool move through the colon. Most guidelines suggest a general target of 1.5-2 litres of fluid per day (Johns et al., 2021; Kurze *et al.*, 2022), but this should be adjusted to suit individual bladder management, continence strategies and risk of urinary complications. It is important to discuss personalised targets with your clinician.

Table 3.2 provides a sample meal plan with practical ways to include fibre and fluids at each meal. Use it as a starting point and adapt portions, textures and volumes with your dietitian.

Table 3.2. Sample meal plan to ensure ~15-20 g fibre a day, as well as fluid intake, as an example to guide meal planning.

1. Breakfast	3. Lunch	5. Dinner
Oatmeal with banana (fibre ~5-6.5 g) • ½ cup rolled oats (4 g fibre) • 1 cup water or milk • ½ to 1 small banana, sliced (1-2.5 g fibre) • 1 glass of warm water (200-300 ml)	**Wholegrain wrap with hummus and protein (fibre ~4.5 g)** • 1 wholegrain wrap (2.5 g fibre) • 1 tbsp hummus (1 g fibre) • Egg or lean meat (0g fibre) • Little spinach/grated beetroot (~1 g fibre) • 1 glass of water (200-250 ml)	**Grilled chicken with quinoa and steamed veggies (fibre ~5.5-6.5 g)** • ½ cup cooked quinoa (2.5 g fibre) • 1 cup steamed broccoli and carrots (3-4 g fibre) • Grilled chicken/fish or tofu (low fibre, protein source) • 1 glass of water (250 ml)
2. Morning tea	**4. Afternoon tea**	**6. Before bedtime**
Green tea (fibre ~1 g) • 1 cup brewed green tea • One handful of cashew nuts (1 g)	**Fruit and yoghurt (fibre 0 g optional)** • 1 small tub yoghurt (0 g fibre)	**Fluid (fibre 0 g)** • 1 glass of milk

For instance, the daily fibre total with morning and afternoon snacks would be ~16-18.5g or ~15-16.5 g without snacks. The focus of this meal plan is the fibre content only. Generic meal plans and plating ideas need to be customised to suit an individual's unique nutrition requirements. An accredited practising dietitian can assist with this. The plan can be adjusted depending on fibre tolerance, bowel presentation and individual preferences.

Important recommendation: Fibre intake

The amount, type, and sources of dietary fibre will depend on the level of injury, the goals of bowel management, the current presentation (such as constipation, bowel accidents, or loose stools), and co-morbidities and medications that affect the bowel. Start with ~15 g of fibre per day, monitor how your bowels respond, and adjust gradually based on symptoms such as constipation, accidents or bloating. Keep a consistent bowel routine and watch for triggers like caffeine or spicy foods. Below are some key resources:

- Baker Institute – Dietary Fibre Fact Sheet: Provides an overview of fibre types, health benefits, daily targets and high-fibre food choices
- SCIRE – Dietary Fibre Guide: Explains the body's fibre needs after SCI, including types, food sources and tips for adequate fluid intake, and
- ACI NSW – Resources for People with SCI: Practical consumer guides on nutrition, bowel health, pain, respiratory training and overall health maintenance.

3.4.1.7. A healthy eating plate for living with SCI (*mindful plating*)

Mindful plating supports diet diversity, environmental sustainability and nutrient adequacy to promote health and well-being after SCI. It provides a practical, visual guide to help with meal planning. Portion cues are relative and illustrative only and are not tied to any specific daily energy target. Meals will vary by culture, personal preference and cooking method, so use this model as a flexible reference and consult an accredited practising dietitian experienced in SCI for personalised advice.

Generic meal plans and plating ideas need to be customised to suit an individual's unique nutrition requirements. A mindful plate **(Figure 3.7)** generally looks like this:

An interactive H5P element has been excluded from this version of the text. You can view it online here:
https://bond.studium.pub/life-well-lived-with-spinal-cord-injuries/?p=119#h5p-5

Figure 3.7. A mindful plating guide for people living with SCI. Image by Priya Iyer using Canva, with HP5 created and added by Jaclyn Szkwara, licensed under a CC BY-NC (Attribution Non-Commercial).

*Portions are illustrative only. Personalise serves and textures with an accredited practising dietitian familiar with SCI.

Important information: Priya's mindful plating

- **Purpose:** The plate is a population-level visual tool adapted from general healthy-eating models to prompt balanced meals for people living with SCI.
- **Limitations:** It is not a personalised prescription. It does not replace individual energy and macronutrient assessment, texture modification for dysphagia or clinical management of a neurogenic bowel, pressure injuries or metabolic conditions.
- **Use in practice:** Pair the plate with a brief assessment (weight, bowel pattern, medications, swallowing status) and tailor portion sizes, textures and timing in collaboration with the individual and their multidisciplinary team. Document the agreed portion guidance and review regularly.

Reminder: New Australian Dietary Guidelines in 2026

The New Australian Dietary Guidelines will be released in 2026. The official website outlines what to expect and includes a Frequently Asked Questions page that answers key questions about the new Guidelines. Early messaging suggests a likely emphasis on reducing red meat and saturated fat, increasing peas, lentils and beans, addressing ***ultra-processed foods (UPFs)*** and strengthening guidance on environmentally sustainable food choices. Read the relevant section in **Chapter 17 (Climate Change and SCI)** for a dedicated discussion of environmentally sustainable diets.

3.4.1.9. The role of the dietitian

A dietitian provides specialised, individualised nutrition care for people living with SCI, addressing immediate clinical needs and long-term health goals. Requirements vary with injury level and completeness, metabolic changes, mobility, medications and co-existing conditions. Dietitians perform comprehensive assessments and, in partnership with the individual, translate clinical goals into practical, safe eating plans that support wound healing, bowel and bladder management, weight control and cardiometabolic risk reduction. They work within the multidisciplinary team to coordinate care, monitor progress and adjust plans as needs change (**Table 3.3**).

Table 3.3. Nutrition roles and referral triggers for some common health concerns associated with SCI.

Health concern	Early signs, risks	Relevant health professionals	Nutrition and dietetics role	Referral triggers
Pressure injuries	Red or discoloured skin, non-blanching spots or open wound	Nurse, wound care specialist, physiotherapist, podiatrist, individual and family or carer	• Ensure adequate macro- and micro-nutrients to support skin integrity and healing • Monitor intake and weight	New or enlarging wound/s; weight loss or rapid gain; signs of infection
UTIs	Increased spasticity, fever, cloudy/ foul urine or discomfort	GP, urologist, nurse, pharmacist, individual and family/carer	• Adequate hydration in line with set personalised fluid targets. Monitor for signs of low fluid intake • Antibiotic treatment and counselling, where appropriate	Recurrent UTIs, fever or systemic symptoms
Constipation, NBD	Infrequent bowel actions, bloating, discomfort or overflow	Gastroenterologist, GP, dietitian, nurse, occupational therapist, pharmacist, individual and family/carer	• Individualise the fibre, fluid plan • Align meals with bowel program • Trial gradual fibre changes and functional foods • Medications as *per* the medical team	New or worsening constipation; impaction or unsuccessful bowel program
Depression, mood disorders	Low mood, sleep disturbances, appetite changes or social withdrawal	Psychologist, Psychiatrist, GP, dietitian, individual and family/carer	• Screen for and monitor changes in appetite and nutritional status • Encourage healthy and balanced meals	Marked appetite loss or weight changes, other psychological symptoms warranting urgent psychological support

Unintended weight gain	Reduced mobility, changes in body composition/ weight	Dietitian, physiotherapist, GP, exercise physiologist, individual and family or carer	• Provide individualised dietary strategies and behaviour support • Support weight monitoring and activity plan by a physiotherapist or an accredited exercise physiologist	Rapid weight gain with metabolic changes
Malnutrition, muscle wasting	Unintended weight loss, fatigue or reduced strength	Dietitian, GP, rehabilitation team, individual and family or carer	• Early nutrition screening and assessment • Optimise nutrition and monitor progress	Significant weight loss or signs of malnutrition
Diabetes, insulin resistance	High blood glucose, fatigue or delayed wound healing	Endocrinologist, GP, diabetes educator, dietitian, podiatrist, exercise physiologist or physiotherapist, individual and family or carer	• Implement cardiometabolic dietary patterns, such as low GI, Mediterranean diet • Educate on dietary management • Support the activity plan by the physiotherapist, exercise physiologist and medical management by the MDT	Poor glycaemic response or recurrent *hyperglycaemia*
Osteoporosis, bone loss	Poor posture, low bone mineral density (BMD)	GP, endocrinologist, physiotherapist, dietitian, individual and family or carer	• Promote adequate calcium, vitamin D and protein intake • Discuss supplements with the medical team • Review medications	New fragility fracture or very low BMD

Dysphagia (swallowing issues)	Coughing when eating, choking, food avoidance, or weight loss	Speech pathologist, dietitian, GP, nurse, individual and family or carer	• Coordinate enteral support and/or texture-modified diets • Monitor weight, nutrient adequacy and hydration	Signs of aspiration, recurrent chest infections, and rapid weight loss
Pain	Chronic pain, appetite changes or sleep disturbance	GP, pain specialist, pharmacist, dietitian, psychologist, individual, family or carer	• Medical and psychological management support • Review drug-nutrient interactions • Anti-inflammatory food choices, such as a Mediterranean diet • Appetite regulatory strategies	Severe appetite changes, weight changes and impact on mood or quality of life

Reminder: Disclaimer

This content is for general information and example purposes only**.** It is not a personalised nutrition plan, medical advice, diagnosis or a substitute for professional assessment. Servings, portion sizes, textures, fluid targets, supplements and clinical recommendations must be individualised based on your medical history, medications, level and completeness of injury, swallowing status, bowel and bladder management, wounds and other health conditions. Always consult an accredited practising dietitian familiar with SCI and your treating clinicians (GP, specialist, speech pathologist, physiotherapist, wound clinic and renal team) before making changes to your diet, starting supplements, altering fluid intake or changing medication-related routines.**If you experience signs of aspiration, infection, rapid weight change, non-healing wounds, severe constipation or other urgent symptoms, seek immediate medical attention.**

3.4.2. Pillar 2: Getting a good night's sleep

Insomnia, which is trouble falling asleep, staying asleep or waking too early, is common after SCI and can affect health and daily life (Sankari *et al.*, 2019). Australian research confirms this problem. Over half had significant insomnia symptoms in one study (Sankari *et al.*, 2019), while 68% people living with SCI in a large Australian survey reported poor sleep quality (Greco *et al.*, 2023). Insomnia often occurs alongside other sleep issues, such as*sleep apnoea* or limb movements (Sankari *et al.*, 2019).

Be aware that insomnia may signal an underlying problem such as sleep apnoea or *restless legs syndrome*, so it is important to follow up with your GP for proper evaluation. Below is an explanation about why sleep is often disrupted after SCI, as well as strategies (non-pharmacological and pharmacological) to manage insomnia.

3.4.2.1. Why does SCI affect sleep?

Many physical and neurological changes after SCI can interfere with normal sleep. Key reasons include:

- **Hormonal disruption:** A high-level (cervical) SCI can reduce nightly melatonin release, a hormone that regulates the sleep-wake cycle. This makes it harder for your body's 'internal clock' to know when to sleep. Also, after SCI, the body may not increase *anti-diuretic hormone (ADH)* at night, leading to more urine production when you should be sleeping. Needing to urinate more at night (called *nocturia*) means more awakening cycles while sleeping (University of Washington, 2013).
- **Temperature and circadian signals:** SCI can disrupt the body's temperature regulation, which in turn affects sleep timing (your brain's sleep schedule partly relies on body temperature cycles) and sleep quality (University of Washington, 2013). In high cervical injuries, the normal day-night melatonin rhythm may be almost abolished due to damage to nerve pathways, disrupting the circadian rhythm (Sankari *et al.*, 2019). Those authors found that complete neck-level (cervical) injuries nearly eliminated the normal melatonin cycle, which can contribute to insomnia.
- **Night-time care and interruptions:** People with significant paralysis often must awaken multiple times for care, such as turning in bed to prevent pressure sores or emptying the bladder via catheter sleeping (University of Washington, 2013). These

necessary routines break up sleep. Even an automatic turning bed or overnight carer check-ins can fragment sleep cycles.
    - **Pain and discomfort:** Nerve pain, muscle or joint pain are common after SCI and can make it hard to fall asleep or may wake you up frequently (University of Washington, 2013). Pain below the level of injury (or residual sensation in incomplete injuries) can flare at night. An uncomfortable posture is one in which one cannot easily adjust one's position. It also causes awakenings (Sankari *et al.*, 2019).
    - **Spasticity and leg movements:** Involuntary muscle spasms or jerking (***spasticity***) in the legs (***restless legs syndrome (RLS)***) can occur with many SCIs, disrupting sleep with sudden movements (University of Washington, 2013). Some people also develop periodic limb movements or restless legs syndrome, causing crawling sensations or leg twitches at night. Research shows abnormal leg movements during sleep are much more frequent after SCI (Sankari *et al.*, 2019), which can fragment sleep.
    - **Reduced activity and daytime fatigue:** After SCI, people are often less physically active during the day, especially those who use wheelchairs or are bed-bound in early recovery. Being less active can mean you are not as sleepy at night. Spending a lot of time in bed during the day for resting or due to limited mobility can also confuse your sleep-wake pattern (University of Washington, 2013). This can lead to a cycle of napping and insomnia.
    - **Mood and mental health:** It is understandable to experience stress, anxiety, or depression after SCI. These feelings can cause racing thoughts at night or poor sleep quality. About 40% of people living with SCI show risk of depression or anxiety disorders (Sankari *et al.*, 2019). Depression and anxiety often interfere with the ability to fall asleep or stay asleep through the night (University of Washington, 2013). Conversely, chronic insomnia can worsen mood and coping.
    - **Medication side-effects:** Medications commonly used in SCI (for pain, spasticity, or bladder issues) can affect sleep. For example, some painkillers and muscle relaxants can cause daytime drowsiness (University of Washington, 2013), disrupting your sleep schedule, while others (or even caffeine in pain relievers) can cause alertness at night. Finding the right timing and type of medication with your doctor is important so that treatments don't inadvertently disturb your sleep.
- **Sleep-disordered breathing:** Sleep apnoea is a major issue after SCI. When sleep apnoea occurs, you stop breathing briefly and wake up repeatedly. SCI increases the risk of ***obstructive sleep apnoea (OSA)***, especially if the injury is in the upper back or neck region (quadriplegia) (Sankari *et al.*, 2019). Australian studies found 60-80% of people with new cervical SCI had sleep apnoea in the acute phase. Even chronically, an estimated ~40-60% of the SCI population has sleep apnoea, with rates much higher than in people without SCI (University of Washington, 2013). Apnoea causes low oxygen and micro-awakenings that the person might not remember, but they lead to unrefreshing sleep. Notably, in paraplegia (lower-level injuries), the apnoea risk is still elevated but closer to general population levels (Sankari *et al.*, 2019). Untreated sleep apnoea often causes loud snoring and marked daytime fatigue; and
- **Autonomic and other physiological changes:** SCI can alter your autonomic nervous system, which controls functions such as blood pressure, heart rate and sweating. With

injuries above the mid-chest (above T6), you might experience episodes of autonomic dysreflexia (AD) or heart rate or blood pressure fluctuations that can disrupt sleep or cause nighttime headaches and/or sweating. Additionally, *a neurogenic bladder* (even aside from *anti-diuretic hormone (ADH)* issues) or *neurogenic bowel* could cause awakenings for toileting. All of these internal changes can contribute to poor sleep quality in different ways.

Research: Causes of sleep disturbance

Lee and colleagues' (2025) recent small Canadian community study found that 75.3% of respondents reported poor sleep quality, with 37.7% experiencing high fatigue and 29.4% experiencing excessive daytime sleepiness. In the last six months, 73.5% experienced ≥1 regular sleep disturbance, 55.2% of whom reported ≥3 disturbances. Disturbances were due to:

1. *Nociceptive pain* (45.6%),
2. Anxiety (44.8%),
3. Bladder care (40.0%),
4. Spasticity (37.6%),
5. Turn routines (34.4%),
6. Neuropathic pain (30.4%),
7. Thermal discomfort (29.6%),
8. Autonomic dysreflexia (episodic hypertension, 23.1%)
9. Sleep apnoea (20.8%), and
10. Bowel care (19.2%).

While 74% of participants managed their sleep independently, 28.8% used non-prescription sleep aids, suggesting that 67.1% of participants have not reviewed their sleep care with a healthcare provider since initial discharge.

Thus, virtually all forms of SCI (complete or incomplete, at any level) can lead to sleep problems, although the reasons for the disturbances may differ. Higher-level injuries tend to involve more breathing problems and circadian disruptions, while lower-level injuries might involve fewer specific issues. Pain is, however, a major contributor to sleep deprivation, followed by anxiety, bladder issues and spasticity. Identifying which factors affect sleep is important because many of them can be addressed with the right strategies

3.4.2.2. Non-pharmacological strategies to manage insomnia

Managing insomnia after SCI involves a combination of non-pharmacological (non-drug) approaches and pharmacological treatments. Often, the best results involve combining

lifestyle changes with targeted therapies. Below are strategies to improve sleep that address different aspects of insomnia and tackle common SCI-related causes of sleep disturbance. Always discuss with your healthcare provider before starting new treatments, especially medications, to ensure they fit your personal needs:

- **Sleep hygiene and routine:** Good sleep habits are important. Try to maintain a regular sleep schedule by going to bed and waking up at a consistent time every day, including weekends. This helps reset your internal clock. Develop a calming bedtime routine, such as reading, gentle stretching, or listening to relaxing music, to signal to your body that it is time to sleep. If possible, avoid long daytime naps, as napping can make it harder to sleep at night. Also limit caffeine and other stimulants, especially in the afternoon and evening, as they can worsen insomnia. Many people find it helpful to keep the bedroom only for sleep and intimacy, such as avoiding watching TV in bed, so their brain associates the bed with sleeping (University of Washington, 2013)
- **Comfortable sleep environment:** Optimise your bedroom for sleep. This includes a comfortable mattress and pillows that protect against pressure injuries and minimise pain. Specialised pressure-relieving mattresses or cushions can help you stay comfortable through the night. Keep the room cool (but not too cold), since temperature regulation might be impaired. Using fans, air-conditioning and appropriate bedding to avoid overheating or getting chilled is key. Ensure the room is dark and quiet. You might consider an eye mask or earplugs. If you use equipment like ventilators or *CPAP*, work with your providers on mask fit and noise reduction (many CPAP machines are now very quiet). For those with high-level SCI who cannot toss and turn easily, proper positioning is crucial. Make sure you are well-positioned, with supportive padding under the knees or ankles if needed, to prevent discomfort that can wake you, and
- **Manage nighttime care schedule:** Where possible, coordinate your nighttime care to minimise sleep disruptions. For example, if you perform intermittent catheterisation, try using a larger-volume leg bag or an indwelling catheter overnight to reduce the frequency of bladder-emptying awakenings. Consult your doctor about this. Carers might be able to adjust turning schedules, such as using specialty mattresses that require less frequent turning, or scheduling turns strategically before you typically enter deep sleep cycles. While health and safety, such as preventing pressure sores, come first, talk with your support worker or carer about balancing care tasks with continuous sleep. Even small adjustments, such as doing a final catheterisation just before sleep or timing pain meds to cover the night, can help you get longer uninterrupted sleep blocks.

Below, **Emma** offers insight from her experiences as a support worker and the role a support worker can play in ensuring quality sleep.

Supporting sleep: Overnight support in active and inactive roles

For many people with SCI, overnight support is essential for safety, comfort, and continuity of care. Whether it is for pressure relief, toileting, catheter management, repositioning or emergency response, the presence of a support worker at night can bring peace of mind. It is,

however, also important to plan this support in a way that minimises disruption because uninterrupted sleep is just as vital to well-being as daytime routines.

Overnight support may be delivered in either an **active or inactive** (also called 'sleep-over') capacity:

- **Active overnight support** involves the support worker remaining awake and available throughout the night to assist as needed. This is usually rostered when regular interventions are required (e.g. two-hourly pressure relief or ventilation assistance), and
- **Inactive overnight support** involves the worker sleeping on the premises but being close by in case of unplanned or occasional assistance, for example, repositioning, getting a drink or continence assistance.

Key recommendations: Emma and planning overnight support

- **Clarify expectations early:** Support needs should be clearly defined by determining how often assistance is required and whether staff are expected to wake at set intervals on their own or respond only when called. It is important to communicate your preferences, needs and responsibilities openly with your health professionals, provider and support team so that everyone understands the expectations and can plan care accordingly.
- **Decide where the support worker will stay:**
  - A separate sleep room is ideal for inactive overnights, providing privacy and boundaries for both parties, and
  - For active overnights, a comfortable chair or space near the person's room allows for regular checks without intruding.
- **Minimise sleep disruption:** Where possible,
  - Use soft lighting, such as dimmable bedside lamps or motion-activated strip lights, to avoid bright overhead lights during nighttime tasks
  - Consider using low-noise equipment and training workers to perform tasks quietly and efficiently, and
  - Reduce unnecessary interruptions by streamlining night routines. Keep commonly used items, such as incontinence pads, wipes and water, within easy reach.

Below, **Dr Kieran Le Plastrier** offers guidance on developing a healthy sleep routine.

Key recommendations: Dr Kieran Le Plastrier's advice for individuals (and carers) about a sleep routine

- **Maintain professionalism and trust:** Night-time support is deeply personal and requires a high level of respect and discretion. Workers should be well-trained and sensitive to the impact of their overnight presence in a person's home. While overnight care may never be completely disruption-free, thoughtful planning, team communication, and environmental adjustments can make a big difference. Preserving the individual's sleep quality wherever possible should be a shared priority
- **Physical activity (during the day):** Increasing your daytime activity can improve nighttime sleep. Within the limits of your injury, try to engage in regular exercise or physiotherapy, such as wheelchair sports, arm exercises or ***functional electrical stimulation (FES)*** cycling, if available. Day-time physical activity can boost your body's drive for sleep at night. It also has mood benefits. Be sure to get some exposure to natural light during the day, especially morning light, as this reinforces healthy circadian rhythms and can help to feel sleepy at night (University of Washington, 2013)
-
Relaxation techniques and stress reduction: Stress and mental tension feed insomnia. Consider incorporating relaxation strategies before bed: deep breathing exercises, progressive muscle relaxation, mindfulness meditation, or guided imagery can calm the mind and body. Some people find that gentle yoga or stretching (if able) in the evening reduces spasticity and signals muscles to relax. If anxiety or racing thoughts are keeping you awake, writing in a journal or practising gratitude exercises before bed can help clear your mind. A highly effective, non-pharmacological treatment is ***cognitive behavioural therapy for insomnia (CBT-I)***. It works by changing unhelpful thoughts and sleep-related habits. CBT-I can be delivered by a psychologist or via online programs and is worth asking your GP or rehab team about if insomnia persists. It has been shown that treating insomnia with such methods can improve sleep even when medical issues are present, and may, in turn, improve your pain tolerance and mood over time, breaking the pain-insomnia-anxiety cycle (University of Washington, 2013)
- **Address underlying physical issues: Since problems like pain, spasms and reflux can wake you up, proactively managing them can improve sleep:** For example, pain management is critical. Use

of appropriate pain-relief measures in the evening, such as prescribed medications, warm packs, and a gentle massage, can help prevent pain from spiking at night. If neuropathic pain (burning or tingling pain from nerve injury) is an issue, talk to your doctor about adjusting medications such as gabapentin or pregabalin to cover nighttime. For spasticity, doing stretches or range-of-motion exercises before bed and ensuring you are warm, as cold can trigger spasms, may reduce episodes. Some find that having a standing frame session or leg passive cycling in the evening (if available) can lessen night spasms by expending some of that muscle tension. If acid reflux or breathing congestion is an issue when lying flat (common in higher injuries), using a slight upper body elevation, such as an adjustable bed or extra pillows under the mattress head, can help. Essentially, identify any discomfort that repeatedly wakes you and work on solutions to address it; and

- **Lifestyle and psychological well-being:** Limiting alcohol and smoking can also improve sleep quality. Alcohol may make you drowsy but disrupts deep sleep later, and nicotine is a stimulant. If you struggle with depression or anxiety, seek support, such as therapy, support groups or medication, if appropriate. Improving psychological well-being often leads to better sleep and *vice versa*. Engaging in relaxing hobbies and social activities during the day can boost your mood and help reduce insomnia. Peer support from others living with SCI can also provide tips and emotional reassurance, which might ease stress-related insomnia.

Clinical resource: Cognitive Behavioural Therapy for Insomnia

SleepHealth Foundation (Australia), Cognitive Behavioural Therapy for Insomnia (CBT-I): This resource is an educational fact sheet that explains what CBT-I is, why it is recommended as the first-line treatment for insomnia and how it works through a combination of sleep education, behaviour changes and cognitive strategies to improve sleep. It outlines the key components of CBT-I, describes typical session structure (usually 4–8 sessions) and emphasises that although improvement takes time, CBT-I provides long-lasting benefits for people with or without other health conditions.

3.4.2.3. Pharmacological strategies (medications and supplements)

Should none of the non-pharmacological strategies work, below is a list of medications and supplements about which you could ask your GP or pharmacist:

- **Melatonin supplement:** Melatonin is a hormone that signals your body that it is time to sleep. Since SCI, especially quadriplegia, can blunt your natural melatonin rhythm, taking a melatonin supplement in the evening may help induce a more normal sleep cycle. In fact, melatonin is often used in people with circadian rhythm issues, such as those who

are blind or have jet lag, to adjust the body clock. In SCI, while research is still emerging, appropriately timed melatonin, usually taken ~1-2 hours before desired bedtime, can assist with sleep-onset insomnia and re-align a disrupted sleep-wake cycle (Sankari *et al.*, 2019). Melatonin is available over-the-counter in some places. In Australia, you may need to discuss the right formulation and dose with your doctor. It has a relatively low side-effect profile. Always use melatonin under the guidance of a health professional to ensure timing and dosage are right for you, as timing is crucial for it to be effective.

- **Prescription sleep medications:** In some cases, doctors may prescribe sleeping pills or other medications to help you sleep. These can be useful in the short term. For example, a benzodiazepine or a Z-drug, such as temazepam or zolpidem, might be used for a few nights or weeks to re-establish sleep if insomnia is severe. These medications help you fall asleep or stay asleep, but they are generally not recommended long-term due to the risk of tolerance and side effects, such as daytime drowsiness, confusion and falls. It is worth noting that these medications can be taken safely long-term for pain control and depression. Sedating anti-depressants, such as low-dose amitriptyline or mirtazapine, especially if a person has concurrent depression or neuropathic pain, are sometimes used. These taken at night can both improve mood and pain, and have a drowsy effect to aid sleep. In older adults or those with high-level SCI who may have breathing issues, doctors choose these meds carefully to avoid suppressing breathing too much at night (University of Washington, 2013). Always follow the prescription and advice. Never mix sleep meds with alcohol or other sedatives. The goal with any sleep medication is to use the lowest effective dose for the shortest period necessary while you implement more lasting lifestyle changes.
- **Pain and spasticity medications at night:** Proper timing of your other medications can greatly improve sleep. For chronic pain, taking a dose of your pain medication (as prescribed) at bedtime can reduce midnight awakenings. Some people with SCI-related nerve pain take medications like gabapentin, pregabalin or duloxetine in the evening, which not only ease pain but can be a bit sedating, helping with sleep continuity. For spasticity, drugs like baclofen, tizanidine or diazepam may be taken at night to calm muscle spasms. Be aware that baclofen by mouth can worsen sleep apnoea by relaxing airway muscles (University of Washington, 2013), so if you have significant sleep apnoea, doctors might adjust your spasticity regimen, for example, using an ***intrathecal baclofen pump (ITB)***, which has less impact on breathing. Work with your rehabilitation physician to balance spasticity relief with minimal side-effects. If bladder spasms wake you, there are medications, such as oxybutynin, that can reduce bladder overactivity at night. Discuss this with your urologist.
- **Addressing restless legs syndrome (RLS):** If you have symptoms of RLS (creepy-crawly feelings in the legs at night relieved by movement) or frequent periodic limb movements on sleep studies, specific medications can help. These might include low-dose dopamine agonists, which are used in *idiopathic* RLS, or gabapentin or pregabalin, which help both nerve pain and RLS. Treating RLS can significantly improve sleep maintenance (staying asleep). A study found that RLS may affect roughly 1 in 5 to 1 in 2 people with SCI (Gillani *et al.*, 2023), so it is worth mentioning any such symptoms to your doctor. Supplementing iron can help if iron levels are low, since low iron can worsen RLS. Again, these therapies

would be guided by a GP or specialist after evaluation.

- **Therapeutic aids for circadian adjustment:** Besides melatonin, a doctor might sometimes recommend bright light therapy in the morning or a prescribed wakefulness agent during the day if you have severe circadian inversion (sleepy in the day, awake at night). Conversely, if falling asleep too early and waking too early (advanced sleep phase), small evening light exposure or timed melatonin in early morning hours might be tried. These are specialised strategies. To this end, a sleep specialist or neurologist can tailor a plan if a circadian rhythm sleep-wake disorder is diagnosed. In quadriplegia, due to melatonin rhythm disruption, working closely with such specialists can be very helpful, and
- *Continuous Positive Airway Pressure (CPAP)* **for sleep apnoea:** While not a medication, CPAP is an important medical treatment to mention for those with obstructive sleep apnoea. If your insomnia or unrefreshing sleep is due in part to sleep apnoea (snoring, gasping and daytime fatigue are clues), treating it can dramatically improve your sleep quality. CPAP is a machine that blows air through a mask to keep your airway open at night. It is highly effective for Obstructive Sleep Apnoea (OSA) in people living with SCI (Sankari *et al*., 2019), although adherence can be challenging. Only ~20-50% of individuals with chronic SCI stick with CPAP long-term. Newer mask interfaces, such as nasal pillows and humidifiers, can make CPAP more comfortable (Sankari *et al*., 2019). In some instances, if CPAP is not tolerated, other options such as a dental splint may do the trick (CPAP Victoria). Next would be *BIPAP (bi-level positive airway pressure)* – see below. Surgery should be the last option. Treating sleep apnoea often resolves the frequent awakenings and greatly improves daytime energy, which in turn can reset a healthier sleep pattern at night.

Important resource: Sydney Children's Hospital Network

Sydney Children's Hospital Network Bi-level positive airway pressure therapy factsheet: The SCHN factsheet explains that bi-level positive airway pressure (BiPAP) therapy is a form of breathing support used during sleep to help children with central sleep apnoea by delivering two levels of air pressure through a mask to keep the airways open and improve breathing.

- **Other medical treatments:** Depending on the individual, doctors might consider other sleep aids. For example, if anxiety is a major component, sometimes a short-term use of an anxiolytic (drug to reduce anxiety) at night, or better, a non-drug anxiety-relief technique, plus an as-needed anxiety medication, is used. If depression is present and contributing to early morning awakenings, an anti-depressant can improve both mood and sleep continuity over weeks. For individuals with chronic insomnia, some newer prescription medications, such as dual orexin receptor antagonists, are available in certain coun-

tries. These target the wake-sleep signals and may be used if first-line treatments fail. Discuss this with a sleep physician. Always weigh benefits and side-effects. For instance, any drug causing muscle relaxation might increase the risk of apnoea or make it harder to cough at night for a high-level SCI, so careful monitoring is required.

Table 3.4. summarises the strategies for different aspects of insomnia, including non-drug approaches and examples of medications. These approaches can be tailored to whether you have trouble falling asleep (sleep-onset insomnia), difficulty staying asleep (frequent night awakenings) or waking up too early in the morning.

Table 3.4. Non-pharmacological and pharmacological strategies to treat various aspects of insomnia.

Insomnia issue	Non-pharmacological approaches	Pharmacological approaches
Difficulty falling asleep (sleep onset insomnia)	• Keep a consistent bedtime and calming pre-sleep routine (dim lights, relaxing activity) to train your body for sleep (University of Washington, 2013). • Avoid stimulants, such as caffeine, in the evening. Limit screen time (blue light) 1-2 hours before bed. • Ensure you are comfortable and pain-free. Take care of toileting, adjust room temperature and use relaxation techniques (breathing or meditation) to unwind. • If worrying at night, try writing thoughts in a journal early evening to clear your mind; consider *CBT-I* techniques to address anxious thoughts about sleep.	• Melatonin supplement about 1-2 hours before bedtime to promote natural sleepiness, especially if you have high-level SCI or circadian disruption (Sankari *et al.*, 2019). • Short-acting sleep medications, such as zolpidem or temazepam, may be prescribed for temporary use in severe cases to help initiate sleep. Use under close medical guidance due to dependency risk. • A low-dose sedating anti-depressant, such as amitriptyline, at bedtime can help if pain or mood issues are present, providing a mild sedative effect to aid sleep onset.
Difficulty staying asleep (frequent night awakenings)	• *Optimise night-time environment and care:* Use a bedside commode or night catheter bag to avoid fully waking for bathroom trips. Ask the carer or support worker to minimise disturbances (cluster necessary care before sleep). • *Address causes of awakenings:* Ensure adequate pain relief through the night (long-acting pain meds or a dose at bedtime). Do gentle stretches to reduce spasms. Use padding to prevent pressure points that cause discomfort. • *Practice relaxation* if you wake rather than tossing and turning, use a calm strategy like slow breathing or listening to quiet music to lull back to sleep. Avoid turning on bright lights or the TV, which can fully alert you. • *Avoid heavy meals or lots of fluids before bed to reduce middle-of-night indigestion or* bathroom trips. If acid reflux wakes you, consider raising the head of your bed a bit.	• Night-time pain medication, such as an extended-release pain reliever or a neuropathic pain agent (gabapentin) at night to prevent pain-related wake-ups, but can also induce drowsiness to help sleep. • Anti-spasmodic medication at night, such as baclofen or tizanidine, to lessen muscle spasticity that interrupts sleep, but monitor for any effect on breathing. • For ***nocturia*** (night-time urination), doctors may advise a medication like desmopressin or an anticholinergic to reduce urine production at night, under careful supervision. • If periodic limb movements are confirmed and disruptive, medications, such as pramipexole or clonazepam at bedtime, might be used to reduce these movements.

Insomnia issue	Non-pharmacological approaches	Pharmacological approaches
Early morning awakening (waking too early, unable to stay asleep as long as needed)	• *Improve sleep schedule consistency:* Avoid going to bed *too early*. Aim for a reasonable bedtime that gives you the 7-9 hours you want. If you find yourself waking up very early, gradually shift your bedtime later by 15-30-minute increments. • *Get bright light exposure* in the late afternoon or early evening (if safe for your eyes) as this can push your body clock later so you wake later in the morning (University of Washington, 2013). Conversely, keep mornings dim until your target wake time. • *Ensure morning disruptions are minimised:* use blackout curtains or a sleep mask to block early dawn light from waking you. If carers arrive early, discuss whether care can be done slightly later when possible. Keeping the environment quiet until your planned wake time by using a white noise machine or earplugs can help. If mood is a factor, engaging in morning exercise or sunlight as therapy can improve both mood and sleep timing. Early awakening is a classic sign of depression.	• Adjust the timing of medications: If a medication's effect wears off too early (e.g., pain returns at 4 am), a doctor might switch to a longer-acting formulation at night. • Low-dose doxepin or other prescription medications are considered for early awakenings: Doxepin at a very low dose can specifically help maintain sleep into the early morning hours. • In cases of suspected circadian advance (body clock set too early), a doctor might suggest a carefully timed dose of melatonin in the very early morning hours (or late at night) to readjust the clock. This is complex and done with specialist guidance (Sankari *et al.*, 2019). • If depression is contributing to early waking, treating the depression with therapy or antidepressants often resolves this. An antidepressant taken in the evening that has some sedative effects (like mirtazapine) could both improve mood and help extend sleep.

3.4.2.4. Follow-up and underlying conditions

It is important to recognise that insomnia is sometimes a symptom of other underlying sleep disorders that are common after SCI. OSA, for instance, is a leading medical cause of poor sleep quality with SCI. If you have loud snoring, gasping, or excessive daytime sleepiness, talk to your doctor about a sleep study. Treating sleep apnoea with CPAP or other methods can dramatically improve your sleep and health. Similarly, RLS or periodic limb movement disorder can cause insomnia. If you feel unusual leg sensations at night or your bed partner notices you kicking in your sleep, this could be RLS. Studies suggest that RLS may affect a notable subset of people with SCI, warranting further investigation (Gillani *et al.*, 2023; Sankari *et al.*, 2019).

Because sleep issues in SCI are often under-recognised (Sankari *et al.*, 2019), do not hesitate to raise your sleep problems with your GP or rehabilitation physician. They may refer you to a sleep specialist for further evaluation. This could involve an overnight sleep study (polysomnography). Sleep laboratories can accommodate wheelchair users and provide accessible set-ups. Home sleep-apnoea tests are another option in some cases (Sankari *et al.*, 2019). Identifying conditions such as sleep apnoea, RLS or circadian rhythm disorders is key to selecting the right treatment.

After SCI, achieving good sleep may require some effort and collaboration with your healthcare team, but many strategies and treatments are available to help. By improving sleep habits, addressing specific medical issues and using medications or devices when appropriate, individuals with SCI can often significantly improve their insomnia and overall quality of life. Always tailor the approach to *your* situation. What works for one person may be different for another. Seek guidance from professionals familiar with SCI. Improving your sleep is not just about feeling rested. It can also reduce pain, improve mood, sharpen thinking and provide you with more energy for rehabilitation and daily activities (Graco *et al.*, 2023). If poor sleep persists despite these strategies, follow up with your GP for further investigation and support, since better sleep is possible with the right interventions.

Clinical resource: CPD Obstructive Sleep Apnoea (OSA)

Slowik J. M., Sankari A., & Collen J. F. (2025). Obstructive Sleep Apnea.*In:* StatPearls. (2025). Treasure Island (FL): StatPearls Publishing: Explains obstructive sleep apnoea as a common disorder caused by repeated upper-airway collapse during sleep, outlining its symptoms, risks, diagnostic methods and a wide range of evidence-based treatments, including lifestyle changes, CPAP, oral appliances and surgery, while emphasising the need for interprofessional management to improve patient outcomes.

3.4.3. Pillar 3: Exercise and physical activity

Regular exercise is crucial, irrespective of your level of SCI, as the video below indicates.

Video: Exercising after SCI

Having SCI does not mean you have to stop exercising! (SCIRE) (9 October 2025): Staying active after SCI is important for maintaining overall health and reducing secondary complications. Many people continue to exercise and remain independent with the right supports and strategies.

Exercise helps maintain and improve physical function and mental health, and reduces the risk of preventable diseases that often accompany SCI. Exercise gets you moving, which helps increase circulation, strengthen muscles and bones and improve the function of organs like the heart and lungs, boosting independence and confidence to get out and do more. Weight-bearing exercise helps prevent osteoporosis, but understanding the restrictions of quadriplegia is important.

3.4.3.1. How much exercise do Australians living with SCI do and what motivates them?

Watson and colleagues (2024) explored two questions about exercise among Australians living with SCI, as part of the InSCI Survey.

Research: Motivations and participation in physical activity among Australians living with SCI

Research Question 1: What motivates Australians living with SCI to engage in exercise?

In a longitudinal cross-sectional study, Watson and colleagues (2024) surveyed (Exercise Motives and Gains Inventory) and interviewed 105 physically active individuals to see what motivated them to engage in

leisure-time physical activity (LTPA) and what the perceived gains were. The most common motives were improvements in health and fitness, management of appearance and weight, and avoidance of illness. The most common gains included improved health, fitness, strength and endurance, increased nimbleness, and enjoyment and revitalisation. The researchers concluded that whilst health enhancement appears to be a significant motivator for LTPA, other psychosocial aspects, such as affiliation and revitalisation, also influence engagement and amount of LTPA. In their opinion, health professionals should promote regular LTPA for its health benefits and well-being, emphasising its ability to reduce illness, facilitate affiliation and manage stress.

Research Question 2: To what extent do Australians living with SCI engage in physical activity?

In this aspect of the research, Watson and colleagues (2025) examined the amount of LTPA Australians living with SCI over 18 (1579 people surveyed) do, while exploring its associations with socio-demographic and injury-related characteristics. About 58% reported some participation in LTPA, with an average weekly LTPA of about 333 minutes. Males, younger people, traumatically injured individuals, participants with less time since their injury and those who required less assistance to ambulate reported between 50% and 200% more engagement in LTPA than their counterparts. Despite this, only 13% of participants met the SCI-specific physical activity guidelines for fitness improvement.

So, how much exercise do Australians with SCI do?

Not enough, apparently. The researchers concluded that participation in LTPA among the Australian SCI population was low and that insufficient activity was performed at intensities associated with beneficial changes. Trends of physical inactivity are globally consistent. Some sociodemographic variables and injury-related characteristics influence the amount and type of LTPA.

Important information: Are there exercise guidelines for SCI?

Australia does not appear to have a single source for SCI-specific guidelines, so presumably health professionals are guided by, for example, a 2017 position statement from the Exercise and Sport Science Australia (ESSA). More recently, Pelletier (2023) reviewed the physiological considerations and evidence-based guidelines for exercise prescription for individuals living with SCI. Canada uses these Physical Activity Guidelines for Adults with SCI, developed by an international group of SCI scientists, people living with SCI, clinicians and representatives from SCI organisations.

Available under a CC BY-NC 4.0 licence from https://sciguidelines.ubc.ca/

To summarise, individuals living with SCI experience gains in fitness, physical and mental health from regular participation in exercise and physical activity. Due to changes in the physiological function of the cardiovascular, nervous and muscular systems, general population physical activity guidelines and traditional exercise prescription methods are not appropriate for the SCI population.

SCI-specific exercise guidelines were developed by an international group of SCI scientists, people living with SCI, clinicians, and representatives from SCI organisations. These physical activity guidelines are based on the best scientific evidence available and recommend progressive training beginning (starting level) with 20 minutes of moderate to vigorous intensity aerobic exercise twice per week, transitioning to 30 minutes (advanced level) three times per week, with strength training of the major muscle groups twice a week.

These population-specific guidelines address the substantial barriers to physical activity faced by people living with SCI and can be used to frame an individual exercise prescription. Rating of perceived exertion, that is, perceptually regulated exercise, is a practical way to indicate moderate to vigorous intensity exercise in community settings. Adapted exercise modes include arm cycle ergometry, hybrid arm-leg cycling and recumbent elliptical equipment. Body-weight-supported treadmill training and other rehabilitation modalities may improve aspects of health and fitness for people with SCI when performed at sufficient intensity. Disability-specific community programs offer valuable opportunities for people living with SCI to engage in high-quality exercise, but are not universally available.

As always, it is best to let the experts plan a routine tailored to your specific needs.

3.4.3.2. What sort of exercise should you be doing?

Many people living with SCI are unable to engage in lower limb (leg) exercise and must use upper limb (arm) modes, such as wheelchair pushing or upper limb ergometers (an arm-crank or a wheelchair). This constraint is important because, compared with lower-limb exercise, upper-limb exercise elicits a considerably reduced cardiovascular response. Different modalities of exercise promote different areas of health:

- **Resistance training:** Involves contracting muscles against a load or resistance. Resistance training can elicit changes in the structure and function of the cerebral cortex, spinal cord and skeletal muscles. This can result in improvements in muscle strength, muscular endurance, motor performance and recruitment, nerve regeneration, body composition, upper and lower limb functionality and quality of life (Santos *et al.*, 2022).

Podcast: Strength training with SCI explained

SCIA's Have the Nerve podcast, Getting to Know your Body: Strength Training (Episode 38, 16 April 2024): In this episode, Exercise Physiologist, **Alicia Payne**, explains that strength training is beneficial and achievable for people of all abilities, including those with SCI. It also highlights NeuroMoves' SCIA's specialised exercise service designed to support people with neurological conditions to improve their independence, health and well-being.

- **Aerobic training:** Can improve cardiorespiratory fitness regardless of the neurological

level of injury. Aerobic training involves rhythmic activities that strengthen the heart and lungs, improving their ability to deliver oxygen to the muscles, such as cycling and swimming. Improvements in cardiorespiratory function can lead to reduced risk of pulmonary infections, improved body composition, reduced metabolic disorders, increased energy expenditure and improved quality of life (Hodgkiss *et al.*, 2023).

- **Activity-based therapy (ABT):** Utilises the principle of neuroplasticity, which means that the brain can change and reorganise itself to form new pathways. ABT involves repetitive, task-specific exercises performed out of the chair, with a strong focus on reloading the affected limbs. Examples include locomotor training and/or body-weight-supported treadmill training and *functional electrical stimulation (FES)* coupled with other exercises, such as resistance training or cycling. ABT can reduce spasticity and the occurrence of pressure injuries and urinary tract infections, improve bone mineral density and bowel motility and strengthen nerve pathways (Kaiser *et al.*, 2020).
- **Hydrotherapy:** Involves exercising in water, typically in a pool at 30-35 ◦C. Exercising in warm water helps increase vasodilation and blood circulation, decrease muscle pain and enhance thermoregulatory responses. Furthermore, hydrotherapy can improve aerobic capacity, increase muscle strength and endurance, increase joint range of motion, reduce spasticity and decrease muscle fatigue (Ellapen *et al.*, 2018).

Podcast: Benefits of hydrotherapy

SCIA's Have the Nerve podcast, Hydrotherapy (Episode 46, 28 August 2024): In this episode, Exercise Physiologist, **Alicia Payne**, offers simple guidance for anyone interested in starting hydrotherapy. *"Why should I exercise in the water?"* If you have ever considered getting into a swimming pool but don't know where to start, Alicia will talk you through it!

The above physical benefits help individuals living with SCI improve independence in daily routines such as self-care, transfers, and pressure relief, as well as self-efficacy and health-related quality of life. Exercise can create opportunities for socialisation, where individuals can make important connections and feel part of their community. It can provide a purpose and be an outlet to help individuals cope with stress, depression and anxiety.

Video: Appropriate exercising after SCI

How do you know if you are exercising properly? (9 October 2025): This video explains that after SCI, it can be hard to judge how hard you're working because blood pressure and heart rate are often lower than average, making them unreliable indicators of effort. Instead, it recommends using the Rate of Perceived Exertion (RPE) scale to help guide how hard you should exercise and safely build an activity program.

3.4.3.3. Assistive technologies to support muscle activation

Many devices and technologies can be utilised to help work the muscles after SCI. *Functional Electrical Stimulation (FES)* has been shown to have beneficial effects for both incomplete and complete SCI, especially when done in conjunction with other rehabilitation and exercise modalities (All *et al.*, 2020). During FES, pads are placed on the skin and electrical impulses are delivered through the pads to stimulate muscles and elicit contractions (movements).

Video: Functional Electrical Stimulation (FES)

SCIA's Functional Electrical Stimulation (NeuroMove, 28 Mar 2019): This SCIA NeuroMoves video explains how FES uses surface electrodes to activate weak or paralysed muscles during activities like arm and leg cycling, helping improve circulation and potentially reducing muscle wastage, pressure injuries, spasms, pain and bone loss.

Podcast: Different types of nerve stimulation

SCIA's Have the Nerve podcast: Episode 49: Get to know your Body: Rehabilitation and electrical stimulation. Listen to a physiotherapist talk about different types of stimulation, including FES and *TENS (Transcutaneous Electrical Stimulation)* to manage pain.

FES can be used in a variety of ways in rehabilitation sessions, including isolated movements, such as bicep curls and bending the elbow and functional movements (e.g. lower limb cycling on a specialised bike). Depending on your needs, your therapist will decide how much stimulation is required to achieve the desired movement (Marquez-Chin & Popovic, 2020):

- **Sensory threshold:** Lowest intensity applied at which stimulation can be felt, but no contraction (movement) is produced. This can help someone understand which muscle they need to activate, as the sensory buzz cues where they need to engage, but the stimulation won't do the work for them.
- **Motor threshold:** Minimum intensity required for a visible contraction that may or may not result in movement. Here, stimulation may help initiate a movement, but the individual must then do the rest of the work to complete it (*incomplete SCI*), and
- **Maximum tolerable threshold:** The maximum intensity an individual can tolerate. It may be used so that the stimulation does all the work and completes the movement for someone who is not able to do so themselves (*complete SCI*). For some, the maximum tolerable threshold may not be needed to produce the full movement.

For both an incomplete and a complete SCI, FES can have many benefits (All *et al*., 2020):

- Pain reduction
- Circulation and blood flow enhancement
- Urinary tract infection reduction, specifically lower limb FES and cycling in particular
- Tissue healing and skin integrity promotion
- Spasticity reduction
- Reducing further atrophy of muscle mass, and
- Reducing further loss in bone mineral density.

For an incomplete SCI, FES has additional benefits (All *et al*., 2020):

- Rewiring and regenerating damaged nerve pathways
- Improving sensation
- Restoring function

- Improving muscle strength, and
- Improving motor control (co-ordination).

FES is thus an important tool in neurorehabilitation and should be administered under the guidance of a trained professional.

3.4.3.4. Exercise for pain relief

Upper body pain, particularly in the limbs and shoulders, is a common symptom among individuals living with SCI who are wheelchair users. Despite the focus on resistance muscle training as a suitable intervention for individuals living with SCI, findings across different populations and conditions have been inconsistent. To address this, Park *et al.* (2024) conducted a systematic review to elucidate the relationships among exercise interventions, muscle strength enhancement, and pain reduction. The results indicate that exercise interventions are effective in reducing pain in individuals living with SCI, with a particular emphasis on alleviating shoulder pain. The researchers concluded that there is a notable lack of experimental research focusing primarily on pain. The development of appropriate measurement instruments is crucial for the prevention and relief of pain in this patient population (Park *et al.*, 2024).

Important information: Exercising outdoors

SCIA's How to make the most of exercising outside this summer explores the benefits of hydrotherapy and of getting out and about in nature with friends or family.

3.4.4. Pillar 4: Benefits of morning and afternoon sun exposure

Another morning routine, which is important from a positive psychology perspective, is getting unfiltered morning sunlight on your skin and in your eyes, which sets the circadian rhythms for the day. People living with SCI have been found to have disrupted circadian rhythms, so light and/or melatonin therapy can be helpful.

Sunlight plays a crucial role beyond regulating melatonin. As discussed in **Chapter 2**, sunlight is essential for vitamin D synthesis, which supports bone health. This is particularly relevant for individuals living with SCI as they are at increased risk of osteoporosis due to reduced mobility and weight-bearing activity. Individuals with SCI are particularly vulnerable to vitamin D deficiency for various reasons, including insufficient dietary intake, the use of anti-convulsant medications and limited sunlight exposure. Adequate vitamin D levels help maintain calcium balance and bone density, making safe sun exposure an important consideration in their overall health management (Wang *et al*., 2023).

It is, however, important to balance the benefits of sun exposure with skin cancer prevention, and excessive ultraviolet (UV) radiation exposure significantly increases the risk of melanoma and other skin cancers. UV damage can occur even on cooler or cloudy days, and cumulative exposure over time contributes to long-term risk. A practical tool for managing safe sun exposure is the free SunSmart Global UV app, developed by Cancer Council Australia in partnership with national and international organisations. The app provides real-time UV levels, forecasts, and daily sun protection alerts tailored to your location, so you can easily check when UV levels are high enough to require sun protection, such as clothing, sunscreen and shade. It also allows you to set custom reminders and view seven-day sun protection times, helping you plan outdoor activities that better balance vitamin D needs and skin cancer prevention.

Clinical resources: Osteoporosis

- StatPearls (CPD), Osteoporosis in SCI (2025)
- Impact of vitamin D on the prognosis after spinal cord injury: A systematic review (2023)
- Revised position statement for Australian adults: Balancing the risks and benefits of sun exposure (2024)

3.4.5. Pillar 5: Social connections and engaging with family and friends

Social connection is important for overall well-being. Strong social support can reduce depression, anxiety and feelings of helplessness, as well as improve physical health, community participation and life satisfaction. After SCI, people may experience changes in their relationships and social roles, which can lead to isolation, so rebuilding and maintaining social connections should be encouraged. Become more social by joining peer support groups, participating in adaptive sports (**Chapter 15**), engaging in community or hobby-based activities and using technology to stay in touch with friends and family. Rehabilitation programs are increasingly recognising the importance of friendships and are developing person-centred approaches to support social participation across inpatient and community settings. Encouraging open communication, creating inclusive environments and providing access to social resources can help individuals living with SCI foster meaningful relationships and improve their quality of life. We discuss the importance of social connection in **Chapter 5.**

Video: Exercising with others

Sometimes your ongoing rehabilitation and strength training is a social outlet. Many of the gyms you visit are community-oriented and organise social events. An example can be found in the short video on this Making Strides website. In **Chapter 1**, we provided information about the Making Strides on the Gold Coast and Neuromoves nationally.

Dinesh Palipana and Perry Cross: On friends

Dinesh Palipana:

"Some of your friends will stick by you, while others will disappear, so it is easy to become socially isolated"

Perry Cross provided this insightful input in terms of those who may not have family:

"Not everyone has family or friends who can provide support for the patient. In some cases, the clinicians and paid support team may be the closest individuals the person has to a family. Understand this, and be as supportive as possible. Some genuine care and attention can go a long way. Emotionally support the patient, have a laugh with them, and smile."

3.4.5.1. What does the evidence say about the importance of social connection?

Humans are social beings and need connection with other humans. Persons living with SCI are particularly at risk for social disconnectedness and/or perceived social isolation, which are key components to overall well-being (Cimino *et al.*, 2022).

Below is research on social disconnectedness and isolation among people with SCI, followed by research findings on addressing social isolation.

Research: Loneliness: *Who is at risk of loneliness amongst people living with SCI?*

- Tough and colleagues' (2022) study of 1283 Swiss individuals with SCI aged 16 or older found that those with the greatest socio-economic disadvantage, as measured by education, income, subjective social position, employment status and financial hardship, had the highest risk of loneliness. Among the socio-demographic characteristics, only age was associated with loneliness, with persons aged 31-45 more likely to experience it. Having a high-level lesion and less functional independence were also associated with loneliness. The researchers concluded that support services should aim to alleviate loneliness among persons from lower socio-economic backgrounds and individuals with greater functional limitations in everyday life.
- Robinson-Whelen *et al.* (2025) conducted the first known comprehensive examination of loneliness and its correlates in a diverse sample of people living with SCI using the UCLA (University of California, Los Angeles) Loneliness Scale-Version 3. In

evaluating loneliness in relation to demographics, disability, physical health and social characteristics, the majority (56%) of respondents had scores indicating high levels of loneliness. At least a quarter reported often feeling alone, left out, isolated and lacking companionship. At least a quarter rarely or never felt that some people really understood them, with whom they could talk and with whom they had a lot in common. Analysis found that social characteristics (social integration, social support, satisfaction with social roles) were the factors most positively associated with alleviating loneliness.

3.4.5.2. Alleviating social isolation and loneliness

LaVela *et al.* (2024) interviewed veterans living with SCI/D (spinal cord injury/disorder) about how to alleviate loneliness and perceived social isolation. They were male (70%), white (78%), and not currently married (35%), with an average age of 66 years (42-88). Participants had paraplegia (61%), with a traumatic aetiology (65%) and had been injured 14 years (1-45) on average. The veterans identified these eight ways of alleviating loneliness and perceived social isolation, which translate into changing one's way of thinking, expanding participation in life and getting involved with others:

1. Engage in and pursue interests
2. Interact with and spend time with others
3. Embrace acceptance
4. Take part in reciprocity
5. Find a purpose and accomplish goals
6. Get out of residence, get outside (see **Section 3.8** below, connecting with Nature and earlier about social)
7. Connect with the SCI community and SCI peers, and
8. Seek help from (mental) healthcare professionals.

Thus, veterans identified ways to alleviate loneliness. The findings can be used to guide health-care delivery and develop interventions to target feelings of loneliness and social isolation in persons with SCI/D, which may be particularly impactful if they involve reciprocal interactions with peers with SCI/D. While the five pillars of health and well-being guide some of the well-documented aspects of daily living, it was not until much later in our research for this resource that we found two neglected areas of health that should be added as additional pillars: Good oral hygiene means visiting the dentist regularly and taking care of one's feet, so adding a podiatrist to your list of health professionals.

3.5. Oral hygiene

Oral hygiene is often neglected, even among the general Australian population, mainly because Medicare does not cover, or provides limited coverage for, dental care for adults. Oral health studies of individuals living with SCI indicate a higher prevalence of irregular oral hygiene practices, plaque index scores,***carious teeth*** and ***gingival bleeding,*** compared with those without SCI. Since everything we eat starts with our mouths, we all need strong teeth and healthy gums. Individuals with disabilities generally report poorer access to dental care and poorer oral health. There are several reasons for poorer oral health amongst those living with SCI:

- *Medications* to treat common conditions and complications after SCI, including spasticity and a neurogenic bladder, can lead to dry mouth that increases the risk of dental cavities. The clinical term for dry mouth is ***xerostomia***. A reduction in saliva production can affect speech, interfere with digestion, and make mastication and swallowing uncomfortable and challenging. Complications with mastication and swallowing can result in the individual's diet consisting only of soft foods. A reduction in saliva may also result in food debris remaining on the teeth longer, as well as the individual not receiving the antibacterial and antifungal effects of saliva. This type of oral environment can place people living with SCI at great risk for developing ***dental caries***. Saliva substitutes include fluoride, xylitol-containing products, gum, mints or lozenges, as well as remineralisation therapies to ensure calcium and fluoride are available to strengthen enamel damaged by acid (Rogers, 2014).
- *Injury-related functional limitations*, such as impaired finger movement and decreased strength, can impair one's ability to brush and floss or necessitate the use of assistive mobility aids and devices.
- Devices such as *mouthsticks can damage teeth and cause oral injuries, which in turn can impede their use*.
- Depending on the nature of the event that resulted in the SCI, people may also have *significant mouth trauma,* which medical insurance may not cover, and
- Depending on the 'plegia', individuals living with SCI may find *oral self-care difficult* and so have to rely on their carers or support workers to perform this daily task.

3.5.1. Oral health care should start while in the hospital. Does this education happen in Australia?

In addition to caries and gingivitis described above, individuals living with SCI are more susceptible to secondary medical conditions and poor oral hygiene can lead to chronic inflammation, putting pressure on an already compromised immune system. Good dental care for those living with SCI should thus begin while still in rehabilitation.

Research: Two Australian studies on dental health and SCI

- A study in a major metropolitan Sydney hospital, Samuel *et al.*(2024) interviewed 11 individuals with SCI to gain an understanding of their oral health knowledge, attitudes and practices as well as the barriers and facilitators in terms of managing their oral health and their recommendations to improve oral care at acute or rehabilitation hospital settings. Generally, participants believed the onus was on them to manage their oral health. Their understanding of the importance of oral health to overall health was limited, and they placed less priority on oral health than on other aspects of health. Factors such as cost, time, resources and prior negative experiences contributed to their neglect of oral care. To improve their oral health while in hospital and during rehabilitation, participants identified the need for support from the multidisciplinary team and family and carers to facilitate oral care and identified various appropriate oral health education formats. Also identified was the need for oral health training for the multidisciplinary team and carers to better integrate oral care into rehabilitation. Oral health interventions would need to utilise a co-design approach to best support clients and their carers to facilitate oral care self-management.
- In another Australian study, Bagdesar and colleagues (2024) investigated the attitude and practices of non-dental professionals in SCI units across New South Wales (NSW), Australia. Registered nurses, assistants in nursing, enrolled nurses, occupational therapists, physiotherapists, dietitians and speech pathologists were recruited from two metropolitan public hospitals, Prince of Wales Hospital and Royal North Shore Hospital, both large tertiary hospitals that provide acute and rehabilitation care to patients with SCI. Nine focus groups (23 participants) were conducted. Based on the discussion, four themes were constructed:

    1. Understanding the impact of SCI on oral health and well-being
    2. Limited support in the SCI unit to promote oral care
    3. Strategies that would enable oral care promotion, and
    4. Recommendations to expand HPs' scope in oral care and education.

Conclusions from these studies: Although most health professionals considered oral health important, there were no guidelines to support standardised oral care practices. Barriers to providing oral health care for patients with SCI included a lack of time, limited oral care resources, low priority and difficulty in accessing treatment. Staff were receptive to an integrated, multidisciplinary approach to oral care. The authors recommended additional research to develop models of care that would promote oral health amongst patients with SCI.

3.5.2. Barriers to oral care in the community

There are several barriers [*with Solutions]* to good oral health care once in the community:

- A low number of dental professionals with the experience and confidence to care for people living with SCI are limited [*Ensure disability is included in HPE, including multidisciplinary integrated care*]
- Affordability of dental service [*Should be in the disability healthcare budget*], and
- Wheelchair accessibility to the dental office, examination room or dental chair. People who identify wheelchair accessibility as a barrier are more than four times as likely to avoid a visit to the dentist [*Ensure dentistry practices are suitably accessible and equipped*].

3.5.3. Strategies to promote good oral health for those living with SCI

Some individuals living with SCI may be able to perform oral self-care with the help of adaptive devices. Other patients may require assistance with oral self-care. If the patient requires assistance, oral care interventions should involve the carer as part of the process.

According to Rogers (2014), dental hygiene interventions should address:

- Education about the disease process, such as caries and ***periodontitis***)
- Oral self-care recommendations (adaptive devices based on the individual's dexterity)
- Nutritional counselling to address oral health issues
- Collaboration with other healthcare specialists (such as OT, dietitian for nutritional counselling and/or psychologist for anxiety)
- Management of ***xerostomia*** (dry mouth).
- The type of therapy recommended, such as prophylaxis *vs.* non-surgical periodontal therapy and the water setting on ultrasonic units should be kept low for individuals who have dysphasia and/or upper respiratory issues.
- Appropriate pain control measures during procedures. Hypertension must be avoided, as it can result in life-threatening conditions. Therefore, a minimum amount of adrenaline should be used in local anaesthesia. Opiates are contraindicated because they can cause depression of the CNS. Barbiturates are not recommended as they can cause severe hypotension; nitrous oxide may be safely administered.
- Adjunctive therapies, such as fluoride, therapeutic mouth rinses and sealants, should be implemented.
- Smoking cessation, if applicable.
- Referral to appropriate specialist, if applicable, and
- Depending on the individual's oral health status, more frequent continuing care visits may be recommended.

3.5.4. Need for accessible and inclusive dental services in Australia

In 2023, Inclusion Australia made a joint submission (with Australian Federation of Disability Organisations (AFDO), Children and Young People with Disability Australia (CYDA) and Down Syndrome Australia) to the Australian Senate's Select Committee on the Provision of and Access to Dental Services in Australia. The website provides the following feedback from people living with a disability:

Individuals with disability: Submission to the Senate's Select Committee on accessible dental services

Below are some of the statements from submissions to specific questions on accessible dental services:

Why do people with disability find going to the dentist frustrating? Here is what they said in the submission.

- *"It costs too much."*
- *"There can be long waits, and they don't tell you how long your appointment will last."*
- *"You spend too much time in the dental chair, which can be frustrating for some people who may have other health issues."*
- *"The information is not provided in a way that makes it easy for people to understand. One often has to rely on a support person for help, which can be frustrating, whereas some people go to the dentist independently."*

What do we want the government to do?

- *"Make it easier for people with disability to afford dental services."*
- *"Spend more money training dentists to work with patients with disabilities."*
- *"Start collecting information on people with disabilities who receive dental care."*

What are some of your own experiences at the dentist?

- *"I feel like you need to have a connection with your dentist so you can talk about what they are going to be doing. I need to be comfortable with the way they communicate with me and how they ask me questions throughout my dental procedure."*
- *"I go to a dentist in Perth, which is government-owned, and I get free dental checkups, but there is always a waitlist. This dentist specialises in people with disability."*
- *"It is easier for me to look at things like flyers and fact sheets when I go to the dentist, especially if they include diagrams on what they are going to do. On paper is easier than showing me on a phone or laptop."*

Important information: Special needs dentists

Below are some of the special needs dentists we found in our search:

- Special Needs Dentist, Dental Clinic & Wheelchair Dentistry (Northside Dental): This clinic provides compassionate, wheelchair-accessible dental care for patients with complex physical, intellectual, or behavioural disabilities, offering sedation options and treatment tailored to special needs.
- Special Needs Dentist – Mind Body Teeth (Sydney): Mind Body Teeth delivers specialist dental care for people with physical disabilities, anxiety, intellectual disability and complex medical needs, using a mobility-friendly clinic and trauma-informed, personalised approaches.
- All Ability Dental – Special Needs Dentistry: All Ability Dental offers specialised oral healthcare for people with disabilities, using modified techniques, sensory-friendly environments and tailored treatment plans to address a wide range of special needs.
- Special Needs Dentistry Australia (SNDA): SNDA is led by specialists, such as Dr Lydia See and provides personalised dental care for medically complex patients, people with intellectual disabilities, dental anxiety and geriatric populations through a collaborative, patient-centred approach, and
- MYTOOTHDOCTOR (Townsville & North-West Queensland): MYTOOTHDOCTOR offers paediatric and special needs dentistry, including wheelchair-accessible care, sedation options and mobile dental services for rural communities, led by Dr Garret Robles, who specialises in treating children and adults with complex needs.

3.6. Podiatry care

When you think about how often you care for your feet, the answer is probably 'not as often as you should.' One important health professional to include in your multidisciplinary team is a podiatrist.

Podiatrists are specialists in the assessment and management of conditions affecting the feet and lower limbs. They can play a vital role in your care following SCI. A primary aim of podiatry is to support your independence and quality of life by maintaining foot and lower limb health, which can help optimise safe function, mobility and participation in daily activities. Even if you are not currently experiencing foot or lower leg problems, it is still beneficial to see a podiatrist for routine assessments and preventative care. This is particularly important if you have incurvated or misshapen nails, hard callus formations and foot deformities, such as contracted digits, which include hammer toes and other bony anomalies. These could have been present before your SCI or may have developed subsequently.

During your initial visit, the podiatrist will take a detailed medical history and conduct a comprehensive, holistic assessment, with a specific focus on your feet and lower limbs. This typically includes assessment of the skin and nails (dermatological), circulation (vascular), sen-

sation (neurological), joints, ligaments, tendons, muscles and overall foot structure and function (biomechanical). If needed, the podiatrist may arrange additional tests, such as diagnostic imaging, or refer to other health professionals. The aim is to establish a baseline, identify any potential risks early and address issues before complications arise.

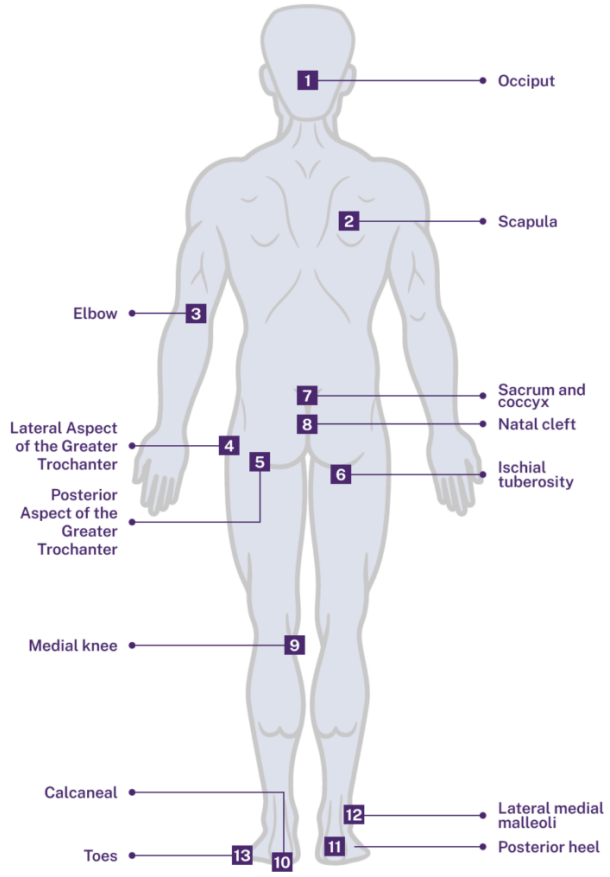
A podiatrist will support you in developing a personalised plan of care, which may include general foot care, nail and skin care, infection management, pressure off-loading strategies such as custom insoles or orthotic supports, and footwear advice. You will also receive education and guidance on daily foot care and hygiene, monitoring for changes, such as altered skin temperature or excess moisture, pressure-relief techniques where appropriate, and strategies to prevent complications, such as skin breakdown, infection, progressive deformity or falls. You will be supported in learning to regularly check your feet using a mirror or with assistance if needed, to help detect early changes. Regular monitoring is essential as early identification and timely intervention can prevent the progression of skin breakdown.

As mentioned earlier, joint contractures and stiffness are common complications during the acute and subacute phases of rehabilitation following SCI. Nas *et al.* (2015) reported that approximately 66% of patients developed at least one joint contracture within the first year, most commonly affecting the foot and ankle (40%), followed by the hip (32%) and knee (11%). Podiatrists can assess your ankle joint range of motion and provide exercises or advice to maintain flexibility and prevent foot contractures. They can also guide proper foot positioning while you are seated in your wheelchair.

Additionally, in terms of **Figure 3.8** below, it is important to be aware that the calcaneus (heel bone, #10), posterior heel (#11), lateral and medial malleoli (#12) and toes (#13) are at particular risk from direct pressure, shear, friction or heat. Your toes are especially at risk from direct trauma and may be injured by items being dropped on them, getting caught between the wheelchair footplate and a firm surface, from ill-fitting footwear, tight or poorly fitted compression stockings and from contact with objects during transfers that you may not notice due to reduced sensation. Wounds may heal slowly due to impaired circulation and/or oedema (swelling), making regular monitoring essential.

Figure 3.8. Points on the body where pressure injuries are common, particularly the feet. Access the interactive site: Pressure injury management by location | QSCIS. *Source:* Queensland Spinal Cord Injuries Service, Pressure Injury Management by Location, CC BY-ND 3.0.

Podiatrists work closely with other members of your healthcare team, including doctors, physiotherapists, occupational therapists and wound care nurses to provide coordinated, integrated care. Regular follow-up is recommended, with frequency determined by your individual risk factors, to support ongoing prevention, early intervention and continued support for safe mobility and long-term foot health.



3.7. Look after your psychological well-being

It is also important to look after your well-being. SCI is a life-altering event that can profoundly affect both physical and mental well-being, imposing immense changes to daily living (Lomas & Williams, 2009). People living with SCI often lose mobility, independence and sometimes their livelihoods, turning simple activities, such as going to work, meeting friends and visiting family, into challenges requiring careful planning. These drastic lifestyle changes can lead to social isolation and put individuals at high risk of reduced *quality of life (QoL)* (Lomas & Williams, 2009). It is therefore not surprising that mental health becomes a critical concern after SCI.

3.7.1. Psychological impact of SCI

The early years will be challenging as you learn to adapt to life with SCI. No one said it would be easy. There will be physical and psychological adjustments you, your family, and your friends will need to make. Taking an active role in your situation will involve making important choices. We hope this e-resource supports you to make informed decisions and access the right services, both of which are key to living a fulfilling and meaningful life.

Adjusting to SCI involves significant emotional upheaval. Immediately after injury, individuals often experience shock, grief, sadness, fear or anger, which are all normal adaptive reactions to sudden disability (Craig, 2025). We can expect that almost everyone with a new SCI will go through a period of mourning their losses. Over time, many people demonstrate remarkable resilience. Studies suggest that a majority (perhaps up to 60%) cope and adjust well in the long run despite ongoing challenges. A substantial minority, however, experience enduring psychological distress or mental health disorders that require attention (Craig, 2025). Below, **Dean Durman** shares his story following SCI.

Dean's story: From emotional collapse to rebuilding identity and purpose

"Acclimating to the home environment after three months in a medical rehabilitation centre is an arduous and challenging journey, one that should never be underestimated. Even with strong support systems, the mental and emotional battles are relentless. The reality of 'what once was and now is not' hits hard. The grief of losing the life once known, while confronting the life now lived, can pull an individual into a vortex of despair and discouragement that easily spirals into depression.

This colossal void was evident in my daily behaviour. I lacked the drive to get out of bed, let alone do anything else. The anger and frustration compounded until they erupted in a massive implosion during hydrotherapy. There were waterworks — both literal and emotional. That collapse became a turning point, forcing me to confront the truth that physical recovery alone was not enough. Healing required something deeper.

Recovery is rarely linear. For me, there came a moment when the weight of grief, frustration and loss reached a breaking point. It was not in a dramatic public setting, but in the quiet routine of rehabilitation, a place where progress was expected, yet despair often lingered beneath the surface.

That moment became an implosion, a collapse of the emotional scaffolding I had built to survive. Yet paradoxically, it was also the beginning of something new. Out of that breakdown emerged the recognition that healing required more than physical therapy. It demanded a deeper shift.

I discovered that these elements – identity, acceptance, accountability, forgiveness, and thereafter living rather than doing – were not optional, but essential. They became the bridge between despair and hope. I will not spell out every detail here, because each person's journey is unique. What I can say is that embracing these principles transformed my trajectory. They opened the door to spiritual healing, which in turn unlocked mental, emotional and physical restoration.

This was not a simple process, nor one that can be reduced to a checklist. It was a paradigm shift of epic proportions, one that propelled me onto a stronger foundation for rebuilding my life and re-entering the community. For those navigating their own turning points, I encourage you to explore these pillars with guidance and support, because the path forward is not walked alone.

Employment became a critical anchor in my reintegration. I was fortunate to maintain my role at Dell Technologies as a Solutions Consultant, something for which I remain deeply grateful. With this metanoia, I was able to shift gears, and it reflected in my work ethic, professionalism and pursuit of excellence.

The company stood by me with unwavering support, assisting in the setup of a home office. This arrangement allowed me to continue working while attending rehabilitation, lifting a heavy burden from both my family and me. Most importantly, I was able to continue providing for my family. This gave me a renewed sense of value and worth, reminding me that despite my physical limitations, I could still contribute meaningfully. Work was not just about financial stability. It restored dignity and reinforced my identity as a husband, father and a professional with purpose."

Reminder: Chapter 14 and spirituality and spiritual health

Since **Dean** mentioned spirituality, **Chapter 14** is devoted to a discussion on having 'spirit' and exploring spirituality and spiritual health.

Dinesh's story: Talking about his poor well-being

In this 43-min video, **Dinesh** talks about his poor mental health before his SCI and then how he has come to live a well-lived life, in which he gives back to society on many levels: **Breaking barriers in Medicine: It takes heart with Dr Dinesh Palipana**. It is well worth watching or even just listening, as it is motivating in terms of being grateful for what we have, despite our various 'issues'.

> *"I didn't do that [grooming or dressing well] for a long time because I couldn't face myself. I didn't want to. I was just like, I can't anymore. It took me a long time back. Two, one and half years.... It's pretty common, I think... The burden that you feel... you're a burden to people."*

Common mental health problems in the SCI population include depression and anxiety disorders, which can arise at various stages, from immediately following the injury, during rehabilitation, or even years later in response to new life changes or health complications (SANE). Notably, most people with SCI do *not* develop a diagnosable mental illness, but many do experience some mental health difficulties and may not realise they are becoming depressed or anxious. In some cases, individuals had pre-existing mental health issues that the trauma of SCI can exacerbate or reactivate.

One major contributor to psychological trauma in SCI is the nature of the injury event. Many SCIs result from sudden accidents or violence, such as car accidents, falls and sports injuries, which can leave 'survivors' with disturbing memories. It is common for people to have intrusive memories or high anxiety initially; for some, these symptoms persist and develop into ***post-traumatic stress disorder (PTSD)*** (SANE). Research indicates traumatic stress reactions are frequent after SCI. One meta-analysis found PTSD symptom prevalence ranging from about 6% up to 60% across studies, with higher rates in low- and middle-income countries. (Yousefifard *et al.,* 2022). A pooled analysis estimated roughly 19-42% of people with traumatic SCI experience PTSD symptoms, a rate well above that of the general population. In short, PTSD is significantly

more common in SCI survivors than in individuals with no injury, reflecting the harrowing circumstances that often accompany these injuries (Craig, 2025).

Important resources and information: Well-being

- In this blog, The complex foundations of well-being and disability, **Dinesh** describes the complexities of well-being for those living with SCI
- Christopher & Dana Reeve Foundation's How do I deal with depression and adjustment to my SCI?
- Queensland Spinal Cord Injury Services' Psychological well-being after spinal cord injury.

3.7.2. Prevalence of mental health conditions in SCI

Depression is one of the most prevalent mental health conditions among people with SCI. Estimates vary, but a meta-analysis concluded that roughly 26% of adults with SCI meet criteria for major depression, depending on time since injury (Craig, 2025). In comparison, the prevalence in the general community is around 5-10%. Large-scale data confirm this elevated risk, for example, a recent U.S. study of health records found that 29.3% of people with a TSCI were diagnosed with a depressive disorder, versus only 9.3% of people without SCI (Peterson *et al.*, 2020). This suggests roughly a threefold higher rate of depression in the SCI population. Similarly, anxiety disorders are more common. The same study found 19.3% of those with SCI had an anxiety disorder (*vs.* 14.1% without). Beyond clinical diagnoses, many individuals experience subclinical depression or chronic sadness; researchers estimate up to 40% of people living with SCI have elevated psychological distress, even if the level does not meet full diagnostic criteria, in the months following injury (Craig, 2025). These rates tend to be highest in the early phase. During inpatient rehabilitation, 20-40% of patients show signs of depression (Lomas & Williams, 2009). Encouragingly, studies indicate this proportion declines over time. Years after injury, around 15% of people living with SCI have persistent depressive disorder, which is above community rates but lower than in the immediate aftermath (Lomas & Williams, 2009). This trend suggests that many individuals gradually adjust, although a large subset of individuals continue to struggle with mood. It is also important to recognise co-morbidity. It is common for depression and anxiety to occur together, with some turning to substance misuse as a coping mechanism. Alcohol or drug problems may co-occur with psychological distress in the SCI community (SANE). In fact, substance use disorders are among the most frequent mental health issues after SCI, along with depression and adjustment disorders (Lomas & Williams, 2009). One longitudinal study using psychiatric interviews found that about 30% of SCI patients met criteria for at least one mental health disorder within the first year post-injury and about 10% had two or more co-occurring disorders. Major depression was often accompanied by either

substance abuse or suicidal ideation in these cases (Craig, 2025). Whilst mental disorders and substance misuse are not inevitable, with many people living with SCI maintaining good mental health or recovering from initial distress with proper support, it is clear that SCI increases the risk of mental illness well above the average population. The key is recognising problems early and providing appropriate intervention, rather than assuming psychological struggles are simply 'expected' or untreatable consequences of SCI (Kennedy & Garmon-Jones, 2017).

3.7.3. Factors affecting psychological well-being after SCI

A variety of interrelated factors influence mental well-being in people with SCI, potentially increasing the risk of mental health problems:

- **Chronic pain:** Physical pain is a pervasive issue after SCI and is closely tied to mood. Approximately 80% of people living with SCI experience chronic pain, and in about half (50-60%), the pain is severe and persistent. This unrelenting pain can significantly impair sleep, concentration and the ability to enjoy life, often leading to or worsening depression and anxiety (Lomas & Williams, 2009; Peterson *et al*., 2020). Pain management is challenging. Even necessary pain medications can produce side-effects, such as fatigue, sedation or cognitive fog that compound the burden. For some, living with constant pain becomes a day-to-day psychological stressor that heightens the risk of suicidal ideation (Lomas & Williams, 2009)
- **Medical complications:** Beyond pain, SCI often brings a host of medical complications that can erode mental health. Examples include frequent infections (e.g. urinary tract or respiratory infections), pressure sores from impaired mobility, and, for higher-level injuries, reliance on ventilators or CPAP for breathing (Lomas & Williams, 2009). These conditions can be frightening and exhausting; for instance, individuals who require ventilatory support report that using these devices can "often lead to feelings of drowning" at night. Recurrent hospitalisations for complications disrupt life and can cause frustration or hopelessness. Over time, managing the myriad of health issues of SCI can wear down a person's resilience and contribute to anxiety or depression (Lomas & Williams, 2009)
- **Loss of independence and identity:** The abrupt loss of mobility and bodily function forces people to depend on others or on assistive devices for basic tasks, a major blow to self-esteem. Many struggle with feelings of helplessness or a sense of being a burden. Role changes are common; for example, a parent living with SCI might now be cared for by their children, or a young adult might have to move back to their parents' home. These shifts can trigger grief for one's former identity and lifestyle. Sexuality and fertility may also be affected by SCI, such as erectile dysfunction, impaired fertility or loss of sensation, which can impact intimate relationships and self-image. The psychosocial loss of sexual function and altered body image has been noted as a factor that can increase the risk of depression or suicidal thoughts in individuals with SCI (Lomas & Williams, 2009). In short, SCI can challenge one's sense of self and purpose, especially if adequate counselling and peer support are not available during the adjustment process. In **Chapter 5**, we discuss

'identity' as being part of having a sense of self and purpose

- **Social isolation and accessibility barriers:** SCI can shrink a person's world. Activities that used to be easy. Travelling, driving, entering buildings and socialising spontaneously now require planning and accommodations (Lomas & Williams, 2009). Without accessible transport or environments, a person might find it easier to stay at home, which can lead to isolation. Friends may drift away if they are uncomfortable or don't know how to help. Additionally, many people living with SCI are young at the time of injury and may have to suspend or alter their education and career plans. Unemployment or financial stress is common, and losing one's work role or income can further contribute to depression. A 2009 report highlighted that ***environmental barriers*** in transport, housing, public spaces and lack of support services make it difficult for many Australians living with SCI to engage fully in the community (Lomas & Williams, 2009). Feeling isolated or marginalised can greatly undermine mental well-being, and
- **Stigma and lack of recognition:** Unfortunately, mental health needs in the SCI population have historically been under-recognised. In medical settings, the emphasis is often on physical rehabilitation, such as walking again, wheelchair skills and medical stability, which can overshadow psychological health (Kennedy & Garmon-Jones, 2017). Some individuals may also feel a stigma in admitting they need help for depression or anxiety, especially when everyone expects them to "be grateful to be alive." This can lead to suffering in silence. Australian experts observe that many living with SCI do not meet the criteria for public mental health services, which often prioritise illnesses such as schizophrenia or bipolar disorder. In many instances, they cannot afford private counselling (Lomas & Williams, 2009). Moreover, not all mental health professionals are knowledgeable about SCI and disability, making it hard for patients to find appropriate care (Lomas & Williams, 2009). These systemic gaps can allow treatable problems to fester. The good news is that awareness is growing. Recent efforts, such as developing psychosocial care guidelines for SCI, aim to ensure mental health is addressed as a standard part of SCI care (Craig, 2025). GPs can provide mental health care plans to assist with Medicare rebates and support access to quality counselling.

Taken together,the above factors create a complex web influencing each person's mental health after SCI. The presence of protective factors, such as strong social support, access to resources and personal coping skills, and recognising risk factors, such as severe pain, lack of support and a prior psychiatric history, can make a big difference in an individual's psychological outcome (Craig, 2025). For example, having a supportive partner or peer group, maintaining hope and gaining a sense of control through rehabilitation can buffer against depression. On the other hand, someone with a history of depression or trauma before the SCI is at much higher risk of post-injury mental health problems. One study found that pre-injury psychological distress made the odds of new psychiatric disorders nearly 24 times greater after SCI (Craig, 2025). Rehabilitation teams must thus assess these factors and provide early interventions to those at risk.

Important resource and information: Mental health module

Health Maintenance Tool, Module 1: Mental Health and Wellbeing: How to stay healthy and well with SCI, A tool for consumers from consumers. This means it was developed in collaboration with people living with SCI.

Clinical resources: Emotional well-being toolkit

- A Clinician's Guide to Working with SCI, Emotional well-being toolkit: Be the reason someone smiles today (to be reviewed in 2027). There is also an app version, and
- ACI: Emotional wellbeing website also has an e-learning course to help implement the toolkit and a psychosocial clinical assessment tool. Refer to the ***algorithm*** in **Figure 3.6** below.

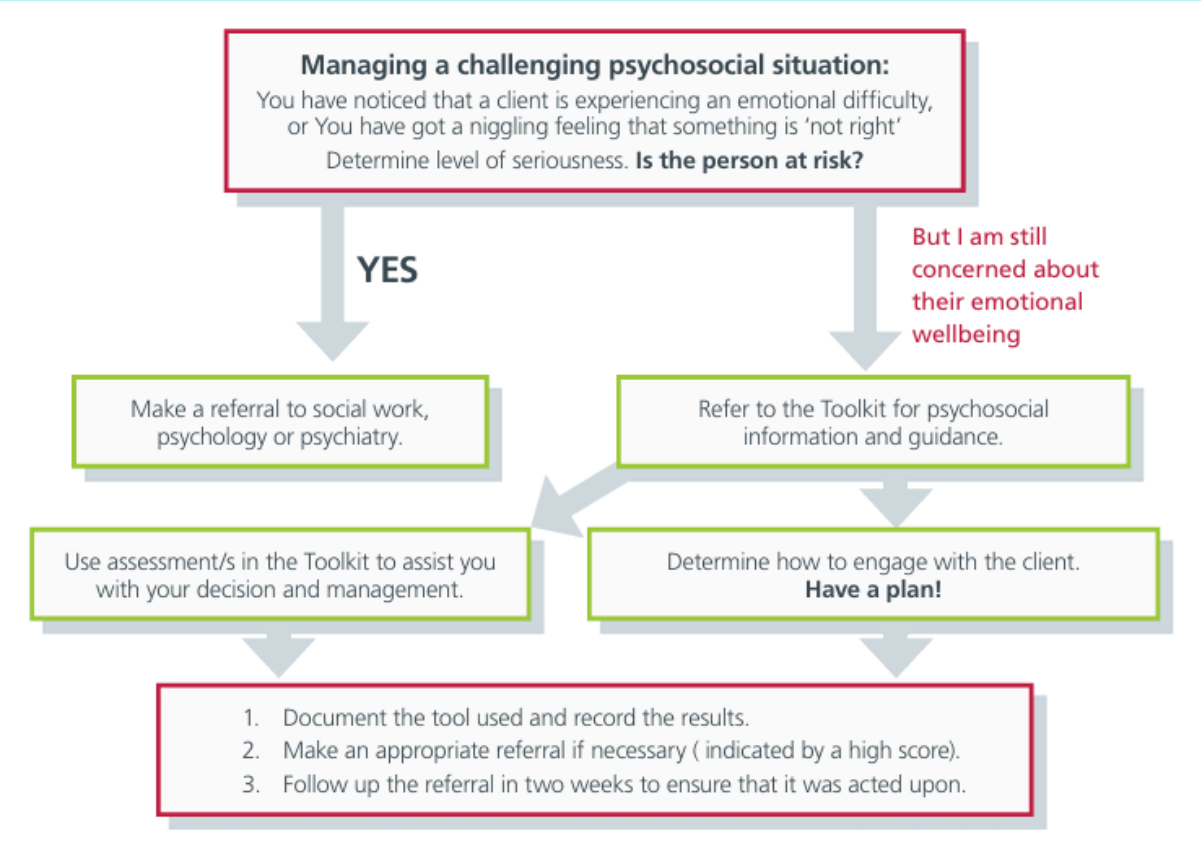


Figure 3.6. An algorithm for managing a challenging psychological situation (p. 3). *Source:* Dezarnaulds *et al.* (2016) © State of New South Wales (Agency for Clinical Innovation), but may be reproduced in whole or part for study or training purposes, subject to the inclusion of an acknowledgment of the source.

Research: Mental and behavioural health in SCI rehabilitation

Schultz *et al.* (2022) undertook a review about the importance of health professionals assessing and addressing the mental and behavioural health concerns of individuals living with SCI during rehabilitation, as untreated mental health distress can lead to reduced gains in rehabilitation and poor overall health. The review provides an overview of recent research on prevalence rates of common mental and behavioural health concerns in the SCI population, highlighting disability-specific factors that may impact traditional assessment and treatment of mental health concerns. While people living with SCI are at a heightened risk for experiencing mental health distress, overall, the majority of those with SCI adapt well and live a full and meaningful life. *Rehabilitation psychologists are thus a vital aspect of rehabilitation teams, as they can address behavioural health and mental health concerns that may impede patients from achieving their rehabilitation goals.*

3.7.4. Suicide risk for people living with SCI

Suicidal ideation and suicide are serious concerns in the SCI community. Research has consistently shown that people living with SCI have a substantially higher suicide rate than the general population.

Research: Two Australian articles on suicide and SCI

- Soden and colleagues' (2000) study at the Royal North Shore Hospital, Sydney, found that suicide risk for people living with SCI was about five-fold higher than the rest of the population, particularly for the first five to six years after injury. Suicide was responsible for 6-10% of SCI deaths and was more common for those with quadriplegia than paraplegia, with drowning the most common method. The assumption is that those living with quadriplegia were unable to use any other unassisted methods, and

- An Australian analysis estimated the suicide risk is about five-fold higher in those with SCI compared with those without the injury, particularly in the first 5-6 years post-injury (Lomas & Williams, 2009). In absolute terms, suicide has been found to account for between 6% and 11% of all deaths among people with SCI, a striking overrepresentation. By contrast, suicide accounts for around 1-2% of deaths in the overall Australian population in a given year. This elevated risk underscores how critical mental health and suicide prevention are for individuals living with SCI. More recently, for disability in general, the AIHW reported that: *"An estimated 41% of people with severe or profound disability self-reported that they had mood disorders such as depression, compared with 29% of people with other forms of disability, and 7.3% of people without disability."*

In terms of risk factors for suicide, a psychiatric diagnosis of 'major depression' is one of the strongest predictors of suicidal behaviour (Kennedy & Garmon-Jones, 2017). This aligns with evidence that treating depression and other disorders can literally save lives in this group. The level of injury may also play a role. A Sydney hospital study found that suicide was more common amongst people with quadriplegia compared with paraplegia (Soden *et al.*, 2000). The researchers speculated this might be due to the greater functional limitations in quadriplegia. Additionally, as mentioned above, uncontrolled chronic pain and worsening physical health problems can increase suicide risk, especially in older adults living with SCI (Lomas & Williams, 2009). Social factors, such as isolation, unemployment or lack of family support, may compound the risk by fuelling hopelessness.

Research: Suicide and SCI

- Kennedy & Garmon-Jones' (2017) systematic review found that between 0% and 6.8% of people living with SCIs acquired their injury through an attempted suicide, such as jumping from a height. Thus, some individuals had mental health struggles leading up to their injury. Post-injury, the challenges of living with paralysis would likely exacerbate suicidal feelings if not addressed
- Bombardier *et al.* (2021) found that anxiety and post-traumatic stress disorder (PTSD) are at least twice as prevalent in those who have sustained SCI. Suicide is at least three times more common. Substance use is also significantly more prevalent. Although individuals with SCI usually have contact with health professionals, mental health disorders are often not recognised and so not addressed optimally. This may be because of the more obvious physical health 'issues' and because a stigma still surrounds 'mental health'
- Faleiros *et al.* (2023) used a quantitative, cross-sectional, descriptive study in a virtual environment to evaluate the factors associated with suicidal ideation (SI) amongst 200 Brazilians (mostly males) aged 18 or over with TSCI. The study found a 32.5% frequency of SI. A statistically significant relationship was found between the duration of injury and suicidal ideation. The shorter the duration of SCI, the greater the likelihood of SI.
- Khong and colleagues (2023) investigated the risk factors associated with SI amongst 246 individuals living with a chronic SCI in the US. Twenty-seven (11.0%) participants endorsed SI, with 6 (22.2%) hav-

ing a plan to self-harm. These individuals had significantly higher depressive symptoms, lower resilience and lower satisfaction with life, as well as lower perceived health, physical independence and lower SCI Functional Index with Assistive Technology domains of basic mobility, self-care and fine motor skills. These individuals were, however, not significantly different in re-hospitalisation rates. Individuals who expressed lower physical independence, lower perceived health, lower satisfaction with life and higher depressive symptoms were more likely to endorse SI.

In the podcast below, **Matt** is a young man who sustained SCI in a suicide attempt.

Podcast: Matt's story about his attempted suicide

SCIA's Have the Nerve podcast, A moment that changed everything (Episode 36, 13 March 2024): Listen to **Matt**, who, as a 16-year-old, attempted to take his life and ended up with SCI. The moment that changed for him after his SCI was a conversation on a train. **Matt** talks about what it was like as a 16-year-old living with SCI.

Despite these concerning statistics, it is important to emphasise that suicide is preventable. Many people living with SCI who experience suicidal thoughts do find reasons to live and ways to cope, especially if they receive timely psychological support. For example, **Dr Dinesh Palipana**, an Australian doctor who sustained a cervical SCI in 2010, has openly discussed his mental health struggles and how he overcame severe depression. Dinesh's depression began before his injury, but the trauma and sudden disability tested his mental resilience. In his own words, he went from feeling *"paralysed by depression"* to eventually *"celebrating life's simple pleasures and remarkable milestones,"* crediting gratitude and support for his transformation. His story, like those of others, shows that with the right support, life after SCI can be meaningful and fulfilling, even when it feels unbearable.

Given the elevated suicide risk, healthcare providers are urged to actively screen for suicidal ideation in SCI patients and not dismiss it. A 2017 review concluded that there is a *"crucial need for risk assessment and psychological intervention"* for those with mental health issues following SCI (Kennedy & Garmon-Jones, 2017). *In practical terms, this means integrating mental health professionals into spinal injury care teams, providing patient and family education about warning signs, and ensuring access to crisis services.* Peers living with SCI who have navigated similar dark periods can also offer hope by sharing how they found purpose again, such as through mentoring, advocacy or spirituality. Open conversations about mental health and suicide that are free of stigma are essential within the SCI community. Organisations in Australia have begun targeted initiatives in this area, such as SANE Australia's *"Better Off With You"* program, which

collaborates with communities, including people with disabilities, to spread suicide prevention messages and real personal stories of overcoming suicidal crises.

3.7.4.1. Support and treatment for psychological well-being

Mental health challenges are not a 'life sentence' for people living with SCI. They can be treated and managed**.** Just as physical complications of SCI require medical care, issues like depression, anxiety and PTSD deserve prompt attention by health professionals. Studies show that effectively treating depression can improve participation in rehabilitation and overall outcomes for those living with SCI (SANE Spinal cord injury and mental health). Individuals should not suffer in silence, thinking mental illness is an inevitable part of SCI or a sign of personal weakness. There are many avenues for help:

- **Professional mental healthcare:** The first step is often to talk to a doctor. In Australia, a GP can assess a person's mental health and create a Mental Health Care Plan (SANE Spinal cord injury and mental health). Under Medicare, this plan entitles the individual to subsidised sessions with a psychologist or mental health professional. Accessing therapy can equip someone with coping strategies, such as cognitive-behavioural techniques to challenge negative thoughts. and provide a safe space to process trauma or loss. Evidence-based therapies like CBT and trauma-focused therapy have been adapted for people with SCI. They are effective in reducing symptoms of depression, anxiety and PTSD. Medication, such as anti-depressants or anti-anxiety drugs, can also be used under careful supervision to avoid interactions with other medications the person may be taking (SANE SCI&MH). The key is a collaborative approach. The GP, rehabilitation specialists, psychologists, and, if needed, psychiatrists, should work together to tailor a plan that fits the individual's needs and medical conditions
- **Peer support and mentoring:** Connecting with others who have 'been there' is incredibly powerful. Many SCI 'survivors' find hope and practical wisdom by talking to peers who are living fulfilling lives after injury. Australia has peer support programs through spinal injury organisations, such as SCIA and State spinal injury units, where recently injured individuals can meet mentors. Peer networks help people share experiences, problem-solve daily challenges and combat the feeling of being alone in their struggles. As one strategy, developing a network of peers or joining a support group can reduce isolation and inspire adaptive coping. Family members and carers can also benefit from peer groups
- **Maintaining an active and engaged life:** Rebuilding one's life after SCI involves finding new sources of meaning and joy. Mental well-being is bolstered when individuals continue to pursue interests, relationships and goals to the best of their ability. Health professionals encourage people living with SCI to stay active in whatever ways possible. This could mean practising wheelchair sports, learning new skills, engaging in hobbies or volunteering. Exercise (adapted to one's capacity) not only improves physical health but also lifts mood and relieves stress. Likewise, resuming social and recreational activities helps restore a sense of normalcy. It is important to set realistic goals and celebrate small

achievements along the way. Many people living with SCI describe how returning to work or studying, travelling with adaptive equipment or contributing to their community gave them back a sense of purpose that countered depression, and

- **Coping strategies and self-care:** Developing personal coping skills is crucial for long-term resilience. Relaxation techniques such as meditation, breathing exercises, or listening to music can help manage anxiety. Some find benefit in writing a journal, practising mindfulness or engaging in creative outlets to express emotions. Establishing a daily routine with enjoyable activities is recommended. Simple pleasures, such as going outdoors, watching a favourite show or spending time with a pet, can improve one's mental state. To summarise, below are a few evidence-based strategies for living well with SCI:
    - *Talk about your feelings:* Open up to a friend, family member or counsellor about what you're going through. Sharing fears and concerns can be a huge relief and help you feel supported
    - *Build a support network:* Stay connected with people who care and consider joining peer groups or online forums with others who have similar experiences. Knowing you're not alone in facing challenges can provide comfort and practical tips
    - *Stay as active as possible:* Engage in activities that interest you, whether hobbies, adaptive sports or community events. An active lifestyle and setting achievable goals (short-term and long-term) give a sense of progress and enjoyment, and
    - *Practice relaxation and mindfulness:* Use techniques, such as meditation, deep breathing or listening to music, to cope with stress. Scheduling pleasant activities into your day can improve your mood and resilience.

Important information: Medicare's mental health service and helplines

- Medicare's Mental Health: Not feeling like yourself lately? You're not alone: Medicare Mental Health is a free service that connects you with the mental health support that is right for you.
- If someone living with SCI is in crisis or experiencing suicidal thoughts, emergency support should be sought immediately. In Australia, a range of services is available through the R U OK? website. These include:
    - Lifeline (13 11 14): *We're here for you*: Call, chat or text (0477 13 11 14), with a LLE YouTube video channel
    - Suicide Call Back Service (1300 659 467)
    - SANE (1800 187 263, Mon-Fri 10h00-20h00)
    - Beyond Blue (1300 224 636), with an interpreting service (13 14 50)
- Below are helplines for men, children, First Nations people and individuals from the LGBTIQ+ community:

- MensLine Australia (1300 789 978)
- Kidshelpline (1800 551 800)
- 13Yarn (13 92 760)
- Q Life (1800 184 527)

- Most of these services provide 24/7 counselling and crisis intervention. No one should feel ashamed to reach out. These resources exist because mental health crises can affect anyone, and prompt help can save lives.

3.8. The value of connecting with Nature

Ivers and Astell-Burt (2023) published 'Nature Rx: Nature prescribing in general practice', in which they explained what nature prescribing is and then offered some advice about which activities might be used for which condition. Nature prescribing involves a health professional recommending that patients spend time in nature and may also encompass a written prescription, verbal counselling, or referral to another provider. Nature prescribing includes prescribing nature-based activities that enhance physical activity and improve social connection, well-being and mental health. Nature therapy is sometimes referred to as ecotherapy, forest bathing or forest therapy.

Interestingly, while the article provides a suggested activity (surfing) for someone with multi-trauma or an amputation, it did not provide anything for someone living with SCI. Many of the suggested activities were physical, such as walking, fishing or restoring the bush, which would exclude many individuals living with SCI. Notwithstanding, while activities may not be possible for some with SCI, there is considerable evidence that simply spending time in green or blue spaces, such as near the ocean, a lake or a river, is good for the soul.

Personal stories: Ocean therapy

- **Joel**, a Forward Ambassador, wrote a blog about recently re-embracing the ocean after his C2 SCI in 2014.
- **Dean Durman**'s friends took him surfing. Watch the video below, kindly provided by **Jacqui and Dean Durman**.

One or more interactive elements has been excluded from this version of the text. You can view them online here: https://bond.studium.pub/life-well-lived-with-spinal-cord-injuries/?p=119#video-119-1

Key resources: Connecting with Nature

- Many of Australia's national parks are wheelchair-friendly, such as NSW and Queensland
- AllTrails has provided the Top 10 wheelchair-friendly trails in Australia, with Uluru #1, the Bay Run #2 and the Three Sisters Walk #3
- Did you know that a visit to a national park may save the health budget $98?
- Nature therapy is included in the Social prescribing playbook – CASCADES Canada.

3.9. Other interventions: Mindfulness, adaptive yoga, art and music therapy and resilience training

A range of other interventions that may be helpful for health and well-being for those with SCI, as well as their family and carers. In a 2024 scoping review, Bhattarai and colleagues (2024) found that while mindfulness and mindfulness-based interventions appear to positively impact health and well-being in adults with SCI, mindfulness interventions were inconsistent in terms of content, delivery frequency, and duration. It is essential to develop multifaceted, tailored mindfulness interventions that utilise a consumer-based approach and established mindfulness theories and practices for adults with SCI.

Wang and colleagues (2025) published a scoping review on the effects of ***mindfulness- and acceptance-based interventions (MABIs)*** on health-related outcomes of individuals with SCI across four countries (US, Iran, China and UK). MABIs are a suite of methods that emphasise present-moment awareness, non-judgment and values-based living. They operate by teaching patients to cope with stressful thoughts, emotions and physical sensations. They concluded that the research generally supports the acceptability and effectiveness of MABIs for improving the overall well-being of individuals living with SCI.

Reminder: SCI may limit some aspects of meditation

In **Chapter 14** (Spirituality), Adrienne commented that her SCI physically limited some aspects of medication.

Below, we provide interventions that have been researched or introduced as therapy for SCI.

3.9.1. Adaptive yoga

A growing body of research supports integrating yoga and mindfulness-based practices into rehabilitation and wellness programs.

Research: Yoga therapy

- Curtis *et al.* (2017) reported enhanced mental well-being in adults living with SCI following a specialised yoga intervention.
- In a ***randomised control trial***, Madhusmita *et al.* (2019) investigated the efficacy of integrating yoga with physiotherapy in persons with paraplegia. The study involved 124 participants aged 18-60 years with incomplete SCIs (AIS-C and AIS-D). Results indicated that the intervention group showed significant improvements on various outcome measures, including the Spinal Cord Injury Independence Measure (SCIM), the Medically Based Emotional Distress Scale and the Quality of Life Index for Spinal Cord Injury (SCI-QOL), compared with the standard physiotherapy care group. The study concluded that a one-month integrated yoga and physiotherapy program is more effective than physiotherapy alone in the management of patients with paraplegia, and
- Arya *et al.* (2024) found that individuals living with SCI who participated in a structured yoga program exhibited significant long-term improvements in psychological resilience and Sense of Coherence (SOC), suggesting emotional empowerment and improved coping mechanisms.

Video: Wheelchair yoga

You may want to try out the moves while watching this US video of a 20-min seated yoga class for individuals with SCI.

To access adaptive yoga services, reach out to your local GP, physiotherapist or OT. Below are services advertised online:

- Special yoga program for people with SCI – Empowering Independence, and
- Adaptive Yoga for Physical Therapy: Benefits and Techniques (Moving With Hope Adaptive Yoga for Disabilities, Healthstin).

3.9.2. Animal-assisted therapy

The organisation Forward explains animal-assisted therapy and how a therapy dog can help people living with SCI. Forward's purpose-built accommodation acquired Odin, a certified ther-

apy dog, in 2023. Another form of animal-based rehabilitation you might not be familiar with is hippotherapy.

Important information: Hippotherapy

- What is hippotherapy? The indications and effectiveness of hippotherapy, and

- In this study of one individual, Therapeutic horse back riding of a spinal cord-injured veteran: A case study, the program resulted in numerous benefits for the veteran, including increased balance, muscle strength and self-esteem. The authors were of the opinion that therapeutic riding, in which a horse is used as a tool for physical therapy, emotional growth and learning, has potential as a therapy for veterans returning from the Iraq and Afghanistan war with traumatic brain injuries, blast injuries, depression, traumatic amputations and SCI.

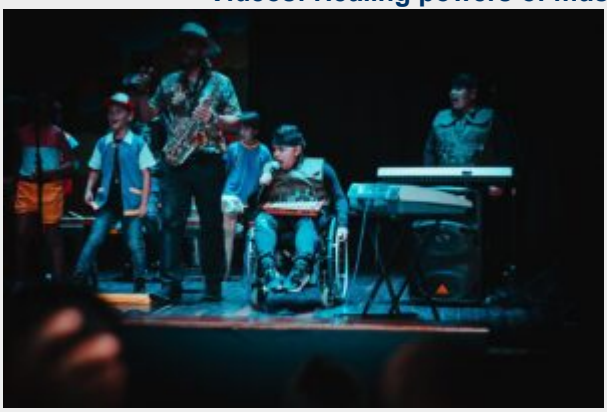
3.9.3. Music as therapy

Below are some examples of how music is being used as exercise and therapy.

Important information: Returning music to the rhythm of life

The Craig Hospital in the USA has been using music for several years to help patients return to the rhythm of life.

Videos: Healing powers of music



- Mount Sinai Beth Israel used music therapy as an integrative treatment that addresses mind, body and spirit. It was also found to reduce pain, and
- The healing power of music video briefly describes some of the work undertaken by the University of Melbourne using virtual reality and music therapy to help individuals living with quadriplegia exercise their respiratory muscles.

The research below provides some evidence about the value of music in SCI.

Research: Music and SCI

- Spinal patients sing to breathe easy in the virtual world explains how these music therapy sessions are also social events, bringing together groups of people living with SCI for therapy sessions, and
- In searching for evidence on the beneficial outcomes of music therapy, Mercier *et al.*'s (2023) scoping review found that, across a range of interventions, group singing and an individual songwriting program for self-concept were the most studied. Mood was the most studied outcome. In terms of rehabilitation, music therapy and music-based interventions can be used to address many health and rehabilitation goals, including mood, gait and respiratory function. The authors concluded that *while current data support the use of music therapy and music-based interventions for individuals living with SCI, additional research, particularly to evaluate individual interventions, is needed.*

3.9.4. Art as therapy

Art is also used as therapy for individuals living with SCI. Franzò *et al.* (2025)used immersive technology, in this case, virtual reality (VR), to create a neuroaesthetic experience based on the Michelangelo effect for SCI rehabilitation. Could the system for virtual art therapy be used to assess patients' deficit performances? Thirteen non-SCI individuals and 13 with SCI wore VR headsets to experience a painting simulation of famous artworks (artistic stimuli) on a colouring canvas (non-artistic stimuli). The trajectories of the hand were studied to obtain various kinematic and spectral parameters for evaluating user performance. Significant differences were observed in most parameters between the two groups, except for normalised jerk and spectral energy. Analysis showed that both groups preferred horizontal movements for painting the canvas. Participants found the system to be comfortable and user-friendly. The authors concluded that the system can be a usable tool and that its rehabilitative efficacy should be tested in patients with SCI. The kinematic and spectral parameters would allow evaluation of performance alongside clinical scales to distinguish pathological from physiological performance.

Important resources: Art as therapy in SCI

- Spinal Injuries Association's (SCI) Art as Therapy site (2024) outlines how to begin using art as a therapeutic tool and describes the mental health benefits it can offer. The resource explains that creative activities, such as drawing, painting, writing, music or other expressive arts, can help people with SCI process emotions, reduce stress and rebuild confidence and identity in a safe, non-judgmental way.
- Christopher & Dana Reeve Foundation's Art and Creativity site explores how art enhances lives and how individuals living with SCI can also become artists.

3.9.5. Resilience programs

The SCIA resilience programs are free and designed to help you and our community improve resilience, wellness and meaning in your life. Please check the following:

- **Engage Program**, a 10-week program with a facilitator with lived experience of a disability, to refocus on what you enjoy, gain a clearer sense of personal satisfaction, connect with others and identify new opportunities, and
- **Electronic Personal Administration of Cognitive Therapy (ePACT)**, a self-led online skills-building and educational course designed to support individuals with SCI who may be experiencing sadness, irritability, worry or changes in sleep and appetite.

3.10. Impact on families and carers

"There are approximately 3 million Australians who care for someone with disability, a medical condition, mental illness or someone who is frail due to age." Australian Government (2025).

SCI not only affect the individual. It profoundly impacts their family, friends and carers. The role of carers, which might be a spouse or partner, a parent, an adult child, a sibling or a close friend, often becomes pivotal after an injury. These loved ones frequently step up to provide physical care, emotional support and advocacy for the person living with SCI. In doing so, how-

ever, they face their own emotional journey and challenges, which deserve attention. Below, **Jacqui Durman** describes Dean's accident.

Jacqui's story: Dean's accident and the impacts

"A spinal cord injury doesn't only change the life of the person who is hurt. It changes the whole family and even the wider community. Before this, we didn't have anyone with a disability in our family, so we only knew about it from work or church. Suddenly, everything familiar—our home, our routines, our lives—felt completely different. It was as if we were living in a bubble inside the world we used to know.

On March 12th, 2011, my husband, Dean, was in a car accident, just two weeks before his 37th birthday and our 12th wedding anniversary. Our son, Jaiden, was only five years old.

The vows "in sickness and in health, till death do us part" took on a whole new meaning. No one prepares for a spinal cord injury when they get married, but those vows remind you of your promise to God and to the person you love.

That Saturday morning, I was driving to work when I passed an accident on the road in Benoni, South Africa. I normally never look at accidents, but something made me turn my head. The first thing I saw was the number plate—PJC. My heart sank. I realised instantly that it was Dean's car. The white BMW was smashed and wrapped around an oak tree.

The paramedics later told me I was incoherent because I left my own car in the road and ran across toward the scene. Bystanders held me back as Dean was pulled from the wreck and placed on a spinal board. I felt helpless and terrified. All I could do was pray that God would spare him. Our son still needed his dad.

The next few hours were full of sirens, medical terms, scans, machines beeping and the sound of the ventilator breathing for Dean. Then came the conversation with the doctor. Out of everything he said, only one sentence stuck with me: "He will be paralysed."

All my medical training as a radiographer vanished in that moment. I wasn't thinking like a professional. I was just a wife and a mother to a little boy waiting at home for his dad to take him to Wimpy Cafe and play in the backyard tree.

Weeks of ICU visits followed, along with two long surgeries. I had to beg the hospital staff to let Jaiden see his dad, who had lost 20 kilos and looked nothing like the strong father he knew. During this time, I also had to visit the few spinal rehab centres in Johannesburg and choose one for Dean, a huge decision, because the quality of care could literally mean life or death."

Dinesh's story: The power of his mother's love

Dean Durman's podcast series, The Power of a Mother's Love ft. Dr. Dinesh Palipana (Episode 9, 28 January 2026): This podcast shares the story of **Dr Dinesh Palipana**, who became quadriplegic at 25 after a car accident and describes how his mother's unwavering love helped him survive depression, rebuild his life, and pursue a career in medicine, leading to his achievements as a doctor, advocate and author. The episode explores resilience, mental health after trauma, disability advocacy and the transformative power of unconditional support.

Based on SANE Family, Friends and Carers, below are the impacts on 'significant others', followed by suggestions for ensuring their well-being:

- **Emotional and mental health effects on carers:** It is common for family members to experience a kind of 'ripple effect' from the trauma and adjustments surrounding SCI. They may feel shocked and grief after the accident, mourning the life changes in their loved one and in the family. Carers often report feelings of anxiety, sadness, guilt and even anger as they adapt to the new reality. In the early post-injury period, partners and close family members are vulnerable to high stress. Research shows many spouses experience elevated anxiety and depressive mood, and even relationship conflicts or breakdown, in the first couple of years after a family member's SCI (Craig, 2025). They are trying to balance worry about medical issues with sudden carer responsibilities and dramatic changes in family roles. For instance, a wife may find herself performing nursing tasks for her husband or parents may become lifetime carers for an adult child. These shifts can be overwhelming. Crucially, studies indicate that carers of people with SCI are at higher risk of mental health problems, such as depression. This heightened risk stems from chronic stress, role strain and sometimes social isolation, as the carer's life may now revolve around the injured person's needs. Carers can burn out if they do not receive adequate support or respite. Unfortunately, health professionals sometimes focus so much on the patient that they overlook the well-being of family members. Families are not always included as partners in care planning and their need for information or training may be underestimated. For example, a mother caring for a son with quadriplegia might suddenly be handling complex personal care and medical equipment with little training or support, which is stressful.
- **Practical and social strains:** In addition to emotional strain, carers often face practical challenges, such as managing appointments, therapies, equipment and finances. If the injured person was an income-earner or an active parent, the family may face financial hardship or childcare challenges. Leisure and social activities can shrink for the whole family, as spontaneous outings give way to scheduling around accessibility needs. Carers

sometimes feel tied down by responsibilities, which can lead to their own social isolation. They might also struggle with feelings of loss of the relationship as it was, with a spouse feeling more like a nurse than a partner, loss of personal freedom and grief seeing their loved one suffer. All of this can contribute to chronic stress. Over time, chronic stress in carers can manifest as health issues, irritability, sleep problems, anxiety or clinical depression if not addressed. Given these challenges, carers must receive support and learn strategies to protect their own mental health. Below are some key approaches for carers and families to maintain well-being while caring for someone living with SCI:

- ***Accept help and share the load:*** Remember that being a carer does not mean doing everything alone. Identify other family members, friends, or community services that can help with tasks or provide breaks (SANE Family, Friends and Carers). It could be as simple as asking a friend to stay with your loved one for an hour while you run errands, or utilising formal respite care services periodically. Accepting help is not a sign of failure. It benefits both you and the person you care for
- ***Watch for signs of stress in yourself:*** Be mindful of your emotional state. Common signs of carer stress include feeling irritable or exhausted, withdrawing from social contact, or getting sick more often. If you notice you're feeling overwhelmed, don't ignore these signs. They are signals to take action, like taking a break or seeking support, before you burn out
- ***Take regular 'time-out' breaks:*** Self-care is not selfish. It is necessary. Make sure to schedule regular breaks for yourself, whether that's an hour each day to do something enjoyable or a weekend off every so often, with someone else stepping in. Use respite care options if available, such as the Australian Government's Carer Gateway, which can coordinate respite services to give carers short-term relief and peer support. Even a small break to go to a movie, take a walk or relax can be a recharge for you. This break may involve respite options such as those offered by the Sargood Foundation in NSW
- ***Talk about how you feel:*** Don't bottle up your emotions. It is very normal to have feelings of frustration, sadness, or grief as a carer. Find a trusted person to talk to, whether a friend, support group, or counsellor. Some carers feel guilty admitting negative feelings (like *"I miss my old life"* or *"I sometimes feel angry about this situation"*), but expressing these in a safe environment is healthy. If needed, professional therapy for yourself can be incredibly helpful. Caring for your mental health enables you to be a better carer in the long run
- ***Set realistic limits and priorities:*** Recognise that you cannot do everything. Prioritise the most important tasks and don't be afraid to let less critical things go. It might help to make a realistic, fair weekly list that includes time for your needs. Learn to say no to additional demands that exceed your capacity. If there are aspects of care you truly can't handle physically or emotionally, discuss this with healthcare professionals. Alternative arrangements, such as in-home nursing visits or equipment, might be possible. Being a good carer does not mean you must sacrifice your well-being
- ***Stay informed and involved as a partner in care:*** Educate yourself about SCI and the treatments your loved one is receiving. When families are treated as 'partners in care'

by professionals, it means they are kept informed, trained in skills, and involved in decision-making. Outcomes are better for everyone. Don't hesitate to ask doctors or rehab teams questions. At the same time, maintain some boundaries: you are a partner and supporter, but not solely responsible for the person's rehabilitation. Encourage the person with SCI to do as much for themselves as possible and to be involved in their own care decisions to the extent they are able. This balanced approach prevents over-dependence and empowers both of you, and

- ***Plan for emergencies and the future:*** Work with other family members and healthcare providers to prepare a plan for potential crises (medical or psychiatric). For example, have a plan for what to do if your loved one becomes severely depressed or has suicidal thoughts. Know what signs to watch for and who to call. Always keep emergency numbers, such as 000 and Lifeline 13 11 14, handy. Also, plan for contingencies if you are unable to provide care due to illness or other reasons. This might involve identifying other relatives who can step in, arranging powers of attorney or exploring supported living options for the future. Having these plans can reduce anxiety for everyone.

Important resources and information: Carers

- Importantly, there are resources to support carers in Australia. The Federal Government's Carer Gateway (1800 422 737) is a free service that provides information, coaching, counselling and respite co-ordination for carers
- Organisations such as SANE Australia host online forums specifically for family, friends and carers, where you can anonymously share experiences and advice with others in similar situations. There are also local carer support groups (both general and specific to SCI or another disability) in many communities. Ask a social worker or search via Carers Australia to find one, and
- Financial support may be available through Centrelink, such as the Carer Allowance or Carer Payment, to alleviate some burden (SANE Family, Friends and Carers). The bottom line is that carers need care too. By looking after your own mental health, you will be in a better position to provide compassionate and effective support to your loved one.

Below are several clinical resources to support health practitioners working with people living with SCI. These resources highlight best-practice approaches to providing holistic, integrated and disability-informed care.

Clinical resource: Providing integrated care for SCI

The optimal approach for caring for someone who has sustained SCI is to treat the 'whole person', not just the injury, but the mind and social situation too. This philosophy is being implemented through new psychosocial care guidelines for SCI rehabilitation. In 2023, a three-part guide on the psychosocial care of adults with SCI for health professionals was released in New South Wales, aiming to ensure that people living with SCI receive holistic psychosocial care to enhance their well-being and life goals. The guidelines recommend routine mental health screening, involvement of psychologists in rehabilitation teams, attention to family dynamics and person-centred goal setting that includes psychological adjustment. By integrating such guidelines, rehabilitation programs can catch problems early, for example, detecting if a patient is developing depression during rehabilitation, and intervening in a timely way (Craig, 2025). Early psychological intervention, even as simple as a few sessions of education and coping-skills training soon after the injury, has been shown to reduce long-term distress and improve adjustment (Kennedy & Garman-Jones, 2017). The takeaway is that mental health care should be part and parcel of SCI care, from hospital through to community living. Progress is being made. Many spinal injury units now have dedicated social workers or psychologists. Initiatives such as "Project Thrive" (hypothetical example) focus on mental wellness in addition to physical recovery. Continued advocacy is needed to expand these well-being programs, especially for those living in rural areas or outside formal rehabilitation systems.

Optimal primary care for people living with SCI and their families includes:

- Routine annual comprehensive health evaluation
- Multidisciplinary follow-up to address issues that accompany long-term disability
- Accessible premises that permit full examination of presenting health complaints
- Access to disability-specific expertise in the form of specialists regarding common secondary complications, such as pain, bowel and bladder complications, and
- Increased awareness of areas in which there are often unmet needs, such as psychological concerns, sexual and reproductive health and lifestyle issues.

Clinical resource: Psychosocial care of adults with SCI

The ACI website provides numerous resources for health professionals, such as this Guide: Psychosocial care of adults with spinal cord injury. Recommendations (July 2023). The website provides three scenarios, which are due for review in 2027:

- Scenario 1: Acute care: Max, a 61-year-old man who sustained a T5 injury
- Scenario 2: Rehabilitation: Nancy, a 36-year-old woman who sustained a complete C6 injury, and
- Scenario 3: Community: Kevin, a 37-year-old man with T6 paraplegia.

In summary, well-being after SCI relies on a coordinated blend of daily routines, holistic healthcare, personalised lifestyle habits and strong support from family, carers and community. Focusing on key areas such as nutrition, sleep, physical activity, sunlight, social connection and mental health helps build stability and resilience. Maintaining meaningful relationships reduces isolation and strengthens a sense of belonging, while resilience training and mindfulness-based therapies support emotional balance and coping. Together, these elements create a foundation for better health, greater independence and a more fulfilling life after SCI.

Key Take-aways

- **Daily routines for well-being:** Establishing consistent morning and evening routines supports physical comfort, predictability, independence and emotional stability. Support workers play a vital role in this by being punctual, organised and responsive to the person's goals, which reduces stress and ensures smoother daily care
- **Australia's progress on disability health:** Australia has shown limited progress on health and well-being outcomes for people with disability. Major health gaps persist, with people living with disability reporting poorer overall health, more avoidable deaths and higher psychological distress than the general population
- **Healthcare and professional support:** A coordinated healthcare team is critical to staying well after SCI. GPs are central to preventive care, monitoring system-wide complications and supporting carers; SCI-specific needs require proactive, accessible and integrated care across disciplines.
- **The five pillars of good health and well-being:** Five foundational areas work together to support health and quality of life after SCI: *Nutrition, sleep, physical activity, sun exposure and social connection.* Proper nutrition helps manage inflammation and supports tissue repair and metabolic health. It must be personalised after SCI due to changes in body composition and energy needs. Tailored physical activity improves circulation, muscle tone, independence and mental health, with a combination of strength, aerobic work, hydrotherapy, activity-based therapy and FES offering the best outcomes. High-quality sleep is essential for healing and cognition. Insomnia is common after SCI, but it can be improved with good sleep habits and targeted treatments. Morning sunlight helps regulate circadian rhythms and supports vitamin D synthesis to reduce osteoporosis
- **Maintaining meaningful social connections reduces isolation and fosters a sense of belonging and purpose:**
    - *Nutrition:* Because energy needs and body composition change after SCI, nutrition must be individualised. Dietitians are essential partners for weight management, bowel care and long-term metabolic health, helping to translate evidence and preferences into practical, safe plans.
    - *Sleep:* Sleep is a pillar of well-being and a frequent challenge after SCI. Insomnia commonly arises from pain, spasms, bladder care, temperature dysregulation and hormonal disruption. Consistent routines, minimising nighttime interruptions and targeted treatments, such as melatonin or CPAP for sleep apnoea, can significantly improve sleep quality.
    - *Exercise:* Regular physical activity is essential for physical and mental health, improving fitness, mood, independence and reducing complications. Like much of the population, many people

living with SCI, however, do not meet activity guidelines. A multimodal approach, combining strength training, aerobic exercise, hydrotherapy, activity-based therapy and FES, provides the greatest benefit.
    - *Sunlight and circadian health:* Exposure to morning and afternoon sunlight helps reset the body clock and stabilise sleep and mood. Sunlight also stimulates vitamin D synthesis, which is important for bone health, particularly given the elevated risk of osteoporosis after SCI, and
    - *Social participation:* Social connection is crucial for well-being, yet many people with SCI experience loneliness and the loss of friendships. Deliberately rebuilding participation through peer groups, adaptive sports, hobbies and community involvement helps restore a sense of belonging and purpose

- **Oral health:** Oral health is generally neglected but is important after SCI due to the risk of dry mouth, dental caries and gum disease. Proactive oral hygiene, accessible dental services and carer support are needed to prevent complications and maintain overall health
- **Podiatry and foot health:** Feet and ankles are particularly vulnerable after SCI due to reduced sensation, altered pressure and deformities. Regular podiatry care and daily monitoring help prevent pressure injuries, infections and progressive deformity, protecting mobility and safety
- **Mental health and suicide prevention:** Mental health conditions, especially depression, anxiety and PTSD, are common after SCI but are treatable. Early recognition, GP mental health care plans, psychological therapies, appropriate medications and peer support improve outcomes. Because suicide risk is significantly higher after SCI, particularly in the early years, active screening and timely support are essential
- **Nature and well-being:** Spending time in nature, whether in green spaces like parks or blue spaces near water, can improve mood, reduce stress and support recovery, even when physical activity is limited
- **Additional therapies and resilience:** Mindfulness, acceptance-based approaches, adaptive yoga, music therapy, art therapy and animal-assisted therapy can enhance resilience, mood and coping. SCI-specific resilience programs, such as Engage and ePACT, provide structured, practical tools for strengthening emotional well-being, and
- **Impact on families and carers:** SCI affects the whole family. Carers often experience emotional strain, role changes, burnout and social isolation. They require structured support, accessible respite and mental health resources and should be included as partners in care while also being supported to maintain their own well-being.

In the next chapter, **Chapter 4**, we will explore, amongst other apps, how the Your Health – SCI Health Maintenance Tool (and app) can help you to manage your health and well-being. This tool is part of a broader initiative to empower individuals living with SCI to proactively manage their health. It can be accessed through the SCI Health Toolkit app, which allows users to track symptoms, share care plans with healthcare providers and receive tailored advice.

Reminder: Relevant chapters

- **Chapter 1:** Chapter 3 is the second of four chapters that reflect a 'lifecycle' following release from rehabilitation: Chapter 1 (coming home), **Chapter 3** (staying healthy and well), **Chapter 5** (getting out there to socialise, work, study or volunteer) and **Chapter 6** (ageing with SCI). Chapter 3 thus picks up where Chapter 1 left off
- **Chapter 2:** In terms of what is happening to the body, we hope that through the language used and the pop-up glossary, many people living rurally and regionally will be able to understand
- **Chapter 4:** Documenting health and well-being is important, especially once in the community. Chapter 4 describes how you can create a personal health record (PHR) (paper or electronic) and provides a range of apps that can be used
- **Chapter 5:** Chapter 5 is all about socialising, working and studying and how your physical and physiological needs need to be adapted or accommodated.
- **Chapter 6:** Chapter 6 is the next logical chapter in the coming home life cycle: **Chapter 1** (early period), **Chapter 3** (the health maintenance period) and Chapter 6 (an ageing body, in which natural degenerative changes overlay an anatomically and physiologically different body following SCI)
- **Chapter 7:** Much of the content of **Chapter 3** can be applied to **Chapter 7**, which discusses SCI in children and adolescents. The discussion relating to GPs needing to also look after carers and other family members is particularly relevant to Chapter 7
- **Chapter 8:** This chapter deals with SCI in regional, rural and remote Australia, as well as a section on First Nations communities
- **Chapter 9:** Intersectionality is important when it comes to staying healthy, well and fit because of the stigma that still exists in terms of neurodiversity or identifying as LGBTQI+ or being an immigrant. Being culturally and linguistically diverse (CALD) may affect maintaining good health and well-being for several reasons, including mistrust of Western medicine and difficulty navigating healthcare support due to language or complexity
- **Chapter 10:** Discrimination and abuse relating to disability was the reason for the 2023 Royal Commission. Health and well-being are negatively affected by discrimination and abuse. Chapter 10 also includes a section on sexuality and fertility (sexual health), which is directly relevant to good health and well-being.
- **Chapter 12:** Travelling to and from health services is important to stay healthy and well, but as **Chapter 9** identified, migrants, for example, may not understand Australia's transport system
- **Chapter 13:** The chapter on surgery and anaesthesia provides detailed information about what happens before, during and after surgery. It is likely that people living with SCI will need to undergo surgery at some stage. The Chapter describes the details of the considerations before, during, and after, depending, for example, on whether a person requires ventilation
- **Chapter 14:** Spiritual health is part of good health and well-being. The discussion in Chapter 14 offers some insight into what this might mean for those living with SCI
- **Chapter 15:** Exercise and sport are an important part of life for most individuals. While Chapter 3 describes the exercise aspect, as one of the five pillars of good health and well-being, Chapter 15 explores different levels of parasport
- **Chapter 16:** Research into SCI provides hope that an individual's outcome may improve. Chapter 16 describes the many avenues of SCI research, including how one might become involved, and
- **Chapter 17:** Australia's changing climate will have an impact on everyone, but individuals living with a

SCI are generally considered 'vulnerable' as they are physically less mobile during flooding and fires. Also, a high-level injury could mean loss of temperature regulation, which could be an issue in extreme heat and cold. For anyone who requires ventilation, having back-up power is necessary. Chapter 17 will highlight the need for an emergency plan for adverse weather events, relevant to the context of where you reside.

References

All, A. H., Liu, X., Luo, S., Xu, H., & Zuo, Y. (2020). A review of functional electrical stimulation treatment in spinal cord injury. *Neuromolecular Medicine, 22*, 447-463. https://doi.org/10.1007/s12017-019-08589-9

Allison, D. J., Thomas, A., Beaudry, K., & Ditor, D. S. (2016). Targeting inflammation as a treatment modality for neuropathic pain in spinal cord injury: a randomized clinical trial. *Journal of Neuroinflammation*, *13*(1), 152. https://doi.org/10.1186/s12974-016-0625-4

Arya, P. (2024). Integrating mindfulness-based yoga practices in the psychological rehabilitation of spinal cord injury patients: A longitudinal study. *Educational Administration: Theory and Practice*, *30*(6), 4529-4537. https://doi.org/10.53555/kuey.v30i6.7652

Australian Institute of Health and Welfare. (2026). *Australia's Disability Strategy 2021–2031 Outcomes Framework: 4th annual report. C*atalogue number ADS 7. Australian Government. https://www.aihw.gov.au/reports/australias-disability-strategy/australias-disability-strategy-2021-2031-outcomes/contents/about

Bagdesar, M., Samuel, R., Brown, T. D. G., Shetty, S., Kaur, J., Kong, A. C., George, A., & Ajwani, S. (2025). Integrated oral care for patients with spinal cord injuries: perceptions of non-dental professionals. *Disability and rehabilitation*, *47*(5), 1266–1275. https://doi.org/10.1080/09638288.2024.2367599

Bombardier, C. H., Azuero, C. B., Fann, J. R., Kautz, D. D., Richards, J. S. & Sabharwal, S. (2021). Management of mental health disorders, substance use disorders, and suicide in adults with spinal cord Injury: Clinical practice guideline for healthcare providers. *Topics in Spinal Cord Injury and Rehabilitation, 27*(2), 152-224. https://doi.org/10.46292/sci2702-152

Borg, S. J., Borg, D. N., Arora, M., Middleton, J. W., Marshall, R., Nunn, A., & Geraghty, T. (2024). Unmet healthcare needs, access to services and experiences with health providers among persons with spinal cord injury in Australia. *Spinal Cord*, *62*(7), 396-405. https://doi.org/10.1038/s41393-024-00997-4

Brochetti, A. M., Brose, S. W., Kuemmel, A. M., Dang, D. J., & Bourbeau, D. J. (2018). Interdisciplinary bodyweight management program for persons with SCI. *The Journal of Spinal Cord Medicine*, *43*(1), 24–30. https://doi.org/10.1080/10790268.2018.1547860

Buchholz, A. C., McGillivray, C. F., & Pencharz, P. B. (2003). Differences in resting metabolic rate between paraplegic and able-bodied subjects are explained by differences in body composition. *American Journal of Clinical Nutrition*, *77*(2), 371-378. https://doi.org/10.1093/ajcn/77.2.371

Buchholz, A. C., & Pencharz, P. B. (2004). Energy expenditure in chronic spinal cord injury. *Current Opinion in Clinical Nutrition & Metabolic Care*, *7*(6), 635-639. https://journals.lww.com/co-clinicalnutrition/fulltext/2004/11000/energy_expenditure_in_chronic_spinal_cord_injury.8.aspx

Buzzell, A., Chamberlain, J. D., Gmünder, H. P., Hug, K., Jordan, X., Schubert, M., Brinkhof, M. W. G., & for the SwiSCI Study Group (2019). Survival after non-traumatic spinal cord injury: evidence from a population-based rehabilitation cohort in Switzerland. *Spinal Cord*, *57*(4), 267-275. https://doi.org/10.1038/s41393-018-0212-x

Castro, M. J., Apple, D. F., Hillegass, E. A., & Dudley, G. A. (1999). Influence of complete spinal cord injury on skeletal muscle cross-sectional area within the first 6 months of injury. *European Journal of Applied Physiology and Occupational Physiology, 80*(4), 373-378. https://link.springer.com/article/10.1007/s004210050606

Chun, S. M., Kim, H-R., & Shin, H. I. (2017). Estimating the Basal metabolic rate from fat-free mass in individuals with motor complete spinal cord injury. *Spinal Cord, 55*, 844-847. https://www.nature.com/articles/sc201753

Cimino, S.R., Cadel, L., Cuilcher, S. J. T., Wasilewski, M. & Hitzig, S. L. (2022). Social disconnectedness and perceived social isolation in persons with spinal cord injury/dysfunction living in the community: A scoping review. *Journal of Spinal Cord Medicine*, *46*(3). https://doi.org/10.1080/10790268.2022.2129170

Clifton, S., Bray, E. Dong, S. McCabe R., & Siddall, P. (2024). Co-design of an intervention exploring meaning and purpose after spinal cord injury. *Disability and Rehabilitation*, *46*(22), 5243-5252. https://doi.org/10.1080/09638288.2023.2300655

Cox, S. A., Weiss, S. M., Posuniak, E. A., Worthington, P., Prioleau, M., & Heffley, G. (1985). Energy expenditure after spinal cord injury: an evaluation of stable rehabilitating patients. *Journal of Trauma*, *25*(5), 419-423. https://journals.lww.com/jtrauma/Abstract/1985/05000/Energy_Expenditure_after_Spinal_Cord_Injury__An.8.aspx

Cragg, J. J., Noonan, V. K., Krassioukov, A., & Borisoff, J. (2013). Cardiovascular disease and spinal cord injury: results from a national population health survey. *Neurology*, *81*(8), 723-728. https://doi.org/10.1212/WNL.0b013e3182a1aa68

Craig, A. (2025). The Sir Ludwig Guttmann lecture 2023: psychosocial factors and adjustment dynamics after spinal cord injury. *Spinal Cord, 63*, 194-200. https://doi.org/10.1038/s41393-025-01060-6

Crane, D. A., Little, J. W., & Burns, S. P. (2011). Weight gain following spinal cord injury: a pilot study. *Journal of Spinal Cord Medicine*, *34*(2), 227-232. https://doi.org/10.1179/2045772311y.0000000001

Curtis, K., L., H. S., Gitte, B., Candice, S., Charlene, A., Nicole, S., Nicole, L., & Katz, J. (2017). Evaluation of a specialized yoga program for persons with a spinal cord injury: a pilot randomized controlled trial. *Journal of Pain Research*, *10*, 999-1017. https://doi.org/10.2147/JPR.S130530

DeVivo, M. & Farris, V. (2011). Causes and costs of unplanned hospitalizations among persons with spinal cord injury. *Topics in Spinal Cord Injury Rehabilitation*, *16*(4): 53-61. https://doi.org/10.1310/sci1604-53

Deznarnaulds, D, Tonkin, H., Catherine Ephraums, C., Middleton, J. Ommanney, X., Perry, K. N., Berelowitz, B. Coren, D., Harvey, T., Hales, A., Smith, J., Sarandrea, A. M., Fosebrook, S., Mckinnon, N., & Cowen, L. (2016. *Emotional wellbeing toolkit. A clinician's guide to working with spinal cord injury.* New South Wales Agency for Clinical Innovation. https://aci.health.nsw.gov.au/__data/assets/pdf_file/0005/326435/ACI-Emotional-wellbeing-toolkit-working-spinal-cord-injury.pdf

Dietitians of Canada. (2023). *What is the effectiveness of dietary strategies to manage neurogenic bowel?*. PEN: Practice-based Evidence in Nutrition. https://www.dietitians.ca/Learn/PEN-Practice-based-Evidence-in-Nutrition%C2%AE

Edwards, G., Dorstyn, D., & Oxlad, M. (2025). Health literacy in adults with a spinal cord injury or disorder: An updated and expanded systematic review. *Disability and Health Journal, 18*(3), 101821. https://doi.org/10.1016/j.dhjo.2025.101821

Ellapen, T. J., Hammill, H. V., Swanepoel, M., & Strydom, G. L. (2018). The benefits of hydrotherapy to patients with spinal cord injuries. *African Journal of Disability*, *7*, a450. https://doi.org/10.4102/ajod.v7i0.450

Faleiros, F., Binati, F., Bimbatti, K., elly Graziani Giacchero Vedana, K. G. G., Jonas Carvalho e Silva, J., de Oliveira Käppler, C., Sousa, L., José, H., Rabiais, I. & Almeida, A. (2023). Suicidal ideation in people with traumatic spinal cord injury. *Psychiatry International, 4*(4), 394-404. https://doi.org/10.3390/psychiatryint4040035

Farkas, G. J., Gorgey, A. S., Dolbow, D. R., Berg, A. S., & Gater, D. R. (2019). Caloric intake relative to total daily energy expenditure using a spinal cord injury-specific correction factor: An analysis by level of injury. *American Journal of Physical Medicine and Rehabilitation*, *98*(11), 947-952. https://doi.org/10.1097/phm.0000000000001166

Farkas, G. J., Pitot, M. A., & Gater Jr, D. R. (2019). A systematic review of the accuracy of estimated and measured resting metabolic rate in chronic spinal cord injury. *International Journal of Sport Nutrition and Exercise Metabolism*, *29*(5), 548-558. https://doi.org/10.1123/ijsnem.2018-0242

Fatima, G., Sharma, V.P., & Shukla, R. (2009). Circadian rhythm in patients with spinal cord injury. *Annals of Neurosciences*, 16(1). https://annalsofneurosciences.org/journal/index.php/annal/article/viewArticle/44/993

Franzò, M., De Angelis, S., Iosa, M., Tieri, G., Corsini, G., Cellupica, G. G., Loi, V., Bini, F., Marinozzi, F. Scivoletto, G. & Tamburella, F. (2025). Applying a virtual art therapy system based on the Michelangelo effect in patients with spinal cord injury. *Sensors, 25*(13), 4173. https://doi.org/10.3390/s25134173

Gillani, S. Y. U. H. S., Iftikhar, S., Bajwa, A. F., & Baloch, T. A. (2023). Prevalence and severity of restless leg syndrome in patients with spinal cord injuries. *Journal of the Pakistani Medical Association, 73*(3), 471-475. https://pubmed.ncbi.nlm.nih.gov/36932744/

Gater, D. R., Jr, Farkas, G. J., & Tiozzo, E. (2021). Pathophysiology of neurogenic obesity after spinal cord injury. *Topics in Spinal Cord Injury Rehabilitation*, *27*(1), 1-10. https://doi.org/10.46292/sci20-00067

Gorgey, A. S., Dolbow, D. R., Dolbow, J. D., Khalil, R. K., Castillo, C., & Gater, D. R. (2014). Effects of spinal cord injury on body composition and metabolic profile – part I. *J Spinal Cord Med*, *37*(6), 693-702. https://doi.org/10.1179/2045772314y.0000000245

Gorgey, A. S., Mather, K. J., Cupp, H. R., & Gater, D. R. (2012). Effects of resistance training on adiposity and metabolism after spinal cord injury. *Medicine and Science in Sports and Exercise*, *44*(1), 165-174. https://doi.org/10.1249/MSS.0b013e31822672aa

Gross-Hemmi, M. H., Fekete, C., Post, M. W. M., Reinhardt, J. D., Pacheco, D., Ehrmann, C., Bickenbach, J., & InSCI Group. (2019). First results from the International Spinal Cord Injury (InSCI) Survey. Swiss Paraplegic Research. https://www.swisci.ch/images/InSCI/News/InSCI_posterA0_17Oct2019_final.pdf

Graco, M., Arora, M., Berlowitz, D. J., Craig, A., & Middleton, J. W. (2023). The impact of sleep quality on health, participation and employment outcomes in people with spinal cord injury: Analyses from a large cross-sectional survey. *Annals of Physical and Rehabilitation Medicine, 66*(5), 101738. https://doi.org/10.1016/j.rehab.2023.101738

Hodgekiss, D. D., Bhangau, G. S., Lunny, C., Jutzeler, C. R., C, S-Y., Walter, M., Lucas, S. J. E., Krassioukow, A. V., & Nightingale, E. E. (2023). Exercise and aerobic capacity in individuals with spinal cord injury: A systematic review with meta-analysis and meta-regression. *PLOS Medicine, 20*(11), e1004082. https://doi.org/10.1371/journal.pmed.1004082

International Spinal Cord Injury Survey (InSCI). (2024a). *International Spinal Cord Injury Survey.* Swiss Paraplegic Research. https://insci.network/

International Spinal Cord Injury Survey (InSCI). (2024b). *International Spinal Cord Injury Survey Infographics.* Swiss Paraplegic Research. https://insci.network/ and https://insci.network/infographics

Kaiser, A., Chan, K., Pakosh, M., & Musselman, K. E. (2020). Characteristics of activity-based therapy interventions for people living with spinal cord injury or disease across the continuum of care: a scoping review protocol. *BMJ)pen*, *10*(7), e040014. https://doi.org/10.1136/bmjopen-2020-040014

Kearns, P. J., Thompson, J. D., Werner, P. C., Pipp, T. L., & Wilmot, C. B. (1992). Nutritional and metabolic response to acute spinal-cord injury. *JPEN. Journal of parenteral and enteral nutrition*, *16*(1), 11-15. https://doi.org/10.1177/014860719201600111

Kennedy, P., & Garmon-Jones, L. (2017). Self-harm and suicide before and after spinal cord injury: a systematic review. *Spinal Cord*, *55*(1), 2-7. https://doi.org/10.1038/sc.2016.135

Khong, C. M., Chan, J., Pasipanodya, E., Dirlikov, B., & Shem, K. (2023). Risk factors associated with suicidal ideation in individuals with spinal cord injury. *Archives of Rehabilitation Research and Clinical Translation*, *5*(3), 100284. https://doi.org/10.1016/j.arrct.2023.100284

Laughton, G. E., Buchholz, A. C., Martin Ginis, K. A., & Goy, R. E. (2009). Lowering body mass index cutoffs better identifies obese persons with spinal cord injury. *Spinal Cord*, *47*(10), 757-762. https://doi.org/10.1038/sc.2009.33

LaVela, S. L., Motl, R. W., Berryman, K., Wirth, M., Bartle, B., Aguina, K., Solanki, P., & Bombardier, C. H. (2024). Facilitators to alleviate loneliness and social isolation as identified by individuals with spinal cord injuries and disorders: A qualitative study. *Rehabilitation Psychology*, *69*(3), 264-274. https://doi.org/10.1037/rep0000540

Laven, G. T., Huang, C. T., DeVivo, M. J., Stover, S. L., Kuhlemeier, K. V., & Fine, P. R. (1989). Nutritional status during the acute stage of spinal cord injury. *Archives of Physical Medicine and Rehabilitation*, *70*(4), 277-282. https://www.archives-pmr.org/article/0003-9993(89)90145-7/abstract

Lee, R., McBride, C., & Claydon, V. (2025). Sleep routines and sleep disturbances after spinal cord injury: Insights from a community survey. *Free Sleep, 48*(Supplement_1), A562. https://doi.org/10.1093/sleep/zsaf090.1306

Lomas, S., & Williams, S. (2009). *Spinal cord injuries Australia and the Australian New Zealand Spinal Cord Injury Network's response to the Senate Community Affairs References Committee inquiry into suicide in Australia.* https://www.aph.gov.au/~/media/wopapub/senate/committee/clac_ctte/completed_inquiries/2008_10/suicide/submissions/sub90_pdf.ashx

Madhusmita, M., Ebnezar, J., Srinivasan, T., Mohanty, P., Singh, D., & Pradhan, B. (2019). Efficacy of yoga as an add-on to physiotherapy in the management of patients with paraplegia: Randomised controlled trial. *Journal of Clinical and Diagnostic Research*, *13*. https://doi.org/10.7860/JCDR/2019/40429.12724

Mann, L., Middleton, J. W., & Leong, G. (2007). Fitting disability into practice. *Australian Family Physician, 36*(12), 1039-1042. https://www.racgp.org.au/getattachment/09d01ef8-fa85-4db4-9303-49e23bb6cbe9/200712Mann.pdf.

Marquez-Chin, C., & Popovic, M. R. (2020). Functional electrical stimulation therapy for restoration of motor function after spinal cord injury and stroke: a review. *BioMedical Engineering OnLine, 19*, 34. https://doi.org/10.1186/s12938-020-00773-4.

Mercier, L. J., Grant, C., Langelier, D. M., & Plamondon, S. (2023). Scoping review of music therapy and music interventions in spinal cord injury. *Disability and Rehabilitation*, *45*(10), 1736-1749. https://doi.org/10.1080/09638288.2022.2073391

Middleton, J. W., Arora, M., Kifley, A., Clark, J., Borg, S. J., Tran, Y., Atresh, S., Kaur, J., Shetty, S., Nunn, A., Marshall, R., & Geraghty, T. (2022). Australian arm of the International Spinal Cord Injury (Aus-InSCI) Community Survey: 2. Understanding the lived experience in people with spinal cord injury. *Spinal Cord, 60*, 1069-1079. https://doi.org/10.1038/s41393-022-00817-7

National Spinal Cord Injury Statistical Center. (2024) *Annual statistical report for the Spinal Cord Injury Model Systems.* University of Alabama at Birmingham: Birmingham, Alabama. https://bpb-us-w2.wpmucdn.com/sites.uab.edu/dist/f/392/files/2025/02/2025-Facts-and-Figures.pdf

Nas, K., Yazmalar, L., Şah, V., Aydın, A., & Öneş, K. (2015). Rehabilitation of spinal cord injuries. *World Journal of Orthopedics*, *6*(1), 8-16. https://doi.org/10.5312/wjo.v6.i1.8

Nevin, A. N., Steenson, J., Vivanti, A., & Hickman, I. J. (2016). Investigation of measured and predicted resting energy needs in adults after spinal cord injury: a systematic review. *Spinal Cord*, *54*(4), 248-253. https://doi.org/10.1038/sc.2015.193

Nevin, A. N., Urquhart, S., Atresh, S. S., Geraghty, T. J., Walter, E., Ryan, E. G., Vivanti, A., Ward, L. C., & Hickman, I. J. (2023). A longitudinal analysis of resting energy expenditure and body composition in people with spinal cord injury undergoing surgical repair of pressure injuries: a pilot study. *European Journal of Clinical Nutrition*, *77*(3), 386-392. https://doi.org/10.1038/s41430-022-01248-6

Nevin, A. N., Dwyer, K., Atresh, S. S., Vivanti, A., Hickman, I. J., & Banks, M. (2025). Nutritional intakes of people with spinal cord injury who have pressure injuries in hospital: A secondary analysis of a randomized controlled trial. *Topics in Spinal Cord Injury Rehabilitation*, *31*(1), 17-29. https://doi.org/10.46292/sci24-00003

Nunn, A., Bragge, P., Goodwin, D., & Bryne, C. (2018). *Output report: Optimal bladder health following spinal cord injury.* Project 138. Austin Health, ISCRR. https://research.iscrr.com.au/__data/assets/pdf_file/0005/1575653/138-Optimal-Bladder-Health.pdf

Park, A. J., Battaglino, R. A., Nguyen, N. M. H., & Morse, L. R. (2018). Associations between lean mass and leptin in men with chronic spinal cord injury: Results from the FRASCI-muscle study. *PLoS ONE*, *13*(6), e0198969. https://doi.org/10.1371/journal.pone.0198969

Park, J., Kim, J., Eun, S. D., & Kang, D. (2024). Effectiveness of exercise programs for alleviation of upper body pain in patients with spinal cord injury: A systematic review. *Journal of Clinical Medicine, 13*(11), 3066. https://www.mdpi.com/2077-0383/13/11/3066

Pelletier C. (2023). Exercise prescription for persons with spinal cord injury: a review of physiological considerations and evidence-based guidelines. *Applied Physiology, Nutrition, and Metabolism*, *48*(12), 882-895. https://doi.org/10.1139/apnm-2023-0227

Pellicane, A. J., Millis, S. R., Zimmerman, S. E., & Roth, E. J. (2013). Calorie and protein intake in acute rehabilitation inpatients with traumatic spinal cord injury versus other diagnoses. *Topics in Spinal Cord Injury and Rehabilitation*, *19*(3), 229-235. https://doi.org/10.1310/sci1903-229

Peterson, M. D., Kamdar, N., Chiodo, A., & Tate, D. G. (2020). Psychological morbidity and chronic disease among adults with traumatic spinal cord injuries: A longitudinal cohort study of privately insured beneficiaries. *Mayo Clinic Proceedings*, *95*(5), 920-928. https://doi.org/10.1016/j.mayocp.2019.11.029

Reinhardt, J. D., Middleton, J., Bökel, A., Kovindha, A., Kyriakides, A., Hajjioui, A., Kouda, K., InSCI, & Kujawa, J. (2020). Environmental barriers experienced by people with spinal cord injury across 22 countries: Results from a cross-sectional survey. *Archives of Physical Medicine and Rehabilitation*, *101*(12), 2144-2156. https://doi.org/10.1016/j.apmr.2020.04.027

Robinson-Whelen, S., Hughes, R. B., Taylor, H. B., Holmes, S. A., Rodriguez, J., Staggers, K. A., & Minard, C. G. (2025). Understanding loneliness and its correlates among people with spinal cord injury. *Disability and Rehabilitation, 47*(14), 3570-3580. https://doi.org/10.1080/09638288.2024.2428822

Rogers, C. (2014). Treating patients with spinal cord injuries. *Dimensions of Dental Hygiene*. https://dimensionsofdentalhygiene.com/article/treating-patients-with-spinal-cord-injuries/.

Sabour, H., Javidan, A. N., Vafa, M. R., Shidfar, F., Nazari, M., Saberi, H., Rahimi, A., & Emami Razavi, H. (2012). Calorie and macronutrients intake in people with spinal cord injuries: an analysis by sex and injury-related variables. *Nutrition*, *28*(2), 143-147. https://doi.org/10.1016/j.nut.2011.04.007

Samuel, R., Bagdesar, M., Brown, T.D.G., Kong, A. C., Shetty, S., George, A., & Ajwani, S. (2024). Perceptions of patients towards oral health care in a spinal cord injury rehabilitation unit: A qualitative study. *Journal of Oral Rehabilitation*, *51*(9), 1701-1711. https://doi.org/10.1111/joor.13762

Sankari, A., Badr, M. S., Martin, J. L., Ayas, N. T., & Berlowitz, D. J. (2019). Impact of spinal cord injury on sleep: Current perspectives. *Nature and Science of Sleep*, *11*, 219-229. https://doi.org/10.2147/NSS.S197375

Santos, L. V., Pereira, E. T., Reguera-García, M. M., Patrocínio de Oliveira, C. E., & Moreira, O. C. (2022). Resistance training and muscle strength in people with spinal cord injury: A systematic review and meta-analysis. *Journal of Bodywork and Movement Therapies, 29*, 154-160. https://doi.org/10.1016/j.jbmt.2021.09.031

Schultz, K.R., Mona, L.R. & Cameron, R.P. (2022). Mental health and spinal cord injury: Clinical considerations for rehabilitation providers. *Current Physical Medicine and Rehabilitation Reports, 10*, 131-139. https://doi.org/10.1007/s40141-022-00349-4

Soden, R. J., Walsh, J., Middleton, J. W., Craven, M. L., Rutkowski, S. B., & Yeo, J. D. (2000). Causes of death after spinal cord injury. *Spinal Cord*, *38*(10), 604-610. https://doi.org/10.1038/sj.sc.3101080

Sutor, T. W., Kura, J., Mattingly, A. J., Otzel, D. M., & Yarrow, J. F. (2022). The effects of exercise and activity-based physical therapy on bone after spinal cord injury. *International Journal of Molecular Sciences*, *23*(2), 608. https://doi.org/10.3390/ijms23020608

Thibault-Halman, G., Casha, S., Singer, S., & Christie, S. (2011). Acute management of nutritional demands after spinal cord injury. *Journal of Neurotrauma*, *28*(8), 1497-1507. https://doi.org/10.1089/neu.2009.1155

Tough, H., Gross-Hemmi, M., Stringhini, S., Eriks-Hoogland, I., & Fekete, C. (2022). Who is at risk of loneliness? A cross-sectional recursive partitioning approach in a population-based cohort of persons with spinal cord injury. *Archives of Physical Medicine and Rehabilitation, 103*(2), 305-312. https://doi.org/10.1016/j.apmr.2021.08.018

Tweedy, S.M., Beckman, E.M., Geraghty, T.J., Theisen, D., Perret, C., Harvey, L.A., & Vanlandewijck, Y.C. (2017). Exercise and sports science Australia (ESSA) position statement on exercise and spinal cord injury. *Journal of Science and Medicine in Sport, 20*(2), 108-115. https://www.jsams.org/article/S1440-2440(16)00032-3/fulltext

Watson, P. K., Arora, M., Middleton, J. W., Quel de Oliveira, C., Heard, R., Nunn, A., Geraghty, T., Marshall, R., & Davis, G. M. (2022). Leisure-time physical activity in people with spinal cord injury-predictors of exercise guideline adherence. *International Journal of Public Health*, *67*, 1605235. https://doi.org/10.3389/ijph.2022.1605235

Yousefifard, M., Ramezani, F., Faridaalaee, G., Baikpour, M., Madani Neishaboori, A., Vaccaro, A. R., Hosseini, M., & Rahimi-Movaghar, V. (2022). Prevalence of posttraumatic stress disorder symptoms following traumatic spinal cord injury: A systematic review and meta-analysis. *Harvard Review of Psychiatry*, *30*(5), 271-282. https://doi.org/10.1097/HRP.0000000000000340

Zadra, A., Bruni, S., DE Tanti, A., Saviola, D., Ciavarella, M., Cannavò, G., & Bonavita, J. (2024). Life expectancy and long-term survival after traumatic spinal cord injury: a systematic review. *European Journal of Physical and Rehabilitation Medicine*, *60*(5), 822-831. https://doi.org/10.23736/S1973-9087.24.08462-4

Zengul, A. G., Ferguson, C. C., Rimmer, J. H., Cofield, S. S., Davis, E. N., Hill, J. O., & Thirumalai, M. (2025). Expert-reviewed nutritional guidance for adults with spinal cord injury: A Delphi study. *Nutrients*, *17*(9), 1520. https://doi.org/10.3390/nu17091520

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Chapter 4. Keeping Track of your Health and Well-being

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"Life in a chair isn't always easy, but I promise that you can get stronger to handle so much of what you're facing. Keep up the fight!"

Amberley Snyder, an American professional rodeo athlete, motivational speaker and advocate after SCI in 2010. Her journey inspired the 2019 Netflix biopic, Walk. Ride. Rodeo.

Chapter 3 provided information on how to stay healthy and well once home from SCI rehabilitation. As you learn more about how your body now works, you will become more confident in managing your health issues and know when to engage health professionals to address your needs. Many people living with SCI become experts in their own health. Keeping a record of your health and well-being is helpful and can prevent hospitalisation. Thus, keeping track of your health and well-being is important as it allows you to:

1. Become familiar with your 'new normal' way of living with SCI
2. Detect changes early, as small differences can herald larger problems, and
3. Create a health record for family, friends, carers and health professionals when you require support or treatment.

There are many ways to keep track of your health and well-being. Paper-based records can be effective. The main advantages include:

- Being able to organise them in a way that makes sense to the person
- Immediate accessibility without the need to request records from health providers
- Durability, if there are changes in digital platforms and technological obsolescence, and
- The ability to include materials such as journal entries and art pieces, which may more accurately reflect health and well-being than can be captured electronically.

The disadvantages of paper-based records, however, are that they:

- Can easily become bulky and disorganised
- Are susceptible to environmental threats such as fire, flooding and pests, and
- Are difficult to access at a distance, such as when they have been accidentally left at

home or need to be provided to someone abroad.

For these reasons, some people use a combination of paper-based and electronic methods to track and document their health and well-being. Increasingly, however, the healthcare system is becoming digital, meaning that at some point, no paper documentation will be issued. It is likely that you are already receiving your e-scripts on your mobile phone or device, probably via SMS.

Key Topics in this Chapter

- How to use health documentation records
- Key considerations when recording your health and well-being
- Digital health record tools for general health, including how to make the most of the Australian Government's My Health Record as a personal health record (PHR), the Health Maintenance Tool, MyNDIS and other platforms
- Digital tools for managing medications, such as MediSafe and MedAdvisor
- Digital care coordination apps, including Caring Village, IANA (I Am Not Alone) Care and Hibi
- Digital health record tools for nutrition, such as Easy Diet Diary, FoodSwitch and others, and
- Additional useful documentation and tracking resources.

4.1. How to use health documentation records

It is important to understand your health and what 'normal' looks like for you. SCI can significantly alter how symptoms, emotions and needs such as hunger, thirst and fatigue are experienced. A daily health and well-being check-in can help establish a baseline, detect variations that may require action, and manage the immense number of new things a person living with

SCI needs to consider, from sleep and appetite to pain, medication, mobility, hygiene, pressure injury prevention, and more.

It is equally important to find what works for you. Recommendations from others with SCI are helpful, but everyone is different, so experiment. One person may thrive with an integrated system using wearable technologies such as smartwatches and pedometers, recording data in real time to an AI-driven dashboard that provides personalised health coaching. Another person may find that simpler is better and they thrive with 'hard copy' health reminders, such as calendars, notebooks and colour-coded charts.

A comprehensive health record provided by a patient can be immensely helpful to a healthcare provider, but they are unlikely to have time to read the entire record. When preparing for an appointment, use the health record to briefly summarise key information such as relevant diagnostic tests, previous treatments for the same condition, allergies and side-effects of medications. It can be useful to note down questions or concerns in advance. Consider sharing the summary, questions and concerns with a support person so that you can both advocate effectively for your needs during the appointment.

Remember that health records, no matter how comprehensive, are only an adjunct to your health. A 'normal' result or measure must never dissuade you from seeking appropriate help if you feel that something is wrong.

Finally, do not forget to celebrate your progress! Health records are a great way to document small wins, acts of self-kindness, creative projects and positive feedback from others.

4.2. Keeping a paper health record

The Internet abounds with websites, social media posts and YouTube videos containing useful suggestions for organising paper medical records. Resources range from generic formats resembling hospital records to specialised requirements such as mental health care plans or toileting charts. Methods for storing paper charts range from clear document wallets and ring-binders to vertical filing systems.

Important resources and information: Checklist of baseline data needed

Below is a **checklist of baseline data recommended for a personal medical record** (Johns Hopkins Medicine, 2021; Sarwal & Gupta, 2025; Schladen *et al.*, 2017):

- Your medical history
- Your family's relevant medical history (especially things that seem to 'run in the family', such as early heart disease or cancers)
- Immunisation status
- Blood type
- Who to contact in the event of an emergency
- Insurance information
- A list of your regular health providers and their contact details
- Historical and ongoing medications, including over-the-counter and alternative treatments; medication allergies and side-effects
- Past medical diagnoses and surgical interventions
- Correspondence or notes from appointments with healthcare providers
  Discharge summaries
- Test results: Laboratory, radiology, functional testing, and
- Legal documents, such as a will, an ***advance care directive*** or a power of attorney. **Chapter 11** discusses legal healthcare issues

Additional **useful suggestions** include:

- Creating a one-page cheat sheet at the front that provides a time-critical summary, such as information needed by emergency providers
- Including a separate section for recent records (such as those from the past year), as these are more likely to be required for quick access
- Adding an 'About Me' page to list your likes, dislikes, passions and preferences, helping new care providers understand you beyond your clinical records, and
- Preparing an 'If I Am Not at Home' page to help family, friends or your care community manage tasks such as watering plants, feeding pets and collecting mail while you are away.

Good health and well-being, however, are more than medical data. Keeping a journal, creating art, dictating a book, and finding time to help others are all ways you can document, track, and maintain your holistic health and well-being. The options are limited only by your creativity.

4.3. Important considerations about recording your health and well-being

In terms of maintaining a record of your health and well-being as a 'health record', either electronically or on paper, below are some important considerations when choosing different formats:

- **Clear identification of whose health record:** This is to avoid care errors arising from similar names, wrong uploads or accidental conflation of you with someone else (a particular hazard of AI). Best practice is at least three points of identification, such as name, date of birth, and a unique identifier, such as the Australian Government's My Health

Record Individual Healthcare Identifier (IHI) 16-digit number. Clear identification of a paper record helps it to be returned to you if it is misplaced. To avoid identity theft or strangers knowing where you live, you may want to limit the identification in a paper record to your name and non-locatable details, such as a phone number or email. You may also prefer to remove identifiers such as your home address from the documentation

- **Data security:** While a breach of security can occur with paper records, for example, if your patient folder is stolen, a data breach is a more common problem with electronic records. In 2025, large-scale Australian data breaches affecting millions of users included Medibank, MediSecure (e-scripts), Melbourne Heart Group, Eastern Health and the NT Ambulance Service. It is not always possible for individuals to avoid corporate data breaches, but you can develop good habits by choosing reputable providers, opting out of sharing data with third parties (often offered through advertising or 'personalisation' services) and deleting all data, not just the app or account, when you stop using an app
- **Control of privacy:** This is relatively easy for paper records if you have the capacity to give consent. For electronic records, there are often mechanisms to control who can see the record, what they can see and for how long they can see it. For security reasons, you may prefer to use features such as two-factor authentication, end-to-end encryption or secure upload portals, such as those offered by some GPs, when sharing health information
- **Access:** This is often a tricky balance between privacy and control. The question remains: *"How can you maintain the privacy of things that may be very personal to you, while maintaining appropriate access, for example, when needed by emergency providers if you are incapacitated?"* The preferred balance between access and privacy varies from person to person. Make sure to consider your preferences, have the necessary discussions, and put in place documentation and systems that reflect your choices
- **Usability:** This will reflect your individual function and needs. Most importantly, the record or app's structure must make sense to you and be easy to navigate. For a paper record, considerations might also include whether you can print from electronic copies, whether you need modified pens or other assistive devices to take notes, and whether upright or elevated reading platforms can help. For electronic recording apps, considerations include whether you can add notes using your preferred method, such as typing, voice control or eye tracking, whether it has accessibility features such as large type for readability or TTS (text-to-speech) and whether it is available for your preferred device
- **Features:** A paper record primarily stores data. Electronic records, however, can have added functionality which may be helpful, such as the ability to track markers (heart rate and blood pressure), provide alerts for abnormal measurements or regularly send updates to a carer. Also consider whether the app should integrate with other apps, devices or platforms you use, such as Google, and
- **Longevity:** This is usually not a consideration for paper records, which will outlive multiple generations of software and obsolete devices. For electronic records, it may not be a consideration if the record is for a short-term project, such as a weight loss plan. For many healthcare needs, however, app longevity is desirable. Indicators of likely longevity include a strong track record, a reputable developer, regular software updates (especially

to maintain security), good customer support, and positive online reviews. Keep in mind that 'longevity' in electronic terms is generally no more than 5-10 years. An additional consideration is that Australian healthcare providers are required to maintain records for seven years (or until age 25 for children). There are a few exceptions in which records can be retained for longer periods, such as for ongoing research or medico-legal proceedings.

Important resource and information: What if my healthcare provider moves, retires or dies?

If a healthcare provider moves, retires or dies, the process may become complex, with procedures varying by state. For example, here is the advice from the Medical Council of New South Wales: Continuity of care and accessing your medical records: what you can do. For these reasons, it is recommended to obtain copies of records contemporaneously or as soon after the event as possible. The longevity of a patient's healthcare record may well exceed that of the healthcare provider.

- **Pricing:** Many government, charity and non-profit health record apps are free. Fee-paying apps may offer a free option with advertising, plus upgrades that remove or reduce ads for a one-off fee or an ongoing subscription. Be wary of apps that sell products, have a conflict of interest (gain monetary or other advantage from having access to your health data, for example, by providing insurance or equipment), make unlikely health claims or require unusual permissions. There is usually no good reason for a health record app to need access to your contacts.

4.4. Digital health record tools: General health

Digital health record tools are difficult to recommend because of the longevity issues discussed above. Even longstanding apps and government resources may move location, be renamed or have a more recent update available. The following list is therefore only indicative. The links are current as of the e-resource publication date (March 2026).

4.4.1. The Australian Government's My Health Record

The Australian Government has developed a personal health record (PHR) called My Health Record, which is a secure consumer-controlled national electronic health record system that contains an online summary of an individual's key health information. A PHR is thus a collection

of electronic health data drawn from multiple sources and managed by the patient, allowing the individual to be proactive in coordinating their care.

This is an opt-out service. Health providers are mandated to upload key information, including diagnostic results, immunisations, prescriptions and discharge summaries. Your personal My Health Record can be accessed through the web-based MyGov portal after linking your Medicare card or via the 1800MEDICARE app (My Health from 1 January 2026). My Health Record allows providers to quickly see critical information if you are unable to communicate and avoids unintended care errors, such as side-effects from an interaction with a medication prescribed by a different health professional. My Health Record, however, does not capture all health information, especially from private or informal providers, and requires a moderate level of digital literacy to navigate.

Video: Introduction to My Health Record

This 22-minute Introduction to My Health Record outlines the features of My Health Record.

Important resource and information: My Health Record website

To read more about My Health Record, visit the Australian Government Department of Health, Disability and Ageing's My Health Record webpage. For additional guidance, including how to get started and download the app, see their informative and user-friendly website.

4.4.2. SCI Health Maintenance Tool

The University of Sydney, in partnership with Royal Rehab, NSW Health Clinical Innovation, the NSW Northern Sydney Local Health District and funded by ICARE, developed the Health Maintenance Tool, which provides extensive information for a range of anatomical and physiological functions, including individual care plans for each, which you can download and personalise to share with your GP. It also has a Glossary. You can download the app here (**Figure 4.1**).

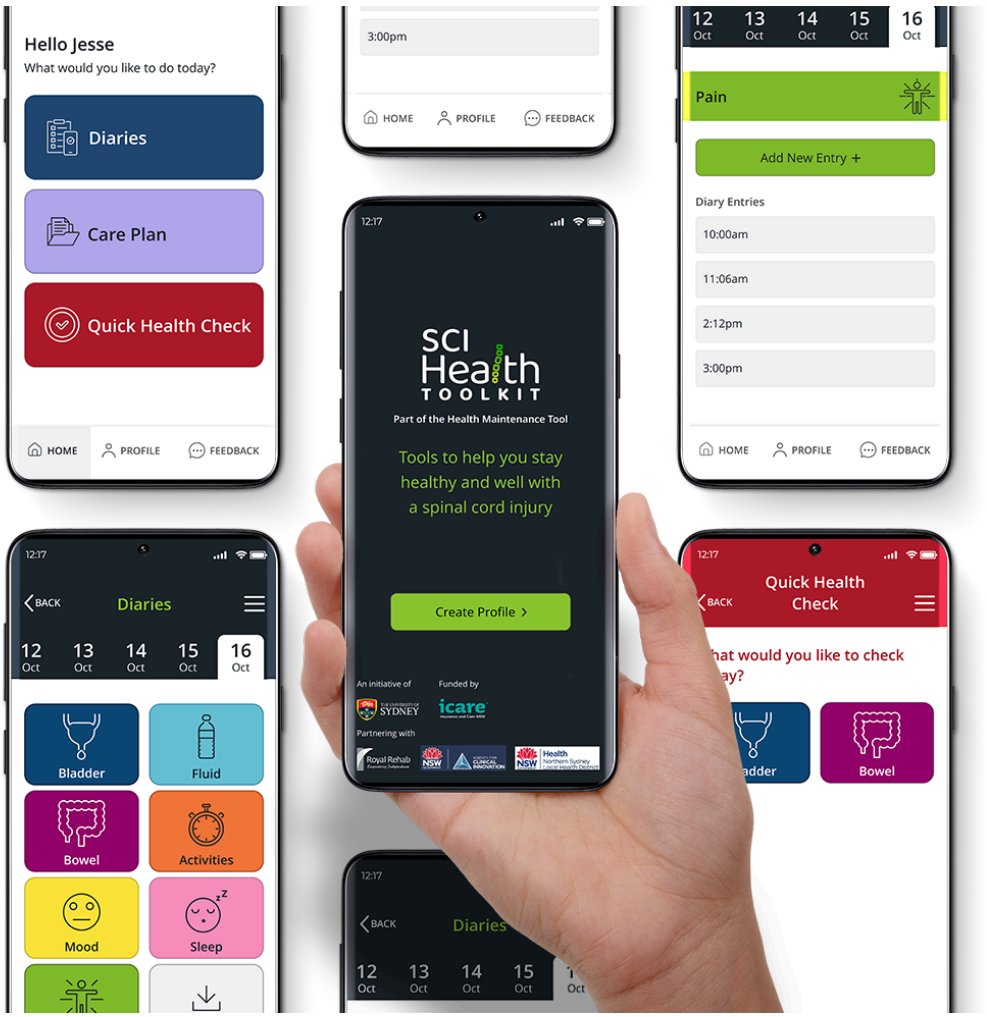

Figure 4.1. SCI Health Maintenance Toolkit app with its various applications. *Source:* Provided by icare NSW.

The information and tools in each key health area work together to support you to:

- Understand your body, health and well-being
- Prevent problems
- Check if you have a problem
- Check how severe the problem is
- Manage problems, and
- Track health patterns and problems.

The website also provides information on the following that you can access via the app.

Important resources and information: SCI Health Maintenance Tool health modules

The links below are to the various module documents:

- Your mental health
- Your bladder
- Your bowel
- Your skin
- Your pain
- Autonomic dysreflexia; and
- All six modules.

The **Health Maintenance Tool** website offers a Quick Health Check (see the top-right corner), which, when you click it, asks: *"What would you like to check today, for example: Bladder? Bowel? Skin? Pain?"* Below is an example of a care plan for pressure injuries. The process involves:

1. **Identifying the problem:** Answering simple questions to recognise potential health issues
2. **Assessing severity:** Evaluating how serious the problem is
3. **Determining interference:** Understanding how much the problem affects daily life; and
4. **Taking action:** Based on the severity and interference, the tool recommends whether to self-manage or seek professional healthcare support.

In each section of Your Health, there is a 'Prevent Problems' section that provides helpful tips and guidance on how to self-manage issues early and when to engage a health professional, so a small health issue doesn't become a bigger problem. The Mental Wellbeing section provides you with tools and tips on how to navigate the different needs you will experience from when you are first injured to later on, once you have 'lived experience with SCI'.

The diary section is particularly useful.

Figure 4.2. Screenshots of the diary section of the Health Maintenance Tool.

4.4.3. MyNDIS

The most valuable aspects of the MyNDIS app are that it allows participants to view their budget, access plan information, and manage claims for self-managed plans.

4.4.4. Patient Passport

Patient Passport is a privately developed app for the Australian context. It includes health records, appointment management, medication tracking, vital sign monitoring, secure sharing

with health providers, and a notification function. It can also be accessed through both the app and the web-based portal.

4.4.5. Manage My Care (Western Australia, WA)

This app allows patients and carers to track their WA Health public appointments and referrals. Manage My Care can also be used to request changes to patient information and, for participating clinics, to reschedule or cancel an appointment.

4.5. Digital health record tools: Medications

Below are a few examples of digital apps for recording medications.

4.5.1. Medisafe

This is a US-based app with good reviews from Australian users. It compiles prescriptions and has an internal AI that notifies of possible interactions between medications. The app can send dosing reminders and missed-dose alerts to a contact or carer and can also 'gamify' medication adherence by providing visual charts of daily, weekly, or monthly medication completeness. The app has been the market leader and free for some years, but it introduced a subscription model on 1 January 2026, with a monthly fee of approximately AUD$8-10, depending on the exchange rate and payment method. A reasonable free equivalent will likely emerge in the app market through 2026.

4.5.2. MedAdvisor

MedAdvisor is an Australian-based app that is expanding internationally. It is optimised for the Australian setting. Once it is linked to your chosen pharmacy, it will provide a full list of your scripts, when they were filled, and any remaining repeats. It also enables remote access to pharmacy functions such as booking vaccinations and health checks, ordering over-the-counter medications for home delivery, and ordering repeats for later (in-person) collection. For patients with diabetes, it is integrated with the National Diabetes Support and Subsidies system. The app can send reminders when scripts are due to be filled, but not dosing reminders, as it is not a medication adherence app.

4.6. Digital care coordination apps

There are many apps available to help coordinate care. Below are a few recommended options for this purpose.

4.6.1. Caring Village

Caring Village is a dashboard designed for informal and formal carers of seniors to connect and coordinate. It includes a wellness journal, a centralised calendar, a medication list, document storage, customisable care plans, personalised To Do lists and a secure messaging function. It is developed in the US but has good reviews from Australian users. The entry tier is free. This is probably all that an individual Australian user needs. The paid tiers allow for two or more users to link their dashboards together to improve coordination. This may be useful for couples or flatmates who both require care, for example.

4.6.2. IANA (I Am Not Alone) Care

IANACare is designed to help connect and coordinate formal and informal carers. It is developed in the US but has good reviews from Australian users. The entry tier is free, and this is most of what Australian users will need. The paid tiers, named 'IANACare PLUS', provide linkage with US health plans and organisations.

4.6.3. Hibi

Hibi is designed for carers of children with complex care needs. It includes a shareable health passport that summarises their diagnosis and story, a medication tracker with dosing reminders, a calendar for appointments and symptom tracking. It was designed in the UK but has good reviews from Australian users.

4.7. Digital health record tools: Nutrition

Below are several nutrition apps to assist with your dietary requirements.

4.7.1. Easy Diet Diary

This is a free Australian app designed for tracking diet, exercise and weight. Easy Diet Diary is ad-free and designed to work around personalised goals, including separate goals for kilojoules/calories, protein, carbohydrates and fat. It can 'gamify' progress through charts, graphs and reminders. Logging meals is made easier with an in-built barcode scanner which links to an extensive Australian food database covering most official sources and brands.

4.7.2. FoodSwitch

This free app, developed in the UK, scans the barcode of a packaged food item and provides immediate nutritional information as well as healthier alternatives based on established nutrition criteria. The app utilises a traffic light system: **Green** for healthy, **amber** for moderate and **red** for less healthy options to simplify decision-making. The website also provides parallel apps, EcoSwitch and GlutenSwitch, which can be used similarly when shopping.

4.7.3. CalorieKing Australia

This industry-developed app includes advertisements but provides high-quality information and tools for calorie counting, exercise journaling and weight management. Its resources can be viewed on the website without an account, although using the tools and app features requires signing in. The entry-level tier is free, while a monthly or annual subscription removes advertisements. According to its privacy statement, data may be shared with third parties for 'research and product development'.

4.7.4. The 3-Step FODMAP Diet

FODMAP stands for 'fermentable oligosaccharides, disaccharides, monosaccharides and polyols, in other words, the foods that produce more gas on interaction with gut microbes. A low *FODMAP* diet is designed for people with irritable bowel syndrome (IBS) and may be helpful for those who had IBS before SCI. After SCI, people who did not have IBS before injury may develop a similar *neurogenic bowel disorder (NBD)* where excessive gas can cause discomfort and toileting challenges.

This website from Monash University provides a three-step approach to trialling a low FODMAP diet. The first stage uses the accompanying Low FODMAP Diet app to swap high FODMAP foods for lower FODMAP alternatives. The second stage involves graded reintroduction of foods to determine which are better tolerated and the third stage develops a personalised plan to avoid poorly tolerated foods while maximising food variety. A strength of this site is its cultural ver-

satility. Diet plans and suggested food alternatives are not predominantly limited to Western cultures.

Clinical resource: Clinical guidelines for the NDB management – FODMAP

In 2021, Johns and colleagues published clinical practice guidelines for the management of NBD in adults living with SCI. FODMAP foods form part of the review:

> *"A diet that is low in fermentable oligosaccharides, disaccharides, monosaccharides, and polyols (FODMAPs) may be useful for improving GI symptoms, particularly in individuals with SCI who had irritable bowel syndrome (IBS) prior to injury. The low FODMAP diet has not been studied in the SCI population."*

4.8. Other useful documentation and tracking resources

Below are other apps that you might find useful.

4.8.1. Julian's Key

Julian's Key was developed by QLD Health as a communication tool for people with disabilities. It is in memory of Mr Julian Klass. It summarises the person's disability and medical history, how they communicate, their support and care needs and their support network. It also stores information such as a Medicare card and NDIS numbers. At present, it is available in hardcopy and fillable PDF versions, which can be uploaded directly to hospital records in a scanned (non-editable) form. Work is underway to develop an app that will allow real-time updating. The website has a video.

4.8.2. Accessible Australia

This Spinal Life app is designed for planning travel outside the home. It offers a map-based search for accessible health providers, transit, amenities, accommodation and entertainment. It can be used without an account, but signed-in users can also leave reviews and suggest updates. It can be used on handheld devices as an app or on tablets and computers via a web portal. There are videos to help you get started.

4.8.3. eCare21 Virtual Care

This app has a Windows/Android version and an Apple YCare Health version. This US collaborative multi-platform app (branded 'YCare' by Apple) has many of the usual health record app functions, such as medical record upload and medication tracking, but is primarily designed to automate health tracking through interfacing with wearable devices, telehealth and AI. It has been designed to help health professionals monitor and follow up patients between clinic visits to initiate timely interventions to prevent complications and hospitalisation, thereby saving money and reducing patient anxiety. eCare21 functionality includes sending alerts to carers and even the provision of remote care, such as via network-enabled insulin pump or drone-delivered defibrillators. A real-life example using the eCare21 system is yet to occur.

Below is an Australian news story about trials using drones to deliver essential medicines, such as during floods.

Media story: Drone technology delivering medicine in emergencies

University of Queensland's How a drone delivering medicine might save your life describes how drone technology might save lives in emergency situations. The website has a short video.

4.8.4. Used disability equipment

MyCareSpace has a list of websites and some possible apps for selling and buying used disability equipment. The site also provides advice when buying second-hand equipment, as well as what the NDIS will pay.

Media story: Beware NDIS scammers!

Always be vigilant of scammers. As this article indicates, Australians with disability are uniquely affected by crime, such as card fraud, identity theft and online impersonation. It states:

> *"An estimated 1.1 million Australians with disability experienced fraud in a 12-month period, according to a new Australian Bureau of Statistics (ABS) report. The bureau's head of crime statistics, William Milne, said: "[The report] shows 18 per cent of people with disability experienced fraud in a 12-month period, compared with 13 per cent of people without disability."*

Key Take-aways

- Documenting and tracking your health and well-being helps you become familiar with your 'new normal', helps with early detection of changes that may require action and helps others to provide care for you
- There are many ways to keep a health record, but the most important consideration is that it works for you. This may require some experimentation
- Paper and electronic records have their advantages and disadvantages. Most people end up using a combination
- When using electronic records, there are additional considerations such as usability, security and longevity
- My Health Record is the Australian Government's digital platform for patients to manage their health records to ensure continuity of care between different health providers
- The Health Maintenance Tool and app is an Australian-designed app specifically for individuals living with SCI
- There is a range of other local and international apps that can assist with other recording and tracking functions, including caring and nutrition. Find one or more that meet your specific purpose
- Be vigilant for scammers, and
- Don't forget to celebrate your progress towards good health and well-being.

The next chapter, **Chapter 5,** will explore integration into the community in terms of work, studying and socialising.

Reminder: Relevant chapters

- **Chapter 2:** To document your health and well-being, use Chapter 2 to remind yourself about some of the changes that your body may be experiencing
- **Chapter 3:** This is the main chapter about the five pillars of good health and well-being, with regular dental and podiatry added
- **Chapter 5:** This chapter will be useful in terms of the advice provided about health and well-being as you start socialising, working or studying, as adjustments will be needed to some of your routines
- **Chapter 6:** Documenting anatomical, physiological and psychological changes as you age is recommended
- **Chapter 7:** You may be a parent or carer documenting your child's health and well-being or encouraging your child to do so
- **Chapter 8:** If you are a First Nations person, Chapter 8 is where culturally appropriate resources can be found
- **Chapter 9:** If you or your child is neurodiverse or part of the LGBTQIA+ community or a migrant or refugee, Chapter 9 has relevant resources.
- **Chapter 10:** Sexual health is part of good health and well-being, with numerous resources available in this chapter
- **Chapter 11:** Chapter 11 covers some of the legal issues relating to healthcare
- **Chapter 12:** Travelling will definitely be a routine change. It is a good opportunity to record how your body responds
- **Chapter 13:** If you are scheduled for surgery, your healthcare team will need as much information about how your body works, so if this is documented, the team would be grateful to be able to review this information
- **Chapter 14**: Spiritual health is also important and could be recorded. It may be something as simple as five minutes of meditation each morning
- **Chapter 15:** Sport is another area where recording your physiological responses to exercise is important, particularly if you have high-level injuries that impact temperature regulation and have experienced AD
- **Chapter 16:** If you are participating in clinical trials, you would need to record your body's response, and
- **Chapter 17:** Recording your physiological response to, for example, a heatwave or extreme cold is important.

References

Johns, J., Krogh, K., Rodriguez, G. M., Eng, J., Haller, E., Heinen, M., Laredo, R., Longo, W., Montero-Colon, W., Wilson, C., & Korsten, M. (2021). Management of neurogenic bowel dysfunction in adults after spinal cord injury: clinical practice guideline for health care providers. *Jour-*

nal of Spinal Cord Medicine, *44*(3), 442-510. https://www.tandfonline.com/doi/full/10.1080/10790268.2021.1883385

Johns Hopkins Medicine. (2021). *Medical Records: Getting Organized*. https://www.hopkinsmedicine.org/health/wellness-and-prevention/medical-records-getting-organized.

Sarwal, D., & Gupta, V. (2025). *Personal Health Record*. In: StatPearls. https://www.ncbi.nlm.nih.gov/books/NBK557757/.

Schladen, M. M., Ljungberg, I. H., Underwood, J. A., & Groah, S. L. (2017). Exploration of the Personal Health Record as a tool for spinal cord injury health self-management and coordination of care. *Topics Spinal Cord Injury Rehabilitation, 23*(3), 218-225. https://doi.org/10.1310/sci2303-218.

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Chapter 5. Getting Out There

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Today, life is different, but I'm probably happier than before the spinal cord injury, although I know that's not the case for everyone.

Dinesh Palipana

Following the transition 'home' (**Chapter 1**) and the establishment of a daily routine that supports a healthy and fit lifestyle (**Chapter 3**), perhaps using one of the many apps suggested in **Chapter 4**, it is probably the right time to seek further opportunities or set new goals. This may include returning to work, pursuing further studies or pivoting to a new career. These next steps align with the title of this e-resource: ***Towards a life well-lived with spinal cord injury.***

For many individuals, life changes forever, often personally and professionally, following SCI. Decisions need to be made about work and life, depending on one's circumstances. We began this Chapter with success stories of lives well-lived, with many examples of Australians who now live with SCI (TSCI and NTSCI) and have become sporting icons such as Kurt Fearnley, Madison de Rosario and Dylan Alcott or the faces behind research projects, such as **Perry Cross** and his Spinal Research Foundation and **Dinesh Palipana** and BioSpine. Some are advocates and voices for people living with SCI and are deeply involved in consultation with Government policies and legislation. Others are motivational speakers or peer coaches. Above all, they are family and community members.

Dean Durman's story: We are not all superstars

Dean Durman, after reading this Chapter to see where he might contribute his experiences as someone living with paraplegia on two continents, provided the following feedback:

"Not many of us with SCI become superstars. One has to make this relevant for the general SCI community. This places unnecessary pressure on individuals to reach that level to fall into the category of a life well-lived. This Section needs to include how to get to a life worth living and finding one's identity after the trauma of suffering SCI. Thereafter, you can explore how individuals with SCI can thrive in society with ease."

We thank **Dean** for reminding us that most people who sustain a SCI, return home after months, perhaps a year, as parents, grandparents, partners, children, siblings, friends, employees or students. Others take on one or more of these roles as they adjust to their 'new' or different lives.

For many, their journey of 'self' begins the moment they realise they have injured their spine or wake up in hospital not being able to feel their legs and, in some instances, arms. This realisation is the start of a long journey to recovery, acceptance, and, hopefully, finding meaning in life that might be very different.

Key Topics in this Chapter

- What a 'life well-lived' might look like when living with SCI
- The multidisciplinary team in this part of your journey
- Re-engaging with the community and the importance of social connection
- Returning to the job market, including disability employment statistics, reassessing work and career after SCI and how OTs support individuals prepare for work, such as developing new skills
- Employment needs and challenges for people with disability, including Return to Work (RTW) assistance
- Opportunities for individuals who are unable to return to their previous roles, with personal stories from people living with SCI who have re-entered the workforce, including former medical students who have gone on to become doctors.
- Negotiating work conditions, requesting workplace modifications and preparing to return to work
- The significance of secure employment
- Studying with SCI, including Vocational Education and Training (VET), tertiary education, relevant statistics and universities' inherent requirements related to disability
- Driving with SCI and accessing transport to work or study, with further details in **Chapter 12**
- Contributing to society through advocacy and participation in clinical trials
- Work and identity after SCI, including insights from current research
- Leadership, respect and inclusion after SCI, and
- Understanding allyship and the importance of advocacy.

Reminder: Chapter 12 and the Return to Drive process

Chapter 12 covers driving after an SCI, which involves a structured Return to Drive process, including specialist clinical assessments to determine readiness, safety and any necessary vehicle modifications. With appropriate adaptations, driving can provide significant independence, but it must be approached with careful consideration of physical capacity, equipment requirements and overall safety.

In 2024, Shane Clifton and colleagues (2024) published an intervention exploring meaning and purpose after a spinal cord injury. They conceptualised post-traumatic growth (PTG) as a tree that had been damaged, but which coppices, with new growth (**Figure 5.1**).

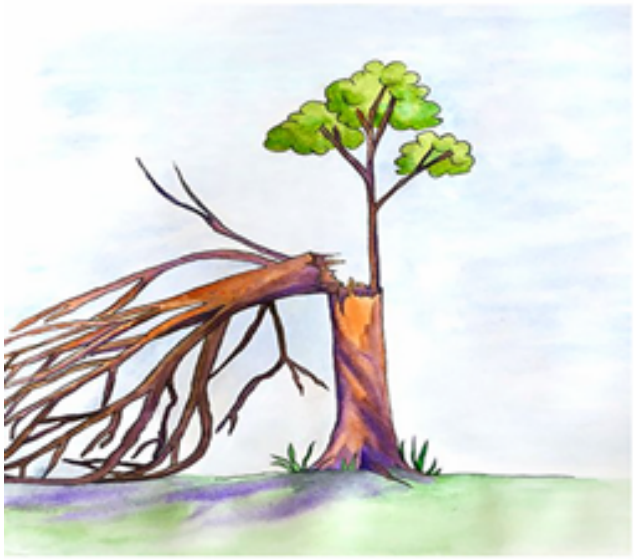

Figure 5.1. A coppicing tree as a metaphor for post-trauma (new) growth (Clifton *et al.*, 2024). Reprinted with permission CC BY-NC-ND.

Using *participatory action research*, the intervention was designed in an iterative process with health professionals and people with lived experience of traumatic SCI. Collaboratively, they developed a ten-week online group program and delivered two pilot programs to 13 participants (**Table 5.1**). Their feedback was used to refine the program.

Table 5.1. Details of the co-designed 10-week PTG program. Adapted with permission from Clifton *et al.* (2024).

Session 1: Introduction to the concept of post-traumatic growth (PTG) • Getting to know facilitators: Who are we? Why are we doing this? • Getting to know participants: Who are you? Why are you here? • Post-traumatic growth (PTG): Concept and evidence	**Session 2: Grief, loss and trauma: Adjustment to spinal injury** • Visual exercise using pictures and art to explore participant grief • Theories and elements of grief and the relationship with SCI • Permission to grieve • Coping with grief and wellness strategies
Session 3: What makes life meaningful • Exploring this before and after injury • Importance and sources of meaning • Making a contribution • *Ikigai*	**Session 4: Strengths of character** • Not the positivity myth • Virtue ethics • Virtues and dependency • SCI and courage, anger, hope and gratitude • Pride: "*I discovered I'm stronger than I thought I was*."
Session 5: Relations • Meaningful relationships before and after the SCI • The essence of meaning is connection. • PTG and relationships • Spirituality, faith, nature • Wonder and awe: SCI as an opportunity to slow down and notice beauty	**Session 6: Activities What makes activities meaningful?** • Aligned with my values, passions, strengths, skills and beliefs • Creative and challenging, worthwhile, significant • Often involves a sense of connection • Science of contribution • Explanation of coaching
Sessions 7-9: One-on-one coaching • Aim to look at the practical implementation of the issues raised by the sessions • Listen to what they have learned, challenges and any goals • Brainstorm options or possibilities • Explore solutions • Action steps	**Session 10: Review, wrap-up and celebration**

The design of this participatory approach was well-received by participants and consumer organisations. Feedback suggested the intervention showed promise in improving functional and psychosocial outcomes and has long-term viability, encouraging PTG to foster a stronger sense of meaning and purpose.

5.1. What does a life well-lived with SCI look like?

Below is an extract from a 2013 SCIA final report, Research into Maximising Life Choices of People with a Spinal Cord Injury that explored lived experiences of SCI in terms of what makes for

a 'good' life [with suggestions where different aspects are addressed in different chapters in this e-resource]:

> *"Access to resources to maximise opportunities and capabilities are necessary for people to be able to make life choices and experience social inclusion. Research participants said that physical and emotional wellbeing are fundamental to being able to access opportunities. Furthermore, two-thirds of participants said the role of the family in terms of emotional, physical and financial support was the most important resource in being able to achieve goals. The key implications arising from this research are the need to:*
>
> - *Support to maintain and improve health* [**Chapters 3**, **4** and **6**]
> - *Support participation in family and social life* [refer to **Chapter 3**, plus this Chapter]
> - *Provide support to family and friends* [this Chapter and **Chapter 6**]
> - *Promote workforce participation and training* [this Chapter]
> - *Improve information resources* [all chapters]
> - *Increase financial security* [**Chapter 1** funding sources, this Chapter and **Chapter 6**]
> - *Improve government policy* [various chapters in terms of addressing Royal Commission outcomes and Acts, particularly **Chapters 8, 10** and **11**], and
> - *Increase accessible housing, facilities and transport* [**Chapters 1** and **12**].
>
> *The implications are of equal importance in terms of supporting a menu of resources for people with a spinal cord injury to enable them to maximise life choices. People have different priorities depending on their individual situation, which changes over their life time."* (Bates *et al.*, 2013).

Below are several LLEs about what and how some individuals living with SCI have found meaning in their lives.

Perry Cross' story: A journey of hope for connection

In this video on Facebook, **Perry** talks about the moment he heard his neck snap while being tackled playing rugby. His life and the lives of many others changed at that moment. He speaks about the many dark times in his life. When asked what one thing he wished could be restored, **Perry** indicated 'sensation', the ability to feel touch. He has been motivated by the hope of restoring movement through research, even if it is a finger.

"When I was… I think I was a medical student or a junior doctor, we were chatting one night and one of my colleagues. She just touched my arm and I was like, "Wow!" That's a sensation! It's different when these guys [his support workers] or mum helps me, but to have another human being touch you…" **Dinesh Palipana**

Dylan Alcott's story: Hope to experience a meaningful human connection

In a candid interview with the TMZ Audio Network in the Big Down Under series,**Dylan Alcott** talks about growing up with disability and discrimination, university, sport, sex and advocacy. **Dylan** knows no other life, as he was born with a tumour on his spinal cord (so an NTSCI) and so spent much of the first few years of his life in the healthcare system. His identity as a person with a disability was formed early in his life, unlike those whose SCI are more traumatic. **Dylan** has lived a life well-lived. He may be well-known now, but it was not always like that.

Sarah and Charles' stories: Adapting and moving forward

- Sarah Wise's time living abroad in London was cut short after a serious fall in October 2019. Over a year on, she reflects on what she learned and what she wanted the world to know about SCI. Once confined to a wheelchair, **Sarah** learned to walk without aids but sometimes uses a stick.
- Feros: Growing Bold with Disability podcasts, **Charles Brice**, from airline pilot to journo, describes his career change following his SCI.

Exploring research into how others have adjusted to life with SCI is also useful. Below are two examples of this research.

Research: What contributes to a fulfilling life or psychological thriving?

- In 2022, Angel interviewed 10 individuals living with SCI over 10 years (Year 1, 2, 5 and 10) to gain an understanding of the factors that contributed to a fulfilling life. The research found that it is possible to live a satisfying life despite a damaged spine by balancing possibilities and a desired life. Reduced body function did not have to hinder people from living a satisfying life. Bodily issues can move into the background when new skills and routines are developed. Thus, life can be experienced as good and can resemble the lives of others of the same age, despite struggle being part of every activity. The 'new normal' was, however, disturbed when bodily conditions resulting from the spinal injury could not be stabilised or worsened during illness. In such events, the body was again foregrounded, becoming the primary focus of a person's effort and attention. The process of balancing possibilities and the life wished for had to be repeated. Angel concluded that life after 10 years of SCI can be good despite limitations, partly resembling the lives of others the same age. Having stable bodily conditions allowed other matters to be foregrounded. This was important in reconciling oneself to the situation and balancing possibilities and the desired life.
- Also in 2022, Allaire and colleagues published Flourishing after traumatic spinal cord injury (TSCI): Results from a multimethod study in which they examined the association between various factors and psychological flourishing, or ideal mental health, after TSCI, as well as the characteristics of adults with average or higher levels of psychological flourishing in terms of personality, social support and executive functioning. Phase 1 of the study collected information on demographic, health and psychosocial variables from 449 adults with chronic TSCI using a mail survey. Phase 1 data indicated that being married, viewing oneself favourably compared with others and reporting better subjective health ratings were significantly associated with higher levels of psychological flourishing. For Phase 2, the researchers conducted individual in-person assessments with 58 Phase 1 participants who had endorsed at least average levels of psychological flourishing and collected data using standardised measures of personality, social support and executive functioning. Phase 2 data suggested that, as a cohort, participants tended to display a resilient personality profile, reported high or average levels of social support and performed highly within normal limits on an executive functioning measure.

"How we think about ourselves and our health and who we compare ourselves to influence what we think is possible and what steps we are willing to take – these factors are more important than the severity of injury, health complications or money,"

Michelle Meade (PhD), senior author of the (Allaire *et al.*, 2022) article and co-director of the University of Michigan Center for Disability Health and Wellness.

To conclude, factors associated with positive psychological outcomes after TSCI, such as a resilient personality profile, good social support and unimpaired executive functioning capabilities, appear to characterise adults who flourish with chronic TSCI.

Drew Clayborn's story: Resilience

- Spinal cord injury survivor: Drew's resilience (21 May 2022), Michigan Medicine
- My life matters': Resilience after traumatic spinal cord injury (20 May 2022), Michigan Medicine

Drew sustained a TSCI in 2010. Motivated by the question, *"How do I get back to doing life?"*, he began building his future. Since then, **Drew** has finished high school, graduated from college and launched a non-profit organisation dedicated to supporting individuals and families affected by SCI. Research at the University of Michigan has identified resilience and strong problem-solving skills as key factors in moving forward. **Drew's** advocacy has become an important part of his life.

Marcus Perrineau-Daley's story: Finding fulfilment in sport

In the UK, the 2025 Spinal Cord Injury Awareness Day's theme was *'A Life Well Lived',* which highlighted life after injury and the importance of support in shaping fulfilling futures. With the right care, many of those living with SCI can and do go on to live well. The organisation shared **Marcus'** story to highlight his resilience and the dedicated team that helped him achieve his goals.

It would appear then that a resilient personality, problem-solving skills, personal goals and good social support are among the important features of a fulfilling life. This does not mean that everyone has to become a professional sportsperson or the Chief Executive Officer (CEO) of a company. Living a fulfilling life means living with meaning and purpose, which is unique for each individual.

Personal stories: *How do you see your future?*

Facingdisability.com, Future Life Planning After a Spinal Cord Injury: Personal Experiences with Paralysis

Watch these short videos to hear how different individuals responded when asked, "***How do you see your future?***"

5.2. The multidisciplinary team involved in this part of your journey

A range of health professionals and others support individuals and their families as they progress through life after SCI. **Figure 5.2** shows the multidisciplinary team involved, with each member contributing expertise tailored to an individual's level of injury and goals. For those with higher-level cervical injuries, such as C1-C5, certain roles, particularly occupational therapy, become especially important in maximising independence and daily functioning. Together, this multidisciplinary team helps the person navigate rehabilitation, manage ongoing health needs and develop the skills required for the next stage of their journey. As each person's SCI is different, their support team will vary, including the need for different support persons.

An interactive H5P element has been excluded from this version of the text. You can view it online here:
https://bond.studium.pub/life-well-lived-with-spinal-cord-injuries/?p=137#h5p-6

Figure 5.2. Summary of team members who can assist with this part of the journey. Click the ⊕ symbol for an explanation of each person's role for this stage of care. Created by Jaclyn Szkwara using Canva and HP5, licensed under a CC BY-NC (Attribution NonCommercial).

5.3. Getting back into the community

Getting back into the community will look different for each individual following an SCI. It may include socialising, returning to the job market, studying, or volunteering. Below are a few key recommendations from individuals with lived experience, along with their advice.

Key recommendations: Emma and Dean's advice on getting back into the community

- **Emma Simpson**, a support worker who became an OT, provided the following advice about getting back into the community:

  "A good life post-injury is not only about physical support. It is also about building and maintaining roles, identity and belonging. Support workers can help enable meaningful living by:

  Supporting return to work, study or volunteering

  - *Encouraging participation in sport or adaptive recreation*
  - *Facilitating social outings and creative pursuits*
  - *Respecting intimate relationships, dating and identity needs; and*
  - *Providing emotional presence without overstepping professional boundaries*

  It is vital to remember that living well includes fun, spontaneity and joy. The support worker can play a role in enabling travel, adventures and quality time with friends or family. Remember that a support worker is there to support you as an individual. It is important that the support is individualised to your everyday tasks and needs."

- **Dean Durman** explains that even with support from OTs and other health practitioners, it remains the responsibility of the individual with SCI to decide how they wish to live their life:

  "I am deeply grateful for the commitment and dedication of occupational therapists, physiotherapists, and other allied health professionals; their contribution is exemplary. Yet their support has natural limits. Ultimately, individuals must also grow in confidence by connecting with others who share similar physical challenges and by participating actively in community life. Living well is not a solitary pursuit. It is shaped through shared experience. When people walk together through both pain and joy, the journey becomes richer and more sustainable."

5.3.2 Socialising

Socialising after SCI can look very different from what it did before the injury. It does not necessarily mean returning to every activity or social role a person once had. Instead, it is about living a life that feels meaningful and enjoyable, within the energy, capacity and priorities that

one chooses. This personalised journey is shaped by an individual's values, interests and circumstances. Socialisation has been defined as the process by which, throughout life, individuals learn and internalise the socio-cultural elements of their environment, integrate them into their persona and adapt to the social context in which they live (Serpa, 2019). This highlights that socialising is not limited to specific activities, but involves ongoing connection, belonging and participation in ways that feel right for the individual.

We all talk about finding our 'tribe'. For individuals living with SCI, this could be at the gym, which may organise social events at church. It could also be with a hobby group, with special friends or with others who are also living with SCI. Below are some resources that may help individuals (and their family and carers) find their 'tribe' if they have not already found one (or two).

Important resources and information: Socialising

- SCIA's Going out and socialising
- SpinalCord.com: Having an active social life after SCI, such as attending live music events, joining a hobby community, joining a peer support group or becoming involved in adaptive sports (**Chapter 15**).
- Aspire Hub: Group disability day programs – Bright futures, which the NDIS provides in South East Queensland, including nature outings, cooking and art.
- FlintRehab's 21 fun activities to do with loved ones with quadriplegia, and
- SCIA's Have the Nerve podcast, Companion Cards and the meticulous planning just to go out (Episode 29).

At the start of **Chapter 3**, we provided 10 Ways to Reconnect with Your Body after SCI. Getting out in the community will allow you to keep up regular grooming, dress well and wear clothes you like from the list. For single people, getting back into the community may also involve dating and perhaps becoming sexually active. This may be daunting. **Chapter 9** provides resources for the LGBTQIA+ community, neurodiverse individuals and CALD individuals. **Chapter 10** provides numerous resources about sexuality and sexual health. **Chapter 12** explores travelling with SCI, while **Chapter 14** discusses spirituality and spiritual health. Many social circles exist where one can find like-minded individuals, perhaps 'similar-bodied'.

In Australia, socialising is, however, often connected to drinking alcohol. There is some international research suggesting that individuals living with SCI may have a greater risk of substance use disorders than non-SCI comparisons:

- **US:** Alcohol dependence following SCI was 44% SCI *vs.* 13% for non-SCI, but this did decrease 17 months after the injury (Davis *et al.*, 2018)

- **US:** Those with SCI had increased odds of having alcohol, cannabis, opioid and nicotine disorders (Gaupensperger *et al.,* 2019), and
- **China:** The SCI group had a greater likelihood of alcohol dependence (Chuang *et al.,* 2022).

In terms of alcohol consumption when socialising, the danger for those with SCI is more related to the physiological impacts of alcohol on the body, which may already be struggling in terms of regulating some functions. The Craig Hospital (US) provides the following potentially dangerous consequences of alcohol intake with SCI:

- Alcohol in combination with daily prescription drugs can impair judgment and coordination, speed up or slow down the effects of the drugs and cause drowsiness
- Alcohol in combination with antibiotics can result in alcohol intolerance. Symptoms include headache, rapid pulse, vomiting, palpitations and breathing too fast
- Alcohol use causes water loss, leading to frequent urination. A binge can disrupt a catheterisation program, interrupt the schedule, lead to a bladder or kidney infection and could cause involuntary urination
- Safety is also affected. Judgment becomes impaired. Falls and car accidents are more likely. A person may forget or be unable to do weight shifts and transfers safely, and
- Alcohol could contribute to insomnia, decreased sex drive and depression.

5.4. Getting back into the job market

Work is a big part of a person's sense of identity, self-esteem and confidence. Many benefits have been reported following successful return to work, such as satisfaction, personal growth and motivation, social connectedness, positive mental health and civic contribution (Hilton *et al.,* 2018). Meaningful employment can also help establish a new normal following SCI (Spinal Life Australia, 2026).

5.4.1. Employment and disability: Australian statistics

Before discussing getting back into the job market, we thought it would be useful to explore employment statistics in Australia from various sources, including research, the Australian Disability Network website, and the January 2026 fourth annual report on Australia's Disability Strategy.

Research: Employment outcomes in Australia following SCI

Borg *et al.* (2021) conducted a population-based cross-sectional study on employment outcomes following SCI in Australia, using self-reported data from 1,579 adults at least one year post-discharge, as part of the International Spinal Cord Injury Community (InSCI) Survey.

The key findings:

- **Post-injury employment rate:** 49.9%, with about one-third currently working.
- **Time to return to work (for those not returning immediately after inpatient rehab):** Mean = 8 months
- **Time to employment without a pre-injury job:** Mean (average) = 59.7 months
- **Underemployment among those working post-SCI:** 16.6% self-reported being underemployed, and
- **Shift toward less manual roles:** Engagement in less manual work increased post-injury, accounting for roughly three-quarters of post-SCI jobs.

To conclude, pre-injury employment and engagement with vocational rehabilitation were associated with higher post-injury employment rates. The authors also recommend more comprehensive early interventions that engage both individuals and employers.

In 2024, the Australian Disability Network (ADN) summarised key statistics on disability, labour force participation, employment, and discrimination based on 2022 Survey of Disability, Ageing and Carers (SDAC) data, released in July 2024. ADN defines *disability* as any condition that restricts mental, sensory or mobility functions. Causes may include accident, trauma, genetics or disease. Disability can be temporary or permanent, total or partial, lifelong or acquired, visible or invisible.

Research: Employment statistics with disability

Key 2022 findings from the ADN website:

- **Labour force participation (ages 15-64):** 60.5% for people with disability, compared with 84.9% for people without disability.
- **Participation by severity:** People with profound or severe limitations had a participation rate of 37.2%, compared with 64.6% for people with moderate or mild limitations.
- **Employment rate (ages 15-64):** 56.1% of people with disability were employed, versus 82.3% of peo-

ple without disability.

- **Job search barriers:** 93% of unemployed people with disability reported difficulties finding work.
- **Discrimination:** One in ten (9.9%) experienced discrimination, but almost one in five specifically among young people aged 15-34 years. For people with disability in the labour force (aged 15-64 years), common sources were employers (40.2%) and colleagues (37.7%), and
- **Transport barriers:** 26% of jobseekers with disability reported transport as a barrier, compared to 16% of jobseekers without disability (Bankwest Curtin Economics Centre, 2024).

In summary, these trends suggest that without targeted supports, people with disability face prolonged unemployment, financial strain and reduced social participation. Early vocational rehabilitation, workplace adjustments and accessible transport planning are essential to reducing barriers and delays in returning to work.

In January 2026, the Australian Government published its fourth annual report on Australia's Disability Strategy 2021-2031, which provided updates on 63 outcomes (with indicators) in seven key areas: Employment and financial security, Inclusive homes and communities, Safety, rights and justice, Personal and community support, Education and learning, Health and well-being and Community attitudes. The Strategy sets out ideas to make life better for people living with disability in areas they have identified as needing improvement for a more inclusive Australia. The January 2026 Report is based on data collected in 2024-2025.

Figure 5.3 below, under the 'Employment and financial security' outcome, shows mixed progress. Small improvements were noted for several indicators, such as the proportion of NDIS participants (aged 15-64) in the labour force in open employment at full award wage (up from 20% in 2021-2022 to 24% in 2024-2025) and a 7% (52% to 59%) increase in the number of 15-24 year olds being employed after completing their Vocational Education and Training (VET) training. There was, however, a regression (from 66% to 63%) in terms of whether they felt they had the support they needed to do their job.

Table 2.1: Employment and financial security measures

Measure	Baseline time point	Baseline value	Latest time point	Latest value	Change since baseline	Progress status
Policy Priority: Economic participation						
Number of valid 52-week full outcome claims for employment in the 12-month period for people with disability*	2020–21	16,041	2024–25	19,297	3,256 valid claims	Improving
Proportion of NDIS participants who get the support they need to do their job[a]	2021–22 Q2	66%	2024–25 Q3	63%	-3 pp	Regress
Proportion of NDIS participants aged 15–64 in the labour force who are in open employment at full award wage	2021–22 Q2	20%	2024–25 Q3	24%	4 pp	Improving
Policy Priority: Transition to employment						
Proportion of VET graduates with disability who are employed on completion of training	2021	52%	2024	59%	7 pp	Improving
Proportion of NDIS young people (aged 15–24) in employment	2021–22 Q2	18%	2024–25 Q3	20%	2 pp	Improving
Policy Priority: Economic independence						
Proportion of Australian Public Service employees with disability*[b]	December 2021	5.1%	December 2024	5.5%	0.4 pp	No change

*Measure wording has been revised to reflect available data more accurately or clarify the measure's intent. See relevant measure section below for more information

pp – percentage points; VET – vocational education and training.

(a) This measure will be replaced in the future by 'Proportion of NDIS participants with an employment goal in receipt of employment income in the last 12 months'.

(b) Due to historical updates, the baseline value may have changed from earlier releases.

Figure 5.3. Status of employment and financial security measures in the 2026 Fourth Annual Report of the Disability Strategy. *Source:* AIHW (2026), Employment and financial security measures, CC BY 4.0

5.4.2. Benefits of employing individuals living with a disability

Figure 5.4 below from the January 2026 Community Attitudes outcome in the Fourth Annual Disability Strategy Report indicates that in 2024, 74% of employers valued the contribution and benefits of employing people with disability, a 3% decrease from the 2022 survey (77%).

Table 8.1: Community attitudes measures updated in 2025

Measure	Baseline time point	Baseline value	Latest time point	Latest value	Change since baseline	Progress status
Policy Priority: Employer attitudes to employing people with disability						
Proportion of employers who value the contribution and benefits of employing people with disability*	2022	77%	2024	74%	-3 pp	Regress

Figure 5.4. Employer attitudes to employing people with disability. *Source:* AIHW (2026), Community attitudes measures updated in 2025, CC BY 4.0

Many employers may be unaware of the benefits of having employees with disability on their team. For **Dinesh Palipana**, there is much work still to be done:

> *"I have been working with the Includeability program at the Human Rights Commission. While there are a lot of good people wanting to do the right thing, for others, it requires an economic argument."*

The benefits of employing people living with disability are described below:

- ADN's Benefits of employing people with disability: This resource outlines 10 good reasons to hire people with disability, such as widening an organisation's talent pool and expanding its consumer base. Each reason is supported by a case study demonstrating the positive impact on businesses.
- JobAccess' Benefits of employing people with disability: This section includes four case studies featuring organisations such as PricewaterhouseCoopers (PwC) and Compass Group Australia, showcasing successful inclusive employment practices. JobAccess also provides access to the National Disability Recruitment Coordinator (NDRC), a free government-funded service that assists businesses in developing inclusive policies, designing and advertising accessible jobs and delivering disability-awareness training. Companies can choose to partner with the NDRC for ongoing support; and
- Australian Federation of Disability Organisations (AFDO): AFDO's resource highlights the benefits of employing people with disability and addresses common misconceptions, including the myth that workplace adjustments are costly. It also notes that modifications can be funded through the Australian Government's Employment Assistance Fund (EAF), which provides financial support for reasonable workplace adjustments.

Besides the value added by employing people with disability, it is important to remember that employment for people with disability is important as they need to have financial security. Employment can offer this security. Additionally, working provides a sense of purpose, which

is important for individuals seeking a sense of normality following SCI. Below are podcasts on disability employment.

Personal stories: Why disability employment matters

- SCIA's Have the Nerve podcast, Something to think about: People with disabilities need to pay bills too, you know (Episode 39, 1 May 2024): **Forrest Campbell** talks about his experiences finding work after sustaining a spinal cord injury in 2015. He explains why inclusive employment should not be the responsibility of the applicant with a disability, but rather the responsibility of employers. Forrest reflects on the challenges he faced and why meaningful inclusion makes a real difference.
- SCIA's Why Disability Employment Matters (4 September 2025): **Shane Clifton** discusses why hiring people with disabilities is not only the right thing to do but also a smart decision for businesses and society. This episode explores the barriers people with disabilities face in the workforce and highlights how inclusive employment practices lead to better outcomes for individuals, teams, and organisations. These benefits include greater innovation, stronger workplace culture, and improved overall performance.
- Feros Care's Q&A series podcast, Debunking the statement that people with disability don't make good employees: **Jo Lynam**, **Karene Gravener** and**Erica Hahn** join Pete to share their experiences as carers, employers and individuals connected to disability, highlighting the strengths, value and contributions people with disability bring to the workplace. They challenge the misconception that people with disability are not good employees, emphasising that real change comes from shifting mindsets rather than altering physical spaces.

The following resources provide practical guidance and advice for employers and individuals on creating inclusive workplaces and supporting employment for people with a recognised disability.

Important information: Guides and advice on working with a recognised disability

- Your Disability Your Way: A guide designed to empower people with disability and employers to build ongoing and meaningful employment opportunities
- Step 2 Education & Employment: A resource that helps families and school-leavers understand pathways to employment (available in QLD, ACT and SA), and
- SCIA's EmployAbility: An Australian organisation providing disability-inclusive employment support, including training, resources and personalised coaching to help job seekers with physical disabilities find meaningful work, while also assisting employers to develop inclusive workplace practices.

5.4.3. Reassessing work and career after SCI

A person's prior job and the impact of the SCI on the body will determine whether an individual can return to the same job. If a person were a surfing instructor, for example, they may not be able to return to that job. If a person was employed in IT, with some retraining, they may be able to return to work. Each circumstance is different, and so each person with SCI will need to reassess their employment options.

Below, two occupational therapists discuss how they prepare people with SCI to return to work, then provide information about the programs that support individuals with disabilities in finding employment.

Video: A conversation about what is needed to get back to work

This Spinal Life website and 15-minute video offers good advice about getting back to work, including back to your former position or perhaps you want to try something different or are not able to return to your former employment as a result of your injury.

5.4.4. Occupational Therapy (OT) support for returning to work

Below, **Michelle Myburg**, a member of Queensland's SPOT, and **Simone Van Groeningen**, an OT who was studying medicine at the time of publication, describe the role of OTs in preparing a person living with SCI for work.

OTs play a central role in facilitating return to work for people living with SCI. They use a person-centred approach, tailoring assessment and intervention to maximise participation and independence. OTs have a holistic focus and work with the person following their SCI to better understand the following:

- Previous job role, tasks and work environment
- Personal goals such as returning to the same job, changing roles or retraining
- Psychosocial impacts of returning to the workforce on the person's health, well-being, motivation and confidence; and
- Lifestyle factors, such as transport, fatigue, and self-care routines (bowel, bladder, medications and transfers).

A comprehensive functional capacity assessment is conducted to determine the impact of the SCI on the individual's work-related abilities and necessary modifications. This includes:

- Upper limb function, such as strength, coordination and endurance
- Fine motor skills, such as typing, handwriting and handling tools
- Sitting tolerance and posture
- Endurance and fatigue management
- Cognitive skills, such as attention, planning and problem-solving; and
- Sensory, pain or autonomic considerations that may affect work.

During the assessment phase, a job task analysis is also undertaken. This involves breaking down job tasks into step-by-step components and detailing the physical and cognitive requirements for each. Strategies are then recommended to facilitate functional independence, safety and successful return to work. These may include, but are not limited to, the use of adaptive technology or specialised equipment, workplace modifications, energy conservation, time management and organisation strategies. OT are trained in the provision of the following interventions:

- Ergonomic workstation set-up, such as adjustable desks, seating and arm supports
- Assistive technology, such as voice-to-text software and adapted keyboards or tools
- Environmental design modifications that include accessible entrances, toilets and parking
- Modified duties or task redesign
- Flexible hours or gradual RTW recommendations, and
- Liaison and education with workplace employers.

"Talk about skills building not just for a job, but that can be utilised for daily life. Soft skills, people skills, communication skills." **Dean Durman**

5.4.5. Returning to work (RTW) assistance

Spinal Life Australia has an RTW program called Back2Work, funded via the Motor Accident Insurance Commission (MAIC). This program provides early vocational rehabilitation for individuals with a newly diagnosed SCI receiving rehabilitation in the Spinal Injuries Unit (Princess Alexandra Hospital, PAH, Brisbane) and in other select hospitals. While this is mainly available to those who have gone through the PAH, anyone in Australia can technically refer themselves.

A range of services is available, including assessment of study options or a new career, job retraining, access to new courses, and support for your employer in education on returning to work. Below are a few useful resources and websites to support employment-related needs.

Important resources and information: JobAccess

- Australian Government's JobAccess website: This is one of the most comprehensive guides to employment after acquiring a disability. It provides resources not only for people seeking work but also for employers and service providers. Under the "I am a person with disability" section, you will find information on skills development, applying for jobs, talking about disability at work, and more.
- Inclusive Employment Australia: A new specialist disability employment program. It assists people with disability, injury or health conditions to prepare for, find and maintain work and grow their careers. It replaced the Disability Employment Services (DES) program on 1 November 2025.
- Disability Employment Australia: This is the national peak body representing disability employment service providers. It supports people with disability to find meaningful work and advocates for inclusive recruitment and employment practices across Australia.

Podcast: Equity and peer-led training

SCIA's Have a Nerve podcast, Episode 54: Dreamers and Allies (3 December 2025): **Forrest, Declan** and **Maz** from SCIA's EmployAbility team discuss equity and the importance of ***lived and living experiences (LLEs)*** in training.

Funding is also available through the Employment Assistance Fund for applicants with disability to be reimbursed for costs associated with workplace modifications, equipment and necessary support services to perform their roles.

Important information: Employment Assistance Fund, plus SafeWork Australia guide

Complimentary workplace assessments are included once registered for the Employment Assistance Fund (EAF). This fund provides reimbursements to an applicant for workplace modifications, equipment and ser-

vices necessary for a person with disability to perform their employment duties. The EAF can help people whether they are working, about to start work or are self-employed. The EAF covers the cost of:

- Building modifications such as automatic doors, lighting changes and ramps
- Changes to work vehicles
- Special equipment, including braille printers, joysticks or mouse alternatives and headsets
- Assistive technology and communication devices, such as a hearing loop system, touch screen or screen-reading software, and
- Auslan interpreting services.

Responsibility for RTW rests with both the individual and the employer. SafeWork Australia has provided the following Guide for employers: Developing a return to work plan for an injured employee.

5.4.6. Stories about getting back to work after SCI

As discussed, the process of returning to work after SCI varies for each person, making individual stories essential for understanding the challenges and successes. This section shares these experiences alongside practical information for individuals with SCI and guidance for clinicians. Through these narratives, we explore the realities of returning to employment and the strategies that enable it.

Below, **Dean Durman** reflects on his positive experience working with an international company that supported him across two countries.

Dean's story: Supported to work on two continents

"On 12 March 2011, I was involved in a motor vehicle accident that left me with multiple severe injuries: a cracked sternum, a shattered scapula, a deep laceration across my right forehead and fractures in three vertebrae: C6, T11 and L1. The L1 fracture was the most devastating, a burst fracture that caused bone fragments

to lodge in the spinal canal, resulting in an incomplete spinal cord injury. This injury left me paralysed in the lower limbs, without motor or sensory function below the knees, into the feet, and extending up the back of the legs into the buttocks.

After three months of intensive rehabilitation, I was able to return home and begin the process of finding a "new normal." Reintegration was not only about physical recovery but also about reclaiming identity and purpose. In this regard, Dell Technologies played a pivotal role. The company demonstrated extraordinary compassion and support, arranging occupational therapy consultations and creating a suitable home workspace. This enabled me to continue working while attending ongoing rehabilitation, a balance that proved essential to my recovery.

I made significant progress in my role as a Solutions Consultant in South Africa. Later, Dell offered me a similar position in Sydney, Australia. Their support extended beyond employment. They assisted with medical assessments, visas, accommodation and a relocation bonus as part of the package. This comprehensive support meant a great deal to my family and me, as it ensured our essential needs were met while we focused on building a new life in a new country, which was an exciting adventure despite the challenges.

As I settled into this new life, I began to thrive professionally, advancing to a managerial role at Dell. In January 2022, Dell was again instrumental in supporting our relocation to the Gold Coast, Queensland. The company's commitment to my reintegration after SCI was extraordinary. Not many organisations would extend such comprehensive support, and I count myself blessed to have had Dell as a partner in rebuilding our lives.

My experience illustrates how employment after a spinal cord injury is far more than a means of financial survival. Work became a pillar of identity, dignity and belonging. The support I received from Dell Technologies not only enabled me to continue contributing professionally but also reinforced my sense of worth as a husband, father, and member of society. At the same time, the challenges I later faced in re-entering the job market highlight the systemic barriers that many people with SCI encounter. These realities remind us that employment is not simply about economic participation; it is about restoring purpose, agency and connection."

Trudie's story: Experiences with workplace accommodation as a physiotherapist and academic

Trudie Fischer, a physiotherapist and university academic, sustained a C6 SCI that resulted in quadriplegia. She describes how she was accommodated at Curtin University and made to feel welcome: *"Employment has made me feel 'normal' and provided me with the opportunity to contribute. No one at work treats me differently. I am expected to reach the same standards as every other employee. And I wouldn't have it any other way. I am grateful for offers of cups of tea though!"*

Trudie is also an IncludeAbility Ambassador with the Human Rights Commission.

Closer to home (Bond University), for many of the contributors to this e-resource, is one of our former colleagues, **Professor Chris del Mar**, and his remarkable return to academic work.

Professor Chris del Mar's story: PhD supervision following SCI

After sustaining a C1/2 complete SCI in 2019, which left **Professor Chris del Mar** with quadriplegia and requiring ventilation, he resumed PhD supervision and contributed to scientific articles using a voice- and eye-activated computer. Read more about **Chris** returning here: RACGP – After a major spinal injury, this renowned GP is determined to get back to work. Sadly, **Chris** passed away in 2022 after being hospitalised with an infection.

A few more Australian stories on individuals being supported to get back to work are below.

Personal stories: LLEs about returning to work

Watch these four videos from Spinal Life Australia's Back2Work's program:

- Keena Fox, who was returning to work as a teacher after her C4 SCI
- Lachlan Chapman had been a FIFO electrician and sustained a T8 SCI. He has developed a passion for advocacy
- Tino Domanti, who was keen to return to work as a research, development and training professional, following a C4 SCI; and
- Paul Gauchi did not think it was possible to return to work as a self-employed builder after sustaining an L4 SCI.

Health professionals can assist people in returning to work after their SCI. The Back2Work program below is an example.

Clinical resource: Back2Work Program

Research has shown that people who return to work and other meaningful activities in a timely, safe and sustainable way after a serious injury experience financial, social, psychological and physical benefits.

As mentioned in **Section 5.4.5** in this Chapter, Spinal Life Australia's Back2Work program is available for individuals with a newly acquired SCI. SLA works with many Queensland hospitals and practitioners as well as major funding bodies. Similarly, if clinicians would like to inquire on behalf of their patient, you can contact back2work@spinal.com.au. Alternatively, patients can be referred by completing this referral form.

5.4.7. Health professionals with SCI returning to work

In the health professions, returning to work may be more challenging. The Australian Health Practitioner Regulation Agency (Ahpra) is the regulatory body that oversees all health professions, including medical doctors. Once a health professional has qualified and registered with Ahpra, they are expected to follow the general regulatory framework set out by the Health Practitioner Regulation National Law, which applies to medical practitioners who experience a significant health event, such as SCI. Key messages related to such an event were confirmed by Ahpra via email on 23 December 2025:

- Under the National Law, an impairment is defined as a physical or mental condition that detrimentally affects or is likely to affect a practitioner's capacity to practise safely.
- Ahpra and the Medical Board of Australia's role is to ensure that only competent, safe practitioners are registered.
- If a health condition does not impact a practitioner's ability to practise safely, there is generally no reason for the board to take any action, although health impairments should be declared at initial registration and in every registration renewal application.
- If a health condition becomes an impairment and affects safe practice, the practitioner may self-notify, or a mandatory notification may be made if there is a reasonable belief that the impairment poses a substantial risk to the public.
- Health-related notifications are managed in a supportive and confidential way, with outcomes focused on risk management rather than discipline.
- Typically, Ahpra works with practitioners to gather information to reassure the Board that any risk to patient safety has been managed. This may include speaking to treating practitioners and employers to confirm appropriate risk management.
- Possible outcomes include no further action or conditions on registration. Specific health-related information is not published on the public register, and
- Ahpra does not manage return-to-work programs or employment arrangements, work-

place adjustments and rehabilitation. Phased return-to-work planning is typically handled by employers, training providers and treating clinicians.

Chapter 18 (Health Professions Education) discusses frameworks for determining eligibility and providing support during medical education and post-graduate training. Below are a few stories about medical students and doctors living with SCI.

Drs Dinesh Palipana and Daniel Wei: Doctors living with SCI

Dr Dinesh Palipana's experiences across his journey to becoming a doctor:

- Dinesh's story begins as a quadriplegic medical graduate (with distinction), anxiously awaiting an internship offer from Queensland Health
- As the first doctor in Queensland to graduate with quadriplegia, he went on to become the state's first intern with quadriplegia. He has spoken publicly about becoming Australia's second quadriplegic doctor
- Technology has played an important role in supporting **Dinesh**'s clinical work; and
- Dinesh now mentors other medical trainees with SCI. This includes a UK medical student who travelled to work with him, and more recently, **Dr Daniel Wei,** who sustained a T6 injury in 2024, came to learn from Dinesh at GCUH in 2025.

Dr Daniel Wei:

> *"This was my first time back in a clinical environment since I sustained a T6 spinal cord injury last year,"* Dr Wei said. *"Being at GCUH with Dinesh helped me overcome the psychological and physical challenges of practicing while seated. He mentored me, helping me refine my positioning and setup for examinations and procedures so I could develop objective, repeatable skills."*

Dr Jonathan Tang's story: From student with SCI to GP

Jonathan's accident while training as an elite gymnast resulted in incomplete quadriplegia. He was a student at the time. He completed his internship and then his GP fellowship (July 2025) and is now a practising GP in Sydney. He is a wheelchair racer and has competed in marathons locally and abroad. **Jonathan** reviewed a few chapters of this resource. For more information:

- Qualified Physiotherapist and elite Gymnast dreams of being a Doctor (Northcott, 30 June 2023); and
- Spinal cord injury patients in Australia call for national register to help track treatment, outcomes (Spinal cord injury zone (original source: abc.net.au), 20 March 2016.

There is little research on how patients feel about doctors with SCI. Some studies suggest that many patients respond positively to clinicians who use wheelchairs, often viewing them as relatable and empathic (Salinger *et al.*, 2023). Experiences described below by **Dr Dinesh Palipana** reflect these findings. He reports that patients are accepting of his role as a doctor in a wheelchair and that his LLE with SCI has increased his empathy and helped him better understand what his patients are going through. He is a strong advocate for more people with disability becoming health professionals.

Dinesh's story: Being a doctor with SCI

Below are two sources that better explain **Dr Palipana's** journey from being a patient with SCI, to a compassionate doctor, helping to reshape medicine for the future:

- Media story: After a horrific car crash, doctor Dinesh Palipana saw the emergency ward from the patients' side (ABC News, July 2022); and
- Podcast: Changing Australia: Dinesh Palipana and reshaping medicine for the future (ABC News, December 2025, 13 minutes).

A Gold Coast surgeon,**Dr Rhea Liang**, an Associate Professor at Bond University, was treated by **Dr Dinesh Palipana** when she was admitted in a semi-conscious state to the ED with sepsis. Below are her memories of that time.

Rhea's story: Grateful that Dinesh was on duty in ED

"There are three days of my life that I have very little memory of- just snapshots, a few seconds each, as I roused briefly in response to stimuli and then drifted away again. Often the memories have no images, as at times I lacked the ability to even open my eyes. Just a voice in my right ear – "We're struggling with your blood pressure. We're calling ICU" or a heavy pressure and then a pain in my left arm as a large bore cannula was inserted. But one visual memory I have is of Dinesh, looking very concerned, wheeling up to the side of the bed as the on-duty senior doctor. I have no memory of what he said or did. But I do remember, as I drifted back to blackness, an overwhelming sense of relief that he was there, and a feeling that everything would be OK. I was later told that it was Dinesh who made the decision to start early antibiotics even though the diagnosis of sepsis wasn't yet clear at that point. As a doctor, given the high in-hospital mortality of sepsis, I know that decision almost certainly saved my life, and for that I will always be grateful."

5.4.8. When individuals are unable to return to their previous roles

As mentioned, returning to work (RTW) after SCI is not always possible, and in some cases, individuals may not be able to return to their full capacity. Every career has different requirements. Some people rely on technology to assist with their transition, while others benefit from advanced therapies or adaptive training. For office-based roles, it may be easier to return or pivot into similar positions, as seen in the experiences of **Dean Durman** and **Professor Chris del Mar**. For physically demanding jobs, the transition can be more challenging. This section shares more success stories of individuals who have made this transition, while the following section explores study opportunities for those considering new career paths.

While it is impossible to cover every job, the following international personal stories highlight the resilience, innovation and diverse paths taken by individuals living with SCI as they re-entered the workforce.

Susan and Jaime's stories: Alternative pathways for returning to work

- **Susan:** Before her injury, Susan was a manager at a Work and Income service centre in New Zealand. In 2017, during surgery for a spinal tumour, she developed a cerebrospinal fluid leak that damaged her spinal cord, resulting in a T5 complete SCI with no sensation or movement from the chest down. She set an early goal to return to work while at the Auckland Spinal Rehabilitation

Unit.

Susan partnered with the New Zealand Spinal Trust's vocational rehabilitation team to plan a sustainable return. This required adjusting expectations and implementing accommodations such as flexible hours, hybrid work and home-office modifications. With persistence and support, she returned to full-time employment in the disability sector, using her lived experience to improve systems and outcomes. Her advice: *"I did have to change my expectations and learn to be more patient with myself and those around me."*

- **Jaime:** Becoming an adaptive sports coach after C6-7 SCI**:** Jaime was a committed athlete and CrossFit enthusiast before his injury. At age 58, he sustained a complete C6–C7 SCI and spent five weeks in critical care. After discharge, he faced the challenges of adapting to a new lifestyle and managing his health. In 2021, he travelled to Institut Guttmann in Barcelona for a 12-week intensive rehabilitation program. Through adaptive training, he regained strength, mobility, and independence, enabling him to return to fitness and explore opportunities as an adaptive sports coach.

Resource: Spinal Network News, August 2024, New Zealand Spinal Trust

5.4.9. Secure employment

Secure employment is the goal. It takes time and energy to get to work, carry a full workload, return home and participate in family and social life. This is stressful even for people with no physical disability.

What does secure employment mean? The study below examines factors that influence 'sustainable' (secure) employment for people with an acquired brain injury (ABI) or SCI. The research was conducted in Switzerland and is relevant to similar contexts.

Research: Secure work following SCI

Although Finger and colleagues (2023) conducted their research in Switzerland, their findings are highly relevant. They interviewed 23 professionals involved in vocational reintegration and job retention for people with acquired brain injury (ABI) or SCI. Using semi-structured interviews and thematic analysis, they identified factors that enable or hinder 'sustainable' employment.

According to Finger *et al.* (2023), a sustainable work situation can be defined as *"a person–job–workplace match that enables a person to stay healthy and satisfied at work over time, with a work performance that meets the expectations of the person and the employer."*

Key issues raised by participants:

- **Value and impact of initial work integration:** Early, multidisciplinary, person-centred work integration with employer involvement is ideal. A good match between the worker and the workplace is essential.
- **Critical factors for long-term sustainability:** For people living with SCI, deteriorating health and secondary conditions are major risks. For people with ABI, workplace changes such as new supervisors, restructuring or new technologies can threaten job retention.
- **Knowledge and experience of professionals:** Professionals need strong knowledge of ABI and SCI, legal and social security systems, and disability management. Practical experience and problem-solving skills influence outcomes.
- **Attitudes of professionals:** Respectful, constructive attitudes toward the injured worker matter. Professionals who expect success and collaborate well tend to support better results, and
- **Communication and knowledge transfer across stakeholders:** Direct exchange of information between the worker, employer, health providers, insurers, and job coaches is vital. A shared understanding supports a coordinated vocational integration strategy. Education for employers, supervisors and co-workers helps them understand the worker's needs and strengths. As one vocational professional noted:

> *"Employers and co-workers, like patients, are lay persons with the new situation and therefore find it very important that good information and a regular exchange can take place."*

In conclusion, professionals report that the enabling and hindering factors for sustainable employment are broadly similar for people with ABI and SCI, although the differing physical, cognitive and psychosocial effects of each condition require tailored support strategies. People living with SCI often require ongoing medical care, and for both groups, accessible long-term counselling and support services are essential when work-related difficulties arise. The authors also recommend diagnosis-specific training programs for professionals involved in employment services and disability management.

5.4.10. Negotiating work hours and working from home (WFH)

In addition to the key recommendations above, one can negotiate working from home, but this would depend on your role and the employer's requirements. Many companies have a hybrid model, such as three days in the office and two days working from home (WFH).

Important resources and information: Accommodating disability in the workplace

- This video from the Australian Government's JobAccess website indicates that you can work from home.

- On the JobAccess website, use the I am working or about to start work on the drop-down menu, to find information on changing your work areas and tasks as well as a section on your rights such as how your personal information is protected and your role in work health and safety. Equally important is how to deal with discrimination, considering the work-related discrimination (employer and colleagues) is high on the list as a source of discrimination. The statistics are presented in**Chapter 10**.
- *For employers*, the Australian Disability Network is a membership-based organisation that helps employers build confidence and capability to welcome and include people with disability as employees and customers.
- Working from home is a good option as it is more sustainable and less disruptive for the individual. In a blog on Forward's website, **Jeol Sardi** writes about employment for people with disability in Australia. This quote from his blog is powerful: *"He [his current employer] employed me because of my capability, my disability was not part of the equation."* This is what we call a strength-based rather than a deficit model, mindset or approach.

Some jobs require you to be on-site, so working from home is not practical. One option is to reduce your hours or schedule work during times that make travel easier and require less energy and stress to get to work.

Dinesh's story: Negotiating working hours

Dinesh was able to negotiate his shifts in ED, stating:

> *"There are three shifts. One starts at 7.30, one starts at 1 pm and the other starts at 10 pm. They've just put me on one shift, so I do the same shift as everyone else. I do the 1 pm shift. Shifts [are] ten and a half hours, so I finish at 11.30 pm. The morning shifts are tricky because although we [Dinesh and his mum] wake up early, it takes a long time, a few hours, to get ready for work. No one else wants the late shifts anyway."*

5.4.11. Requesting work modifications

Workplace modifications are changes made to your work environment, equipment, or processes to help you perform your job effectively after an injury or disability. These adjustments aim to remove barriers and create a safe, accessible, and productive workspace. Modifications can include:

- Physical changes such as ramps, widened doorways, height-adjustable desks, or accessi-

ble bathrooms
- Assistive technology like voice recognition software, adapted keyboards, or specialised seating
- Flexible work arrangements such as adjusted start times, reduced hours, or remote work options, and
- Task redesign to match your abilities, for example, reallocating physically demanding tasks or introducing ergonomic tools.

The goal is to ensure you can continue working with dignity, independence, and minimal stress while meeting your health and functional needs.

Below are two lived experiences of workplace modifications to accommodate their new needs. For **David Deitz**, it was at his school, while for **Dean Durman**, it was at home.

David and Dean's stories: Physical accommodations

- In the *ABC News* article, Smith Hill principal returns after cycling crash leaves him with quadriplegia, **David's** office was modified to enable his return to work as the school principal.
- **Dean** explains his work-from-home modifications below:

> *"In my situation, NDIS does not cover work-from-home modifications. This is handled by JobAccess. A request would need to be submitted and the required process needs to be followed. An assessment is conducted by an assigned OT who is outsourced by JobAccess. Justification is submitted, and once approved, funding for the modifications is completed and service providers are paid. The link is here."*

Reminder: JobAccess site for submitting a request

The JobAccess website is where one can submit a request for work adjustment support.

Below, read about how technology can assist individuals living with SCI.

Important resources and information: Assistive technology

- AbilityNet – How technology can help you if you have an SCI: This factsheet explains how people with SCI can adapt everyday technology, such as accessibility settings, alternative keyboards and mouse, voice control and smart-home tools, to enhance independence and make devices easier to use, and
- Augmental – MouthPad: The MouthPad is a custom-fitted, intraoral Bluetooth touchpad operated through tongue and head movements. It allows hands-free use of computers, tablets and smart-phones, offering an accessible alternative to a traditional mouse for people with limited hand function. The site includes a video demonstration and examples, such as **Keely**, an engineering student who uses the device for studying and everyday digital tasks.

5.4.12. Getting ready for work each morning

A morning routine can be challenging for anyone preparing for work, especially in a busy household with family and young children. Later in life, hormonal and physical changes can also make mornings harder for those who need or want to work. For individuals living with SCI, these challenges are greater because many rely on carers or family members at specific times of day and must manage additional needs, such as bowel and bladder routines, skin care and transfers.

Below are personal stories from individuals' LLEs of SCI, sharing how they manage their morning routine and prepare for work.

Dinesh's story: Preparing for an ED shift

Following on from **Dinesh**'s story about starting work later due to his morning routine, he explains why this is necessary. As a person with quadriplegia, his morning bladder and bowel routine is essential to ensure he can manage a 10.5-hour shift in the ED.

> *"My mum helps me. You have to do this before work. This is a big thing for people with a spinal cord injury. They make sure that it [bladder, bowel, dressing, etc.] is done before they leave the house. The problem with that is sometimes it can take a lot longer than expected, which can throw your time. Because if you go out without making sure that your bowel is empty, you won't be able to function at*

work or in the community. This has happened to me a handful of times in 15 years. It is a big problem. I know people who have stopped going out because of that. Some people choose to have a colostomy because it becomes super inconvenient."

Dean's story: Routine is key

In some of **Dean's** roles, he was required to travel from the Gold Coast to Brisbane some days a week. This was a 70-minute commute. Dean explains the importance of having a routine:

"The extent of independence varies greatly. For me, these tasks can be managed without assistance. For individuals with more complex injuries, the involvement of a support worker may be essential to ensure daily routines are completed and employment remains accessible.

A daily routine may look something like this:

- **Getting out of bed:** *Always the first step and often a significant achievement in itself.*
- **Bathroom routine:** *For some individuals, this includes bladder and bowel management regimes that must be carefully followed.*
- **Getting dressed for work:** *A task that may range from independent dressing to requiring assistance, depending on the level of injury.*
- **Transport to and from employment:** *Either driving independently or relying on accessible transport options, and*
- **Performing the job itself:** *Engaging in professional responsibilities once at the workplace."*

Below are several recommendations gleaned from the research findings discussed, as well as the personal stories of and from individuals living with SCI.

Key recommendations: Checklist for a secure career

- **Start early and plan your work reintegration:** Ask your rehabilitation team to include work goals as soon as possible and involve your employer early. Early person-centred planning improves long-term success

- **Aim for a strong job fit:** Seek roles and tasks that match your skills, health needs, transport, and energy levels. A good worker-to-workplace match supports staying in work
- **Involve your employer and co-workers in the plan:** Invite your supervisor and team to discuss practical needs and strengths. Shared understanding helps with adjustments, reduces confusion, and builds support
- **Use coordinated support:** Ask for a clear plan that links your health providers, job coach, employer and insurer. Regular information exchange keeps everyone aligned and reduces delays
- **Secure the right modifications and adjustments:** Work with your team to arrange equipment, scheduling changes, task redesign and remote or flexible options that protect health and performance. Review these as your needs change
- **Monitor health risks proactively:** Plan for prevention and early management of secondary conditions, fatigue, pain and transport barriers. Early action protects work continuity
- **Develop your self-management and advocacy skills:** Practise explaining your needs, negotiating adjustments and asking for help. These skills matter when supervisors change or roles are restructured
- **Know your legal rights and social security basics:** Learn the essentials of your local disability rights, income support and insurance pathways and ask professionals to guide you through key processes
- **Request ongoing check-ins, not just early support:** Schedule periodic reviews with your manager and support team to update adjustments, training needs and workload as your situation evolves
- **Encourage team education:** Ask your job coach or case manager to provide simple, practical education for supervisors and co-workers so they know how best to support you
- **Identify a single point of contact:** Nominate a coordinator, such as a vocational counsellor or case manager, who can help you troubleshoot issues quickly across stakeholders, and
- **Plan for change:** Anticipate potential risks such as new supervisors, restructuring or technology changes. Agree in advance how you will review tasks and support if changes occur.

5.5. Studying with SCI

This section provides an overview of what to consider when planning to study with SCI and what to expect from the higher education sector in terms of accessibility. It covers physical access, inherent requirements, available resources and key statistics, as well as personal stories that illustrate real experiences.

Before exploring these aspects, here are a few examples of lived experiences from individuals who have pursued education after SCI.

Dean and Belinda's stories: Studying and reshaping careers

- **Dean's** story about studying and personal growth:

  "In parallel with professional work reintegration, I pursued studies in counselling. This decision was not incidental; it was born out of lived experience. Having navigated trauma and recovery myself, I recognised the need to equip myself with tools that could transform personal adversity into structured support for others. Education became a pathway to reclaim agency. It provided intellectual stimulation, a sense of progress, and the opportunity to reframe my story in ways that could empower others. Studying counselling was more than academic pursuit. It was an act of hope, a declaration that growth remains possible even in the face of permanent change."

- **Belinda** drew on her experience travelling as an athlete with a disability in her 20s to reshape her career. After completing a Bachelor of Business at the University of the Sunshine Coast, she built a new professional path as an honorary researcher in accessibility in adventure tourism.

5.5.1. Vocational Education and Training (VET) and tertiary education statistics

Vocational Education and Training (VET) and tertiary education are central to post-school learning in Australia and New Zealand. VET delivers practical, job-focused skills through qualifications, such as Certificates I to IV, diplomas and advanced diplomas, offered by TAFEs (Technical and Further Education), registered training organisations and some universities. These qualifications align with the Australian Qualifications Framework (AQF) and the New Zealand Qualifications Framework (NZQF), ensuring national consistency and recognition. In Australia, the Australian Skills Quality Authority (ASQA) regulates most VET providers and accredits VET courses to maintain quality and protect the integrity of qualifications. Tertiary education encompasses all post-school education, including VET and higher education, with higher education typically referring to university-level study leading to bachelor's, master's and doctoral degrees. These qualifications are structured by AQF and NZQF levels and learning outcomes to provide clear pathways and standards.

The decision to pursue VET or tertiary education depends on a range of factors, including a person's interests, financial circumstances, available support, career aspirations and physical ability, amongst others. Each educational pathway offers distinct opportunities for skills development and career progression. Below is a table extracted from the January 2026 Fourth Report of Australia's Disability Strategy in the *Education and Learning Outcome*. The data in **Figure 5.5** are disappointing. While undergraduate enrollment in higher education has increased

by 3% over two years (from 10% to 13%), only 55% complete their studies. For VET students, only 42% qualify, which is not that much lower than for those without disability (49%). The % of VET students with disability is, however, low and regressing (from 4.4% in 2021 to 3.9% in 2023).

Policy Priority: Participation in tertiary education						
Proportion of VET students with disability (aged 15–64)	2021	4.4%	2023	3.9%	-0.5 pp	Regress
Proportion of undergraduate higher education students with disability	2021	10%	2023	13%	3 pp	Improving
Qualification completion rate for VET students aged 15–64 with disability, compared with students without disability	Cohort 2017–2021	40% *with disability* 46% *without disability*	Cohort 2019–2023	42% *with disability* 49 % *without disability*	Baseline value gap: 6 pp Latest value gap: 7 pp Difference in gap: 1 pp	Regress
Proportion of students with disability who complete a higher education qualification	Cohort 2016–2021	54.9%	Cohort 2018–2023	55.3%	0.4 pp	No change

*Measure wording has been revised to reflect available data more accurately or clarify the measure's intent. See relevant measure section below for more information.

pp – percentage points; VET – vocational education and training.

Figure 5.5. Participation in and completion of higher education and VET (AIHW, 2026), Policy priority: Participation in tertiary education, CC BY 4.0

In 10 Ways to Reconnect with Your Body after SCI, *Learning new things* was identified as a way to maintain a sharp mind, avoid boredom and spend time that is positive, rewarding, and fulfilling. Studying is one way, but learning new life skills is also important. Drawing on the 2025 Third Annual Disability Strategy Report, 54% of people with disability reported participating in an informal learning activity in the last 12 months in 2024.

5.5.2. Inherent requirements of universities in terms of disability

Understandably, for individuals with disability who want to study, two considerations need to be included in any inherent requirement university policies: How can the university support students with disability to be inclusive and, depending on the qualification, there will be related skills and competencies required to be able to work in the field or profession. These are called inherent requirements.

Back in 2016, Brett and colleagues published a report through La Trobe University entitled, *The role of inherent requirement statements in Australian universities*, in which they made the following recommendations:

1. University stakeholders interested in inherent requirements explore options to achieve greater consistency, clarity, and transparency in inherent requirement statements across institutions and disciplines
2. University stakeholders with responsibility for students with disabilities, including disability practitioners, disciplinary heads, and equity and related staff, monitor the impact of inherent requirements on prospective, enrolled, and graduating students
3. Further research should be undertaken regarding the impact of inherent requirement statements on prospective, enrolled, and graduating students, including their effects on participation, achievement, and graduate outcomes. Such research could focus specifically on capturing the voices of students with disabilities, who are often unheard, and
4. Universities ensure that descriptions of academic requirements and their use in processes for identifying reasonable adjustments are accessible to and transparent for students, and that these descriptions are consistent with the Higher Education Standards Framework, the Disability Discrimination Act 1992 (Cth) and the Disability Standards for Education 2005 (Cth).

Under the 2005 Disability Standards for Education, post-secondary education providers are required to take reasonable steps to ensure that a student with a disability can participate in courses and access facilities and services on the same basis as students without a disability. If a student meets the essential entry requirements, educators must make 'reasonable adjustments' to the course design or delivery to enable a student to have a fair chance of participating. Importantly, individual staff members can be held liable if it is found that they deliberately or inadvertently discriminated against a student.

Corcoran and colleagues (2022) highlighted that the challenges faced by staff in implementing inherent requirements, such as 'reasonable adjustments', are often due to limited awareness and training. Creating an inclusive educational environment requires well-informed staff, clearly articulated institutional policies and transparent criteria that effectively support the diverse needs of all students.

Additional information, if interested: Disability Standards for Education 2005

The 2005 Disability Standards, co-designed with Children and Young People with Disability Australia, provide a range of shareable resources, including social media tiles and practical guidance, such as Social post #5: Education providers complying with the Disability Standards for Education.

Social post #5, Shareable resources, CC BY 4.0

These resources outline students' rights and the responsibilities of education providers. For example:

> *"If you are a student with a disability, your education provider must:*
>
> - *Consult with you. They should meet with you to discuss what changes they need to make to help you join in and learn. They may also meet with your parent, caregiver, or associate*
> - *Make reasonable adjustments. These are changes to allow you to join in with your peers; and*
> - *Put steps in place to prevent you from being mistreated."*

Since the Australian Disability Discrimination Act 1992 also protects people who are associates of a person with a disability from discrimination (DDA Part 1, 1.4), this means that carers, friends, parents, work colleagues or advocates of a person with a disability are also protected under both the DDA and the Disability Standards for Education 2005.

The next key Australian education report was the Final Report of the 2020 Review of the Disability Standards for Education 2005, prepared by the Australian Disability Clearinghouse on Education and Training. That report examined the effectiveness of the 2005 Standards through an extensive community consultation process. Numerous recommendations were made, which aligned with the following four reform directions (Summary document):

- Empowering and supporting students with disability and their families
- Strengthening the knowledge and capability of educators and providers
- Embedding accountability for the Standards throughout the education system, and
- Building awareness and capability in the early childhood education and care sector.

The education standards were reviewed again and published in September 2025. In this 2025 Review of Disability Standards in Education, stakeholders were asked to provide input on the Draft Principles (p. 19), with three options for including them in the Standards. The draft principles, or a version of them, were proposed to be included in the Standards in three ways:

- **Option 1:** Include principles to guide best practice, but there is no enforceable requirement to follow the principles: *Include the principles as an additional example of a measure that an education provider may take to assist them to comply with the Standards for enrolment, participation, curriculum development, accreditation and delivery, student support services and preventing harassment and victimisation*
- **Option 2:** Include a requirement to develop and comply with policies that must be consistent with the principles: *Requires education providers to develop, implement and comply with their own publicly available policies that must be consistent with the principles,* and
- **Option 3:** Include a requirement to follow the principles when applying the Standards:*Requires an education provider to follow the principles when they consult, resolve issues or handle complaints arising in relation to the Standards and a student or prospective student.*

Beyond the principles, the 2025 Review team was also interested in hearing from stakeholders whether there is anything else that needs to be done to support improved consultation, issue resolution and complaint-handling for students with disability.

In September 2025, the Australian Government Department of Education published a 2025 Review of the Disability Standards for Education – Discussion Paper, which reviewed the Disability Standards for Education 2005. This work was in response to the Royal Commission's recommendations and focuses on three key areas: *Effective implementations of the Standards*, *Inclusive decision-making* and *Clear responsibilities for assessment authorities and course developers.* The consultation process on the 2025 Discussion document closed on 21 November 2025.

Reminder: Chapter 18

Chapter 18, Health Professions Education, explores the current Guidelines regarding access to and accommodation within Australian and New Zealand medical programs for applicants and students with disability.

To conclude, for universities and other education providers, inherent requirement statements and the Disability Standards for Education are more than legal obligations. They are practical tools for creating fair and inclusive learning environments. When providers clearly explain course requirements and apply them consistently, and when they make reasonable changes to support students with disability, more students, including those with disabilities, should be able to start and complete their studies. This leads to better graduation rates, stronger

job prospects and less inequality. To achieve this, providers should set clear goals, monitor progress and work closely with students with disability to design policies that meet real needs. Doing this moves beyond compliance and shows a genuine commitment to equity and social inclusion.

5.5.3. Finding the best study options for your individual needs

There are several factors to consider when choosing a place to study:

- **Accessibility:** Look for universities with accessible campuses, including accessible buildings, classrooms and accommodation options
- **Disability support services:** Investigate the university's services, including advisors, support staff and assistive technology
- **Research focus:** If you are interested in research, explore universities with strong SCI research programs, such as those mentioned above
- **Community and support networks:** Consider the university's overall culture and whether it fosters a welcoming and supportive environment for students with disabilities, and
- **Financial support:** Investigate scholarships and financial aid options from universities and TAFEs specifically for students with disabilities or those pursuing research in SCI.

Those interested in pursuing a career in SCI research (**Chapter 16**), below is a list of institutions and programs to explore in Australia:

- **Griffith University: Dr Dinesh Palipana** explains the work of the BioSpine Laboratory in this video., while the Perry Cross Spinal Foundation's current clinical trials involve transplanting nose cells into the spinal cord.
- **Queensland University of Technology (QUT):** Offers a Spinal Cord Injury (SCI) PhD and Master of Philosophy Top-up Scholarship and the Alan Mackay-Sim Spinal Cord Injury Travelling Fellowship.
- **The University of Sydney:** Involved in the SMART trial (Spinal Cord Injury, Mind and Heart Trial), which focuses on pain and injury.
- Neuroscience Research Australia (NeuRA): Features research into brain health, including dementia and Parkinson's disease, as well as chronic pain, and
- Spinal Cord Research Hub (SCoRH): A collaborative initiative uniting the SCI research sector, including grants, fellowships and consumer engagement participation.

The best place to study in Australia with SCI depends on individual needs and preferences. Several universities and research centres are known for their strong support systems and research focus on SCI. It is advisable to:

- Contact the universities directly and speak with disability support services and relevant

academic departments to discuss your specific needs and learn more about their programs
- If possible, visit the campus to check accessibility and get a feel for the university environment; and
- Reach out to individuals involved in SCI research and support networks to gain insights and advice.

5.6. Getting to and from work or study

Again, depending on your mobility, there will be several options, including self-driving, public transport and WATs (wheelchair-accessible taxis). For further information, **Chapter 1** includes travel resources, while **Chapter 12** is devoted to getting around locally and abroad, including the rules governing driving with SCI and travelling by air locally and internationally with SCI.

Be sure to check what your State offers in terms of accessibility tickets and concessions for people with disabilities and students. In NSW, for example, tertiary and TAFE students receive discounted fares.

5.7. Contributing to society in other ways

In addition to the examples already discussed in this chapter, there are many other ways in which you can contribute to society. Below are just some examples:

- **Volunteering:** Career pathways – Spinal Life Australia. Volunteering is a great way to test the waters of a new career path. It will help you discover if a particular industry suits you. Each State will have a coordinated volunteering program, such as Volunteering Queensland
- **Peer mentoring:** Several SCI organisations seek peer mentors to assist those who have recently sustained SCI. For example, Estera has a peer support program in which mentors who live with SCI share their experiences and offer guidance during rehabilitation. SCIA also has a Peer and Family Support Team that offers practical, non-clinical support, advice and mentoring as well as the Can You Ask That? series. There is also a Community Peer Support Education Series, such as this one on Pressure Injuries and Bladder and Bowel
- **Coaching:** This comes in many forms, from a life coach to a sports coach. Dr Olivia Lee Ong, who sustained SCI in Australia in 2008, is now an international life and business coach for doctors experiencing burnout
- **Participating in research trials:** These are some examples of research trials at the time of writing this Chapter. Cure-related SCI trials in Australia provide details of Australian-based clinical trials that aim to restore function or feeling to people living with SCI. Also included are clinical trials exploring treatments for neuropathic pain. Not all studies are

listed on the site. Other trials that had been completed or were ongoing in 2025 include the Spinal Cord Length of Stay Study, the SMART Study and UTIs and self-catheterisation. The Spinal Cord Research Hub (SCoRH) encourages consumer engagement, and

- **Being an advocate:** The SCIA website has a section, Taking Action Yourself, with resources to help you advocate through your local council and tackle housing issues. The website is for NSW, but the principles apply across Australia.

Three inspiring stories: Giving back to the community

- **Ava**: Ava Costa's Sharing Shed aims to connect people with the disability equipment they need, when they need it. After noticing unused items gathering dust in her own home, the former gymnast created an online network to help people living with SCI swap and share essential equipment. You can read more in the ABC article
- **Breanna:** Breanna is a state-wide health, education and disability advocate. Having spent significant time as a health consumer in both paediatric and adult services, she now uses her lived experience to influence change. While studying law, she continues to advocate across health, education and disability sectors, and
- **Lauren:** Lauren is losing her sight, but is advocating to ensure inclusive sport and recreational activities for people with disability in regional areas. There are other inspiring stories at Inclusive Sport and Recreation Communities – Carers Queensland.

5.8. Identity and SCI: Three research studies

Identity is an important part of who we are. We all have multiple identities, including personal and professional ones, that change as we live, learn and grow older. Our identities are also shaped by our culture and circumstances. For people with SCI, this experience can become a significant part of their identity. For example, Dylan Alcott spent the first few years of his life in hospital after being born with a tumour on his spinal cord, which resulted in paraplegia at a young age (NTSCI). Living with SCI has been part of his identity for his entire life. For many others, SCI may occur later in life, either from non-traumatic causes, such as a cyst, tumour or surgery or from traumatic events, such as a car, motorcycle or bicycle accident, a fall from a ladder or horse or while playing sport. These injuries change lives forever and often lead to decisions about the future that involve negotiating and reconstructing identity.

Below are three examples of identity research following SCI. The first examines personal experiences of identity after SCI (Cao *et al.*, 2022). The second focuses on TSCI among veterans living

with SCI (Mitchell & Johnsen-Buss, 2025). The third explores the development of professional identity among Canadian healthcare students and clinicians with disabilities during their education and career journeys (Mayer *et al.*, 2024).

Research: Identity and SCI

Cao and colleagues (2022) synthesised the qualitative evidence on individuals' personal experiences of identity following SCI. Five overarching themes were identified from the literature in terms of participants' discussions about how they incorporated disability into their new identity and the role of support networks and the broader social environment in shaping their new identity:

- Constructing and negotiating the disability identity
- Navigating the psychosocial sphere in an able-bodied world
- Taking on and managing various roles following SCI
- Impact of hospitalisation and rehabilitation on personal identity post-SCI, and
- Sexual identity post-SCI.

The study shed light on the multifaceted nature of identity following SCI and the complexity of the identity reconstruction process. The researchers concluded that:

> *"For health professionals wanting to facilitate identity reconstruction in individuals post-SCI, it is important to employ person-centred approaches in clinical practice and to involve family members and peers in rehabilitation settings."*

Research: Veterans and identity following SCI

Mitchell & Johnsen-Buss (2025) conducted a qualitative study to explore identity development among veterans living with SCI. Using semi-structured interviews with 21 participants, supplemented by brief surveys and record reviews, the researchers examined how SCI influences identity and the process of re-establishing an integrated sense of self in adulthood.

The thematic analysis revealed that a TSCI often disrupted identity in three areas: Career roles, social roles and independence. Despite these challenges, many veterans reported continuity in aspects of their identity, indicating that identity after SCI reflects both change and persistence.

Common strategies for rebuilding identity included adapting activities and maintaining an active life, demonstrating that identity exploration continues well into adulthood following injury. For these veterans, their military identity and the culture had dual effects, providing resilience and commitment during recovery while also creating vulnerabilities tied to ideals of self-sufficiency and physical fitness.

In summary, the findings highlighted that disability identity development and integration are central tasks after SCI. Purposeful adaptation and role re-engagement can foster a cohesive sense of self, and recognising both the strengths and pressures of pre-existing identities can inform tailored rehabilitation and educational support. Ultimately, identity after SCI is shaped by disruption and continuity and active engagement in meaningful roles can promote integrated, resilient identities for veterans.

Research: Professional identity formation: Canadian medical students and clinicians

In the third study, Mayer and colleagues (2024) explored the development of a professional identity amongst Canadian disabled healthcare students and clinicians during their educational and professional journeys. Up to three interviews over a year were conducted with 27 students and 29 clinicians, resulting in 124 interviews with participants from medicine, nursing, occupational therapy, physical therapy and social work. A professional identity seemed to develop through interactions with others in the education and practice communities, including faculty, professors, supervisors, peers, colleagues, friends and family. Data analysis revealed two prominent dimensions:

- **Contextualisation of identity formation processes:** This refers to the healthcare context in which these processes occur and are shaped by the social context. Context is important in PI development because professional roles must be legitimised by the group or by the community of practice. For some participants, their professional identity role was not always legitimised because of their disability. The doubt they experienced from 'significant others' in the healthcare community hindered their professional identity formation and sense of belonging to the professional community. This was more prevalent among students because their sense of professional identity was still in development. Despite their diverse contexts, the five professions exhibited similar patterns. Two prominent categories of the social context contributed to the challenges faced by disabled students and clinicians: (1) healthcare settings are competitive, stressful, and protocol-driven; (2) within these social contexts, disability is, at times, perceived as a weakness and risk (a liability) to patient safety and professionalism, and
- **Identity navigation dimension:** Relates to exploring the PI and the disability identity. **Figure 5.6** is a model developed by the researchers to explain the two identities. Two factors appeared to impact the nature of identity navigation. First, the duration of the disability. The longer someone had the disability, the more it became part of the student's or clinician's general professional identity. Living with a disability for longer provided more opportunities to form a disability identity and to incorporate this into an evolving PI. Second, with higher levels of education and more professional experience, the merging of the disability and professional identities was more likely. Students new to the field, subject to a hierarchical structure of healthcare and constantly being evaluated and still feeling insecure about themselves as part of the community, were more likely to integrate their disability identity into their professional identity. A higher level of experience and longer time living with a disability seemed to interact, such that both led to higher levels of integration.

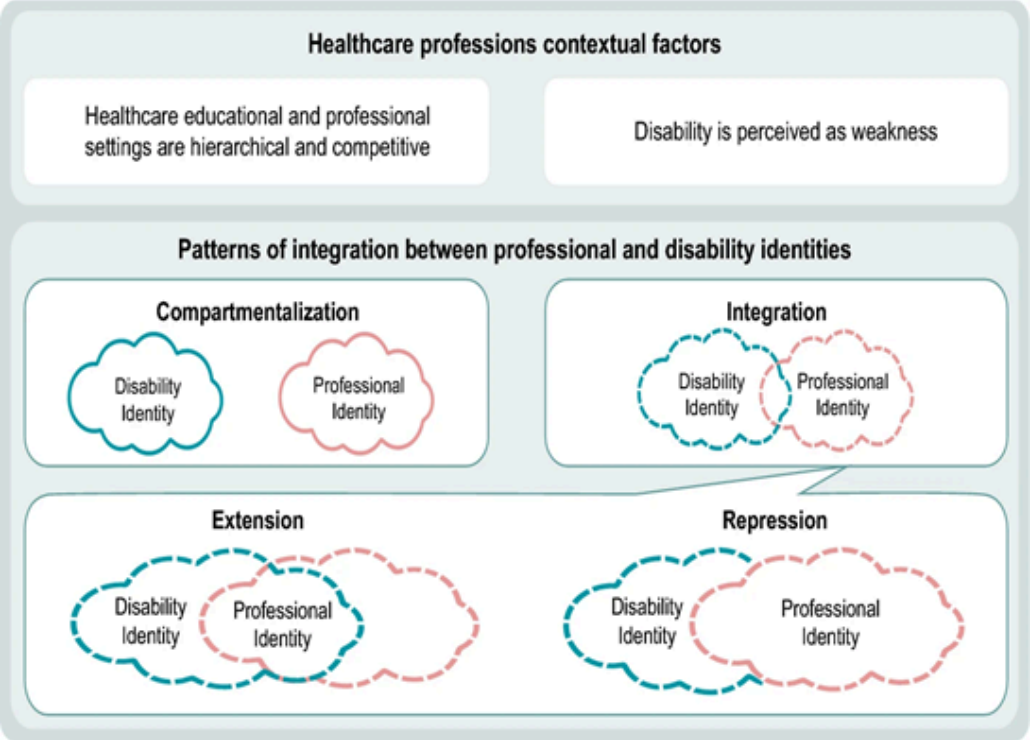

Figure 5.6. Patterns of integration between disability and professional identities. *Source:* Mayer *et al.* (2024). CC BY 4.0.

To conclude, the social environment is important in identity formation, emphasising the significance of a supportive environment for disabled students and practitioners. A supportive environment fosters the negotiation of both professional and disability identities. The research also highlights the importance of understanding and supporting the multifaceted identity formation processes among individuals living with disability in healthcare professions. These conclusions are applicable across numerous social contexts and relate to inclusion and acceptance, as well as possibility trust.

Taken together, these studies show that identity reconstruction after SCI is not a simple or uniform process. It is deeply personal and shaped by social context, cultural expectations and life stage. Whether negotiating personal identity, adapting to disability or integrating professional roles, individuals face complex challenges that require more than physical rehabilitation.

For health practitioners and educators, these studies highlight the importance of person-centred approaches that go beyond clinical care to include psychosocial support, peer and family involvement and recognition of cultural and professional identities. Creating environments that validate and integrate these identities can foster resilience, belonging and meaningful participation, ultimately improving long-term outcomes for people living with SCI.

Clinical resource: Doctors for Disability

Doctors for Disability is a community-driven Facebook page that promotes inclusion, accessibility, and best practices for patients and professionals with disabilities. The Facebook page shares educational content, practical strategies and opportunities for collaboration among healthcare providers committed to improving care for individuals with disabilities.

5.9. Leadership and inclusion after SCI

Leadership is not often discussed in the disability literature, despite the leadership roles many individuals living with disability, including SCI.

5.9.1 Leadership representation

As highlighted in the Introduction of this e-resource, the inclusion of individuals with lived and lived-like experiences (LLEs) of disability at all levels of society, including in leadership roles, is essential. Although people with disability form an important part of the workforce, they remain significantly underrepresented in decision-making positions. The 2025 Third Report of Australia's Disability Strategy 2021–2031 notes:

> *"People with disability are significantly underrepresented on boards, in politics and in other leadership roles in Australian society. Increased inclusion of people with disability in leadership roles will facilitate the inclusion of the perspectives of people with disability in decision-making. This will make decisions more reflective of the community (*Australia's Disability Strategy 2021–2031*). The inclusion of people with disability in leadership roles can play a key role in progressing disability responsiveness throughout the workforce and demonstrate commitment to supporting diversity* (Australian Council of Learned Academies 2022)."

When people living with disability were asked if they felt valued and respected in their community, just over half indicated that this was so. This percentage has remained similar for two consecutive surveys (2022 and 2024) (**Figure 5.7a**). When asked *"Do you feel that people with disability are well represented in leadership roles?",* only 19% reported feeling represented in leadership roles in the Third Annual Report on Australia's Disability Strategy. This had increased to 23% in the January 2026 Fourth Annual Report (AIHW, 2025, 2026) (**Figure 5.7b**).

Feel valued and respected

Latest update: 53% (2024)

Baseline: 54% (2022)

Progress status: No change

In 2024:

- most people with disability aged 65 and over (65%) felt valued and respected in their community, compared with people with disability aged 25–44 (43%)
- people who reported having severe or profound disability (41%) felt less valued and respected than people with other disability status (57%)
- those whose highest education level was a Bachelor Degree or higher (60%) felt more valued and respected than those whose highest education level was Year 12 (54%), a Certificate/Diploma (51%), or none or below Year 12 (50%).

Feel represented in leadership

Latest update: 23% (2024)

Baseline: 19% (2022)

Progress status: Improving

In 2024:

- a higher proportion of men with disability (28%) reported feeling represented than women (18%)
- a higher proportion of people with sensory and speech disability (26%) reported feeling represented compared with people with psychosocial disability (16%)
- those whose highest education level was none or below Year 12 (30%) reported feeling represented more than those whose highest education level was Certificate/Diploma (22%), Year 12 (22%) and a Bachelor Degree or higher (18%).

Figures 5.7a and b. Comparison between the 2022 and 2024 surveys in terms of people with disability feeling valued (no change) and represented in leadership roles (improving). *Source:* AIHW (2026). CC BY 4.0

These findings reinforce the need for strong, visible leadership by people with disability, not only to influence policy and organisational culture, but also to shape a society where people with disability feel valued, respected and represented. Increasing leadership opportunities, strengthening pathways to decision-making roles and embedding disability inclusion across institutions are essential steps toward achieving Australia's broader goals under the Disability Strategy.

5.10. Allyship and Advocacy

The Australian Disability Network (AND) provides a practical resource, 10 Tips for Inclusive Allyship and Advocacy. This guide emphasises that being an effective ally and advocate for disability inclusion means actively supporting and amplifying disabled voices while using influence to create positive change. It is about consistent actions, not just intentions.

5.10.1. What does this allyship look like in practice?

Allyship begins by including individuals with LLEs in decisions that affect them personally. Whether designing schools or hospitals, drafting disability or inclusion policies or testing assessment tools, individuals with LLEs should, wherever reasonably possible, have a seat at the table.

Individuals living with SCI often belong to a distinct subculture and identity. Those reintegrating into the community are sometimes portrayed as 'heroes', which can create pressure when they are expected to represent disability on multiple forums. This expectation can be overwhelming.

Therefore, people without disabilities are encouraged to respect and partner with individuals with LLE in a meaningful way. Input should be sought systematically, only when necessary, in an accessible manner, and with sufficient time for feedback. The best approach is to discuss involvement openly and ask what they feel able and willing to contribute.

As Wolbring and Lillywhite (2023) noted:

> *"Disabled people are constantly engaged in activism to decrease their problems. However, disabled people cannot do all the work by themselves and need allies (who can be so-called non-disabled people or disabled people of a different background to other disabled people) given the many barriers disabled people face in being activists, given the precarious lived reality of many, and given the many problems in need of solving."*

Their scoping review found that while allyship is frequently mentioned in academic literature, detailed coverage of challenges, stressors and risks such as burnout for allies is minimal. Of 577 abstracts reviewed, only a handful addressed these issues, revealing a significant gap in understanding how to support ongoing and authentic allyship.

5.10.2. Why does allyship and advocacy matter?

Practical strategies are needed that not only empower disabled voices but also provide guidance and support for allies to maintain their effectiveness without undue stress or burnout.

To conclude **Chapter 5**, **Dean Durman** shares his perspective and life philosophy on living today after a TSCI.

Dean's story: Strength and connection through giving

"Beyond studying, I found meaning in sharing my story publicly. Speaking at events, engaging with communities and mentoring individuals allowed me to transform brokenness into beauty. Contribution became reciprocal: As I gave, I received strength, connection and renewed purpose.

Counselling, coaching, and mentoring young men in the community has become a central focus. This work provides fulfilment that surpasses the conventional nine-to-five role, allowing me to channel my knowledge, resilience and lived experience into guidance for others navigating uncertainty, identity, and adversity.

Contribution is not simply about service; it is about belonging. By engaging with society, I re-established my place within it, not as someone defined by disability, but as someone defined by resilience, purpose and the ability to empower others.

Reintegration after trauma is not a single step but a layered process. Returning home revealed the depth of loss. The implosion during hydrotherapy became the catalyst for transformation. Acceptance, accountability and forgiveness formed the foundation of spiritual healing, which in turn unlocked mental, emotional and physical restoration. Work provided stability and dignity, enabling me to re-engage with society and reclaim a sense of worth.

Study offered growth and intellectual renewal. Contribution created meaning and belonging. Together, these elements formed a holistic pathway back into the community. This lived experience demonstrates that reintegration requires more than physical recovery. It demands holistic healing – spiritual, emotional, and social – supported by community, family, and meaningful contribution. It is through this process that brokenness can be transformed into beauty and despair into resilience.

I now host a podcast called **One to the Power 3**, *a safe and welcoming space where those who have faced adversity share how they overcame their challenges and the valuable lessons they learned along the journey. Each episode offers listeners hope, a shift in perspective and a powerful reminder that even the most broken stories can be transformed into testimonies of resilience. It is a platform dedicated to taking our brokenness and turning it into something beautiful."*

Key Take-aways

- A fulfilling life with SCI does not happen overnight. It requires an individual to consider the 'new nor-

mal' and the future. This is likely to involve 'significant' others
- Problem-solving and goal-setting are important aspects of the journey following SCI, as is having a resilient personality
- Getting back into the community means being social. For singles, this may mean being back on the dating scene, which can be daunting
- Getting back into the community can also involve getting back to work, either by returning to your old job, perhaps with some adjustments and flexibility or by making a career switch. There are funds to support both of these
- Getting into the community could mean studying for the first time or changing careers, which can be supported
- Volunteering is also a way of getting out into the community. Volunteering may be within the SCI community, such as peer mentoring or participating in research clinical trials, which may also be paid roles. It could also be volunteering for your favourite charity
- For most individuals who have sustained SCI, particularly if the injury happens when one already has a sense of oneself, there will be internal negotiations about one's personal and professional identities, and
- Allyship and advocacy matter to those living with SCI.

The final chapter in Part A of this e-resource, **Chapter 6**, is about an ageing body and SCI. The Chapter will explore what happens as the body ages, as well as consider some of the rising conditions in our modern world, such as dementia.

Reminder: Relevant chapters

- **Chapter 1:** The natural flow of the chapters is **Chapter 1** (getting settled), **Chapter 3** (staying healthy, fit and well) and then this current Chapter (**Chapter 5**) about getting out there
- **Chapter 2:** A resource for when the body does strange things while being out and about
- **Chapter 3:** Chapter 3 is about reaching equilibrium and understanding your body's peculiarities to manage different contexts, such as studying, working and socialising. The five pillars of health and well-being help ensure that your body gets what it needs: good nutrition, quality sleep, exposure to sunlight and social connection
- **Chapter 4:** Tracking health and well-being is important to manage a body that is already anatomically and physiologically different, particularly as studying, working and socialising change the routine
- **Chapter 6:** Ageing will impact the body and so needs to be managed when working, studying and socialising.
- **Chapter 8:** Getting out and about in rural, regional and remote Australia might be challenging. The chapter has resources for First Nations people living with disability and their carers
- **Chapter 9:** Chapter 9 addresses other elements of our intersectional selves, such as culture, sexual orientation, and neurodiversity
- **Chapter 10:** This is a useful chapter as it discusses discrimination, abuse and violence, including

domestic violence. It links with **Chapter 11**, which covers legal issues related to discrimination and disability

- **Chapter 11:** You need to know your rights in terms of working, studying and being out in the community. This links with the discussion on discrimination and abuse in **Chapter 10.**
- **Chapter 12:** If you play sport, you are likely to be flying locally and perhaps internationally. Chapter 12 offers numerous resources and LLEs
- **Chapter 16:** There may be opportunities to engage in research, including clinical trials
- **Chapter 17:** The impact of a changing climate is important for those engaged in sport, particularly if they are unable to regulate their body temperature. There could be mobility issues during calls to evacuate in the event of a bushfire or flood. This may also happen while abroad for a sporting event. Having an appropriate emergency plan is crucial, and
- **Chapter 18:** For those interested in pursuing a career in the health professions, particularly medicine, discusses inclusivity for applicants and patients with disabilities.

References

Allaire, T., Perera, M., Drossel, C., Sol, K., Theisen-Goodvich, M., & Meade, M.A. (2022). Flourishing after traumatic spinal cord injury: Results from a multimethod study. *Rehabilitation Psychology*, *67*(1), 53-68. https://pubmed.ncbi.nlm.nih.gov/34928640/

Australian Disability Network. (2024). *Disability statistics*. https://australiandisabilitynetwork.org.au/resources/disability-statistics/

Australian Institute of Health and Welfare. (2025). *Australia's Disability Strategy 2021-2031 Outcomes Framework: 3rd annual report*. Australian Government. https://www.aihw.gov.au/reports/australias-disability-strategy/australias-disability-strategy-outcomes-framework/contents/summary

Australian Institute of Health and Welfare. (2026). *Australia's Disability Strategy 2021-2031 Outcomes Framework: 4th annual report*. Australian Government. https://www.aihw.gov.au/reports/australias-disability-strategy/australias-disability-strategy-2021-2031-outcomes/contents/about

Angel, S. (2022). Ten years of living with an injured spinal cord: A qualitative longitudinal study. *International Journal of Nursing Studies Advances*, *4*, https://www.sciencedirect.com/science/article/pii/S2666142X2200039X.

BankWest, Curtin University. (2024). *Employment and disability in Australia.* Focus on the States Series, No. 10/24. Bankwest Curtin Economics Centre. https://bcec.edu.au/assets/2024/03/BCEC-Employment-and-disability-in-Australia-2024-WEB.pdf

Bates, S., Kayess, R., Fisher, K. R. (2013). *Research into maximising life choices of people with a spinal cord injury (SPRC Report 01/2013)*. Sydney: Social Policy Research Centre, The University

of New South Wales. Prepared for Spinal Cord Injuries Australia. https://www.unsw.edu.au/content/dam/pdfs/ada/sprc/research-reports/2021-06-research/2021-06-Maximising_life_choices_of_people_with_spinal_cord_injury_final_report_2013.pdf

Brett, M., Harvey, A., Funston, A., Spicer, R., & Wood, A. (2016). *The role of inherent requirement statements in Australian universities: Final report.* Access and Achievement Research Unit, La Trobe University. https://www.ncsehe.edu.au/app/uploads/2016/05/The-Role-of-Inherent-Requirement-Statements-in-Australian-Universities.pdf.

Borg, S. J., Geraghty, T., Arora, M., Foster, M., Marshall, R., Nunn, A., & Middleton, J. W. (2021). Employment outcomes following spinal cord injury: A population-based cross-sectional study in Australia. *Spinal Cord, 59*(11), 1120-1131. https://doi.org/10.1038/s41393-021-00639-z

Cao, P., Harnett, A., McIntyre, A., Mehta, S., Schmidt, J., Upper, R. & Teasell, R. (2022). Identity negotiation and reconstruction following a spinal cord injury: A meta-synthesis of qualitative evidence. *Archives of Medicine and Rehabilitation*, *103*(12), e207. https://www.sciencedirect.com/science/article/abs/pii/S0003999322006396.

Chuang, C. H., Chen, P. C., Bai, C. H., Wu, Y. L., Tsai, M. C., & Li, C. Y. (2022). Association between spinal cord injury and alcohol dependence: A population-based retrospective cohort study. *Journal of Personalized Medicine, 12*(3), 473. https://www.mdpi.com/2075-4426/12/3/473

Clifton, S., Bray, E. Dong, S. McCabe R., & Siddall, P. (2024). Co-design of an intervention exploring meaning and purpose after spinal cord injury. *Disability and Rehabilitation*, *46*(22), 5243-5252. https://doi.org/10.1080/09638288.2023.2300655.

Corcoran, T., Whitburn, B., & Knight, E. (2022). Inherent requirements in higher education: locating You in Us. Perspectives: *Policy and Practice in Higher Education, 26*(2), 69-75. https://www.tandfonline.com/doi/full/10.1080/13603108.2021.1986166

Davis, J. F., Cao, Y., & Krause, J. S. (2018). Changes in alcohol use after the onset of spinal cord injury. *Journal of Spinal Cord Medicine*, *41*(2), 230-237. https://doi.org/10.1080/10790268.2017.1319996

Finger, M., Karcz, K., Schiffmann, B., Staubli, S., Hund-Georgiadis, M., & Escorpizo, R. (2023). Factors influencing sustainable employment of persons with acquired brain injury (ABI) or spinal cord injury (SCI): A qualitative study evaluating the perspective of health and work professionals. *Frontiers in Rehabilitation Science*, *20*(3), 906567. https://www.frontiersin.org/journals/rehabilitation-sciences/articles/10.3389/fresc.2022.906567/full

Graupensperger, S., Corey, J. J., Turrisi, R. J., & Evans, M. B. (2019). Individuals with spinal cord injury have greater odds of substance use disorders than non-SCI comparisons. *Drug and Alcohol Dependence, 205,* 107608, https://www.sciencedirect.com/science/article/abs/pii/S0376871619303850

Hilton, G., Unsworth, C., & Murphy, G. (2018). The experience of attempting to return to work following spinal cord injury: a systematic review of the qualitative literature, *Disability and Rehabilitation, 40*, 15. https://doi.org/10.1080/09638288.2017.1312566.

Mayer, Y., Nimmon, L., Shalev, M., Gross, E., Bulk, L. Y., Battalova, A., Krupa, T. & Jarus, T. (2024). Belonging in dual roles: Exploring professional identity formation amongst disabled healthcare students and clinicians. *Advances in Health Sciences Education, 30,* 1101-1121. https://doi.org/10.1007/s10459-024-10386-4.

Mitchell, L. L., & Johnsen-Buss, E. (2025). Identity development among veterans with spinal cord injury: A qualitative study. Rehabilitation Psychology. Advance online publication. https://doi.org/10.1037/rep0000603

Salinger, M. R., Feltz, B., Chan, S. H., Anna Gosline, A., Davila, C., Mitchell, S., Iezzoni, L.I. (2023). Impairment and disability identity and perceptions of trust, respect, and fairness. *JAMA Health Forum, 4*(9), e233180. https://doi.org/10.1001/jamahealthforum.2023.3180.

Serpa, S. (2019). Socialization: A key concept in social sciences. *International E-journal of Advances in Social Science, 5*(14), 599-605. http://ijasos.ocerintjournals.org/en/pub/article/591428

Spinal Life Australia. (2026). *Back2Work*. https://www.spinal.com.au/back2work/

Wolbring, G., & Lillywhite, A. (2023). Coverage of allies, allyship and disabled people: A scoping review. *Societies, 13*(11), 241. https://doi.org/10.3390/soc13110241

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PART A: GOING 'HOME' AND STAYING FIT, HEALTHY AND WELL: STAGE 3 (CHAPTER 6)

Stage 3: Ageing with Spinal Cord Injury (Chapter 6)

In many parts of the world, populations are ageing. The mean age at death rose from about 46.8 years in 1990 to 63.4 years in 2023, reflecting sustained reductions in mortality across childhood and mid-life and continued gains in later life (GBD 2023 Causes of Death Collaborators, 2025). The World Health Organization's (WHO) February 2025 brief reported that life expectancy at birth had reached approximately 73.3 years in 2024, an increase of 8.4 years since 1995. In the same brief, WHO projected that the number of people aged 60 years and older would rise from 1.1 billion in 2023 to 1.4 billion by 2030, with the fastest growth anticipated in developing regions. In response to an ageing global population in many parts of the world, the UN Decade of Healthy Ageing 2021 to 2030 program has identified four action areas, for which extensive resources have been provided:

1. **Combating ageism:** Changing how we think, feel and act towards age and ageing
2. **Providing age-friendly environments:** Ensuring that communities foster the abilities of older people
3. **Integrating care:** Delivering person-centred integrated care and primary health services responsive to older people, and
4. **Improving access to long-term care:** Providing access to long-term care for older people who need it.

Video: UN's Decade of Health Ageing (2021-2031)

UN Decade of Healthy Ageing (2021–2030): This program provides a global platform dedicated to supporting ageing well, including an introductory video and an extensive collection of practical resources.

Key one-page guides address topics such as carer support and limited mobility, offering quick, accessible information for individuals and communities. The platform also features a comprehensive **Partnering Kit** as part of the **Be Part of the Decade** movement, as well as a range of additional tools designed to help organisations, carers and older adults engage meaningfully in healthy ageing initiatives.

Thus, ageing is a universal phenomenon, but how we age individually is highly variable and is influenced by genetics, lifestyle, overall health and well-being, as well as psychosocial factors such as social and financial supports and access to healthcare. A variety of terms have been used to describe 'ageing well'. Earlier models, such as one proposed by Rowe and Kahn (1997), emphasised a low probability of disease and disease-related disability as central to successful ageing. More recent perspectives have, however, adopted a more inclusive view, recognising that many individuals age with disability and should not be excluded from definitions of successful or healthy ageing. The WHO (2020) provided this holistic definition of *healthy ageing*: *"The process of developing and maintaining the **functional ability** that enables wellbeing in older age."*

As a reminder, **Part A** of this resource book has been organised around three stages that reflect the journey of individuals living with SCI from hospital discharge to living long-term in the community. **Stage 1** (Chapters **1** and **2**) focused on coming home and getting settled. It explored what returning 'home' can look like, the importance of early planning with a multidisciplinary team and the practical supports needed to make daily life manageable and safe. These include finding suitable accommodation, carer and support arrangements and financial support opportunities and an understanding of how injury level and severity influence function and potential complications. **Stage 1**, thus, hopefully provided guidance on the essentials of living confidently and independently after leaving the hospital or transitional rehabilitation and going home.

Stage 2 (Chapters 3-5) focused on staying healthy and well and engaged in life in the community. This Stage describes strategies for maintaining physical health and psychological well-being, remaining vigilant in terms of early signs of health problems and using tools such as health maintenance apps to support self-management. It also emphasised participation in the community through social connection, sport, advocacy and volunteering, as well as returning to study or work or upskilling to pursue new career options. The focus was on developing routines, relationships and supports that sustain long-term health and well-being and purpose.

Now, in **Stage 3**, the final chapter, **Chapter 6** will focus on ageing with SCI and examine how age-related physiological changes can interact with, and at times, exacerbate the long-term effects of the original SCI as the body ages.

It should be noted that while *traumatic spinal cord injuries (TSCIs)* resulting from sport or vehicle accidents are more common amongst younger people,*non-traumatic spinal cord injuries (NTSCIs)* are more common in older individuals, mainly due to degenerative changes or pathology such as tumours. Most of the SCI ageing research relates to TSCI, with individuals often having lived with SCI for many years.

References

GBD 2023 Causes of Death Collaborators. (2025). Global burden of 292 causes of death in 204 countries and territories and 660 subnational locations, 1990–2023: a systematic analysis for the Global Burden of Disease Study 2023. *Lancet, 406* (10513), 1811-1872. https://www.the-lancet.com/journals/lancet/article/PIIS0140-6736(25)01917-8/fulltext

Roew, J. W., & Kahn, R. L. (1997). Successful ageing. *The Gerontologist, 37*(4), 433-440. https://doi.org/10.1093/geront/37.4.433

World Health Organization (WHO). (2020). *Healthy ageing and functional ability*. https://www.who.int/news-room/questions-and-answers/item/healthy-ageing-and-functional-ability

World Health Organization (WHO). (2025). *Ageing: Global Population*. https://www.who.int/news-room/questions-and-answers/item/population-ageing

Chapter 6. Ageing Well with Spinal Cord Injury

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"If I can laugh, I can live."

Christopher Reeve, actor and SCI advocate.

Life expectancy for people living with SCI varies, depending on numerous factors, including the level and completeness of the injury, whether the SCI was traumatic (***TSCI***) or non-traumatic (***NTSCI***), the presence of chronic diseases, as well as the social and environmental factors that influence health and well-being, such as health literacy and access to healthcare. In the USA, the National Spinal Cord Injury Statistical Center (NSCISC) regularly publishes national SCI data. The 2024 NSCISC Report outlines the historical information about life expectancy*:*

"Life expectancies for people with SCI remain substantially below normal, particularly for persons with tetraplegia and ventilator dependency. Moreover, although mortality rates during the first post-injury year have decreased steadily since the 1970s, annual mortality rates after the first post-injury year have not changed since the early 1980s. Therefore, although general population life expectancy is increasing, life expectancy for persons with SCI who have survived the first year after injury has remained relatively constant, and the gap in life expectancy between persons with SCI and the general population of comparable age, sex, and race, is increasing..... At a minimum, important prognostic factors that should be considered in determining an individual life expectancy include age, exact neurologic level of injury (particularly among persons with tetraplegia), AIS grade, length of survival that has already occurred after injury, and to a lesser extent, etiology of injury, gender, race, education, and access to care (availability of good insurance coverage or other financial resources). Significant co-morbidities (cancer, heart disease, diabetes, etc.) should also be considered when present." (p. 12).

Long-term studies in the UK and Denmark show a similar trend of substantial improvement in life expectancy until the late 20th century, followed by relative stability. In those populations, age at injury and injury severity, including ventilator dependence, strongly influenced survival and, therefore, the age of death (Noe *et al.*, 2017; Savic et al., 2017).

Taken together, the evidence suggests that while life expectancy among people living with SCI has improved dramatically, it has now stabilised. Mortality remains higher than in the general population, underscoring the need for integrated and person-centred health approaches

aligned with the aims of the UN Decade of Healthy Ageing program to ensure that people living with SCI age well.

This Chapter will provide an overview of how to understand, anticipate and manage these changes as one ages with SCI. The Chapter builds on concepts introduced in **Chapter 3,** which highlighted the importance of maintaining physical health and psychological well-being throughout life. In the context of ageing, these foundations become increasingly significant, as the ageing process can lead to secondary health issues. These challenges may be further compounded by degenerative and pathological conditions associated with typical ageing, including cancer and dementia.

Key Topics in this Chapter

- An overview of some of the current research on ageing with SCI
- Emerging evidence on the relationship between SCI and dementia
- What to expect as ageing progresses with SCI
- How ageing with SCI differs from typical ageing
- Common health issues and risks that may arise over time
- Strategies for healthy ageing with SCI, including staying up to date with health checks, maintaining an active lifestyle, supporting nutrition and bone health, protecting joints, preventing skin and pressure injuries, managing bladder and bowel function, remaining socially connected and using adaptive equipment and home modifications
- Experiences and needs of ageing carers
- Financial implications of ageing with SCI
- Intersection of ableism and ageism and its impact on the ageing experience
- Considerations involved in transitioning into residential care
- The sensitive topic of suicide risk in later life; and
- A discussion about end-of-life care, including ***Voluntary Assisted Dying (VAD)*** in jurisdictions where it is legally available.

6.1. Ageing and life expectancy with SCI

For people living with SCI, the ageing process is more complex because age-related changes often occur at the same time as existing anatomical and functional alterations caused by the SCI. In their recent review, Tan *et al.* (2025) discuss the "Double Jeopardy" theory, which describes the compounded effects of age and SCI, leading to *"accelerated ageing"*, which is marked by earlier onset of physical and functional decline due to secondary conditions and SCI-related cumulative stresses over time. Functional decline often commences around age 45 or 15 years post-SCI. Common secondary conditions, such as cardiovascular and respiratory issues, bowel and bladder problems, neuropathic and musculoskeletal pain, fatigue, pressure injuries, weakness and spasticity have been found to affect independence, support needs and quality of life (Tan *et al.*, 2025).

In an earlier narrative review, Guízar-Sahagún *et al.* (2023) found that the most prevalent general symptoms of ageing with SCI were *fatigue, pain, weakness, spasticity and decreased activity*. Of note is the seven-fold greater odds of chronic fatigue after SCI. The longer the time post-injury, the greater the need for personal assistance and equipment to maintain independence. The most frequent pathological conditions with increasing age were cardiovascular diseases, metabolic disorders, osteoporosis, respiratory conditions, cerebrovascular disease, cancer, osteoarthritis, sensory deficiencies (especially decreased vision and hearing) and cognitive disorders (dementia). With increasing years post-injury, conditions such as pressure ulcers, gastrointestinal problems, urinary tract conditions, autonomic dysreflexia and musculoskeletal conditions, including abnormal curvature of the spine, contractures and fractures, are more likely (Guízar-Sahagún *et al.*, 2023).

Below, **Dean Durman** describes how he sees ageing with SCI.

Dean's story: Healthy ageing involves more than physical health

Dean Durman highlights that healthy ageing involves attention to all aspects of life, including physical, emotional and spiritual well-being:

"Living with a spinal cord injury is a life-long journey. After 15 years, I've seen how its effects echo across every stage of life, with each challenge different from the one before. The question beckons: How do I develop daily patterns that embrace every facet of my being, so I live each day fully poured out, as if it were my last? As I remind myself, "Let my every word and my every action be that of a dying man."

Ageing with SCI requires more than medical management. It demands close awareness of your body. Being sensitive to changes helps prevent complications, whether skin issues, musculoskeletal strain or broader health challenges such as cardiovascular disease and chronic pain. Building a strong support network assists

in navigating these challenges as they arise. Staying on top of bowel routines, bladder management and overall hygiene is critical to avoid mishaps and maintain confidence when out and about.

One of my greatest challenges has been frequent urinary tract infections. Repeated courses of antibiotics take a toll, while reduced bladder capacity and increased neuropathic pain remain constant. Developing a routine that works for you is essential. It allows you to live with positivity despite the difficulties. The saying, "Your attitude determines your altitude", holds true.

I have made significant lifestyle adjustments: Eating a balanced diet, cutting sugar and unnecessary carbs, keeping portions in line with daily needs and using intermittent fasting to help the body reset. Regular exercise is vital. I push boundaries by training areas that haven't been worked before. Just as important are practices that nurture mental and spiritual well-being: Reflection, quietness, prayer, creating space for others and embracing life's full spectrum — fun, laughter, and even tears.

Ageing with SCI is not only about managing decline. It is also about building the toolset for resilience with joy. It means letting go of unhelpful thought patterns and creating new pathways toward positive thinking. With awareness, preventative strategies, good support system and lifestyle adjustments, the difference becomes clear – You move from merely coping to truly living."

Since Dean's reflection includes spiritual well-being, below is a reminder about where in this e-resource we have discussed or will discuss spirituality, spirit and spiritual well-being.

Reminder: Spirituality and spiritual health

- In **Part A**'s prelude to **Chapters 1-6**, we introduced the 3Ss of resilience: *Self-efficacy, Social supports and Spirituality*, based on Jenkins and Cosco's (2012) *Spinal cord injury and aging: An exploration of interrelatedness between key psychological factors contributing to the process of resilience*. The prelude is worth reading if you have not already done so.
- **Chapter 14** is devoted to a discussion of spirituality, spirit and spiritual health.

As the years progress, ageing with SCI often increases the need for regular engagement with the healthcare system, which may have financial implications. Ageing may also prompt changes to accommodation arrangements, including the possibility of moving to residential aged care. These transitions require careful planning. In addition, family dynamics can shift as carers and family members age themselves. In some circumstances, a person living with SCI may become responsible for ageing parents, introducing new interpersonal and emotional considerations, as **Dr Dinesh Palipana** has identified below.

Dinesh's story: What are his thoughts on ageing?

When invited to reflect on ageing with SCI, **Dinesh Palipana** spoke not only about his own health (which he tends to carefully) but also that of his mother, who has been his primary carer since his accident in 2010. Being financially secure is also important:

> *"Maybe because I look after myself [I am doing ok]. There are things that I can do, like maintaining skin integrity and keeping good heart health. The other is screening, like making sure you get screened for cancer.*
>
> *I love the work things that I get to do [as a doctor]. But everyone has a limit, I guess. So, I just want to make sure that I can continue [to work for as long as I can.*
>
> *I think about my mum. I think about it because you want to be present for your parents when they need you. So, will I be physically present for my mum as she has been for me? I think about that. I wonder if it's different if you have kids and you're aging.*
>
> *And I suppose the other important thing is financial security. Because the costs [of a spinal cord injury] are so high. How much will you actually need to retire? One doesn't know."*

Both of these ***LLEs*** illustrate the breadth of considerations involved in ageing with SCI. They reflect that ageing is not only a biological process but also a social, emotional and practical one, influenced by health challenges, lifestyle choices, relationships and financial pressures.

6.2. What does the research say about ageing with SCI?

A growing body of current research provides important insights into the experience of ageing with SCI. This work highlights the complex interplay between physical, psychological and social factors across the lifespan. Studies show that ageing affects individuals with SCI differently from the general population, with certain risks emerging earlier or progressing more rapidly. At the same time, research identifies protective factors that support well-being, adaptation and resilience in later life. Collectively, these findings create a more comprehensive understanding of the challenges, adjustments and opportunities associated with ageing with SCI.

The research topics explored below include:

- The long-term health risks among individuals ageing with SCI, including TSCIs
- Gender-related differences in the experiences and outcomes of ageing with SCI
- Functioning as a health indicator for modelling healthy ageing trajectories in people living

with SCI
- The importance of health literacy for people ageing with SCI; and
- Health service utilisation.

6.2.1. Long-term outcomes of SCI

As described in **Chapter 2**, SCI results in a range of anatomical and physiological changes to one's body, which is influenced by whether the injury was due to trauma (*TSCI*) or pathological or degenerative processes (*NTSCI*), level and completeness of the injury and the age at which the SCI happened. As TSCI occur predominantly in younger individuals and NTSCIs in older individuals, the time since injury becomes a factor in understanding the impact of ageing with a SCI.

Research: Elevated risk of chronic conditions with TSCI

Mashlah and colleagues (2025) conducted a retrospective two-cohort study to determine whether a TSCI increases long-term risk for chronic disease. They used electronic health records from Mass General Brigham (MGB) and the University of California Health System (UCHS) from 1996 to 2024 and created matched cohorts of adults with and without TSCI. Matching was based on age, sex and race. Individuals with pre-existing conditions were excluded to focus on new diseases that developed after injury. The team tracked 21 pre-specified diseases across four body systems or functional domains:

- **Cardiovascular:** Hypertension, hyperlipidaemia, obesity and coronary artery disease.
- **Endocrine:** Hypothyroidism, pituitary dysfunction, diabetes, adrenal insufficiency and erectile dysfunction.
- **Neurological:** Ischaemic stroke or transient ischaemic attack, seizure and dementia; and
- **Psychiatric and substance use:** Depression, bipolar disorder, psychosis, anxiety disorder, sleep disorder, suicide ideation or attempt, substance misuse, opioid misuse and alcohol misuse.

Across both healthcare systems, TSCI was associated with meaningfully higher long-term risk of many chronic conditions, with ***hazard ratios*** often between about 1.5 and 2.5. Compared with controls, those at MGB with TSCI had a significantly higher risk of hypertension, hyperlipidemia, ischaemic stroke, coronary artery disease and diabetes, as well as other neurological and psychiatric conditions. The risk of post-TSCI comorbidities was elevated across different age groups, including patients with TSCI aged 18 to 45 years, compared with age-matched controls, with higher rates of hypertension and ischaemic stroke. Similar findings were noted for the UC Health cohort. Post-injury hypertension, pituitary dysfunction, adrenal insufficiency, depression, substance misuse, seizures and dementia were associated with higher mortality.

Overall, the study suggests that TSCI leads to long-term multi-system vulnerability and elevated mortality, even in adults who were healthy at the time of injury. The authors recommend lifelong, multidisciplinary follow-up with proactive screening and management across cardiovascular, endocrine, neurological and psychiatric domains, as well as further research to understand mechanisms and guide prevention.

Research: Healthy ageing

Guízar-Sahagún and colleagues' (2023) narrative review examined the broad consequences of ageing with SCI and identified both positive adaptations and challenges. The authors reported a range of negative outcomes that may progressively increase disability and restrict participation. These included:

- Progressive physical deterioration
- Secondary health conditions, such as UTIs
- Reduced mobility
- Changes in family and social support structures
- Carer ageing; and
- Depletion of financial resources.

The authors concluded that:

> *"People with SCI and all those who take care of them must have up-to-date information to carry out the necessary measures to promote healthy aging in a more inclusive social environment."*

In their review, *they noted that some individuals experience favourable psychosocial adjustments, including improved coping and better quality of life over time. These positive outcomes highlight that ageing with SCI can involve personal growth, resilience and strengthened relationships.*

Research: Factors impacting ageing with SCI

Tan and colleagues' (2025) scoping review provides a comprehensive summary of the challenges and supports for ageing well with SCI. It is, however, important to note the scope of their review: Individuals over 50 years of age with either TSCI or NTSI (≥ 2 years) in 'developed economies' living in the community or in residential aged care.

Key findings in relation to the age at which SCI occurs significantly affect physical functioning and independence, include:

- People who sustain SCI at a younger age adapt to their condition before experiencing the effects of ageing. Conversely, those who acquire SCI later in life face the dual challenge of adapting to both their SCI and pre-existing age-related physical and cognitive declines, making rehabilitation and psychological adjustment more difficult
- Social and financial support structures also tend to vary with the age of onset, with older people potentially facing reduced resources or greater limitations.
- Older age of onset is also associated with a more rapid increase in disability. In addition, the severity

and type of SCI differ by age, with older people being less likely to experience high-velocity trauma and more likely to suffer from falls and associated head strikes. This generally results in more cervical spine and incomplete injuries, in contrast to the lower-level severe injuries seen in younger people; and
- SCI after age 40 is linked to a higher mortality risk, often due to pre-existing age-related deterioration, which can complicate adjustment and adaptation to SCI-related impairments.

To conclude, major challenges and support needs for people ageing with SCI exist, but the evidence on age of onset remains limited, making it difficult to draw firm conclusions about how the timing of injury influences long-term outcomes. The authors also emphasise broader gaps in the literature on ageing with SCI, which contribute to inconsistent guidance for individuals and practitioners. They recommend ongoing involvement of health professionals across the lifespan to support continuous education, proactive management of secondary conditions, navigation of health and social systems and timely adaptation to changes in health and function. Advances in communication technology can also assist clinicians in sharing information and providing support to people living in the community.

To summarise, these studies show that ageing with SCI is shaped by increasing health needs, ongoing vulnerability to secondary and chronic conditions and the complexity of navigating multiple providers across the lifespan. Despite these challenges, most individuals ageing with SCI can cope and have a good quality of life.

In practical terms:

- **For individuals living with SCI:** This means that health issues are likely to become more diverse and accumulate with age, proactive engagement with primary care and preventive health services is essential for maintaining independence, function and quality of life, and
- **For health practitioners, educators, researchers and service providers:** The findings reinforce the importance of coordinated, multidisciplinary care that anticipates secondary conditions, supports continuity and reduces fragmented services. Health professionals should prioritise early screening, timely referrals, and person-centred planning that recognises the interplay among ageing, long-term effects of SCI and environmental barriers. Educators, researchers and service planners also need to address gaps in knowledge about ageing with SCI, including the limited evidence on the age of onset and ensure that health systems, training programs and policies are equipped to support people living with SCI to age well.

6.2.2. Gender-related differences in the experiences and outcomes of ageing with SCI

Research suggests that gender may shape some aspects of ageing with SCI, although the evidence is variable.

Research: Gender and ageing with SCI

- McColl and colleagues (2004) compared men and women who were living with SCI for more than 20 years. They found that, despite similar overall quality-of-life ratings, women described their ageing as *"accelerated"* and reported more pain, fatigue, skin problems and transportation barriers. Men, on the other hand, experienced more general health problems, more diabetes and more frequent changes to adaptive equipment. Both groups differed in how they spent their time, which reflected socially traditional gender roles.
- Tan *et al.* (2025) also reported that women living with SCI often have a perception that they are experiencing accelerated ageing, possibly influenced by societal views of appearance as they age. On a positive note, women living with SCI reported that their lifelong adaptations to disability have equipped them better for handling age-related changes compared with their non-SCI counterparts. Interestingly, women are twice as likely to utilise digital tools, such as smartphone apps and wearables, to assist with health monitoring, due to their proactive approach to managing health. Tan *et al.* (2025) reported gender differences for individuals ageing with SCI, with women experiencing additional physical, physiological and psychosocial differences. These include:
    - Anatomical and biomechanical issues because of differences in strength, which affect women's ability to transfer their weight to relieve pressure. Women may therefore experience greater functional impacts from age-related deterioration
    - Gynaecological issues, such as heavier menstrual flow, interfere with mobility and transfers. A lack of knowledge about menopause can lead to anxiety
    - A higher risk of osteoporosis as women age. This not only increases the likelihood of sustaining SCI but also exacerbates existing injuries, leading to reduced participation in activities due to fear of falls or injury aggravation. Women may then be less likely to participate in these activities; and
    - The information for women ageing with SCI is scarce, with most research and resources focused on males (Tan *et al.*, 2025).

Taken together, the research suggests that women's experiences are under-represented and that more targeted studies and resources are needed to understand and support women as they age with SCI.

Important resources and information: For men and women

- Christopher & Dana Reeve Foundation: Women aging with spinal cord injury (Part 1) and Women

aging with spinal cord injury (Part 2), and
- Forward Factsheet: Men and Ageing.

6.2.3. Functioning as a health indicator for modelling healthy ageing trajectories for people living with SCI

Research: Functioning as a health indicator

Sabariego *et al.* (2023) examined how ***functioning*** can be used as a health indicator to understand ageing among people living with SCI across 11 European countries. The study used data from the International Spinal Cord Injury (InSCI) Community Survey and applied a common functioning metric to compare patterns across countries.

In that study, functioning refers to a comprehensive health indicator describing how well a person carries out daily activities and participates in life situations, taking into account physical, psychological and social abilities. The functioning metric, developed for the InSCI survey using the International Classification of Functioning, Disability and Health (ICF) framework, captures multiple dimensions of life with SCI, including mobility, self-care, social participation, relationships and environmental facilitators and barriers. Its purpose is to assess overall functioning rather than focusing solely on impairment or medical complications.

In their analysis, functioning served as the outcome, with chronological age, age at injury and time since injury as predictors. The study found that functioning declined with increasing chronological age amongst people with paraplegia, while no such association was observed for those with quadriplegia (tetraplegia). Age at injury was also associated with functioning, although the nature of this relationship varied across countries. Time since injury showed no consistent association with functioning in most countries, suggesting that the passage of time alone does not reliably predict changes in everyday functioning.

Environmental factors emerged as key determinants of functioning. Limited accessibility in the homes of friends and relatives, reduced access to public places and challenges with long-distance transportation were consistently associated with poorer functioning outcomes. The findings demonstrate that ageing with SCI is shaped not only by biological or injury-related factors but also by the physical and social environments in which people live. The study aligns with broader evidence showing that functioning can decline with age for some individuals living with SCI and highlights the importance of addressing environmental barriers to support healthy ageing.

6.2.4. Importance of health literacy relating to ageing, including amongst health professionals

Health literacy is key to ensuring good health and well-being. As we have already seen in the sections above, individuals with SCI and their carers and health professionals need to be extra vigilant as the body ages because of compounding degenerative changes. The research below highlights that knowledge gaps exist in terms of ageing with SCI, including amongst health professionals. The research also suggests that the LLEs of peers are increasingly being included to raise awareness of the issues of an ageing body with SCI.

Research: Health literacy

- Silva *et al.* (2023) conducted a systematic review exploring health literacy among people living with SCI. Only five eligible studies were identified, with health literacy levels varying widely across participants. Some individuals demonstrated adequate understanding of their condition, while others showed significant gaps in knowledge, particularly in areas related to long-term self-management, which may involve an increased burden of co-morbidities and progressive functional change.

  A key finding was that education tends to focus on immediate post-injury needs, while issues related to ageing and long-term health trajectories are rarely addressed. This leads to incomplete knowledge once individuals return to the community and have fewer structured opportunities to receive updated information. The authors argue *that ongoing, personalised and stage-appropriate health education is essential to support informed decision-making as people age with SCI.*

- Tan *et al.*'s (2025) scoping review of 98 studies on ageing with SCI, identified accelerated functional decline, reduced mobility and self-care and constraints on social, leisure and work roles. Environmental and system barriers were prominent, including gaps between disability and aged-care funding that limit access to appropriate supports. The authors argue *for a lifelong, multidisciplinary approach with proactive monitoring and ongoing education rather than front-loaded inpatient education.*

  Just as Silva and colleagues (2023) found health literacy to be a central theme, Tan *et al.*'s (2025) review identified that education about SCI has focused on the acute (hospital) and rehabilitation phases, leaving long-term knowledge gaps once contact with providers decreases. As the authors state:

  "Education about SCI predominantly occurs during the acute and rehabilitation phases before discharge to the community. During this adjustment period, large volumes of information are provided, typically focusing on immediate rehabilitation needs rather than on long-term issues like ageing. This leads to knowledge gaps post-discharge as people lose regular contact with healthcare providers, limiting informed decision-making and proactive management of age-related changes. Although challenging during the inpatient phase, ageing education is important to help people access relevant information when required" (Tan *et al.*, 2025, p. 11).

Importantly, their review also found that this lack of knowledge about SCIs beyond hospital and rehabilitation included health professionals. This could result in insufficient health guidance on long-term management of ageing with SCI.

Research: Peer-led health education programs

Chaffey and Bigby (2018) conducted a scoping review examining peer-led health education programs for adults living with SCI. The review identified eight studies and found that people living with SCI face ongoing health challenges, including risks arising from nerve damage, secondary health conditions and the impact of sedentary lifestyles. The authors noted that peer education is increasingly being used because peers bring lived expertise, shared experience (LLEs) and credibility, making them valuable contributors to rehabilitation and health promotion.

In several programs, peer education was only one component of broader interventions, yet all reported positive outcomes, including improved self-efficacy, enhanced understanding of health management and increased confidence in navigating life with SCI.

To conclude, peer-led education is a promising and meaningful approach to supporting health learning across the lifespan. The authors, however, highlighted the need for further research to more clearly isolate and measure the specific contribution of peers to health education outcomes.

Building on the findings, suggested practical next steps might include:

- **For individuals living with SCI:** Track changes in day-to-day functioning (as we suggested in **Chapter 3** and **Chapter 4**) as one ages. Seek early support if activities become harder and identify and address physical and social barriers that limit participation, especially in terms of access and transport; and
- **For health practitioners and educators:** Incorporate brief environmental checks, such as accessibility, into routine reviews and support referrals for home or community modifications. Tailor anticipatory guidance to differences in ageing patterns between paraplegia and quadriplegia, and use *functioning* as a core outcome in care planning.

Taken together, the evidence suggests that ageing with SCI is shaped not only by biological changes but also by when, how and by whom information is delivered across the life course. Concentrating education while inpatients leaves enduring knowledge gaps that could hinder timely decisions about prevention, screening and supports in the community. System-level barriers and funding transitions amplify these gaps, while peer-led education offers a practical way to sustain learning, confidence and self-management over time. In short, health literacy is a modifiable lever that can reduce avoidable complications and support participation and well-being in later life (Chaffey & Bigby, 2018; Silva *et al.*, 2023; Tan *et al.*, 2025). There may also

need to be ongoing professional development of health professionals responsible for the care of individuals with SCI once they return 'home'.

6.2.5. Health service utilisation as individuals age with SCI

Research: Increasing age and health service utilisation

Pacheco Barzallo *et al.* (2025) explored the health service needs of and use by people ageing with SCI using the first (2017-2019) and second (2022-2024) InSCI Survey. Key findings included:

- Overall, healthcare needs increase with age, reflecting the cumulative burden of secondary conditions.
- The most frequently utilised health professionals and services were GPs (59.2% of respondents), inpatient services (48.5%), physiotherapists (43.5%) and rehabilitation physicians (40.4%).
- Primary care utilisation was highest among individuals with pain (13.3%), bowel dysfunction (12.7%), bladder dysfunction (10.1%), UTIs (9.0%) and circulatory problems (7.9%).
- Rehabilitation physician utilisation was higher among individuals with spasticity (19.2%), pain (12.3%) and bowel dysfunction (8.9%).
- Many individuals living with SCI engage with multiple providers simultaneously, reflecting the complex and overlapping nature of their care needs. For example, a person may consult a physician for medical management while also receiving physiotherapy or nursing support to maintain functional independence. Even when used less frequently, services such as psychological counselling, chiropractic care and OT remain essential components of care over the life course, addressing mental health, pain and the adaptation of daily activities; and
- Some conditions, such as pain, sexual dysfunction and spasticity, were found to decline over time, which may explain shifts in provider use as someone living with SCI ages.

Importantly, in healthcare systems in which no provider assumes responsibility for organising care, inefficiencies can emerge due to unnecessary reliance on specialised services, but also through overuse of inpatient care. Thus, *having a GP, family doctor or rehabilitation physician in a coordinating role is essential for both meeting complex needs and reducing the costly downstream consequences of delayed or fragmented care.*

6.3. Emerging research: SCI and dementia

Alzheimer's disease and related dementia (ADRD) are on the rise globally. The 2024 *Lancet* Dementia Commission Report concluded that 14 modifiable risk factors across the life course account for about 45% of dementia cases that might be prevented or delayed. The 2024 update added high *LDL (low-density lipoprotein)* cholesterol and vision loss to the prior list. The other risk fac-

tors include low level of education, hearing loss, depression, traumatic brain injury, physical inactivity, smoking, hypertension, obesity, diabetes, excessive alcohol consumption, social isolation and air pollution.

Research: TSCI and dementia

There is some evidence suggesting that TSCI is associated with ADRD. Lin and colleagues (2024) conducted a ***retrospective case-control longitudinal cohort study*** using national data for American adults aged 45 years and older with probable (likely and highly likely) TSCI, adjusting survival models for age, sex, years of living with certain chronic conditions, exposure to six classes of prescribed medications and neighbourhood characteristics of place of residence. Their study found that people aged 45-64 with TSCI were at high risk for ADRD, but there was no significant risk after age 65. The authors recommended *updating clinical guidelines to include cognitive screening after TSCI to address the heightened risk of cognitive decline and to shed light on the causal relationship between TSCI and ADRD* (Lin *et al.*, 2024).

6.4. Ageing with SCI: What can you expect?

Ageing is essentially the time-dependent functional decline that affects most living organisms and is characterised by a progressive loss of physiological integrity. WHO's October 2025 website explains that ageing is the result of the accumulation of molecular and cellular damage over time, leading to a gradual decline in physical and mental capacity, a higher risk of disease, and eventually, death. These changes are not linear, vary greatly between individuals and are only loosely linked to chronological age.

Ageing is considered the primary risk factor for many human diseases, including cancer, cardiovascular disorders and neurodegenerative conditions. SCI has been proposed as a model of premature or accelerated ageing, particularly regarding the cardiovascular, musculoskeletal and respiratory systems. The 'Double Jeopardy' theory describes the compounded effects of age and SCI, leading to accelerated ageing and earlier onset of physical and functional decline due to secondary conditions and cumulative SCI-related stresses over time (Tan *et al.*, 2025).

Functional decline often begins around age 45 or 15 years post-SCI, with secondary conditions such as cardiovascular and respiratory problems, bowel and bladder dysfunction, neuropathic and musculoskeletal pain, fatigue, pressure injuries, weakness and spasticity. The conditions have substantial impacts on independence, support needs and quality of life (Tan *et al.*, 2025).

Ageing with SCI thus presents unique challenges that differ from ageing in the general population. The interaction between age-related changes and the long-term effects of SCI means

that many individuals experience earlier onset of health issues, increased vulnerability to secondary conditions, reduced physical function and a heightened risk of falls and injuries (Pili *et al.*, 2018; Saunders & Krause, 2015; Savic *et al.*, 2010; Tan *et al.*, 2025). These challenges call for a comprehensive approach to healthcare that addresses both the physiological and psychosocial aspects of ageing with SCI.

Ageing with SCI requires a multidisciplinary approach that recognises the diverse needs of this population. Integrating emerging research with practical clinical resources enables healthcare providers to deliver care that supports health, function and quality of life as people age with SCI. The good news is that people living with SCI today are living much longer than in the past (SCIA, 2021).

Below are several resources that focus on preventive and treatment strategies tailored for individuals ageing with SCI. These resources emphasise regular health monitoring, proactive management of secondary conditions and the importance of physical activity and social engagement in maintaining quality of life. The clinical resource extends to ageing workers.

Important resources and information: Ageing with SCI

- SCIRE: Aging following spinal cord injury (2013)
- NSW ACI: Ageing with a spinal cord injury (2014, for review 2027)
- Things to Know About Aging and Spinal Cord Injury Factsheet (2018)
- SCIA (2021): Ageing and Spinal Cord Injury, and
- Queensland Spinal Cord Injuries Services (2026): Ageing with a spinal cord injury.

Clinical resource: Form for clinical assessment in ageing individuals

Ageing with a Spinal Cord Injury (FSP034, v1023) is a form that staff and service providers can complete to support participants and workers ageing with SCI. It covers social participation, cultural and spiritual needs, sexuality, physical activity, regular management and screening, legal issues and others.

6.5. How ageing with SCI differs from typical ageing

As already mentioned, while ageing affects everyone, SCI can speed up some ageing processes (SCIA, 2021). Individuals living with a long-term SCI often experience age-related health issues at younger ages than individuals who do not have SCI:

- This happens because years of paralysis or reduced mobility can put extra strain on the body's systems. For example, the RACGP Aged Care Clinical Guide (2019) states older adults with SCI are more vulnerable to complications of immobility such as bone loss (osteoporosis), pressure sores, weight gain and even constipation, compared with their peers without SCI. They also face higher risks of chronic conditions such as heart disease, pneumonia and blood clots.
- Another difference is the higher burden of secondary health conditions. The SCIA (2012) guide notes that those ageing with SCI have higher blood pressure and cholesterol, Type 2 diabetes and infections, such as pneumonia and UTIs, than the general population. Long-term use of catheters can lead to complications such as bladder infections or even bladder cancer over time. A lack of sensation in the lower body can also make skin care more challenging, sometimes leading to chronic leg ulcers or pressure wounds if not carefully managed (RACGP, 2019); and
- Causes of death have shifted from early complications of SCI, such as kidney failure from infections, to more typical age-related illnesses, such as heart disease. Quality of life can, however, remain high. Even after 10-20 years post-injury, most people with SCI continued to rate their life satisfaction as good or excellent (Mortenson *et al.*, 2014). This suggests that with the right adjustments and support, ageing with SCI can be a meaningful chapter of life, not something to fear.

On a positive note, life expectancy for people with SCI has improved dramatically, now approaching that of the broader community (SCIA, 2021). The population of people ageing with SCI is increasing due to three main factors: Advances in medical and rehabilitation technology, treatment and support (Tan *et al.*, 2025).

6.6. Common biological, social and psychological issues as you age with SCI

Understanding potential challenges helps with planning. Common health risks include:

- **Reduced mobility and strength:** It is normal to lose some muscle and fitness with age, but SCI can accelerate this. There may be increased difficulty with transfers or pushing a wheelchair over time (SCIA, 2021). Muscles below your injury remain weak. Even above-injury muscles, such as one's arms, can be overused and become tired. This can make

daily tasks and getting around more challenging if one does not adapt equipment or routines; and

- **Chronic pain and shoulder overuse:** Years of using a wheelchair or crutches put extra wear on the shoulders, arms and neck. About 70% of long-term wheelchair users report shoulder or wrist pain as they age (Middleton *et al.*, 2008). There may also be overuse injuries in the rotator cuffs, elbows or hands and arthritis may develop. Neuropathic pain (nerve pain from the injury) can also persist or even worsen slightly with age in some cases. Back or neck pain can arise from years of altered posture.

Brad's story: Managing pain with ageing

SCIRE: Aging with SCI: Managing pain and Brad on pain.

- **Skin problems and pressure injuries:** Ageing skin becomes thinner and more fragile. Combined with reduced sensation and long hours sitting, this means pressure injuries can develop faster and heal more slowly in older adults living with SCI (RACGP, 2019). There may be skin changes, such as chronic leg swelling or ulcers due to poor circulation (SCIA, 2021). Regular skin checks and pressure relief are critical to avoid serious wounds or infections, including on the feet; and
- **Bladder and kidney issues:** Decades of catheter use or difficulty emptying the bladder can lead to complications. UTIs become more frequent with age (SCIA, 2021). Some people develop kidney or bladder stones. Long-term irritation of the bladder from an indwelling catheter can increase bladder cancer risk in later life (RACGP, 2019). Although this is uncommon, it should be monitored by one's GP.

Mary-Jo's story: Taking care of your ageing bladder

SCIRE: Aging with SCI: Taking care of your bladder as men and women age, which, for women, includes menopause. In addition, Mary-Jo talks about bladder management.

- **Bowel changes:** Many living with SCI already manage a neurogenic bowel, but ageing can bring slower digestion. Dietary changes and medication can worsen constipation. Lack of activity and weakened abdominal muscles put people living with SCI at risk of severe constipation or bowel blockage if not managed (RACGP, 2019). Haemorrhoids or bowel incontinence episodes might also become more frequent unless bowel programs are adjusted.

Brian's story: Taking care of your ageing bowel

SCIRE: Aging with SCI: Changes in bowel management and Brian on bowel health

- **Cardiovascular and metabolic health:** Research shows that those living with SCI have higher rates of cardiovascular risk factors, such as high blood pressure, high cholesterol and insulin resistance, which can appear at younger ages (SCIA, 2021). Paralysis can lead to lower overall muscle mass and fewer calories burned, so weight gain is easier, contributing to risks of Type 2 diabetes and heart disease (SCIA, 2021). Also, circulatory changes resulting from SCI may increase the risk of blood clots. Heart disease and stroke have emerged as leading causes of death in the SCI population, similar to those without SCI but often occurring somewhat earlier (Mortenson *et al.*, 2014).

Important resource and information: Ageing with diabetes

Forward Factsheet*:* Health ageing with diabetes: Helpful tips.

- **Respiratory decline:** If the injury affected the chest muscles, especially in quadriplegia or high paraplegia, one might have reduced lung capacity. With ageing, lung function naturally declines, and the cough reflex weakens. Older adults living with SCI are at a higher risk for pneumonia and chronic respiratory infections (RACGP, 2019). Some also develop sleep apnoea (breathing pauses during sleep), which is common in SCI and can worsen with age. It is important to watch for signs, such as frequent lung infections, shortness of breath or morning headaches (which can hint at sleep apnoea) with increasing age (Middleton *et al.*, 2008).

- **Bone loss (osteoporosis):** Because of limited weight-bearing and mobility, bone density can drop faster after SCI, especially in the legs. This increases the risk of fractures. Older people living with SCI are prone to early osteoporosis and need to watch out for fragile bones (RACGP, 2019). A simple fall from a wheelchair or during a transfer can cause broken bones if bone density is low.
- **Falls and injuries:** Many people with incomplete injuries or those who use braces or walkers experience balance issues as they age. Even wheelchair users can have falls, for example, tipping a chair or slipping during transfers. In one study, about 1 in 5 people with a long-term SCI had at least one injury in a year, and roughly 1 in 10 had a fall that led to injury (Saunders & Krause, 2015). Falls can cause serious setbacks like fractures or head injuries, so prevention is key.

Podcast: Falls prevention

SCIA's Have the Nerve podcast's Get to Know your Body: Falls prevention (Episode 42).

- **Social isolation:** Beyond the physical, there are social changes to consider. Friends or family may retire, move or have their own health issues. One might no longer be working or may find it harder to get out due to mobility or transportation issues. All this can lead to feeling isolated or lonely if steps are not taken. Staying connected tends to require more planning for a person living with SCI, and even more so as one ages, such as arranging accessible transport or personal assistance to attend events. Interestingly, social isolation is a risk factor for dementia identified by the 2024 *Lancet* Dementia Commission Report, and

- **Mental health changes:** It is normal to feel down or frustrated at times, but ageing with a disability can add extra stress. Chronic pain, isolation or new health problems can increase the risk of depression or anxiety in people with SCI. Older adults with SCIs have notable rates of mental health issues like depression or even post-traumatic stress disor-

der (PTSD) (RACGP, 2019). Cognitive changes (memory, thinking) usually age the same as in the general population, but mood and coping might be negatively impacted by the accumulation of challenges. It is important to remember that help is available and many people overcome or manage these hurdles with the right support.

6.7. Healthy ageing strategies with SCI

While the list above may seem long, there are many ways to prevent or lessen these issues. With preparation and the right habits, one can improve one's health and independence long into one's senior years. Doctors in Australia, such as those in the SCI health networks and the RACGP, emphasise a proactive approach to ageing with SCI (RACGP, 2019).

Drawing on the eco-biopsychosocial model advanced in the Introduction, below, are some evidence-based strategies and tips, which address biological, social and psychological factors (environment, equipment, social participation).

6.7.1. Biological factors: Health and body-related strategies

6.7.1.1 Stay on top of health checks

This section targets early detection and prevention of internal health risks that may accelerate with age and a long-term SCI. Prevention is far better than a cure.

Regular medical check-ups are vital. Make sure the GP knows about a person's SCI and the specific risks. They should actively monitor for the complications, such as checking blood pressure, blood sugar (glucose) and cholesterol. Bone density scans should be performed periodically, as should screening for signs of heart disease (RACGP, 2019). It is easier to manage issues identified early. Also, keep up with vaccinations, such as influenza, COVID-19, pneumococcal pneumonia and shingles, to reduce infection risks (Middleton *et al.*, 2008). Some specialists recommend periodic urology reviews to screen for silent UTIs, kidney stones or bladder changes and skin checks, especially if one has had pressure sores before. Do not hesitate to ask the healthcare team about the preventive screenings needed as you age.

6.7.1.2. Maintain a reasonable level of physical activity (adapted for the individual)

This section emphasises physical activity as a core health strategy that supports cardiovascular fitness, musculoskeletal conditioning and metabolic health.

'Use it or lose it' applies to everyone, especially with SCI. Exercise in any form can help maintain muscle, flexibility and cardiovascular health (SCIA, 2021). This might mean wheelchair sports, resistance training for one's arms, using an *FES (functional electrical stimulation)* bicycle to move one's legs or simply doing range-of-motion exercises with a therapist. Regular activity can slow bone density loss and help control weight, reducing diabetes and heart risks (SCIA, 2021). It also boosts mood and reduces pain. Consult a physiotherapist or exercise physiologist with SCI experience. They can tailor a program to one's ability level. Even small things like daily stretching, transferring a bit more independently or wheeling short distances instead of using power assist (if safe) can maintain mobility. Avoid extended periods of sitting still. Incorporate pressure lifts and posture changes throughout the day to protect your skin and improve circulation.

Key recommendation: Short bouts of physical activity

Consider tracking physical activity in short, achievable bouts across the day, which can be as effective as longer sessions and easier to sustain.

Marney's story: Exercise and ageing

SCIRE: Marney on Exercise and Ageing: This resource can help translate exercise principles into day-to-day routines tailored for ageing with SCI.

6.7.1.3. Make sure of good nutrition and bone health

This section links good nutrition with healthy bone and skin integrity. As nutritional needs change over the lifespan, a review by a dietitian with SCI experience can align protein, fibre and micronutrient targets with bowel programs, skin goals and cardio-metabolic risk.

A balanced diet becomes increasingly important. Aim for plenty of fruits, vegetables, adequate protein and enough fluids and fibre to aid bowel function (SCIA, 2021). Maintaining a healthy weight will reduce strain on the shoulders and make transfers easier on bones and joints (SCIA, 2021). To combat osteoporosis, ensure one gets enough calcium and vitamin D, through diet or supplements as advised. Stay active! Some people living with SCI use standing frames or leg braces to put weight on their legs a few times a week. This weight-bearing can signal to bones to stay stronger. A bone density medication might be beneficial with increasing age. Prevent falls by keeping the environment safe, including grab bars, securing loose rugs and having good lighting at home. The walker or crutches need to be maintained and updated. A wheelchair may be required for longer distances to avoid fatigue-related falls.

Important resource and information: Nutritional requirements change with age

How your nutritional requirements change with age, which includes a video from a dietitian, **Dr Natalie Colson**. The website highlights the need for protein to maintain muscle and bone mass, as well as minerals such as calcium, iron, magnesium and zinc and important vitamins such as vitamin D and B12. There is a downloadable meal planner.

The article also identified some common nutritional challenges for older people, which include gut absorption issues, weight management and slower digestion. The author advocates for good oral health as tooth decay increases, with decreased saliva production (*xerostomia*) as we age. **Chapter 3** has a section on good oral health.

6.7.1.4. Protect shoulders and joints

As has already been mentioned, with age, overuse injuries may become an issue, impacting independence. Given the high chance of shoulder overuse pain, joint care should be routine,

with gentle stretching and strengthening exercises (a physiotherapist can demonstrate rotator cuff exercises). Prioritising good wheelchair ergonomics, such as appropriate wheel height and push technique, can reduce strain. If pushing a manual wheelchair long distances is painful, a power-assisted device or a power wheelchair for daily mobility should be considered. This can greatly reduce wear-and-tear on shoulders and preserve independence longer (Middleton *et al.*, 2008). When possible, enlist help or use patient lifters for heavy transfers (such as into a car) to avoid injury. Pain is telling the body to modify something. Early intervention with physiotherapy, occupational therapy or orthopaedic care can prevent minor issues from becoming serious.

Key recommendation: Regular check-ups and the Health Maintenance Tool (with an app)

Scheduled preventative reviews with therapy teams every 6-12 months, as advised. Support early detection of technique or equipment problems, reducing the risk of cumulative strain and chronic pain.

The Health Maintenance Tool we introduced in **Chapter 4** provides a section on *Ageing with your spinal cord injury*. Scroll down to the relevant section and then use the menu bar on the left-hand side to review the recommendations for the various organs or organ systems. For example, under Endocrine, the Actions to take include seeing the doctor for a regular health check-up, with blood glucose and weight monitoring (related to Type 2 diabetes). The individual with SCI may need to visit a health facility for their weight to be measured.

6.7.1.5. Prevent skin tears and pressure injuries, including your feet

Never underestimate the importance of skin care. It is easier to prevent sores than to heal them. With age, self-checking of one's skin every day, or with the help of a carer, is important. Use a mirror for hard-to-see areas. Keep using pressure-relieving cushions and mattresses; replace them once they wear out, as cushions can lose effectiveness over a few years. Relieve pressure often by lifting or shifting in one's wheelchair every 15-30 minutes if possible or tilt if one is using a power chair. At night, ensure that a turn can happen periodically, with or without the help of carers. Keep skin clean and well-moisturised to prevent cracking. Watch for any red or darkened areas that do not blanch (fade, go white) after the pressure has been removed. This is a warning sign. If there is a potential pressure injury, seek medical advice quickly. Treat even small sores seriously to prevent deep infections. Good nutrition and not smoking also help skin stay healthy. Overall, be vigilant. A long-term SCI means areas like the tailbone, hips and heels have endured years of pressure and deserve extra care.

Podiatrist, **Dr Katrina Reynolds**, who has treated several clients with SCI, provides the following advice:

Key recommendation: Take care of your feet

As discussed in **Chapter 3**, foot care should not be overlooked as one ages. Loss of sensation increases the risk of pressure injuries, which can develop while lying or sitting, with the feet, heels and other bony areas commonly affected (Vecin & Gater, 2022). Your feet also change with age. Common issues in older adults include ***hyperkeratosis*** (hard, dry skin) on the soles, as well as changes in foot size and shape that may affect shoe fit (James *et al.*, 2020). Feet should be inspected and physically touched every day. A long-handled mirror can help you see the soles of your feet or a carer may assist if one is unable to do this independently. Check for changes in skin colour, cracks, open sores, calluses, corns or blisters, which can develop in response to abnormal pressure or friction that may progress to ulcers if left untreated.

After showering, ensure feet are dried thoroughly, especially between the toes. Moisturise one's feet, but avoid applying cream between the toes as excess moisture can increase the risk of skin breakdown. Persistent moisture or wearing non-breathable footwear can lead to fungal infections (***tinea pedis***), soft corns between the toes and even cellulitis, if not treated adequately. Change socks daily or twice daily if needed and ensure they fit well. Moisture-wicking socks help keep one's feet dry. Socks that are too tight can restrict circulation or pinch the skin, while socks that are too loose can increase friction.

Carefully check the inside of one's shoes for foreign objects before wearing them. Shoes should fit according to foot length and width, with about one thumb's width between the longest toe and the end of the shoe. Ill-fitting shoes are a common cause of foot blisters (Rushton & Richie, 2024). Tightly fitting shoes may press against bony prominences or compress your toes, while loose shoes may allow excess sliding, increasing shear, which can also damage the skin and underlying tissue. Wearing appropriate shoes is a primary preventative measure for persons with poor sensation and, as such, should be worn even inside the home to protect one's feet. Footwear should be chosen to meet an individual's specific needs. A podiatrist can provide advice on suitable shoe characteristics as a primary intervention (Tedeschi *et al.*, 2024).

Toenails should be trimmed straight across to help prevent ingrown nails. Avoid cutting too low at the corners. Because sensation in one's feet may be reduced or absent, it is especially important to check for rough edges and smooth them gently with a file if needed. If it is difficult to complete foot care safely or there are changes in the skin or nails, seek prompt help from a podiatrist, who may advise on the need for regular ongoing care. Toenail growth and callus formation vary between individuals. For people with reduced sensation, podiatry appointments may be needed every 4-6 eight weeks as a general guide.

6.7.1.6. Maintain good bladder and bowel habits

This section focuses on good bladder and bowel habits, which require monitoring and periodic adjustment with age. Bladder and bowel routines may need to be adjusted with body changes. Consult a health professional when new symptoms emerge, such as leakage, UTIs or constipation. Treatment changes might include intermittent catheterisation frequency, trying a dif-

ferent catheter type, medications to relax the bladder or bladder scans to ensure you are emptying fully. For bowels, a dietitian can help increase fibre or suggest mild laxatives or stool softeners if needed. Staying active and well-hydrated also keeps the bowels moving. Importantly, plan for potential screenings. Some doctors may advise yearly renal ultrasounds to check for kidney or bladder stones or changes. In the long-term, a urologist might be involved to check the bladder with a scope (cystoscopy) if there have been decades of catheter use, to catch any early abnormalities. While bladder cancer is rare, awareness is important. Do not ignore signs like new bleeding in urine (RACGP, 2019). *To summarise*, keep the dialogue open with the healthcare team about bladder and bowel health and do not be embarrassed to seek help.

Key recommendation: Documentation helps identify abnormalities

A shared plan that documents routines and red-flag symptoms can help carers and clinicians act quickly when patterns change. You may want to return to **Chapter 4** to review some of the apps available.

6.7.2. Psychosocial factors: Social participation, equipment and home modifications

6.7.2.1 Stay socially connected

An elderly woman on her own. The photographer described the loneliness of dementia.

This section highlights the support for psychological well-being and social engagement. Mental and social health are as important as physical health. Try to maintain social networks and activities. Join peer support groups in-person or online for people living with SCI or other disabilities. Sharing experiences can combat loneliness and give practical tips. Organisations, such as SCIA or local

SCI associations, usually organise community events, outings or forums. Pursue hobbies and interests in an adapted way, from wheelchair sports to art, technology or volunteering. If transportation is a barrier, investigate community transport services or NDIS-funded supports for accessible travel. Invite family and friends over or schedule regular phone or video chats. Do not hesitate to seek professional help if feeling down or anxious (low mood or anxiety). Seeing a counsellor or psychologist who understands disability can be immensely helpful. Depression is not a personal failing. It is often a medical issue that can be treated. Staying socially engaged and seeking mental health support when needed will keep one feeling positive and purpose-driven with increasing age.

Key recommendation: Make social interactions a priority

Plan social routines with the same priority as medical routines, for example, scheduling regular peer sessions or community activities in advance. For travel options, **Chapter 1**, but particularly **Chapter 12,** will be useful.

6.7.2.2. Use adaptive equipment and home modification

This section focuses on external, environmental changes that reduce injury risk and conserve energy. What worked when one was in their 20s or 30s might need an update when one is in their 60s. That's okay. Regularly review equipment for safety and comfort (RACGP, 2019). For example, check one's wheelchair: *Are the cushions still effective? Is a lighter frame or power assist now required?* Small tweaks like automatic door openers, a ramp instead of a few steps or a shower chair with more support can prevent accidents and make daily life easier. Consider a

home assessment by an OT who can recommend modifications, such as handrails and accessible and lightweight appliances, to suit changing needs. Technology is improving. There are now smart home devices, advanced wheelchairs, and other gadgets that might increase independence. Embrace these tools as they become necessary. They are there to preserve energy and prevent injuries, not to signal declining health or frailty. Planning prevents a crisis, such as installing a ramp before a bad fall occurs, which will be less stressful long-term.

Key recommendation: Does my assistive equipment still meet my needs?

Reassess equipment after any hospitalisation or notable health change, since needs and capacities often shift at these times.

To summarise, ageing with SCI requires mindfulness and proactive management, but it does not mean that life cannot be enjoyable or that health will inevitably decline. By focusing on prevention and adaptation, individuals can continue to live well and engage in the activities that matter to them (**Table 6.1**).

Table 6.1. Summary of the key risks and how to reduce or manage them.

Ageing risk or challenge	How to reduce or manage it
Reduced mobility and strength	Keep as active as possible with regular exercise therapy (physio-guided workouts, stretching, adapted sports). Use mobility aids (wheelchairs, walkers) that fit your current needs. Don't hesitate to upgrade to power-assisted devices to conserve energy.
Bone loss (osteoporosis)	Ensure calcium and vitamin D intake is adequate. Do weight-bearing activities (standing frame, guided exercise) if possible. Have periodic bone density scans. Consider osteoporosis medications if recommended. Prevent falls with home safety modifications and the use of proper support during transfers.
Falls and injuries	Fall-proof your environment (ramps, grab bars and remove tripping hazards). Use appropriate assistive devices. Stay attentive during transfers by using belts or lifts as required. Avoid alcohol or sedating medications that affect balance. If you feel your balance worsening, get a physiotherapist assessment for exercises or equipment to help.
Chronic pain and shoulder overuse	Protect your shoulders and joints with strengthening and range-of-motion exercises. Use ergonomic wheelchairs (proper cushion, adjusted axle position) to reduce strain. Take rest breaks during long pushes. Switch to power mobility for daily activities if pain persists. Consult pain specialists or therapists for medications, massage or other treatments to control pain and maintain function.
Pressure injuries and skin tears or sores	Skin checks twice daily: Look for redness or breakdown. Use quality pressure-relieving cushions and mattresses (and replace them as needed). Reposition frequently (every 15-30 minutes in chair, per schedule in bed). Keep skin clean and dry. Maintain good nutrition for skin health. Address any small sore immediately to prevent worsening. Don't forget your feet.
Bladder issues (UTIs)	Stick to a consistent bladder routine, which includes adequate fluids and regular emptying. Practice good catheter hygiene if using catheters. Watch for *UTI* signs (fever, cloudy urine) and treat promptly. Get medical advice on possibly acidifying urine or taking low-dose preventive antibiotics if UTIs are recurrent. Long-term SCI might require occasional checks, such as an ultrasound, to catch issues like stones or kidney changes early.
Bowel issues	Follow a scheduled bowel program and adjust as needed, with guidance from a nurse or doctor. Eat high fibre foods, stay hydrated and exercise to aid digestion. Use stool softeners or mild laxatives on medical advice if constipation becomes frequent. Don't ignore new bowel changes as they might have fixable causes, such as diet or medication side-effects.
Heart and metabolic health	Maintain a heart-healthy lifestyle by following a balanced diet (limit sugars and unhealthy fats), keep weight in check and doing aerobic exercises suitable for you such as hand cycling and swimming with assistance. Do not smoke, as it greatly adds to cardiovascular risk and slows circulation. Have your blood pressure, blood sugar and cholesterol checked routinely and treat any high values with diet and medication, under your GP's guidance.
Respiratory health	Do breathing exercises if recommended (like using an incentive spirometer or assisted coughing techniques). Get annual flu shots and the pneumonia vaccine (Middleton *et al.*, 2008). Avoid smoking and second-hand smoke. If you have high-level tetraplegia, see a respiratory therapist about equipment such as a cough assist machine or nocturnal ventilation to use *before* you get a serious infection. Watch for signs of sleep apnoea such as snoring and daytime sleepiness. This is treatable, often with CPAP machines and can hugely improve your energy and heart health.
Social isolation	Stay connected. Schedule regular social activities (family gatherings, club meetings, online groups). Use technology (video calls, social media) to reach friends if travel is hard. Consider joining SCI support groups or community programs through organisations, such as SCIA. Do not be shy to seek a support worker or carer for help with outings. Staying engaged is worth it. Plan for retirement or downtime that includes hobbies or volunteering to keep you interacting with others.

Psychological well-being	Prioritise your psychological well-being. Talk openly with someone you trust about how you feel. Engage in activities that give you purpose. Practice stress-reduction techniques that work for you, such as mindfulness, prayer and hobbies. If you notice signs of depression or anxiety, such as persistent sadness, loss of interest or excessive worry, reach out to a GP or counsellor. Mental health conditions are common and treatable. Connecting with peer mentors or a psychologist who understands disability can provide coping strategies. Never hesitate to ask for help. Taking care of your mind is a sign of strength, not weakness.

Reminder: Daily, monthly and yearly checks

In **Chapter 4**, the features of the Health Maintenance Tool were provided. It covers additional topics such as the impact on the endocrine glands, which produce, amongst other things, growth hormone and testosterone. It also provides a list of checks from daily to ten-yearly. Examples include:

- Daily, such as a self-skin check (or done by your carer or support worker)
- Monthly, such as breast and testicular self-examination or carer examination
- Yearly, including vital signs, mammograms and flu vaccination
- 1-2 yearly, including a comprehensive eye examination if over 55
- 3-5 yearly, including a bone health check for osteoporosis
- 5-yearly, such as a pulmonary function test; and
- 10-yearly, a tetanus booster and a colonoscopy.

6.8. Ageing carers

In addition to the physical and physiological changes that accompany ageing, which may occur earlier or more rapidly in people living with SCI, there are also significant psychosocial changes to consider. These include shifts in family and social support networks, the ageing of primary carers and possible reductions in financial resources. As carers grow older, their capacity to provide support may decline, which can require a reversal or reshaping of care roles. This transition can be challenging when the person with SCI is also experiencing age-related declines in their own health. Women ageing with SCI may face additional pressures as they balance responsibilities as carers, homemakers and workers while managing the increasing physical demands associated with both ageing and long-term disability.

Susan's story: It's her turn to take care of her mother

SCIA's Have a Nerve podcast: Episode 55: Meet the Mother: Listen to**Susan** interviewing her mother, **Alma**. Alma came from Kabankalan, Negros Occidental, in the Philippines to Australia in 1981. She shares her perspective on raising Susan, observations as she got older, advice for parents of children with disabilities and the switch from being the carer to being cared for by Susan at the age of 85.

6.9. Financial implications of ageing with SCI

While many individuals who have lived with SCI for many years have become adept at managing their needs, increased co-morbidities and physical impairments may expand their care needs, potentially heightening both physical and emotional burdens, especially if carers are also ageing (Tan *et al.*, 2025). This can increase stress, so both carers and those living with SCI may need additional education and support and possibly respite. These, too, have financial implications.

In their scoping review, Tan *et al.* (2025) wrote that:

> *"In Australia, there is substantial inequality in financial support and access to healthcare, care support, and services for people ageing with SCI due to the disparity between ageing and disability services, impacting the ability of people with SCI to age well."*

Disparities between the disability and aged-care funding systems should, however, be addressed to ensure equity of access to support for people ageing both with or without disability. Research is, however, needed to address the many knowledge gaps about ageing with SCI (Tan *et al.*, 2025).

Reminder: My Aged Care

As we identified in **Chapter 1**, Australia has a binary system of disability support. If you are under 65 when you sustain your injury, you are covered by the NDIS even when you turn 65. If, however, you are over 65 when you sustain SCI, you need to apply for funding from My Aged Care.

6.10. Intersection of ableism and ageism

Tan *et al.* (2025) found that while research on systemic inequity for ageing individuals living with SCI exists, minimally discussed in the literature were more subtle forms of discrimination, such as the *intersection of ableism and ageism* :

> *"The literature briefly discussed aspects of discrimination due to disability; however, it did not explicitly name this as 'ableism.' 'Ableism' describes discriminatory or negative attitudes towards people with disability. This may often be manifested through well-meaning but dis-empowering stereotypes; however, it results in systemic bias, oppression, prejudice, and exclusion."*

An example of this intersection of ableism and ageing is when an able-bodied person uses an accessibility parking space, which then excludes both those with physical disabilities and the general ageing population.

Important resource: WHO and ageism

The WHO has a page dedicated to ageism. Ageism refers to the stereotypes (how we think), prejudice (how we feel) and discrimination (how we act) towards others or oneself based on age.

Tan and colleagues (2025) also identified that the literature did not examine how *ableism can be internalised as people hold on to and embody negative and limiting conceptions of their own bodies and capacities.* This can undermine adjustment to disability and lead to passive acceptance

of exclusion and self-destructive notions such as *"I don't want to be a burden."* Negative beliefs about ageing can also compound internalised ableism.

6.11. Going into residential care

At some stage, one might have to make a decision about needing to go into residential care. It is reassuring that Australian GP training involves a unit of learning about caring for individuals with disability, which includes a section on caring for patients with disability in residential care, which describes the following competencies*:*

- Depending on the person's age and cognition level, communicate with them appropriately and gather information from multiple sources, including carers and family members, regarding health complaints
- Understand the importance of appropriate communication, both verbal and written, between health professionals working at the facility and ensure management plans are clear and actionable with appropriate safety netting and follow-up
- Recognise and manage polypharmacy, especially in the context of after-hours prescribing
- Understand the principles of falls prevention; and
- Understand and advocate for behavioural management strategies instead of psychotropic medications, wherever possible.

Disclaimer: The next few sections (**6.12-6.14**) discuss suicide, palliative care and voluntary assisted dying (VAD), all sensitive topics that may raise difficult or emotional issues for some readers. Below are important contact numbers if you or a person you know needs to talk to someone.

Important information: Helplines

If you or anyone you know needs help or support, you can contact the following services:

- Lifeline on 13 11 14
- Suicide Call Back Service on 1300 659 467
- Beyond Blue on 1300 22 4636
- Headspace on 1800 650 890, and
- QLife on 1800 184 527.

6.12. Suicide and ageing

Clark and Krause (2024) investigated the prevalence of ***suicidal ideation (SI)*** in an aging cohort of people living with SCI for about three decades. In their cross-sectional analysis of self-reporting US data (2018-2019), more than 14% of the sample reported experiencing recent *SI*. Individuals reporting SI had greater pain severity, pain interference, depressive symptom severity and frequency of anxiety. Having a cervical injury level, lower self-reported general health, instrumental social support, emotional social support and fewer days spent outside the home were associated with SI. When all the factors were taken together, having a cervical-level injury and greater depressive symptom severity remained significantly associated with SI. The researchers highlighted the importance of health professionals continuing to assess depressive symptoms and SI as individuals age with SCI.

As discussed in **Chapter 5**, anxiety and depressive symptoms are higher amongst people living with SCI. It is likely that SI are also more prevalent than in the general population and can vary throughout life. Depressive symptoms and mental health are, however, associated with reduced participation in productive activities, which decline with disability and ageing (Tan *et al.,* 2025).

6.13. Palliative and end-of-life care

At some point, we all need to think about what will happen as we near the end of our lives. This can be overwhelming. The My Aged Care website will probably provide sufficient information and resources for both individuals and for carers, the latter drawn from the LLEs of other carers.

Important resource and information: End-of-life care

The My Aged Care page on end-of-life care takes you through the steps in terms of:

- Thinking about your preferences: *Where would I like to be? Who do I want to provide the care? Who would I want to make decisions if I am not able to?*
- Knowing what is available in terms of palliative care and the final days of life
- Starting the conversation with the people who matter and letting them know your wishes; and
- Advance care planning, which helps you think about future medical treatment and health care needs so that you can share your wishes with family, friends and doctors.

6.14. Voluntary Assisted Dying (VAD)

A recent media story (April 2025) of an alleged assisted death by suicide of a 43-year-old Coast man who had lived with quadriplegia for many years, has brought this topic to the forefront. Three individuals were arrested, two in their 80s. Read more about this below.

Media stories: Assisted dying (illegal)

- Quadriplegic Australian has illegal assisted suicide after failing to qualify under State law
- Investigation into the alleged assisted suicide of a Gold Coast man is underway
- Three charged over alleged black market assisted dying operation; and
- Gold Coast man Brett Daniel Taylore charged with third count of aiding suicide.

In Australia, VAD exists in Victoria, Queensland, Western Australia, Tasmania, South Australia, NSW and the Australian Capital Territory.

Important resource and information: End-of-life law

- The Queensland University of Technology's End of Life Law in Australia website offers an informative overview of VAD, including what it is and the specific eligibility and procedural requirements in each State and Territory; and
- End of Life Directions for Aged Care (ELDAC): Provides an overview of VAD as it relates to Aged Care.

6.14.1. Voluntary assisted dying and long-term SCI: Knowing your rights

Chapter 11 focuses in depth on the legal considerations relating to long-term SCI in Australia. However, this section focuses specifically on VAD as it relates to people living long-term with a SCI as a rights-literacy guide, not legal advice. It aims to help readers understand how the law approaches requests to die in the context of disability, dependency and autonomy, and why

SCI occupies a legally sensitive space in these debates (Colburn, 2020; United Nations (UN), 2006).

While most people with SCI may never seek VAD, a few individuals may consider it for various reasons. Understanding how the law frames suffering, choice, and protection matters. These frameworks shape how disabled lives are valued, whose suffering is recognised as legitimate, and when the law prioritises autonomy versus protection (Mullock & Lewis, 2025; Vidal, 2025).

6.14.1.1 What the Voluntary Assisted Dying Law in Australia is and is not

In the few allowed Australian states and territories, which will be discussed later, VAD laws are strictly limited to people who meet narrow eligibility criteria, typically requiring:

- An advanced, progressive, and expected-to-cause-death medical condition
- Suffering that cannot be adequately relieved; and
- Decision-making capacity at the time of the request.

Importantly, disability alone, including severe or permanent paralysis, is not an eligibility basis for VAD in Australia. VAD statutes are not designed for SCIs as such, even where impairment is profound or lifelong.

This legal boundary reflects an explicit policy choice: to avoid framing disability as a reason for death, while still permitting assisted dying at the end of life. That boundary, however, is contested in law and human-rights scholarship.

6.14.1.2. Autonomy, capacity and the reality of profound physical disability

A foundational legal principle is that physical paralysis does not negate legal capacity. People with SCI, including those with high-level tetraplegia or ventilator dependence, retain the legal right to make decisions about their own lives if they have decision-making capacity.

Legal scholarship, including analysis of people with locked-in syndrome, emphasises that the need for technological or human assistance to communicate does not undermine autonomy or agency. What matters legally is cognitive capacity, not physical independence (Vidal, 2025).

This distinction is critical in VAD debates. Some scholars argue that excluding people from end-of-life options because they lack the physical ability to self-administer medication risks shifting the focus from autonomy to bodily function, an outcome that sits uneasily with disability rights principles (Keown, 2022; Ouellette, 2017; Shavelson *et al.*, 2022).

6.14.1.3. Protection, vulnerability and the risk of paternalism

Opposition to extending assisted dying to contexts of disability often rests on concerns about vulnerability. People with SCI may face:

- Extensive physical dependency
- Reliance on under-resourced care systems; and
- Social isolation or reduced economic security.

Legal and medical-law scholars caution that these structural pressures can subtly influence a person's sense of choice; the fear is not necessarily overt coercion, but indirect pressure, 'feeling like a burden', inadequate care or seeing no acceptable alternatives (Bertini, 2025; Mullock & Lewis, 2025).

International human rights bodies have warned that, in such contexts, legal systems risk mistaking socially produced despair for autonomous choice. From this view, denying assisted dying is framed as a form of protection (UN, 2021). Importantly, coercion in this context is rarely explicit or intentional; it may arise through subtle, cumulative pressures, such as fear of being a burden, withdrawal of adequate supports or institutional signals that continued life with severe disability is unreasonable, all of which can undermine the voluntariness of a person's expressed wishes.

Scholars warn, however, that over-emphasising vulnerability can slip into paternalism, where disabled people are seen as uniquely incapable of making serious decisions about their own lives. This tension between protection and respect for autonomy sits at the heart of VAD law as it relates to SCI (Colburn, 2020; Mullock & Lewis, 2025).

6.14.1.4. Disability, the Right to Life and International Human Rights Limits

The UN Convention on the Rights of Persons with Disabilities (CRPD) plays a central role in global debates about assisted dying and disability. UN human rights experts have stated that disability should never, by itself, be treated as a justification for assisted dying, grounding this position in the equal right to life.

From this perspective, laws that permit death in response to disability-related suffering risk reinforcing ableist assumptions about quality of life. The concern is not theoretical. In fact, history shows that disabled lives have often been undervalued by legal and medical systems (UN, 2006; UN, 2021).

For people living with SCI, these arguments explain why Australian VAD laws draw a firm line between terminal illness and disability, even when lived suffering is significant (Adashi & Cohen, 2026; Deliens, 2025). One such example is persons diagnosed with locked-in syndrome

(LIS). People with Locked-in syndrome are unable to move their bodies (quadriplegic) or speak, but they are fully conscious and able to think, feel and understand. Although they are physically paralysed, their decision-making ability remains intact. They can make choices, understand the consequences of those choices and take responsibility for their decisions. To communicate these decisions, such as about medical care, finances or voting, they rely on assistive technology or support from others (Vidal, 2025).

6.14.1.5. Why this matters

It is important to understand how VAD law treats disability. Importantly, these laws reflect deeper assumptions about whose lives are considered worth protecting, how autonomy is recognised or limited and when suffering is medicalised versus social (Colburn, 2020; Mullock & Lewis, 2025).

VAD debates influence clinical culture, policy design and how professionals respond to expressions of distress by disabled people. Knowing one's rights includes being aware of when the law is acting to protect you and when its protective instincts may silence legitimate experiences of suffering (UN, 2021).

A life well lived with SCI includes the right to be taken seriously as a moral and legal agent, even when the law ultimately draws boundaries around assisted dying. Understanding those boundaries is part of navigating long-term life with disability in an informed and empowered way (Vidal, 2025).

Dr Bradley Ng explains that VAD is a sensitive and deeply personal topic. His thoughts on the topic are below.

Important information: Dr Bradly Ng, psychiatrist

"Every state and territory in Australia, except the Northern Territory, now has legislation to help people with VAD. This comes in the form of medical assistance for people to have a dignified death on their own terms and choosing, when faced with specific illness situations. In general terms, the person requesting such assistance has to be 18 years of age or over, be an Australian citizen or permanent resident and be a resident in the state or territory for a minimum period. The person has to have an illness that will cause death within six to 12 months, depending on the condition and legislation. The person has to be suffering from the condition. Finally, the person must have 'capacity' to make such a decision, to make the decision consistently and to make the decision freely and without coercion.

SCI, by itself, does not cause death and hence people will be excluded from VAD legislation if applying with SCI only. This is despite SCI and its co-morbidities (central neuropathic pain, muscle spasms and pressure injuries, to name a few), potentially causing marked disability and suffering for some. Many of these co-morbidities do not lead to death within the short timeframe outline in VAD legislation.

Individuals living with SCI, however, have access to VAD legislation if they develop a serious illness, such as cancer, which has a poor prognosis and causes significant suffering. They should not be denied access just because they have SCI. They are assumed to have capacity to make decisions about their health care like anyone else or at least be allowed to proceed with an assessment of eligibility, which includes capacity to understand the process, weigh up options and communicate a free and consistent decision without coercion or undue external pressure.

Like others in the general population, people living with SCI have psychiatric co-morbidities such as clinical depression. Depression, per se *is not necessarily a barrier to VAD, but severe depression affecting insight and thinking ability might be. This may require an assessment from a psychiatrist or liaison with the person's regular mental health clinician. In instances when severe depression affects capacity, treatment of the depression restores capacity to the point where the individual with SCI can then make a decision about VAD."*

Dr Ng suggests the following academic papers for further reading:

- Boyle *et al.* (2025). How to determine the capacity of a person with depression who requests voluntary assisted dying. *Psychiatry, Psychology and Law, 32*(2), 276-290
- Peisah *et al.* (2019). Biggest decision of them all – death and assisted dying: Capacity assessments and undue influence screening. *Internal Medicine Journal, 49,* 792-796, and
- White *et al.* (2022). Who is eligible for voluntary assisted dying? *UNSW Law Journal, 45*(1), 401-444.

Table 6.2 below, which has been redrawn from White *et al.* (2022), is a comparison of nine medical conditions (*cancer, motor neurone disease, chronic obstructive pulmonary disease, chronic kidney disease, Alzheimer's disease, anorexia, frailty, SCI, Huntington's disease*) and VAD across five legal frameworks (Victoria, Western Australia, a model Bill for Australia, Oregon (US) and Canada)**.**

Table 6.2. Comparison of four diseases in terms of VAD in two Australian States, a model bill for Australia, Oregon and Canada (extracted from White *et al.*, 2022, p. 432).

Condition/ Jurisdiction	Victoria	Western Australia	Model Bill	Oregon, US	Canada
Frailty	No, because no single medical condition will cause death	No, because no single medical condition will cause death	No, because no single medical condition will cause death	No, because no single medical condition will cause death	Yes, if a person is in an advanced state of irreversible decline in capability
SCI	No, because SCI is a disability	No, because SCI is a disability	No, because SCI is not progressive	No, because SCI is a disability	Probably, if a person is interpreted as being in an advanced state of irreversible decline in capability
Colorectal cancer	Yes, by the later stages and once death is expected within 6 months	Yes, by the later stages and once death is expected within 6 months	Yes, by later stages and without curative options	Yes, once death is expected within 6 months and without curative options	Yes, once there are no curative options the person will accept, and the person is in an advanced state of irreversible decline in capability
Alzheimer's disease	Very unlikely because the capacity is not retained when death is expected within 12 months	Very unlikely because the capacity is not retained when death is expected within 12 months	Very unlikely because capacity is not retained when the condition becomes advanced	Very unlikely because the capacity is not retained when death is expected within 6 months	Possible if the person retains decision-making capacity (or final consent waiver)* when in an advanced state of irreversible decline in capability

* Where a person's natural death is reasonably foreseeable, a final consent waiver is possible in Canada, provided the person meets the eligibility criteria for VAD. This is noted only in relation to cases where loss of decision-making capacity was discussed in the text.

Below are a few more related media stories relating to individuals living with SCI and VAD.

Media stories: People who have chosen VAD

- He wasn't prepared for a second-class life: Why injured rugby star went to Switzerland to die
- Euthanasia of people with quadriplegia; and
- Professional horse rider dies aged 31 by apparent assisted suicide after life-changing injury.

Interesting information: VAD in New Zealand

New Zealand legalised assisted dying via a binding referendum held on 17 October 2020, with the official result released on 6 November 2020, with 65.1% support for bringing the End of Life Choice Act 2019 into force. The bill, a Member's Bill from ACT MP David Seymour, had passed in 2019 conditional on referendum approval and followed an extensive select-committee process that received more than 35,000 submissions, with hearings held nationwide and submissions published through the Justice Committee's page. The Act, now the legal basis for assisted dying in Aotearoa New Zealand, commenced on 7 November 2021, establishing strict eligibility, safeguards and oversight mechanisms. Current official information for the public and providers is maintained by the Ministry of Health and Health New Zealand | Te Whatu Ora.

Below are a few interesting official links to see how people voted, some of the submissions and debates, as well as the official websites:

- Electoral Commission media release (official results, 6 Nov 2020)
- End of Life Choice referendum (2020)
- End of Life Choice Act 2019 (in force)
- End of Life Choice Bill – Parliament bill page (history, Hansard, debates) (05 Jul 2024)
- Hearings begin on the End of Life Choice Bill (21 May 2018)
- Justice Committee hearings continue across the country (includes submission note)
- Ministry of Health assisted-dying hub; and
- Health New Zealand | Te Whatu Ora Assisted Dying Service.

6.15. Looking ahead with confidence

Ageing with SCI will likely have some bumps in the road, but with knowledge and support, you can navigate this journey successfully. Remember that many people with SCI have lived into their 70s, 80s and beyond, enjoying rich lives filled with family, work, hobbies and adventure.

Most importantly, do not lose sight of yourself in the process of ageing. Your worth, identity and potential do not diminish just because you have hit a certain age or use a wheelchair. Stay engaged in what you love, keep your curiosity alive and surround yourself with people who uplift you. Ageing is not a defeat. It is an achievement, and, with the right approach, your later years can be healthy, fulfilling and empowering.

The key is to plan and adapt by anticipating possible changes and adjusting your health routines, home set-up and social supports. You set yourself up for the best possible outcomes. Focusing on preventative care for high-risk conditions associated with SCI and being vigilant are essential for long-term health and well-being (RACGP, 2019; SCIA, 2021). That is something you and your multidisciplinary team can actively do.

For Tan and colleagues (2025), a lifelong multidisciplinary approach is needed to support people ageing with SCI to maintain health, quality of life and participation in meaningful roles and to facilitate ageing well. Understanding that ageing brings complex health issues as the changes relating to the SCI are overlaid by natural degenerative ageing processes, **Figure 6.1** reflects an extended multidisciplinary team for this stage of life. Medical specialists have been added to the support team profile because of the likelihood of chronic diseases.

An interactive H5P element has been excluded from this version of the text. You can view it online here:
https://bond.studium.pub/life-well-lived-with-spinal-cord-injuries/?p=146#h5p-7

Figure 6.1. The multidisciplinary team that is likely to be involved in ongoing health and well-being as one ages. Click the ⊕ for an explanation of each member's role for this stage of care. Created by Jaclyn Szkwara using Canva and HP5, licensed under a CC BY-NC (Attribution Non-Commercial).

Key Take-aways

- Ageing is a natural biological process, but individuals living with SCI have to navigate the double jeopardy of natural ageing and accelerated degenerative changes, which leads to an increasing need for health services, which will have financial implications
- In Australia, funding for SCI differs depending on the age at which the SCI happened. If it was before 65, then the NDIS is the funding source. If after 65, then the application needs to be made via My Aged Care
- For several reasons, including medical advances, individuals with SCI are living longer, although sustaining SCI after age 40 is linked to higher mortality risk
- Comprehensive access to multidisciplinary medical and healthcare support throughout life is required to ensure regular monitoring of function and health and participation in meaningful and productive life roles
- Women living with SCI experience additional differences: Physical, such as less strength for relieving pressure, physiological, such as osteoporosis and gynaecological issues and psychosocial, including parenting responsibilities
- The age at which the SCI occurs affects physical functioning and independence, with SCI later in life due to a fall being a less traumatic injury
- Carers also age, and if the carer is a parent, there are support implications
- It is important to plan for the end of life
- Having SCI is not a consideration in terms of VAD in Australia, unless there are extenuating circumstances such as a cancer diagnosis; and

- Suicide ideation was found to be highest amongst individuals living with a cervical-level injury and those with greater depressive symptom severity.

Next, we provide an overview of the key issues covered in **Part A**, **Chapters 1-6**, before introducing the **Special Topics** chapters in **Part B** of this resource.

Reminder: Relevant chapters

- **Chapter 1:** The section on funding, which for most is the NDIS, unless the SCI was sustained over 65, which falls under MyAgedCare. At 65, MyAgedCare kicks in. For First Nations people, this will be earlier. Other funding sources may also be important
- **Chapter 2:** As this xhapter deals with the anatomy, physiology and pathophysiology of different injury levels and completeness of SCIs, it is an important chapter for understanding ageing on a body that is already anatomically and physiologically different
- **Chapter 3:** Irrespective of one's age, the five pillars of good health and well-being are important: Good nutrition, quality sleep, physical activity, exposure to sunlight and socialising. We added good oral health and foot care, which becomes particularly important as we age
- **Chapter 4:** Tracking health and well-being is important to manage a body that is already anatomically and physiologically different
- **Chapter 5:** Social isolation has been identified as a risk factor for dementia in older people in the *Lancet* Commission on Dementia
- **Chapter 8:** Living rurally, regionally or remotely as one ages is an important consideration because of the distributed health services
- **Chapter 9:** Intersectionality, such as neurodiversity and sexuality, should always be considered in terms of health and well-being
- **Chapter 10:** Ageism is a form of discrimination. Abuse in aged care facilities in Australia led to the 2023 Royal Commission into Aged Care Quality and Safety
- **Chapter 11:** The legal issues relevant to ageing include the ability to consent to procedures and hence guardianship, advanced health directives and complaints against a health professional
- **Chapter 12:** The travelling chapter offers useful advice on travelling
- **Chapter 13:** With advancing age, there is an increase in the need to use the healthcare system, which may include the need for surgery and hence anaesthesia
- **Chapter 14:** As already discussed, spirituality is one of the three Ss of resilience, the other two being self-efficacy and social supports
- **Chapter 15:** Sport should continue as we age, not only in terms of exercise but also in terms of social connection
- **Chapter 16:** There may be opportunities to engage in research related to sport as well as clinical trials
- **Chapter 17:** A changing climate impacts everyone, but the elderly are considered 'vulnerable', mainly because of diminishing sensations relating to feeling hot or cold or thirsty. Some medications impact heat tolerance. Having an appropriate emergency plan in terms of a bushfire or flood is crucial, particularly if one has mobility issues; and

- **Chapter 18:** Health professions education explores how members of multidisciplinary teams are trained and educated to assist with the health and well-being of individuals living and ageing with SCI.

References

Adashi, E. Y., & Cohen, I. G. (2026). Medical aid in dying state laws: A thirty-year evolution. *Journal of the American Board of Family Medicine*. Advance online publication. https://doi.org/10.3122/jabfm.2025.250175R1

Bertini, I. (2025). The right to die: Autonomy at the limits. *Voices in Bioethics, 11.* https://doi.org/10.52214/vib.v11i.13787

Boyle *et al.* (2025). How to determine the capacity of a person with depression who requests voluntary assisted dying. *Psychiatry, Psychology and Law, 32*(2), 276-290. https://doi.org/10.1080/13218719.2023.2296486

Chaffey, L., & Bigby, C. (2018). Health education by peers with spinal cord injury: A scoping review. *Journal of Developmental and Physical Disabilities, 30*(1), 141-154. https://doi.org/10.1007/s10882-017-9569-6

Clark, J. M. & Krause, J. S. (2024). Suicidal ideation among individuals aging with a spinal cord injury. *Rehabilitation Psychology, 69*(2), 1530-158. https://psycnet.apa.org/doiLanding?doi=10.1037%2Frep0000529

Colburn, B. (2020). Autonomy, voluntariness and assisted dying. *Journal of Medical Ethics, 46*(5), 316–320. https://doi.org/10.1136/medethics-2019-105720

Deliens, L. (2025). Assisted dying and the slippery slope argument—No empirical evidence. *Journal of the American Medical Association Network Open, 8*(4), e256849. https://doi.org/10.1001/jamanetworkopen.2025.6849

Guízar-Sahagún, G., Grijalva, I., Franco-Bourland, R. E., & Ignacio Madrazo, I. (2023). Aging with spinal cord injury: A narrative review of consequences and challenges. *Ageing Research Reviews, 90*, 102020. https://doi.org/10.1016/j.arr.2023.102020

James, K., Orkaby, A. R., & Schwartz, A. W. (2021). Foot examination for older adults. The *American Journal of Medicine, 134*(1), 30-35. https://doi.org/10.1016/j.amjmed.2020.07.010.

Jenkins, H-T., & Cosco, T. D. (2021). Spinal cord injury and aging: an exploration of the interrelatedness between key psychosocial factors contributing to the process of resilience. *Health Psychology and Behavioral Medicine, 9*(1), 315-321. https://doi.org/10.1080/21642850.2021.1911656

Keown, J. (2022). The logical link between voluntary and non-voluntary euthanasia. *The Cambridge Law Journal, 81*(1), 84–108. https://doi.org/10.1017/S0008197321001057

Lin, P., Kamdar, N., Rodriguez, G. M. et al. (2024). Incident traumatic spinal cord injury and risk of Alzheimer's disease and related dementia: longitudinal case and control cohort study. *Spinal Cord, 62*, 479-485. https://doi.org/10.1038/s41393-024-01009-1.

Livingston, G., Huntley, J., Liu, K. Y., Costafreda, S. G., Selbæk, G., Alladi, S., Ames, D., Banerjee, S., Burns, A., Brayne, C., Fox, N. C., Ferri, C. P., Gitlin, L. N., Howard, R., Kales, H. C. Kivimäki, M., Larson, E. B., Nakasujja, N., Rockwood, K., Samus, Q., Shirai, K., Singh-Manoux, A., Schneider, L. S., Walsh, S., Yao, Y., Sommerlad, A., & Mukadam, N. (2024). Dementia prevention, intervention, and care: 2024 report of the *Lancet* standing Commission. *Lancet, 404*(10452), 572-628. https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(24)01296-0/fulltext

Mashlah, A., Marini, S., Mills, H., Yahya, T., Radmanesh, F., Chalif, J., Zusman, B. E., Bernstock, J. D., Al Mansi, M. H., Grashow, R., Abd-El-Barr, M. M., Zaidi, H. A., Lu, Y., Salim, A., Fahed, A. C., Manley, G. T., Halabi, C., Digiorgio, A., Zafonte, R., & Izzy, S. (2025). Traumatic spinal cord injury and subsequent risk of developing chronic cardiovascular, neurologic, psychiatric, and endocrine disorders. *JAMA Network Open*. https://doi.org/10.1001/jamanetworkopen.2025.41157.

McColl, M.A., Charlifue, S., Glass, C., Lawson, N., & Savic, G. (2004). Aging, gender, and spinal cord injury. *Archives of Physical Medicine and Rehabilitation, 85,* 363-367. https://www.sciencedirect.com/science/article/pii/S0003999303009717?via%3Dihub.

Mortenson, W. B., Sakakibara, B. M., Miller, W. C., Wilms, R., Hitzig, S., & Eng, J.J. (2014). Aging following spinal cord injury. In J. J. Eng, R. W. Teasell, W. C. Miller, D. L. Wolfe, A. F. Townson, J. T. C. Hsieh, S. J. Connolly, V. K. Noonan, E. Loh, & A., McIntyre A (Eds.), *Spinal cord injury rehabilitation evidence* Version 5.0 (pp.1-90). SCIRE. https://scireproject.com/wp-content/uploads/2022/02/Aging-v.5.0.pdf.

Middleton, J. W., Leong, G., & Mann, L. (2008). Management of spinal cord injury in general practice – Part 2. *Australian Family Physician, 37*(5), 331-338. https://www.racgp.org.au/getattachment/4bae8974-7024-4d22-9755-eca46f26284f/attachment.aspx.

Mullock, A., & Lewis, J. (2025). Assisted dying, vulnerability, and the potential value of prospective legal authorisation. *Medical Law Review, 33*(2). https://doi.org/10.1093/medlaw/fwaf014

National Spinal Cord Injury Statistical Center. (2024). *SCIMS 2024 Annual Report – Complete Public Version.* NIDILLR, UAB Medicine, SCIMS. https://bpb-us-w2.wpmucdn.com/sites.uab.edu/dist/f/392/files/2025/06/2024-Annual-Report-Complete-Public-Version-xx.pdf

Noe, B. B., Stapelfeldt, C. M., Parner, E. T., & Mikkelsen, E. M. (2017). Survival after traumatic spinal cord injury in Denmark: A hospital-based study among patients injured in 1990-2012. *Spinal Cord, 55*, 373-377. https://doi.org/10.1038/sc.2016.154.

Ouellette, A. (2017). Barriers to physician aid in dying for people with disabilities. *Laws, 6*(4), 23. https://doi.org/10.3390/laws6040023

Pacheco Barzallo, D., Baricich, A., Grisales, M. P., Yousefzadeh-Chabok, S., Chan, E., Otom, A. & InSCI. (2025). Health services needs and utilization of persons ageing with SCI. A cross-country comparison, *Archives of Physical Medicine and Rehabilitation.* https://doi.org/10.1016/j.apmr.2025.10.003

Peisah, C., Sheahan, L., & White, B. P. (2019). Biggest decision of them all – death and assisted dying: capacity assessments and undue influence screening. *Internal Medicine Journal, 49,* 792-796. https://onlinelibrary.wiley.com/doi/10.1111/imj.14238

Pili, R., Gaviano, L., Pili, L., & Petretto, D. R. (2018). Ageing, disability, and spinal cord injury: some issues of analysis. *Current Gerontology and Geriatrics Research*. https://doi.org/10.1155/2018/4017858.

Royal Australian College of General Practitioners. (2019). *Disability in aged care (Silver Book – Part B)*. RACGP. https://www.racgp.org.au/clinical-resources/clinical-guidelines/key-racgp-guidelines/view-all-racgp-guidelines/silver-book/silver-book-part-b/disability-in-aged-care

Rushton, R., & Richie, D. (2024). Friction blisters of the feet: A critical assessment of Current prevention strategies. *Journal of Athletic Training*, *59*(1), 8-21. https://doi.org/10.4085/1062-6050-0341.22.

Sabariego, C., Ehrmann, C., Bickenbach, J., Barzallo, D. P., Leiulfsrud, A. L., Vegard Strøm, V., Osterthun, R., Tederko, P., Seijas, V., Eriks-Hoogland, I., Le Fort, M., Gonzalez Viejo, M. A., Bökel, A., Popa, D., Dionyssiotis, Y., Baricich, A., Juocevicius, A., Amico, P. & Stucki, G. (2023). Ageing, functioning patterns and their environmental determinants in the spinal cord injury (SCI) population: A comparative analysis across eleven European countries implementing the International Spinal Cord Injury Community Survey. *PLOS One, 18*,4, e0284420 https://doi.org/10.1371/journal.pone.0284420. With 2025 corrections: https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0337486

Saunders, L. L., & Krause, J. S. (2015). Injuries and falls in an aging cohort with spinal cord injury: SCI aging study. *Topics in Spinal Cord Injury Rehabilitation*, *21*(3), 201-207. https://doi.org/10.1310/sci2103-201.

Savic, G., Charlifue, S., Glass, C., Soni, B., Gerhart, K., & Jamous, A. (2010). British ageing with SCI Study: Changes in physical and psychosocial outcomes over time. *Topics in Spinal Cord Injury Rehabilitation*, *15*(3), 41-53. https://doi.org/10.1310/sci1503-41.

Savic, G., DeVivo, M. J., Frankel, H. L., Jamous, M. A., Soni, B. M., & Charlie, S. (2017). Long-term survival after traumatic spinal cord injury: A 70-year British study. *Spinal Cord, 55*, 651-658. https://doi.org/10.1038/sc.2017.23.

Shavelson, L., Pope, T. M., Battin, M. P., Ouellette, A., & Kluger, B. (2022). Neurologic diseases and medical aid in dying: Aid-in-dying laws create an underclass of patients based on disability. The American Journal of Bioethics, 22(9), 1-12. https://doi.org/10.1080/15265161.2022.2105422

Silva, F. A. R., Barbosa, M. A., Prudente, C. O. M., Morais, L. A., Moraes, K. L., Vila, V. S. C., & Porto, C. C. (2023). Health literacy of people with spinal cord injury: A systematic review. *Spinal Cord, 61*(5), 409-414. https://doi.org/10.1038/s41393-023-00903-4

Spinal Cord Injuries Australia. (2021). *Ageing and spinal cord injury.* https://scia.org.au/resource-hub/ageing-and-spinal-cord-injury/

Tan, E., Mackenzie, L., Wesson, J., & Clifton, S. (2025). Challenges and supports for ageing well with spinal cord injury: A scoping review. *Disability and Rehabilitation,* https://doi.org/10.1080/09638288.2025.2570413.

United Nations Decade of Healthy Ageing. (2022). *Decade of Healthy Ageing.* The Platform. https://www.decadeofhealthyageing.org/

Tedeschi, R., Giorgi, F., & Donati, D. (2024). Footwear and foot health: unveiling the role of proper shoe fit in preventing podiatric issues and enhancing well-being. *Applied Sciences*, *14*(21), 9938. https://doi.org/10.3390/app14219938.

United Nations. (2006). *Convention on the rights of persons with disabilities (A/RES/61/106).* UN Digital Library. https://digitallibrary.un.org/record/588742.

United Nations Office of the High Commissioner for Human Rights. (2021, January 25). Disability is not a reason to sanction medically assisted dying – UN experts (Press release). https://www.ohchr.org/en/press-releases/2021/01/disability-not-reason-sanction-medically-assisted-dying-un-experts

Vecin, N. M., & Gater, D. R. (2022). Pressure injuries and management after spinal cord injury. *Journal of Personalized Medicine, 12*(7), 1130. https://doi.org/10.3390/jpm12071130.

Vidal, F. (2025). Legal personhood and legal capacity: The case of the locked-in syndrome. *Journal of Law and the Biosciences, 12*(2). https://doi.org/10.1093/jlb/lsaf015

White, B. P., Willmott, L., Del Villar, K., Hewitt, J., Close, E., Ley Greaves, L., Cameron, J., Meehan, R., & Downie, J. (2022). Who is eligible for voluntary assisted dying? Nine medical conditions assessed against five legal frameworks. *UNSW Law Journal, 45*(1), 401-444. https://www.unsw.edu.au/content/dam/pdfs/law/unsw-law-journal/2020-2029/2022/Issue-451-White-et-al.pdf.

World Health Organization. (2025). *Ageing and health*. https://www.who.int/news-room/fact-sheets/detail/ageing-and-health

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SUMMARY PART A (CHAPTERS 1-6)

Contributors: Elmarie Stander and Michelle McLean

> *"We can either watch from the sidelines or actively participate. We can rationalize inaction … either let self-doubt and feelings of inadequacy prevent us for realizing our potential, or embrace the fact that when we turn our attention away from ourselves, our potential is limitless."* **Christopher Reeve**, actor and SCI advocate.

In terms of content, **Part A** is probably the most important aspect of this resource, *Towards a Life Well-lived with Spinal Cord Injury*. It brings together the first and most important decisions and actions individuals living with SCI, and often their family, carers and health professionals, need to consider. Returning 'home' and successfully reintegrating into the community requires considerable planning that begins while still in the hospital or in rehabilitation.

Before moving on to **Part B**, with 12 Special Topics chapters (Chapters 7-18), which 'add value' to Part A, it is appropriate to provide a consolidated summary of what has been covered thus far in Chapters 1-6 and then offer key recommendations, based on the lived and living experiences of affected individuals following SCI, as well as those of carers and health professionals.

Towards an eco-biopsychosocial approach to living with SCI

Across Chapters 1-6, we applied many of the lenses discussed in the **Introduction**, such as rejecting SCI as a deficit and adopting a more social, functional perspective. This is reflected in the eco-biopsychosocial model (Introduction, **Figure 5**). The model positions the person living with SCI (*micro level*) at the centre and illustrates how biological, psychological and social factors interact within a broader policy and legislation (*meso level*) framework within an overarching environmental and ecological (*macro level*) context.

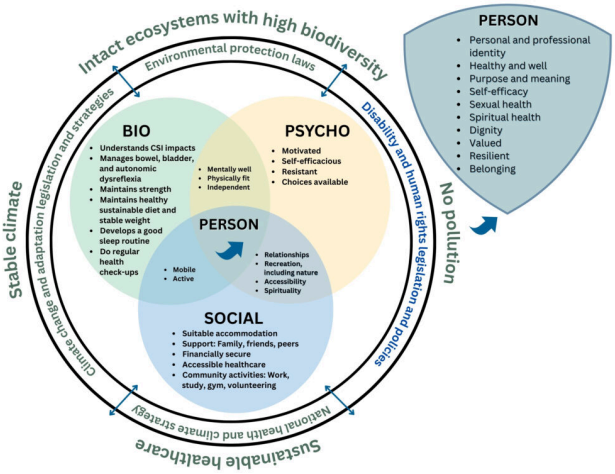

Figure 5. An eco-biopsychosocial model reflecting what is needed to live a life well-lived with SCI in Australia. Designed by Michelle McLean and created by Elmarie Stander using Canva, licensed under a CC BY-NC (Attribution NonCommercial).

Below, we revisit some of the elements addressed in Chapters 1-6, which contribute to supporting a life aligned with an individual's goals and well-being. Although

grounded in theory and evidence, the material is written in plain language to support practical use by a wide range of readers, including individuals living with SCI, their families and carers, health professionals, educators, service providers, system leaders and policy and decision makers.

Micro level: Person-centred

Living well with SCI begins with the person and what matters to them. This includes values, goals, purpose and meaning and identity, including spiritual and sexual health. The descriptors used are affirming, such as dignity, being motivated, resilient and self-efficacious and feeling valued and belonging. These shape daily choices, guide goal-setting and help people integrate into the community, while staying healthy and well.

How to use this in practice

The structure that follows connects each element to Chapters 1-6. At the micro level of integrating biological and psychosocial factors, we also include practical links for care plans. These are added as prompts to support day-to-day application when developing or updating care plans. We will continue to build on these ideas in **Part B** of the resource.

In terms of the *biological (bio) domain:*

- **Chapter 2** provides foundational knowledge about what has happened to a body injured by SCI, which depends on the level of injury and whether it is complete or incomplete. Chapter 2 also explores the implications of a damaged nervous system on other organ systems, such as the musculoskeletal system and the urinary, respiratory and gastrointesinal systems, in particular. For many, pain is part of daily life, and so the non-pharmacological and pharmacological approaches were discussed in detail
- With this awareness, **Chapter 3** provides strategies to prevent secondary complications through the five pillars of good health and well-being by following daily routines, such as eating healthy, quality sleep, physical activity, getting sun exposure and socialising. Chapter 3 also added oral health and podiatry services to the biological domain. Finding a GP who understands the impacts of SCI not only on the individual but also on carers and other family members is important to ensure, for example, that vaccinations and screening are up-to-date as preventative measures
- **Chapter 4** provided a range of ways of tracking health through a *personal health record (PHR)*, which allows identification of changes and allows continuity of health services, such as My Health Record, and
- **Chapter 6** discusses the impact of ageing with SCI, which often accelerates the normal ageing process. Care needs to be taken to monitor chronic diseases, such as Type 2 diabetes and osteoporosis. Ageing carers were also discussed, as were accommodation and

end-of-life decisions.

In terms of the *psychological domain:*

- **Chapter 1** discusses burnout for carers
- **Chapter 3** focuses on resilience, mindset and sleep. These support stable routines and help with symptom control, as well as psychological well-being through music, art, nature and animal therapy
- As outlined in **Chapter 4**, a *PHR* should include psychological well-being
- **Chapter 5** discusses returning to the community, such as socialising, returning to work, studying and perhaps volunteering, all of which strengthen one's sense of purpose and identity
- **Chapter 6**, where continuity of care across service providers is offered to offer psychological security, and
- **Chapters 3** and **6** cover psychological well-being and suicide prevention. They encourage early screening, GP mental health care plans and access to peer support.

Key recommendations: Practical links for care plans

- Add a strengths and values page that connects daily routines with what gives the person purpose, and
- Add a sleep optimisation checklist and a suicide risk escalation pathway to the shared record.

In terms of the *social domain:*

- **Chapter 1** covers coming home and getting settled. It includes housing, carers, transport and GP access that match daily needs, as well as telehealth and outreach
- **Chapter 3**, where one of the five pillars is socialising
- **Chapter 4** focuses on tracking and sharing information so that services can hand over safely and reduce repeated assessments
- **Chapter 5** explores work, study, dating, volunteering and other activities that rebuild participation and identity, and
- **Chapter 6** highlights the needs of carers, including respite, mental health support and planning for the future as carers age.

Key recommendations: Practical links for care plans

- Add a home and transport checklist that covers access, travel time, backup power and telehealth readiness, and
- Create a community participation plan that lists activities and the support worker tasks that make them possible.

Meso level: Systems that enable daily life through policy, funding and service design

This is demonstrated in:

- **Chapter 1**, which explains how people can access and navigate a range of services, such as the NDIS, HEN and aged care pathways and how this links to home modifications, assistive technology and travel support
- **All chapters**, which highlight the central role of primary care, where prevention, monitoring and escalation occur in everyday life, and
- **Chapter 4**, which emphasises the importance of digital continuity, noting that safe and consistent information sharing depends on secure systems, easy-to-use platforms and clear consent processes.

The *Macro level* will be discussed in **Chapter 17**, which explores a changing climate and its physical, physiological and psychological impacts.

Media Attributions

- Figure 5. An eco-biopsychosocial model reflecting what is needed to live a life well-lived with SCI in Australia. © Michelle McLean & Elmarie Stander is licensed under a CC BY-NC (Attribution NonCommercial) license

PART B: SPECIAL TOPICS

Part B. Special Topics

Chapters 1-6 provided evidence-based and *lived and living experiences (LLEs)* of day-to-day living once discharged from the hospital or following transitional rehabilitation. The chapters focused on many elements of the eco-biosychosocial model of health and well-being discussed in the **Introduction** to the resource. More of these elements will be discussed in the Special Topics chapters.

Now, **Chapters 7-18**, the Special Topics chapters, discuss some aspects of areas touched on in Chapters 1-6 in more detail, while others tackle topics that are not easy to discuss. Notwithstanding, we hope that these chapters will be useful for anyone associated with SCI, from those affected directly to health professionals and health professional students who are studying at a time when universities are becoming more inclusive in admitting and supporting students with disabilities. Similarly, many professional bodies are embracing disability as part of a diverse workforce that more closely mirrors the diversity of multicultural Australia. This more embracing approach of valuing disability (rather than viewing it as a deficit) is thanks to the advocacy of many individuals, and in some instances, their allies. The stories we provided in **Chapters 1-6** are evidence of their work in terms of addressing the historical and ongoing discrimination and abuse that some people with disability may endure at work, in the community, on public transport or at home. The next 11 chapters will continue to offer LLEs as well as ongoing evidence-based research findings.

For convenience, the links to the **Special Topics** chapters are below.

- **Chapter 7: Children and Adolescents with Spinal Cord Injury:** Differences from adults, rehabilitation, mental health, education, family dynamics and transition to adulthood
- **Chapter 8: Spinal Cord Injury in Rural, Regional and Remote Australia:** Incidence, research, cultural safety and a GP's perspective on treating First Nations patients
- **Chapter 9: Spinal Cord Injury and Marginalised Communities:** Impacts on individuals who identify as LGBTQIA+, people with neurodiversity, homeless populations, prisoners, migrants, refugees and asylum-seekers
- **Chapter 10: Dignity, Discrimination, Abuse, Violence, Relationships, Intimacy and Fertility:** Sensitive issues including dignity in healthcare, abuse risks, discrimination and relationship challenges
- **Chapter 11: Legal Considerations Relating to Long-Term Spinal Cord Injury:** Human rights protections, consent, privacy and complaint processes, particularly in healthcare

- **Chapter 12: Getting Around and Travelling with Spinal Cord Injury:** Local transport, flights, accessible tourism, and travelling with complex medical needs
- **Chapter 13: Surgery and Anaesthesia for Individuals with Spinal Cord Injury:** Preparation, anaesthesia considerations, common surgeries, recovery and guidance for healthcare professionals
- **Chapter 14: Spirituality and Spinal Cord Injury:** Definitions, benefits of spiritual care, meditation, prayer and humour as a source of resilience
- **Chapter 15: Engaging in Sport with Spinal Cord Injury:** Benefits of sport, para-sport pathways, classification, risks and practical advice for carers and clinicians
- **Chapter 16: Spinal Cord Injury Research and Innovation:** Therapies for SCI repair, clinical trials, cell transplantation, stimulation techniques and nutritional research
- **Chapter 17: A Changing Climate: Implications for Individuals Living with Spinal Cord Injury:** Physiological and mobility risks during extreme weather, preparedness strategies, emergency protocols and policy frameworks, and
- **Chapter 18: Health Professions Education: Curriculum and Inclusion:** Explores how the training and education of various health professionals include SCI (and disability in general) in the curriculum, and, in terms of Medicine, inclusivity of applicants and support for students who may become disabled during their studies.

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Chapter 7. Children and Adolescents with Spinal Cord Injury

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> *"I don't know what alternative you have, other than like, just accepting it and moving on. There is nothing to change. The only thing to change is to adapt to the circumstances. We could not change the circumstances."* **Annie**, who had a spinal stroke the night before seventh grade (Episode 6: Annie, "Miss Independent", FacingDisability.com)

Spinal cord injury (SCI) in children and adolescents is a complex and vast topic. While it deserves an entire book, this Chapter focuses on key concepts and practical insights, placing the child and adolescent with SCI within the broader context of their family, school and community.

In 2021, globally, an estimated 72,628 children experienced a spinal injury, with a global incidence rate of 3.6 cases per 100,000 children. Currently, nearly 600,000 children live with these injuries, accounting for approximately 200,000 years lived with disability (YLDs). Although global rates of paediatric spinal injuries, including SCI, have declined since 1990, projections suggest that these injuries will continue to place a substantial burden on children and health systems through to 2046 (Zeng *et al.*, 2025). In Australia, national data exclude those under 15 years, so the true incidence in this age group is unknown (SCIA, 2021).

Paediatric SCI, whether caused by traumatic events (such as transport or sporting injuries, or falls), or non-traumatic conditions (such as tumours, infections or ***transverse myelitis***), is relatively rare in children 0-15 years but is often severely disabling and associated with lifelong impacts on health, mobility and participation. Despite declining incidence and prevalence globally, children continue to experience a high burden of long-term disability, with modelling indicating that the global impact of paediatric SCIs will remain substantial over the coming decades (WHO, 2024; Zeng *et al.*, 2025).

A clearer understanding of pediatric SCI and its broader impacts is essential. It empowers parents, carers and clinicians to better support the health, quality of life and meaningful community participation of affected young people. Through this lens, health professionals can gain valuable insight into how to more effectively support families and communities, enabling children and adolescents living with SCI to thrive as active and valuable members of society.

Below are two resources from facingdisability.com for families. The website has numerous *LLEs* from clinical experts, family members and affected individuals.

Personal stories: Children with SCI and their parents adjusting to new realities after the injury

Listen to these personal stories from facingdisability.com:

- I Was a Wheelchair Kid: A collection of true stories from US children and teenagers who became paralysed and had to learn how to navigate life in a wheelchair. The podcasts share personal accounts of how young people found their own solutions and adapted to new ways of living. Although the storytellers are now adults, their childhood experiences and memories remain vivid and powerful. There are no lectures here, only real-life stories, humour, and honest reflections about returning to school, finding ways to feel 'normal' again, beginning to date and creating a new vision of the future. Each episode features one person sharing their true story, and
- Paediatric SCIs: Short videos in which a medical expert explains why adult and paediatric SCIs are different, as well as a mother and a young man answering the question: ***"How did you deal with the transition from hospital to home?"***

This Chapter includes resources for children and adolescents directly affected by SCI, as well as their parents or carers. At the end of the Chapter is specific guidance for health professionals.

Key Topics in this Chapter

- Differences between children and adolescents with SCI and adults with SCI
- Mechanisms and causes of SCI in children and adolescents
- Communication about SCI with children, adolescents, families and carers
- Physical rehabilitation and medical treatment considerations
- Secondary complications associated with paediatric and adolescent SCI
- The multidisciplinary therapy team in paediatric and adolescent SCI care
- Mental health, emotional wellness and psychological well-being in children and adolescents with SCI
- Day-to-day living and functional considerations
- Educational participation and extra-curricular activities
- Family dynamics, carer roles and carer well-being
- Preparing for long-term care and transition to adulthood, and
- Primary care roles and clinical considerations for health professionals.

7.1. Differences between children and adolescents with SCI and adults with SCI

Children and adolescents living with SCI differ in important ways from adults with SCI. These differences mostly relate to anatomical, developmental, functional and psychosocial factors. Young people are also more likely to have an associated acquired brain injury, which can bring additional challenges with movement, sensation, language, emotions and cognition.

Anatomically, children do not reach full skeletal development until puberty. Their spine and vertebrae are more flexible than those of adults. They are more susceptible to SCI with ligamentous injury without bony vertebral involvement or Spinal Cord Injury Without Radiographic Abnormality (SCIWORA) at younger ages. Further, children are more likely to injure the cervical spine due to a larger head-to-body ratio, underdeveloped muscles and more flexible ligaments, which increases strain. As injury mechanisms and severity differ from those in adults, ongoing

assessments must be tailored to reflect this. As in adults, the functional outcomes of SCI in a child will vary greatly depending on whether the injury is complete or incomplete and on the level of injury (cervical, thoracic, lumbar, or sacral) (Palombi *et al.*, 2025; Pang & Wilberger, 1982). As discussed in **Chapter 2**, 'complete' means there is no motor or sensory function below the level of injury, while 'incomplete' means some function remains. This distinction is important because it affects movement, sensation, independence and rehabilitation potential for children and adolescents. Understanding these terms helps families set expectations and guides health professionals in planning care and therapy.

An SCI can have a significant impact on a child's growth and development as well as their day-to-day function. From a musculoskeletal perspective, children with SCI are more susceptible to secondary complications such as scoliosis, joint contractures, or limb length discrepancies (Vogel *et al.*, 2014). The impacts of injury, reduced mobility, and recovery can also affect a child's overall development, including gross and fine motor skills, speech, and social development. Children may have associated problems with their bowel and bladder control. All these potential complications will have lasting impacts (see **Section 7.4** below).

Caring for a child or adolescent with SCI requires a balanced approach that prioritises their psychosocial well-being. As a parent or carer, you will adapt your understanding of your child's abilities, goals and needs. The injury will impact their education, access to education and community services, identity development, friendships, play, and family dynamics. Several teams (families, healthcare professionals, including the therapy team and educational providers) need to work together to optimise the child's functional outcomes.

The Sydney Children's Hospital Network fact sheet below is a key, up-to-date resource that we have used extensively in this Chapter.

Important resource and information: Sydney Children's Hospital Network SCI fact sheet

Sydney Children's Hospital Network: Spinal cord fact sheet (2025) provides information about managing children living with SCI.

7.2. Mechanisms of injury and diagnosis

Compared with adults, children are less likely to incur a *[traumatic SCI (TSCI)*. Instead, the most common causes of SCI in children include*congenital abnormalities*, such as *tethered cord syn-*

drome, *spina bifida*, spinal cord tumours, infections and blood vessel abnormalities (Cunha *et al.*, 2023).

For children who do experience TSCI, the mechanism of injury differs from that of adults and has different long-term care and considerations. In infants, SCIs can result from trauma during the birthing process. Infants and younger children may experience injury from falls, being dropped, motor vehicle accidents (as pedestrians or passengers) and non-accidental injury, such as abuse. Adolescents are more likely to suffer injury due to sporting accidents or high-speed trauma (ACI, 2020; Vogel *et al.*, 2014). Acquired brain injuries are more commonly associated with SCI in children, adding complexity to treatment and recovery (Sydney Children's Hospitals Network, 2025).

Children living with SCI must be monitored closely during their development to recognise and diagnose complications related to SCI. They will require adapted assessments for diagnosis and reassessment, as immobility may affect their developmental trajectory. Signs and symptoms of an injury or secondary complications in children may, in many cases, be similar to those observed in adults. However, it is important to note that children may not be able to describe their symptoms in the same way as adults due to their developmental stage, and infants or non-verbal children may be unable to communicate their symptoms at all. Being able to prevent injuries and recognise 'issues' is important in preventing secondary complications, summarised in**Section 7.4** below (Sydney Children's Hospitals Network, 2025).

7.3. Communicating about SCI: Navigating conversations

For parents, the impact of a SCI diagnosis in a child cannot be underestimated. This life-changing diagnosis and its implications should be communicated to the child in an age-appropriate manner. Below are two Australian resources that may assist parents and caregivers when discussing SCI with children, depending on the child's age. An animated video created in Africa, specifically designed for primary school-aged children, is also provided.

Important resources and information: Families adjusting to SCI

Families and carers often need guidance as they navigate the changes that follow a SCI, and these resources offer practical support and information.

- NSW State Spinal Cord Injury Services, Talking to Children About Spinal Injury – A Practical Guide for Families (Unger *et al*., 2013): A helpful resource for explaining spinal injury to children and supporting them through the adjustment process, and
- SCIA's SCI Rookie Book, The Spinal Cord Injury Basics for Supporters (2025): A useful guide for families and carers that covers the essentials of supporting someone with SCI.

Chapter 2 might also be useful for explaining some Anatomy and Physiology.

Video: SCI education for children

What is a Spinal Cord Injury? (At School with Ubongo Kids: African Educational Cartoons*):* This video introduces primary school children to the concept of SCI in an engaging and age-appropriate way.

Below, **Liv** and **Brooke** share their SCI LLEs. Liv's is an animation, while Brooke's is a video.

Personal stories: Children's perspectives and experiences after SCI

- **Liv's story:** An animated story about a young girl who acquires a SCI after an infection damages her spinal cord. Liv's experience offers children an accessible way to understand the challenges of SCI and the resilience required to adapt to life after injury.
- **Brooke's story:** Brooke became paralysed as a teenager after a diving accident. A passionate surfer growing up, she still loves the ocean. Her new dream is to design homes that better support wheelchair users. Her story highlights recovery, adaptation and the vital role of family support.

Below,**Joel**, **Marzet** and **Maggie** reflect on their LLEs as adults who have successfully navigated their SCI. Their experiences and their stories are a testament to the fact that there is life beyond the SCI. Their reflections offer guidance on overcoming challenges.

Joel's story: Experience in the hospital after SCI

Injured in 1998 at age 17 (paraplegic), **Joel** reflected on the early hospital period in response to the question: ***"What was the hardest part of the first days in the hospital?"***

> *"The hardest part was just not knowing, because nobody would talk to me. You know, I just remember the doctors passing by and just saying my diagnosis. They're like, "T11, ASI-A A, complete," but nobody would explain that to me, so I didn't know what was going on. And when I was finally told, you know, the doctor was just very blunt. I asked him, "Hey doctor, I can't feel my legs, you know, when's the feeling going to come back? When am I going to walk out of this hospital?" And he was very nonchalant, like, "Well, you're never going to walk again." You know, instantly my world just shattered."*

Listen to more of**Joel**'s story: Living with Spinal Cord Injury, Joel (Facing Disability).

Marzet's story: Memories about going home after the injury

Injured in 1996 at age 15 (paraplegic), **Marzet** reflected on this question: ***"What was the hardest part about coming home?"***

> *"A lot of things did come with my injury, like not being able to get in and out of the house. And when it came down to that, I had to pay people to get me in and out of the house, and I couldn't come right outside because I was, due to the type of injury I got, I was kind of scared to go back into society; this was a gang-related shooting. I was afraid of seeing new faces, because I had a violently acquired injury, and the way I looked at other people then—I didn't know this person, and any day now I could end up in a worse situation from some, just, a silly confrontation, you know."*

Listen to more of **Marzet**'s story: Living with Spinal Cord Injury, Marzet (Facing Disability).

Maggie's story: Reflection on experiences following SCI

Injured in 2011 at age 17 (quadriplegic),**Maggie** responded to the question, ***"What do you wish you had known in the beginning?"***

> *".... I wish I would've been told more about devotees on Facebook, because devotees are like sexual predators for people with disabilities, it's disabled devotees. And on Facebook—like I remember I read an article at Shepherd and it was of a woman getting married and—someone added me with a different name on Facebook, and had mutual friends, and it was all random people I didn't know, who would send weird messages, and they're devotees. And I couldn't count the number of message adds I've had of people that look like devotees. It's profiles without much information, few friend interactions and it's scary. They take your pictures and use them to get other people to be friends with them."*

Listen to more of **Maggie**'s story: Living with Spinal Cord Injury, Maggie (Facing Disability).

Parents are directly impacted by their child's diagnosis of SCI. Below, **Mary-Ellen**, a mother and a physician, reflects on her journey with her adolescent daughter.

Mary-Ellen's story: A mother and physician supporting her daughter after SCI

A physician whose daughter was injured in 2005 at age 15 (quadriplegic), **Mary-Ellen** reflected on the early hospital period in response to the question, ***"What do you wish you had known at the beginning?"***, stating:

> *"Now, five years out, I'm surprised at how normal our lives have become. To a large extent, we're in many respects where we were before the accident, and I never in the early years thought for a moment that we would reach that point. Certainly, we have to do things differently; family vacations are different, and there are some things we can do, some things we can't do. But we're still able to pretty much do all the things as a family we did before. And instead of Molly's disability being front and center, it's become sort of a sideline—"Oh yeah, by the way, we have to do it differently because of this." It's not front and center any more which is good..."*

Listen to more of **Mary-Ellen's** story: Living with Spinal Cord Injury, Mary Ellen (Facing Disability).

7.4. Physical rehabilitation and medical treatment

The initial rehabilitation period, as well as ongoing treatment, should emphasise developmental goals and a family- and community-centred approach. For younger children, it includes play-based therapy. As children and adolescents continue to grow and develop, early intervention and rehabilitation can help the nervous system adapt and heal. This process, called neuroplasticity, means the brain and spinal cord can create new pathways to improve movement, sensation and function after injury. This can also help prevent secondary complications, as outlined below.

7.4.1. Musculoskeletal complications

Below, we describe a range of musculoskeletal complications related to SCI.

- **Muscle wasting:** Loss of nerve supply to muscles can lead to their degeneration, which affects mobility, bone strength and the ability to breathe. Physiotherapy and occupational therapy can help prevent muscle wasting. Standing and weight-bearing programs using standing frames or tilt tables can stimulate weight-bearing and help maintain bone and muscle integrity. *Neuromuscular electrical stimulation (NMES)* can activate inactive muscles.

Optimising nutrition to include adequate calories and protein is also essential to prevent muscle loss.

- **Contractures and spasticity:** Children and young people are at risk of developing contractures when there is a fixed loss of joint range due to imbalances between opposing muscles. Additional problems include immobility, poor positioning, involuntary contraction and posturing (*dystonia*) and stiffness (*spasticity*). This can be prevented to some extent with regular physiotherapy and occupational therapy, stretching and splinting. Spasticity can be addressed with specific oral medications. Botox injections have been used successfully for spasticity in children with cerebral palsy (Gormley *et al.*, 2023).
- *Scoliosis (spinal deformity)*: This can happen when there is an asymmetric 'pull' on the spine due to muscle paralysis or spasticity, postural instability, leading to abnormal vertebral growth and curvature. It can affect breathing and posture. In severe cases, it may require bracing or surgical intervention.
- **Hip instability:** Low tone and increased stiffness (spasticity) in the pelvic and thigh muscles in children who are non-weight bearing can result in hip dislocation. This is especially common in younger children under the age of five and may be painless, but it can significantly affect their positioning and functioning. They will usually undergo surveillance hip X-rays to look for this. An identified dislocation may require surgical correction.
- **Low bone density (osteoporosis) and fractures:** Reduced muscle use from immobilisation can lead to decreased bone density, especially in the legs. Reduced bone density can increase the risk of fractures, even from a minor injury. Vitamin D and calcium supplementation, along with targeted physiotherapy to improve muscle strength, can help prevent osteoporosis.
- **Growth abnormalities and discrepancies in leg length:** Children who sustain an SCI at a young age are prone to growth plate abnormalities due to uneven loading through the limbs, stiffness or spasticity. Growth patterns are altered and final height is often reduced. Careful monitoring during growth spurts is essential, including spinal surveillance X-rays to track alignment. Deformities can be prevented by addressing spasticity, engaging in weight-bearing activities through standing programs, improving positioning, and using orthoses (bracing). In some cases, surgical correction is needed.

7.4.2. Bladder and bowel complications

Bladder and bowel problems can occur in children living with SCI due to the interrupted neural connection to the muscles controlling the bladder and bowel and reduced anal sensation. The extent of these complications depends on the level and completeness of the injury.

Bladder complications following SCI may include the following:

- **Overactive bladder**, which can lead to an underfilled bladder and urinary incontinence. Urinary incontinence may be distressing and can contribute to skin breakdown, and
- **Underactive bladder**, which results in an overfilled bladder (urinary retention). This can

lead to:

- Abdominal fullness and pain
- Urinary tract infections (UTIs)
- Bladder stones, and
- Backward flow of urine to the kidneys (***vesicoureteric reflux)***, which can lead to kidney scarring and renal failure (Sydney Children's Hospitals Network, 2025).

Some individuals may experience a combination of both overactive and underactive bladder dysfunction.

The management of an underactive bladder includes regular bladder emptying using intermittent self-catheterisation. In some cases, catherisation may need to be done via a ***stoma*** (a small, surgically created opening) connecting the bladder to the abdominal wall. These techniques must be performed using sterile procedures due to the increased risk of urinary tract infections (UTIs) with catheterisation.

Catheterisation is typically initiated by carers early in life, with children gradually developing independence in this process over time. When children become unwell and there is concern for a possible urinary tract infection, antibiotics are recommended as part of management. Treatment of an overactive bladder may include medications aimed at reducing bladder muscle overactivity. In addition, ongoing monitoring of kidney health through blood tests and ultrasound may be required, particularly for children who have experienced recurrent urinary tract infections or vesicoureteric reflux.

Bowel complications are common and include constipation, faecal impaction and overflow diarrhoea, leading to stool retention, faecal incontinence and abdominal distention. Management includes:

- Regular stool evacuation and routine
- Scheduled toileting programs, which can include rectal stimulation or suppositories or enemas that are timed with meals
- A high fibre diet and increased water intake to reduce constipation
- Stool softeners and laxatives, and
- At times, surgical procedures may be required.

7.4.3. Skin complications

The nerve pathways for skin and joint sensation can be affected by SCI, resulting in several complications. Children living with SCI and spina bifida are prone to developing pressure injuries. It is important to identify and mitigate risks and prevent a minor pressure injury from becoming a chronic wound.

Important resources: Pressure injuries in children with SCI and *spina bifida*

The NSW ACI Pressure Injury Toolkit provides the following specific risk factors for pressure injuries in children living with SCI and spina bifida:

- Playing and moving on the ground between hard surfaces, such as concrete, gravel, rocks, rubber playground flooring, plastic playground equipment and sandpits.
- Insect bites from playing on the ground, heat burn from sliding on play equipment, and ingrown toenails.
- Transferring and sitting on plastic classroom chairs, the classroom floor, school toilet seats and playground seats.
- Quickly outgrowing equipment such as wheelchairs, cushions, backrests, postural supports, commodes, thoraco-lumbar-sacral orthoses (braces) and footwear and allowing for the time required to prescribe and order equipment.
- Scoliosis and additional postural changes, such as pelvic obliquity and hip dislocation, impact positioning and functional mobility.
- Limited insight into changing pressure injury risk for families and children who may receive little ongoing information about the implications of impaired sensation as they grow. They may demonstrate complacency with pressure management and routines to prevent pressure injury.
- Not having the necessary information, skills or motivation to self-manage pressure injury risk with growing independence as an adolescent or young adult; and
- Exposure to risks is a normal part of growth and development during childhood and adolescence.

Clinical resource: Checklist for pressure injuries

The NSW ACI website also has a comprehensive Checklist to support the multidisciplinary assessment and management of pressure injury for people with SCI.

The most common locations of pressure injuries (interactive site) are the lower back, heels, bottom (sitting surfaces), back of the head (in infants), back, and elbows. Prevention strategies include:

- Regular repositioning every 20-30 minutes.
- Pressure-relieving mattresses and wheelchair cushions.
- Daily skin checks, especially in the at-risk areas mentioned above.

- Ensuring orthoses and braces fit properly.
- Management of high-moisture areas (incontinence and sweating can lead to skin breakdown)
- Optimised nutrition with adequate protein, calories and micronutrients including vitamins A, C, E, D and zinc, and
- Early involvement of wound care specialists if injuries develop.

Chapter 2 provides a detailed description of how pressure injuries form and how they can be prevented.

7.4.4. Cardiovascular and nervous system

Physical examination of children with SCIs should include an assessment of the blood pressure (using the correctly sized cuff) and heart rate due to the risk of ***autonomic dysreflexia (AD),*** which is covered in **Chapter 2.** Signs of AD include high blood pressure, goosebumps, facial flushing, headaches, a low heart rate, and, in some cases, excessive crying and unsettled behaviour. These symptoms and signs can be challenging to identify in children with varying developmental communication abilities. Parents and carers should be educated to recognise these as abnormal and seek emergency care. Notably, children and adolescents with higher-level (cervical and upper thoracic) SCIs have lower baseline blood pressures than age-matched peers without injury. As a consequence, elevation of blood pressure may be mistaken as being within the normal range when it may instead represent an elevated blood pressure for the child with SCI and possible AD (Kliegman *et al.,* 2020).

It can be difficult to identify the trigger for AD, but it is often a painful stimulus that may include a distended bladder, faecal loading, pressure injury or even menstrual cramps. Other factors that may contribute include excessive alcohol or caffeine intake, the use of diuretics or stimulant medications, and other recreational substances.

Treatment of AD includes managing the underlying trigger. This may include catheterising the bladder, bowel discompaction, loosening clothing, pain relief and sitting up or elevating the head of the bed. Usually, triggers can be identified and treated to relieve AD without the use of blood pressure medications, but this may be needed in select situations. Measures to manage the risk of AD outside of the hospital include children and adolescents wearing a medical alert bracelet, providing supervising adults with education on recognising the signs of AD and creating an emergency plan for AD that should be kept with the child and adolescent in case such an event happens.

Prevention of other potential cardiovascular complications of SCI includes assessment of a child's weight and body mass index (BMI) and lipid and cholesterol levels to ensure they are maintaining cardiovascular health and preventing coronary heart disease.

Children and adolescents are at an increased risk of ***deep vein thrombosis*** *(DVT)* and ***pulmonary embolism*** (clots in the blood vessels of the lung). This is due to their prolonged periods of reduced mobility. In some instances, blood-thinning medication may be required to prevent clots (Kliegman *et al.,* 2020).

7.4.5. Breathing issues

Spinal cord injuries can make a person prone to breathing issues for several reasons, including muscle weakness of the diaphragm, intercostal muscles (between your ribs) and abdominal muscles. Other reasons include a weak cough that results in reduced clearance of secretions, having scoliosis, which limits full lung expansion, resulting in smaller lung volumes, reduced mobility and impaired swallowing in children with high cervical injuries. Reduced lung reserves can mean that children can reach the point of decompensation sooner than children without SCI. The possible lung complications include:

- Recurrent lung infections (pneumonia)
- Mucous plugging of the airways and retained secretions
- Sleep disordered breathing, which can lead to daytime fatigue and cognitive changes, and
- Reduced exercise tolerance and fatigue.

Prevention strategies include:

- Positioning and posture (upright with good trunk support)
- Chest physiotherapy, cough assist devices, and incentive spirometry can help with airway clearance
- Some children may need ventilation support
- Immunisations including influenza, ***respiratory syncytial virus (RSV)*** and ***Pneumococcus*** (conjugate or polysaccharide, depending on age)
- Avoidance of smoke exposure, and
- Prompt recognition and treatment of respiratory infections.

7.4.6. Pain

Pain can be a debilitating concern for children and young people with SCI and has a considerable impact on the success of rehabilitation and a child's level of functioning. It can be challenging for a child to describe the location and nature of their pain. It can also trigger AD. Management should be multi-modal and can include the following:

- Identifying triggers that may be causing pain, such as pressure injuries, discomfort from a full bladder or constipation
- Physical therapy or hydrotherapy

- Psychological therapy that includes relaxation and *cognitive restructuring*
- Pharmacological therapies, including anti-depressants such as amitriptyline and duloxetine, and
- Treatment of dystonia or spasticity.

7.4.7. Gastrointestinal issues

Children living with SCI have a higher risk of swallowing difficulties, slow gut transit, gastric ulcers and *superior mesenteric artery (SMA) syndrome*, a rare but serious condition in which the small intestine becomes compressed, blocking the passage of food. Assessing a child with acute abdominal pain and SCI can be incredibly challenging because children's perceptions and experiences of pain vary. They may present with non-specific signs and symptoms such as vomiting, a dull pain that does not localise, but have vomiting, abdominal pain and fever. These symptoms and weight loss should prompt you to seek medical attention (Kliegman *et al.,* 2020).

7.4.8. Allergies

Latex*hypersensitivity* is a unique complication for children with SCI due to their repeated exposure to latex early in life. Latex-free catheters and gloves should be used from the time of diagnosis. Signs include localised or generalised hives, wheezing, swelling of the throat and/or tongue or anaphylaxis. Families and carers, as well as all care providers, should be able to recognise and manage anaphylaxis with an EPI-PEN or an Ana-PEN and should call the ambulance if this occurs.

7.4.9. Overweight and obesity

Muscle paralysis and weakness can limit a child's ability to move and be physically active, reducing their energy expenditure. Other factors, such as muscle loss, altered metabolism, medications, and reduced participation in outdoor activities, can also contribute to weight gain. Obesity is an under-recognised complication in children. It places young people at increased risk of Type 2 diabetes, high blood pressure and high cholesterol levels. It also impacts mobility, mental health and self-esteem. It can increase the risk of pressure injury and reduce lung capacity. Additionally, it can be more physically challenging for a carer to provide the care children need.

Prevention and management include referral to a dietitian who can monitor caloric intake closely and provide the best advice and guidance to optimise nutritional intake. A psychologist can assist with goal setting and support the development of a healthy relationship with food.

Close monitoring is required during puberty, as this period is often associated with increased weight gain. Physical activity should be encouraged as part of everyday life, as it can improve weight, fitness, balance/coordination, flexibility, bone and muscle strength, posture, bowel movements, mood and self-esteem. It is also especially important to build upper body and core strength (depending on the level of injury) to aid transfers and mobility in a wheelchair or walking device (Sydney Children's Hospitals Network, 2025).

7.5. Multidisciplinary team and rehabilitation

A similar multidisciplinary team to that discussed in **Chapter 1** will cover all aspects of a child's development and rehabilitation. The team needs to include:

- **Physiotherapists** to assist with gross motor movement, including spasticity, respiration, mobility and return to activity, sport and community participation
- **Occupational therapists** who assist with home modifications, equipment and upper limb fine motor function, as well as support children with their daily living activities and community participation
- **Speech pathologists** to help with oral motor control following high-level injury and with language development in younger children
- **Psychologists** assist with supporting the mental health of the child and family and provide strategies for coping with a long-term injury
- **Dietitians** to provide advice on optimal nutrition to meet energy expenditure requirements and prevent complications such as obesity or muscle loss, and
- **Social workers** to assist with accessing financial aid, disability services and educational support. They can help the family or community have the necessary resources to care for the child.

The coordination of care of the family, school and the multidisciplinary team is crucial to the success of the child's management and physical rehabilitation and is essential for promoting early intervention, leading to better long-term outcomes (ACI, 2020; Australian and New Zealand Spinal Cord Society, 2020).

Below is a personal story from **Chase**, who sustained an injury in his teens and one from a mother, **Freda**. Both reflect on the milestones of rehabilitation that deserve celebration.

Chase's story: Rehabilitation experiences

Injured in 2007 at age 17 (paraplegic), **Chase** reflected on the question, ***"What were the important milestones in rehabilitation?"***

> *"Being able to do things myself, like get dressed, be able to get out of bed, into cars, stuff like that. And, now I can do all that myself, and I'd say that was the biggest piece was being able to do everything on my own."*

Listen to more of **Chase's** story: Living with Spinal Cord Injury, Chase (Facing Disability).

Freda's story: A mother supporting her daughter through SCI rehabilitation

Freda's daughter was injured in 2011 at age 17 (quadriplegic). **Freda** reflected on the question, ***"What were the important milestones in rehabilitation?"***

> *"Being able to have use of her arms, to be able to drive her wheelchair herself was a big step. I remember that because she wasn't able for two or three months to move any limbs. And so, to be able to get her muscle use to drive her own wheelchair, that was a big milestone. To be able to, you know, just hold her arms up, or to breathe on her own, take the ventilator off, and be able to breathe on her own, talk, being able to talk again. There's been a lot over the years. There have been so many milestones and we still have them today. It's the best part of it, you know, we're not done."*

Listen to more of **Freda's** story: Living with Spinal Cord Injury, Freda (Facing Disability).

7.6. Promoting mental well-being

Experiencing SCI can result in grief, depression, anger, anxiety and identity issues. Children may feel stigmatised and have challenging relationships with their peers. They can benefit from counselling and psychotherapy as they adapt to the new diagnosis and its consequences.

Important resources and information: Support helplines

- Kids Helpline: Call 1800 551 800 for free, confidential support for children and young people.
- ReachOut: A safe online space to chat anonymously and get mental health support.

If your child is experiencing signs of low mood, social withdrawal or school refusal, impaired sleep, interpersonal conflicts, increased aggression, risk-taking behaviours or is in denial about their feelings, then they require additional support, which may include a psychologist, social worker, school counsellor or mental health professional.

Parents and carers should also encourage and empower their child to learn about their condition so they can advocate for themselves as they mature, become independent and manage their emotions and relationships with peers.

7.7. Everyday life and functional considerations

Children and adolescents are vulnerable to the significant impacts that SCI can have on their growth and development. As a result, they face challenges that differ from those of the adult population. Promoting independence and identity is incredibly important to ensure that a child with SCI can continue to develop into a functioning member of their community and lead a dignified life. There should be an emphasis on developing functional skills that are aligned with the child's age, injury and their social environment.

Mobility is a functional skill that will look different for each child, depending on the level of injury and will require some aids. Some examples include powered wheelchairs, walking aids or orthoses. Mobility will require frequent reassessment as needs and abilities change throughout development and growth. They may need additional assistive technology to support toileting, sleeping, and seating, as well as other home modifications, depending on age and functionality, to allow completion of activities of daily living (ACI, 2020).

One crucial aspect of children's and adolescents' development that requires specific consideration is their sexual development (Papadakis *et al.,* 2017). This period can be marked by low self-esteem and body image issues. It is important to receive the appropriate education that is tailored to their development and sexual function.

Parents and carers play an important role in normalising a child's exploration of identity and sexuality. Importantly, they also have a role in advocating for children and educating them

about safety. Children and young people with SCI may be more accustomed to reduced privacy due to the nature of their care, which can increase vulnerability to exploitation. Young people should be encouraged to ask questions of trusted adults or professionals to support understanding of bodily changes and sexuality. Carers can provide a safe and open channel for communication and education about sexual development, while healthcare professionals are a key resource for discussions related to sexual functioning and fertility.

7.8. Participation in education and activities

Children need a smooth transition plan to enter school and other community, recreational, and sporting activities. Such a plan should be tailored to the child's strengths, while taking into consideration their physical, functional, behavioural and cognitive needs, as well as whether the injury was acquired or long-standing before attending school. When starting school, parents and carers should meet with the school staff, including the principal, support staff and teacher, to understand the child and their needs to determine if they can participate in mainstream classes, need support classes, a hybrid of the two or otherwise attend schools with specific purposes for children with higher-level support needs. The school can then determine the level of support to offer the child. In particular, the ability to mobilise between classes and having access to appropriate toilets for bladder and bowel care needs to be assessed and addressed.

The transition to starting school can be particularly anxiety-inducing for children with SCI and their families. School staff represent a new team who need to understand the child's needs to support their wellbeing and learning. School absences may be common due to medical commitments, including specialist appointments and therapy sessions, making close collaboration with the school essential to support educational participation. As children transition to secondary school, the focus often shifts to navigating peer relationships, which can be challenging. Children and adolescents also need to develop a sense of identity, increasing independence, and emotional resilience to help build confidence.

Important resources: Students with disability and their carers

- Australian Government – Department of Education: Information resources for students with disability and their carers, including guidance on understanding rights and access to supports for parents, carers, and students.
- Children and Young People with Disability Australia (CYDA): Take Charge of Change was co-developed with young people and families with lived experience of disability, including autism, intellectual, physical and psychological disability. It offers resources for parents of children aged 0–12 and for young

people aged 13–25.

- SCIA's Have the Nerve podcast, Be Curious, Not Judgmental: Disability and Primary School (Episode 23): Explores what parents need to do (start the process early) and how a child may be supported in primary school.
- SCIA's Have the Nerve podcast, The Underdogs: Disability and high school (Episode 25): Provides parents with guidance on the transition to high school and finding the right school.

Participation in activities outside of schooling should also be based on their strengths, enabling a young person to flourish in the areas they most enjoy. Joining inclusive sports teams offers physical benefits and can also help your child develop meaningful relationships with peers. Encouraging participation in extra-curricular activities can enhance a child's self-efficacy, mental health, and confidence (Vogel *et al.*, 2014). Through planning and addressing barriers to access, community engagement improves quality of life for both the child and the family (Australian and New Zealand Spinal Cord Society, 2020). Below, **Kaitlin** describes her passion for sport following SCI.

Kaitlin's story: Pursuing her passion for sport

Kaitlin Gunn (15 years old), a basketballer and aspiring Paralympian: **Kaitlin** was 15 when an accident left her a paraplegic, but she has since become an emerging star in wheelchair basketball. Now representing South Australia and Australia, including competing in China at the three-by-three Asia Oceania Cup, **Kaitlin** continues to chase her dream of becoming a Paralympian.

7.9. Family well-being

A diagnosis of SCI is devastating and can have a lasting impact on everyone in the family. This includes siblings, who will need extra support to cope with the changes in their family. Parental roles will shift to accommodate the child's needs. These changes can strain relationships. Parents and carers are required to balance the high care demands of their children with their own well-being and physical and emotional needs. Practising self-care, having access to respite, and strong support systems are critical to carer well-being. These measures can help prevent burnout and fatigue, promote bonding with the child and allow their future independence. **Chapter 1** provides several resources relating to care burnout and carer support networks.

Siblings in particular can have significant difficulties navigating the changes to a family when a brother or sister has a new disability. They may require support from a psychologist and counsellors.

There are additional employment and financial considerations for families, as time will need to be taken off from work for appointments and caring responsibilities. The financial costs associated with caring for a child with SCI are substantial and it can be challenging to navigate funding applications and access support through the National Disability Insurance Scheme, Third Party Insurance Schemes and Centrelink in Australia. Social workers, with the rest of the therapy team, can help support this.

7.10. Preparing for long-term care and transition to adulthood

Sustaining an SCI during childhood requires lifelong monitoring, regular review and proactive intervention to optimise function and reduce the risk of secondary complications, as outlined earlier in this Chapter. Below, we provide several resources that children, adolescents and families may find helpful in understanding long-term care needs and accessing appropriate supports.

Important resources: Supporting children and young people with SCI and their families

- Neuromoves Kids: A specialised physiotherapy and exercise physiology service for children, operated by SCIA (a registered NDIS provider) with multiple locations across Australia
- Spinal Cord Injuries Australia (SCIA): Free to join for patients and families. SCIA offers peer and family support, NDIS navigation, employment services and resilience programs. Their Have the Nerve podcast series covers topics relevant to children and young people living with SCI
- Northcott NSW Paediatric Spinal Outreach Service: Provides nursing, physiotherapy, occupational therapy and social work support to children and young people with SCI, and
- Nursing guidelines: Spinal cord injury (acute management): Clinical guidance for health professionals on both initial and longer-term management of SCI in children.

7.11. Transition to adult care

Most have heard the age-old adage in paediatric healthcare: 'children are not just little adults'. There is certainly truth to this in the setting of SCIs. While many of the issues that are discussed in other chapters of this book apply to children and adolescents, there are specific considerations that need to be made that account for the child's growth and development, their added vulnerability and need for advocacy, as well as their position within their family, school and community circles. Early investments in a child's health and well-being have the potential to reap a lifetime of rewards. Small interventions can make a difference for young patients and their families.

As adolescents with SCI approach adulthood, they may encounter new developmental, social and practical challenges. Early planning and collaboration with the multidisciplinary team, with a strong family-centred focus, are essential to ensuring a smooth and well-supported transition to adult services (Bray *et al.*, 2022).

Transition planning should support the young person to develop independence in:

- Self-care and health management
- Functional and daily living skills
- Financial literacy and accessing financial supports, and
- Planning for further study, vocational pathways or employment.

A successful transition occurs when the young person is functionally ready, rather than transitioning solely based on age. This approach promotes long-term health, independence and engagement in a meaningful adult life.

Below, we provide several resources that may be helpful.

Lisa's story

Personal stories: Families and adults reflecting on childhood SCI and

- SCIA's 40 Voices: A podcast for families affected by childhood SCI, featuring parents discussing their experiences and adults reflecting on living with SCI from childhood and the supportive role their parents played, and
- The Bucket List: What do I wish for in five years? A heartfelt letter written by 16-year-old Lisa Grimson to her future self, sharing her aspirations and hopes as a young person living with SCI.

Important resource: Transitioning from paediatric to adult SCI services

SCI Healthcare Transition: Provides national and state-based information on transitioning from paediatric to adult SCI services. It includes introductory videos, as well as a young person's video explaining the website's development, and age-specific health resources for ages 12–14, 15–16, 17 and 17–19. There are parent and carer resources for the same age groups, plus a peer support page with videos, such as 'Top tips for young people' and 'Top tips for parents and caregivers'.

7.12. Clinical considerations for health professionals

General practitioners or paediatricians caring for children and adolescents living with SCI should consider the physiological changes that young people might undergo and ensure routine preventive care is provided. They also play a key role in facilitating their transition to adult services (Zebracki *et al.,* 2020).

Preventive care includes ensuring immunisations are up to date, especially given the increased risk of respiratory complications, and that growth and developmental milestones are tracking as expected. Children who have an injury at T6 or higher are at risk of AD and should have their blood pressure monitored at each visit and compared against age, height and sex-adjusted reference values. As young people with SCIs tend to have a greater risk of metabolic syndrome and cardiovascular disease, specific focus should be given to ensure they have an appropriate diet, engage in physical activity and get quality sleep, which are three of the five pillars of good health and well-being described in **Chapter 3.**

When individuals with SCIs present with fever, it is worth remembering that it may be difficult to identify an infectious cause for the fever due to their altered sensorium. Fever may not always be a result of infection, but could be due to venous thromboembolism, fractures or drug-related reactions and perhaps impaired thermoregulation or AD. A UTI needs to be excluded, and an appropriate antibiotic should be prescribed to prevent future antibiotic resistance. It is important to regularly screen for AD orthostatic hypotension and for skin, bladder and bowel issues.

GPs, as primary care providers for the child and their family, are uniquely positioned to provide family-based care and screen for psychosocial issues in both the child and family at regular intervals to ensure their psychological well-being. Adolescents can be prone to seeking substances as a way of coping with the implications of their injury or due to their own interests in experimentation. Clinicians play an important role in providing appropriate counselling regarding the use of substances and the impact they can have on an individual's outcomes (Zebracki *et al.,* 2020).

Research on paediatric SCIs, however, is scant compared with adults. Most primary care providers have limited experience in caring for children and adolescents with SCI. Below, we report the findings of an Australian study on the increasing incidence of TSCI and the associated costs to the healthcare system.

Research: Trends in Australian paediatric traumatic SCI hospitalisations

A population-based study found that hospitalisation rates for TSCI increased by 1.2% per year from 2002-2012, with estimated hospital treatment costs of AUS$43 million. In response, there have been calls to establish a paediatric SCI registry in Australia that incorporates consumers, health professionals and researchers, to aid clinical practice and build on current knowledge in this area. This information has the potential to improve understanding from population data and to inform better care for children and adolescents with SCI (Lystad *et al.*, 2020).

Additional information, if interested: Paediatric SCI educational videos for families and caregivers

Paediatric SCI Basics (facingdisability.com): **Dr Lawrence Vogel**, Emeritus, Medical Director, SCI Program, Shriners Hospital for Children, has a series of videos with detailed answers to questions about paediatric SCIs and the implications of the SCI as a child grows. There are other topics, such as family life, with videos.

Key Take-aways

- Children and adolescents living with SCI require coordinated and person-centred approaches that support both the individual and their family.
- Although clinical management and rehabilitation for young people may differ from those for adults, care should remain holistic, encompassing the family, peers, schooling, and community, tailored to the young person's strengths to help them thrive.
- Young people must receive continuity of care from initial rehabilitation through to adulthood to support them across their lifelong journey.
- By working with a multidisciplinary team and in a supportive educational environment, a child can be

empowered to see beyond their injury and grow into an independent, valued member of their community.

The next chapter, **Chapter 8**, considers SCI in the context of rural, regional and remote Australia. Also included in**Chapter 8** are spinal injuries (including fractures and soft tissue injuries) and general disability amongst First Nations people.

Reminder: Relevant chapters

- **Chapter 1:** Provides information about many of the day-to-day aspects of returning home and how this is funded. Children and adolescents will more than likely be returning to the family home, so there are resources for parents as carers
- **Chapter 2:** There are numerous resources that parents may find useful to explain the injury impacts and the potential complications to their children, as well as videos they can watch
- **Chapter 3:** Five pillars of good health and well-being, including regular visits to a dentist and adding a podiatrist to the clinical team to keep feet healthy, are just as applicable to children and adolescents as they are to adults
- **Chapter 4:** Older children and adolescents could document their health and well-being, particularly as they would be comfortable with digital technology
- **Chapter 5:** Adolescent goals are likely to include studying and socialising
- **Chapter 8:** Living rurally, regionally or remotely adds another layer to coming home and navigating more distributed health services.
- **Chapter 9***:* Today, intersectionality in terms of neurodiversity and LGBTQIA+ is particularly important
- **Chapter 10:** Of relevance in this Chapter is abuse and discrimination, which may manifest as bullying at school and on public transport. Adolescents are likely to be thinking about dating and perhaps becoming sexually active
- **Chapter 12:** Travelling is part of our lives today. For young people, this is likely to include public transport and flying. Adolescents may consider taxis, and for some, it may be about driving
- **Chapter 13:** There is a section on paediatric anaesthesia and surgery (**Section 13.6**)
- **Chapter 14:** Spiritual health is important, no matter one's age
- **Chapter 15:** Sport is likely to become a big part of young people's lives
- **Chapter 16:** Research, including clinical trials, provides hope, and so people with SCI and their families will probably be interested in research, and
- **Chapter 17:** Impact of a changing climate, as children are vulnerable to heat, as are those living with CSI, particularly if the person cannot regulate their body temperature, or has mobility issues during adverse weather events. Having an emergency plan is crucial.

References

Agency for Clinical Innovation (ACI). (2020). *Paediatric spinal cord injury: Model of care.* NSW Government. https://aci.health.nsw.gov.au/resources

Australian and New Zealand Spinal Cord Society. (2020). *Spinal cord injury clinical guidelines.* https://anzscos.org

Cunha, N. S. C., Malvea, A., Sadat, S., Ibrahim, G. M., & Fehlings, M. G. (2023). Pediatric spinal cord injury: A review. *Children*, *10*(9), 1456. https://doi.org/10.3390/children10091456

Gormley, M., Chambers, H. G., Kim, H., Leon, J., Dimitrova, R., & Brin, M. F. (2023). Treatment of pediatric spasticity, including children with cerebral palsy, with Botox (onabotulinumtoxinA): Development, insights, and impact. *Medicine, 102*(S1e), 32363. https://journals.lww.com/md-journal/fulltext/2023/07011/treatment_of_pediatric_spasticity,_including.12.aspx

Kliegman, R. M., Stanton, B. F., St. Geme, J. W., Schor, N., & Behrman, R. E. (2020). *Nelson Textbook of Pediatrics* (22nd ed.). Philadelphia, USA: Elsevier.

Lystad, R. P., Curtis, K., Soundappan, S. S. V., & Mitchell, R. (2020). Trends of traumatic spinal injury-related hospitalizations in Australian children over a 10-year period: A nationwide population-based cohort study. *The Spine Journal, 20*(6), 896-904. https://doi.org/10.1016/j.spinee.2020.01.002

Unger, C., O'Reilly, L., Serratore, L., & Tulinsky, C. (2013). *Talking to your children about spinal cord injury: A practical guide for families*. Agency for Clinical Innovation. https://aci.health.nsw.gov.au/__data/assets/pdf_file/0008/194399/ACI-Talking-children-spinal-cord-injury.pdf

Pang, D., & Wilberger, J. E. (1982). Spinal cord injury without radiographic abnormalities in children. *Journal of Neurosurgery, 57*(1), 114-129. https://doi.org/10.3171/jns.1982.57.1.0114

Palombi, D., Galeazzi, M., Brigato, P., De Salvatore, S., De Saint Denis, T., Massimi, L., Tamburrini, G., & Oggiano, L. (2025). Redefining pediatric SCIWORA: A systematic review of the literature on clinical patterns, imaging Profiles, and management insights. *Journal of Clinical Medicine, 14*(17), 6338. https://doi.org/10.3390/jcm14176338

Spinal Cord Injuries Australia (SCIA). (2021). *Spinal cord injury statistics.* https://scia.org.au/resource-hub/spinal-cord-injury-statistics/

Spinal Cord Injuries Australia. (2025). *SCI Rookie Book: Spinal cord injury basics for rookie supporters* (V1.0, March 2025). https://scia.org.au/wp-content/uploads/2025/06/SCI-Rookie-Book-SCIA.pdf

Sydney Children's Hospitals Network. (2025). *Living with a spinal cord injury – Factsheet.* https://www.schn.health.nsw.gov.au/living-spinal-cord-injury-factsheet

Vogel, L. C., Krajci, K. A., Anderson, C. J., & Chlan, K. M. (2014). Spinal cord injury in children and adolescents: A review of the literature and clinical guidelines. *Journal of Spinal Cord Medicine, 37*(3), 277-285. https://doi.org/10.1080/10790268.2003.11753682

World Health Organization. (2024). Spinal cord injury: Key facts. https://www.who.int/news-room/fact-sheets/detail/spinal-cord-injury

Zebracki, K., Melicosta, M., Unser, C., & Vogel, L. C. (2020). A primary care provider's guide to pediatric spinal cord injuries. *Topics in Spinal Cord Injury Rehabilitation, 26*(2), 91-99. https://doi.org/10.46292/sci2602-91

Zeng, Z., Fang, K., & Cai, G. (2025). The global burden of pediatric spinal injury: An epidemiological analysis across injury subtypes in children under 14 years. *Pediatric Surgery International, 42*, Article 44. https://doi.org/10.1007/s00383-025-06262-w

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Chapter 8: Spinal Cord Injury in Rural, Regional and Remote Australia

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> *"We argue that feelings of belonging produced by powered wheelchair journeys in rural contexts are often predicated on notions of disability shame that reinforce normative identities and ideologies aligned with conventional discourses of independence that privilege solitary encounters."*
>
> Gordon & Harada (2023), researchers exploring the embodied experiences of powered wheelchair users in rural Australia.

Australia is a vast country, often with thousands of kilometres between towns in rural and remote regions. According to the Australian Institute of Health and Wellbeing (AIHW) Rural and Remote webpage (updated 20 November 2025), about 27% (about 7 million people) of Australia's population live in rural and remote areas, comprising diverse locations and communities. As of 30 June 2023, the proportion of Australians by area of remoteness was:

- 73% in Major cities
- 18% in Inner regional areas
- 8.0% in Outer regional areas
- 1.1% in Remote areas, and
- 0.7% in Very remote areas.

On average, people living in Inner regional and Outer regional areas are older than those in Major cities. For Inner regional areas, 22% of the population were aged 65 and over in 2023 compared with 16% in Major cities, 15% in Remote and 11% in Very remote areas.

These Australian Government census data align with the Modified Monash Model (MMM), which was developed to better target health workforce programs to encourage health professionals to regional, rural and remote (RRR) communities. **Table 8.1** reflects the MMM classification for Australia, with descriptions of each MMM category in terms of population and examples of towns.

Table 8.1. The Modified Monash Model (MMM) categories of Australia's geographic regions (redrawn from Australian Government, 2025).

MMM Category	Description
MM1	Metropolitan areas: Major cities account for 70% of Australia's population.
MM2	Regional centres: Inner and Outer Regional areas within 20 km of a town with > 50,000 residents. Examples: Ballarat, Mackay, Toowoomba, Kiama, Albury, Bunbury.
MM3	Large rural towns: Inner and Outer Regional areas that are not MM2 and are in or within a 15 km drive of a town between 15,000-50,000 residents. Examples: Dubbo, Lismore, Yeppoon, Busselton.
MM4	Medium rural towns: Inner and Outer Regional areas that are not MM2 or MM3 and are within a 10 km drive of a town, with 5,000-15,000 residents. Examples: Port Augusta, Charters Towers, Moree.
MM5	Small rural towns: All remaining Inner and Outer Regional areas. Examples: Mount Buller, Moruya, Renmark, Condamine.
MM6	Remote communities: Remote mainland areas AND remote islands < 5 km offshore. Examples: Cape Tribulation, Lightning Ridge, Alice Springs, Mallacoota, Port Hedland. Additionally, islands with an MM5 classification and a population < 1,000, without bridges to the mainland, are now classified as MM6. Example: Bruny Island.
MM7	Very remote communities: Very remote areas. Examples: Longreach, Coober Pedy, Thursday and all other remote island areas > 5 km offshore.

According to the 2021 census, First Nations people comprised 3.8% of the Australian population. While First Nations people are more likely to live in urban and regional areas (85% in 2021) compared with more remote areas, the proportion of the total population who are First Nations increases with increasing remoteness from 2.2% in Major cities to 30% in remote and very remote areas (2021 Census estimates). Around 15% of First Nations people live in remote and very remote areas of Australia compared with 1.4% of non-Indigenous Australians (AIHW, 2025).

Important information: First Nations people or Aboriginal people?

In this resource, the term 'First Nations' refers to Aboriginal and Torres Strait Islander peoples, acknowledging them as the First Peoples of Australia.

The term, 'non-Indigenous', refers to people who do not identify as Aboriginal or Torres Strait Islander, while 'Westerner' refers to groups of people whose ancestry or worldviews are generally derived from European traditions.

Of note, while this resource is predominantly focused on Australia, the contributors also acknowledge Māori as tangata whenua (people of the land) and recognise *Te Tiriti o Waitangi* (Treaty of Waitangi) as the

foundational partnership agreement of Aotearoa New Zealand, and Māori health and cultural frameworks. Aotearoa New Zealand's rural, remote and regional contexts are, however, not within the scope of this resource, as these topics are too important to be addressed only briefly and cannot be sufficiently covered here.

In terms of disability, in 2022, an estimated 5.5 million Australians were living with disability (21% of the population), with 27% of these living in inner regional and 26% living in outer regional and remote areas, compared with 19% living in major cities. People living in rural and remote areas have higher rates of hospitalisations, deaths and injury, as well as poorer access to, and use of, primary health care services, than people living in major cities (Australian Bureau of Statistics, 2024).

Important resource: National Rural Health Alliance Snapshot 2025

People living in more remote areas may experience greater difficulties accessing health services due to variations in health service supply and geographical distribution. There is evidence that these disparities are greater among people living with disabilities, as the National Rural Health Alliance Snapshot 2025 highlights. The resource provides a graphical summary of RRR Australia in terms of population distribution and health demographics.

Key Topics in this Chapter

- Incidence of SCI across different parts of Australia

- Barriers to equity in healthcare access in RRR Australia
- Research relating to SCI in RRR Australia

- General SCI services and support, including two state-based services and supports
- Disability among First Nations people, including spinal injuries (fractures, soft tissue injury, open wounds, nerve injury) and SCIs
- Wellness as a holistic approach to practising healthcare, and
- Impacts of a changing climate on RRR Australia, particularly for First Nations communities.

8.1. Incidence of SCIs across different parts of Australia

Before presenting SCI incidence data across Australia, it is worthwhile listening to the podcast below by a young man from rural Australia who sustained SCI after a motorbike accident.

Sam Tait's story: From SCI to a Paralympic skier

Ripper sit-skier Sam aiming for a Winter Paralympic medal (Episode 6, 2021) on the Build 'Em Up podcast, posted on the National Rural Health Alliance website, shares the inspirational story of Australian professional athlete **Sam Tait**, who explained that at the time of the podcast, his life was more fulfilling than he had ever imagined as a young man. This includes competing at the Paralympic Winter Games in Beijing. In his conversation with the Build 'Em Up podcast team, the now-celebrated sit-skier reflects on his journey and describes feeling happier than ever since the fateful day in 2013 when a motorbike accident left him a complete paraplegic due to a T10 SCI.

Access to recent data on the distribution of SCI, specifically in Australia, is not easy. The last AIHW report (2017-2018) on SCIs, as opposed to spinal injuries 2020-2021, which includes fractures, soft tissue injuries, nerve damage and open wounds, was released in 2021, based on data collected for 2017-2018 from the Australian SCI Register.

More recent SCI data related to how many people live with SCI can be accessed through the NDIS Spinal Cord Injury annual and quarterly dashboard. Using September 2025 data from the NDIS, it states that:

- 65% of all SCI participants lived in major cities, with the remaining 35% distributed as follows: 12% (regional; population >50,000 = regional), 8% (in large rural towns; population 15,000-50-000), 4% (in medium rural towns; population 5,000-15000), 9% (in small rural towns; < 5,000), 2% (remote) and 1% (very remote)

- There was a 5% annual growth of SCI NDIS participants from September 2024 to September 2025
- There were 6,404 active participants with SCI in the NDIS system (69.7% male, 29,4% female, 0.89% 'other'), which equates to 0.85% of all NDIS participants
- First Nations participants with SCI comprise 6% of all participants with SCI and 8% of all NDIS participants.
- 12% of SCI participants were culturally and linguistically diverse (CALD)
- NSW, Queensland, and Victoria (the three states with the most NDIS 'cases') accounted for 75.8% of active participants
- The 55-64 age group accounted for 30.4% of SCIs, followed by the 45-54 age group (21.6%), for a total of 62% in the 45-64 age group, and
- 49.8% were classified as having a medium level of function, followed by 32.2% with a low level of function, with 3.8% not classified.

8.2. Barriers to equity in healthcare access in RRR Australia

In 2011, Vines, a psychologist, made the case for her profession to equip more practitioners with skills to promote community resilience and general health and well-being in regional, rural and remote (RRR) Australia, to address healthcare inequity between urban and other regions.

In terms of 'rural' (taken as RRR) health, the National Rural Health Alliance's June 2023 Report, Evidence base for additional investment in rural health in Australia, provides evidence of poorer health outcomes and social determinants of health and disease risk, inequitable access to care as well as greater environmental vulnerability, such as to drought, bushfires, flooding and insect vector-borne diseases, as described in **Chapter 17**. The Report demonstrates a clear equity disparity in outcomes and *per capita* public healthcare funding between RRR and urban Australia.

People living in remote and very remote areas, in particular, face barriers to accessing and using healthcare for a range of reasons, including geographic spread, low population density, limited infrastructure and the higher costs of delivering healthcare in rural and remote areas, which can limit service availability. The time and transportation costs to access healthcare services also mean that people in remote and very remote areas may delay preventive and primary care and rely on hospital care to meet their needs (National Rural Health Alliance, 2023).

Access to SCI rehabilitation and follow-up services is severely limited in RRR Australia, with the availability of GPs, other health professionals and support workers who understand both the clinical and cultural aspects of SCI being patchy at best (Lakhani *et al*., 2020). Although not relating to SCI only, but included in the spinal injuries (mainly fractures, but also soft tissue injury, open wounds and nerve impairment), the AIHW 2020-2021 Report shows that the number of

people hospitalised (per 1000,000) increased by remoteness: 1.5 x and 1.6 x more likely in remote and very remote areas, respectively.

Research: Cultural inequities in NDIS access for First Nations people

Understanding how the NDIS operates for First Nations people is essential, as emerging research shows a significant cultural disconnect between the scheme's structure and the Indigenous ways of living. These studies highlight how systemic barriers can shape access, participation and equity for First Nations people with disability.

Johnson (2021), in his 2021 PhD research on the NDIS roll-out, found that disability service models often failed to accommodate the kinship obligations and cultural protocols that shape how First Nations peoples live. With the NDIS based on Western notions of individualised funding and decision-making, this does not align with First Nations people's ways of being.

Smith-Merry and colleagues' (2023) exploration of 10 years of the NDIS found cultural barriers to equity in the operation of the NDIS, with lower levels of plan utilisation for First Nations people living with disability for several reasons:

- The number of First Nations people living outside of major cities (56.8% vs. 31.6% non-Indigenous) and in remote areas (9.8% vs. 0.8%)
- The process of providing evidence of disability often causes significant stress and trauma, which is situated in a deficit model, requiring people to prove the experience of disability as a burden. This model of disability is the antithesis of Indigenous cultural ways of experiencing disability, in which disability is interpreted as part of the diverse human experience as opposed to a limitation or impediment, and
- The NDIS is also designed on Western-centric assumptions that all people with disability exist at the same starting point in that they have a house, shelter, food and family support. Many First Nations people living with disabilities experience homelessness, poverty, or live in overcrowded houses. Community-controlled service providers offering whole-of-life case management can facilitate equitable access to and understanding of the scheme to support Indigenous people with disabilities.

Together, these findings indicate that achieving genuine equity within the NDIS requires culturally informed approaches, community-controlled service delivery and structural change that aligns with First Nations values. Strengthening these areas is key to ensuring that First Nations people with disability receive the support they deserve.

8.3. Research relating to SCI in RRR Australia

Below is a chronological summary of some research findings on SCI in RRR Australia. It would not be an understatement to say that compared with urban areas, much less research has been undertaken in rural and remote areas.

Research: Geographic inequities in SCI health service access in rural and remote Queensland

In 2018-2019, Lakhani and colleagues (Hopkins Centre: Research for Rehabilitation and Resilience) produced a poster from their Griffith University-funded research, *Clarifying the geographic dispersion of essential health services for people with spinal cord injury in rural and remote Queensland: A spatial study,* in which they concluded the following:

- To the best of their knowledge, their first study was the first to use ***spatial methods*** to investigate the geographic dispersion of health services in relation to people living with SCI in Australia
- Their study confirmed previous Australian research showing that rural regions have poor proximate availability of health services, particularly GPs. Given that people living with SCI typically identify their GP by trialling several until they find one that best suits their needs, those living with SCI in RRR Australia are thus less likely to find a GP that suits their needs
- The lack of health service options for people living with SCI in RRR Queensland may mean that people within these regions live with health conditions that go untreated and potentially result in avoidable hospital visits, and
- Their study suggests that travel time to receive emergency care is less sensitive to rurality. This is likely because people in the study sample preferred to live near hospitals and health services, irrespective of rurality.

Research: Preventing pressure injuries in rural Australians living long-term with SCI

Around 2014-2015, Catherine Brabrook, an occupational therapist who was the Rural Spinal Cord Injury Coordinator for the Rural Spinal Cord Injury Service (New England), undertook research into the lived experiences of how individuals living with SCI in a rural area prevent pressure injuries. Below is a slightly edited abstract from the final report:

> *"Participants were recruited from the Rural Spinal Cord Injury (New England) database. Inclusion criteria were having SCI for > 10 years, having no motor ability below the level of injury, living at home and not having had a severe (Grade 3 or 4) pressure injury. Five semi-structured interviews were conducted in participants' own homes. Three participants lived on rural properties (two outer regional, one remote) and two lived in inner regional towns. They were 'White' males aged 35-60. The average time since injury was 23 years."*

How did they maintain their skin integrity?

- They maintained autonomy over their skin care management
- They were flexible and problem-solved in terms of their skin care management
- They were proactive in responding to minor body signals, and
- They practised pressure relief as part of their daily living activities.

The men were motivated to maintain their skin integrity due to fear of further incapacity and their strong sense of responsibility to others. They accessed equipment in an *ad hoc* manner in the absence of local specialist SCI seating services, without adverse effects on their ability to prevent pressure injuries.

Research: Rural transition challenges after SCI

Kendall and colleagues (2021) described the lived experiences of four males returning rurally after SCI and transitional care, which is usually 8-12 weeks of multidisciplinary care, either at home for urban-dwellers or in homelike accommodation if people live rurally. The men highlighted the difficulties associated with adjusting to the different environments during each transition. This is unique for individuals from rural areas because the transition environment is not their own home and their own rural home environment lacks the specialist support provided by transitional rehabilitation.

The study also explored their social integration once leaving formal rehabilitation. In terms of settling in at home, the following was noted:

- The challenges were learning the 'new normal' after having been away for so long, which included sometimes inadequate or incomplete modifications to accommodate their changed needs and altered routines
- If support workers were available, adjusting to new ones who may be less experienced than those in transitional care and who also change frequently
- Difficulty identifying and accessing various forms of support, including specialist services and other health professionals, and
- Returning to the family whose lives had continued while they were in the hospital and rehabilitation.

In terms of returning to community life:

- SCI was not fully understood, even though reconnecting with friends provided previously absent support
- Peer support from transitional rehabilitation was difficult to maintain
- Travel was complicated as it required time to prepare and reliance on others, as there was little or no public transport, and
- Getting out and about in the community was complicated by distance, community layout and inaccessibility in terms of infrastructure.

The authors concluded that*transitional rehabilitation, while providing a forum within which to develop skills necessary to transition to their rural home, does not eliminate the challenges experienced by individuals living with SCI who return to live in rural communities. The researchers suggested that telehealth models may be practical and economically sound to extend transitional rehabilitation services to rural communities.*

Research on SCI in rural and remote Australia highlights consistent challenges, including limited access to appropriate health services, the need for strong self-management skills, and significant barriers when transitioning back to rural life after rehabilitation. These findings reinforce the importance of improving service accessibility, strengthening support pathways, and exploring models such as telehealth to meet the needs of people with SCI living outside metropolitan areas.

The next section explores how people living with SCI in rural and regional Australia navigate self-advocacy, mobility, community belonging and systemic barriers that impact their daily lives.

Podcast: Self-advocacy

SCIA's Have the Nerve podcast, Have the courage to be your own advocate (Episode 28)

Listen to **Geraldine**, a wife and mum with paraplegia, talking about the journey of her mental health and how she became an advocate for people with disabilities in rural areas.

Research: Powered wheelchair mobility and belonging in rural communities

Gordon & Harada, in their 2023 research article, Mundane powered wheelchair journeys and embodied rural disability geographies of (not) belonging, purposefully selected 15 individuals who were powered wheelchair users from eight NSW rural or remote shires to explore their LLEs with various physical disabilities resulting from NTSCI, TSCI, cerebral palsy, spina bifida and multiple sclerosis, among other causes. Their research addressed a gap in the literature – the relationship between the mobility experience of everyday rural journeys for disabled people and their social inclusion and hence belonging. The researchers assert that mobility is essential for social inclusion and for daily activities. Therefore, mobility disability can negatively impact a person's well-being and independence. Since their research was framed though the spatial concept of 'situated and embodied belonging', which reflects *"the desire for some sort of attachment, be it to other people, places or modes of being, and ways in which individuals and groups are caught withing wanting to belong, want to become, a process fuelled by yearning rather than positing of identity as a stable state"* (Probyn, 1996:19, in Gordon & Harada, 2023).

The narratives of these 15 individuals in terms of the positive impact of a powered wheelchair compared with a manual wheelchair in terms of their sense of belonging are powerful, with Gordon and Harada stating, "*To belong in country towns through accommodating the powered wheelchair in these narratives words*

towards, rather than against, the normalisation of the abled-body" (p. 6). In this context, the 'abled-body' relates to an individual becoming 'able' and hence independent through technology (powered wheelchair) that can, for example, lift someone to allow them to engage in eye-level conversations (so not 'looked down on') or reach items on high shelves in supermarkets and be able to board a rural bus because of a disability ramp.

The research also identified the challenges of using a wheelchair in rural NSW, despite the 2014 legislation (New South Wales Disability Inclusion Act), which requires all government departments to develop Disability Inclusion Action Plans, including rural authorities and Transport New South Wales. These challenges, which led to a sense of not belonging in their rural and powered wheelchair journeys, included:

- The lack of disability parking and accessible footpaths to allow easy access to shopping precincts
- Poor service regarding Wheelchair Accessible Taxis (WATs) left them feeling vulnerable and unsafe, and
- Inaccessible access to buildings, such as restaurants and hairdressers, is largely due to the legislation not including retrofitting older buildings.

In situations where participants felt like 'misfits', several became disability political activists. Through writing to local councils or the Human Rights Commission or serving on access committees, these individuals developed a sense of embodied belonging.

Gordon & Harada (2023) concluded with this:

> *"Our paper highlights that rural disability geography that engages with embodiment and experience can understand the ambiguities of disabled people's belonging configured by dominant representations of the rural as a place suitable for only fit, abled-bodied, and solitary individuals. Our hope is that we have promoted others to think through the inclusionary and exclusionary affects of everyday journeys. We hope further work explores the diversity and ambiguous rural-experiences of disabled people in the pursuit of a more inclusive and enabling rurality."* (p. 9).

Research: Rural perspectives on the NDIS Independent Review

Quilliam *et al.* (2023) provided an overview of the outcomes of the 2023 Government's Independent Review into the NDIS through a rural lens. The authors concluded the following:

> *"Review into the National Disability Insurance Scheme considered regional, rural and remote contexts. The Review offered ideas for improving services for regional, rural and remote people with disability; however, it failed to adequately consider these contexts. The Independent Review into the National Disability Insurance Scheme missed a key opportunity to rural proof Australian disability support policy. Future disability policymaking requires active engagement of regional, rural and remote people with disability and use of relevant service provision concepts to ensure regional, rural and remote people with disability equitably benefit from the National Disability Insurance Scheme."* (p. 1077).

These studies highlight how rural environments shape the everyday experiences of people with disability, particularly those using powered wheelchairs, and reveal the barriers that limit mobility, belonging and social inclusion despite legislation intended to support access. Gordon & Harada's work shows how powered mobility can enhance independence and connection in rural towns while also exposing gaps in infrastructure and transport that undermine inclusion, while Quilliam and colleagues emphasise that national disability reforms still overlook the realities of regional, rural and remote communities. ***Together,*** these findings point to the need for policy and planning that genuinely reflects rural contexts and strengthens opportunities for participation and equity.

8.4. General and state-specific supports for people with SCI

Below, we provide general resources, followed by examples from Queensland and NWS, two states with the highest incidence of SCI.

8.4.1. General services

- **NDIS:** As of 1 July 2025, the NDIS changed how it pays for disability supports. Johnson's (2025) *Conversation* article identified what this means for rural communities. The article concludes with the following:

  "The NDIA's strategy includes a shift toward "differentiated pricing", which could eventually support more tailored approaches. The Department of Social Services has also promised to offer "foundational supports" outside the NDIS, but it is currently unclear what the nature of these supports will be. Right now, though, rural communities are being asked to absorb the reduced funding and limited flexibility. Without further adjustment, these changes risk widening the gap between metropolitan and non-metropolitan service access. A single national price does not guarantee equal access. Equity comes from recognising and responding to different contexts. For rural and remote Australians living with disability, that recognition is long overdue. Until then, it will be up to 7 million rural Australians to make it work for themselves in places where resources are already stretched thin."

- State Spinal Cord Injury Service resources, Agency for Clinical Innovation*:* Although pertaining to NSW, the website provides a range of resources for individuals living with SCI to support the management of their health and well-being.

Important resource: Farmers requiring assistive technology devices

AgrAbility Australia: Farmers with disability assistive technology project: This health and well-being project has created resources to help farmers living with disabilities return to work.

Examples include:

- Wheelchair transfer to the vehicle, and
- Additional seat for easy quad transfer.

8.4.2. Queensland services

Below are a few useful services within Queensland:

- December 2024 Spinal Cord Injury Service Delivery Model for Queensland: While the entire document is valuable, Figure 6 on page 18 is particularly relevant, as it shows the services provided across the care continuum. Part B identifies where individuals accessing SCI injury services reside. More than one-third of people who need care for a new SCI live outside South-East Queensland
- Queensland's Metro South Health: Celestine Fisher, an Aboriginal and Torres Strait Islander Capability Officer in Metro South Health, has been undertaking important interventions in the Spinal Injuries Unit to improve cultural capability and cultural safety
- Queensland's Rural and Remote Health & Wellbeing Strategy 2022-2027: This strategy commits to achieving health equity of rural and remote Queenslanders through four overarching goals (that is, equity of health outcomes, integrated person-centred care, strong partnerships, and a sustainable, skilled and supported workforce) and two part-

nership goals (First Nations Health Equity and being Digitally Enabled), and
- CheckUp Australia, a not-for-profit organisation that delivers health services for rural and remote Queensland, offers an Access for All: Disability awareness for health providers online course.

8.4.3. NSW services

Some services aim to deliver comprehensive, community-based care aligned with the principles of the NSW State Spinal Cord Injury Service, ensuring equitable access to high-quality rehabilitation and support. Details of remote services and resources available in NSW:

- NSW Spinal Outreach Service (SOS) delivers specialist multidisciplinary support, education, health promotion, counselling and advocacy across metropolitan and rural NSW
- The Rural Spinal Cord Injury Service (RSCIS, Northern NSW Local Health District (LHD)) assists people with SCI in rural and regional areas to access services, support and evidence-based information to optimise their health outcomes and opportunities. The Mid North Coast Rural Spinal Cord Injury Coordinator (RSCIC) is based in Coffs Harbour and travels to all areas within the Mid North Coast Local LHD, and
- NSW Government ACI's SCI referral directory offers plenty of resources, including regional services, such as the Hunter Spinal Cord Injury Service and the Illawarra Shoalhaven LHD's rehabilitation, Aged and extended care program.

Clinical resources: Neurotrauma and spinal injury care in rural and remote settings

- In 2009, the Neurological Association of Australasia Inc. published a set of guidelines for the care of head and spinal injuries in rural and remote locations: The Management of Acute Neurotrauma in Rural and Remote Locations (third edition), and
- The Queensland Trauma Education site includes a neck and spinal trauma section with training resource kits and links to other resources, such as clinical practice guidelines from the Queensland Ambulance Service, including one on autonomic dysreflexia, which was due for review in 2025.

8.5. Disability amongst First Nations people

Before exploring what it means to live with SCI as a First Nations person, we provide information below on the incidence of disability amongst First Nations people more generally. Also provided are statistics related to primary carers, who are mainly women, many of whom have a

disability. In February 2025, the ABS released its 2022 Aboriginal and Torres Strait Islander Peoples with Disability report, based on the 2022 Survey of Disability, Ageing and Carers (SDAC), which drew on respondents who identified as Aboriginal and/or Torres Strait Islander and had disability, as defined by the survey. The website provides the following key statistics:

- One-quarter (25.3%) of First Nations people lived with disability, with 11.6% having a profound disability.
- Disability incidence was similar for males and females, and
- 70.7% of First Nations people with a disability aged 5 years and over had a schooling or employment restriction.

On the website, the following statement reminds us of the importance of culture and identity when considering the collection of data:

> *"Identifying one of these attributes (being First Nations or having a disability), let alone both, is influenced by a mix of cultural and social factors. One or more factors can influence an individual's decision to disclose their Aboriginal and/or Torres Strait Islander status and the degree to which they fully disclose their disability and its impact on their lives. These factors include:*

- *A cultural understanding of 'disability' within the Aboriginal and Torres Strait Islander community as an accepted part of community life, so it is not viewed as a deficit in a way that disability can be viewed in other societies*
- *Barriers to obtaining disability diagnoses can mean that many Aboriginal and Torres Strait Islander people may not have access to the vocabulary through which to identify their disability and seek out support. This issue may be elevated for Aboriginal and Torres Strait Islander people with disability in outer regional and remote communities, and*
- *An apprehension to disclose Aboriginal and/or Torres Strait Islander status in addition to disability out of a fear that disclosure will attract discrimination such as racism and/or ableism."*

Other noteworthy information from the Report that further highlights the extent to which disability, particularly physical disability, impacts the daily activities of First Nations people includes:

- 13.5% had a physical disability such as breathing difficulties, chronic pain, limited use of limbs, or disfigurement that restricts everyday activities, and
- Those aged 55 years and over were more likely to have a physical disability (40.2%) than other age groups. For those aged 5-20 years who reported disability, one-quarter (24.6%) had a physical restriction.

In terms of needing assistance, almost two-thirds (64.8%) of individuals with a disability needed assistance with at least one activity of daily life:

- 40.7% for cognitive and emotional tasks
- 29.4% for mobility
- 24.1% for healthcare
- 23% for self-care, and
- 22.5% for household chores.

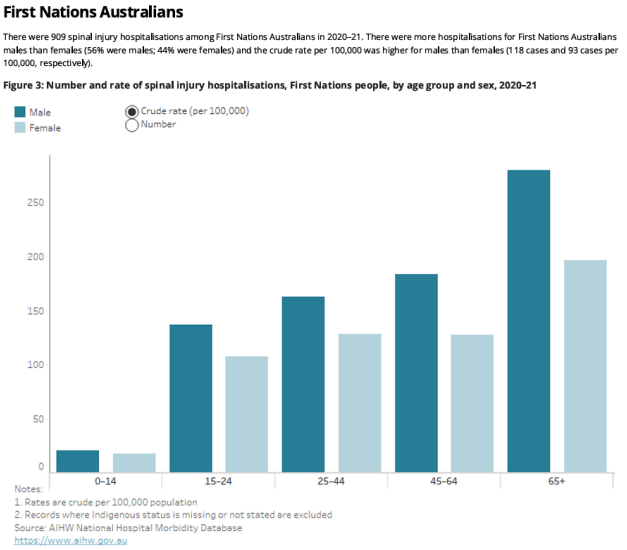
As has been well described in this e-resource, disability often requires the support of carers and/or support workers. The 2022 Report identified the following, highlighting the extent of caring undertaken by women, particularly in First Nations communities:

- More than half (51.7%) of Aboriginal and Torres Strait Islander people with disability had informal providers of assistance, such as family members, while 33.7% received assistance from paid formal providers
- One in seven (14.1%) Aboriginal and Torres Strait Islander people were carers. Of Aboriginal and Torres Strait Islander people with disability, one in five (20.2%) was a carer, almost double that of Aboriginal and Torres Strait Islander people without disability (11.9%), and
- 70.1% of primary carers were females, with an average age of 43 years, and 43.6% had a disability themselves.

8.5.1. Spinal injuries (fractures, soft tissue, open wounds, nerve injury)

Exploring the AIHW's 2020-2021 data for spine-related injuries, which includes nerve injury and hence SCI, allows us another way of understanding the incidence and impact of disability on First Nations communities. The age-standardised rates of spine-related injury hospitalisations for First Nations males (56%) and females (44%) and non-Indigenous Australians showed that the rate for First Nations people was ± 1.5 times that of non-Indigenous people (**Figure 8.1)**.

Figure 8.1 Increasing number and rate of spinal injury hospitalisations for First Nations people, by age and sex (AIHW, 2024). CC BY 4.0.



In the general population, *falls* accounted for the largest number of hospitalisations, which occur mainly while sleeping, resting, eating or engaging in other daily activities, followed by *transport-related causes*, in particular car occupants, motorcyclists, cyclists and pedestrians.

8.5.2. Spinal cord injuries amongst First Nations people

As identified earlier from the NDIS Spinal Cord Injury (September 2025) dashboard, 65% of people living with SCI are located in major cities, with the remaining 35% residing regionally (12%) or in rural towns (± 21%) and 3% living remotely or very remotely. Also, based on the 2021 census data presented, it is likely that First Nations people with SCI would comprise the majority of this remote 3%. The NDIS Spinal Cord Injury (September 2025) dashboard revealed that First Nations NDIS participants comprised 6% of all patients with SCI. Considering that First Nations people comprise about 3.8% of the Australian population, then First Nations people receiving NDIS SCI support is 1.6 times that of others being supported for SCI.

To gain a greater understanding of the experiences of having SCI as a First Nations person in RRR Australia, **Dr Halima Goss** (a GP) describes her encounter with a First Nations man living with SCI in rural Australia.

Dr Halima Goss' story: Working as a GP in rural Queensland

Dr Halima Goss recalls her experience in rural Australia treating a First Nations man with pressure injuries.

A patient story: Mr A., a 35-year-old Indigenous man with SCI in rural Australia

Note: To maintain patient confidentiality and anonymity, the location has not been identified.

"My first encounter of the soon-to-be-three-times-a-week appointment schedule over approximately six months with Mr A, a 35-year-old Indigenous man with a non-traumatic SCI after a childhood ill-

ness, leaving him with an intellectual impairment, was as a fill-in doctor in a small rural general practice in Queensland, Australia. I was asked to "look in on him" as he attended for routine dressing changes with a registered nurse (RN) for pressure injuries on both sides of his buttocks. What I saw stunned me since I had had very little experience with the challenges faced by people living with SCI in this region.

His pressure injuries were significant. The area of skin breakdown was approximately 10-15 cm in diameter. Wound infection was noted with multiple purulent patches and ***exudate*** *across both buttock regions and deep ulcerations to the* ***fascia*** *with visibility to the level of bone in several patches. His urinary and bowel incontinence presented a challenge in wound care infection control. Other soft tissue injuries were noted on both lower limbs. Their appearance had 'bite' qualities with frayed edges along tears to the skin on his calf regions and the top of his feet. Sometime later, it was ascertained that there had been a rat infestation in his home. His lesions were bites that happened at night while he was sleeping. With his SCI, he could of course not feel the rats biting.*

Each time we discussed a hospital stay, the man refused, as the hospital was considered a 'place where people go to die'. Over many months and with ongoing visits three times a week, numerous discussions about unweighting (i.e. getting weight off pressure points) as a way of helping healing, the local small hospital was able to provide a flexible admission. Mr A was admitted and allowed to come and go over the duration of a week. This enabled him to have some unweighting time, receive IV antibiotics, avoid further bites and feel less distressed about why he was in the hospital. His sense of freedom was an important consideration, and his happiness depended on his interactions with others in the community, many of whom were also fearful of the hospital environment.

We were fortunate to have a very wise and well-respected Indigenous health worker who would visit Mr A regularly and have discussions with his family at home about the situation. The roles of Indigenous health workers in very remote communities are critical linkages to the healthcare system to help develop trust relationships and provide support for patients who may experience challenges in accessing and following up with health services. This enabled some changes to be made to his home environment, including pest control and improved hygiene. We submitted an application for a more appropriate wheelchair and cushions through the OT team at the nearest tertiary hospital. For Mr A, his interaction with the healthcare system, which considered all aspects of his 'wellness' led to a good outcome. His wheelchair received some major upgrades, including better cushioning. I am happy to report that he was well a year later when I left the area."

Next, **Jake Briggs**, a First Nations man, discusses his journey from carpenter to sustaining a SCI and now managing director of a company that facilitates NDIS support.

Jake's story: From carpenter to Managing Director

In this SCIA's Have the Nerve, Episode 31 podcast with **Jake Briggs**, a Wonnarua and Kamilaroi man, who was a carpenter before his C5/C6 SCI talks about his work as the Managing Director for Culture Connex, a company that facilitates NDIS support.

Probably some of the remotest places in Australia are the Torres Strait Islands, as **Dr Dinesh Palipana** reflects below on a man from the Torres Strait Islands who was in hospital at the same time he was. The man was far from his Country and far from his family, who may not have had the resources to visit often.

Dinesh's story: Can't imagine what it is like to be off Country, away from family

> *"When I was in the hospital [after my car accident in 2010], there was a guy.... He messaged me just today [November 2025]. He was from the Torres Straits. Back then, you could only get treatment for spinal cord injuries at the PA [Princess Alexander, Brisbane]. He was away from family.* How do you transition back to a place like the Torres Straits with a spinal cord injury?"

The next section of wellness is thus relevant. **Dr Halima Goss** explains her Wheel of Wellness as a tool for clinical practice to facilitate health and well-being for patients and the 'self'.

8.6. Wellness, a holistic approach to practising healthcare

Drawing on her extensive experience working in rural and remote Australia, **Dr Halima Goss** shares her own reflections along with those of her primary care colleagues, who often deliver care under challenging circumstances. She recognises the resilience, patience and creativity required of health professionals who may work in professional isolation, particularly in remote settings. **Dr Goss** uses the term 'primary care' to include all health professionals involved in caring for people with SCI and notes that her experiences have taught her that serving patients well requires a team approach and a broad view of wellness that considers both the people they care for and their own well-being.

Key recommendation: Dr Halima Goss' view on wellness and person-centred care

"According to Queensland Health's Statewide Guideline for Access to Primary Rehabilitation for New Spinal Cord Injuries (QH-GDL-987), *around 300 people are newly diagnosed with SCI every year. By sharing one patient story and the subsequent considerations for care, I hope to offer a model for health professionals to chart their journey towards identifying their learning needs in similar situations.*

The primary care of patients in any location requires healthcare that encompasses multiple dimensions. Having a philosophy that has emerged from the Wellness frame of reference has helped me consider patient care as 'person' care, focused on wellness rather than just health. A dynamic, holistic construct such as 'wellness' in which balance is the goal for a person (we as health professionals included) across multiple dimensions, seems to fit with the ideal of optimum health and well-being. Here (Figure 8.3), I share the Wheel of Wellness, which I constructed from my work with the National Wellness Institute of Australia (NWIA), incorporating considerations of a person-centred approach to care from the original 2010 Nautilus model of wellness dimensions available on the NWIA website.

Figure 8.2. Dr Goss' Wheel of Wellness (image provided by Dr Goss).

Taking a spin on the wheel means considering all dimensions of wellness with an individual patient, exploring perceived needs and priorities, and assessing the level of motivation for change to prioritise actions that optimise functioning for the person and their family. Some of the key considerations in applying this Wheel of Wellness to our patients and to ourselves, who must also be well for our patients:

- **A choice:** *A decision you make to move toward optimal health and well-being.*
- **A way of life:** *A lifestyle you design to achieve your highest potential for well-being*
- ***A process:*** *Developing the awareness that there is no endpoint, but that health and happiness are possible in each moment, here and now.*
- **A balanced channelling of energy:** *Energy received from the environment, transformed within you and returned to positively influence the world around you.*
- **Integration of the body, mind and spirit:** *The appreciation that everything you do, think, feel and believe has an impact on your health and well-being, and*
- **The loving acceptance of 'self' (including imperfections):** *A mindful approach to oneself with gratitude for strengths and a non-judgemental appreciation of the hidden and visible facets of humanness with its magnitude and the capacity to impact on others.*

8.6.1. Wellness as a central philosophy in cultural safety for First Nations people

Echoing the Wheel of Wellness framework shared earlier, wellness from a First Nations perspective must address mind, body, spirit and connection to Country. SCI rehabilitation must incorporate not only physical therapy but also cultural and social healing. The work of health workers embedded in communities, often the unsung heroes of the system, provides a model for person-centred care grounded in relationships, culture and trust.

Important resource: Social and Emotional Well-being (SEWB) and delivering culturally safe services

The Victorian Aboriginal Community Controlled Organisations (VACCOs) deliver culturally safe services using the Social and Emotional Wellbeing (SEWB) Framework, which is also a wheel. Read about how one centre in Victoria, the Balit Durn Durn Centre, uses the SEWB wheel.

8.6.2. Cultural safety and SCI

Australia's health system continues to face significant challenges in delivering equitable and culturally safe care to Aboriginal and Torres Strait Islander peoples, particularly in the context of SCI. For First Nations people, the impacts of SCI are intensified by systemic barriers, cultural disconnection and limited access to services that are culturally informed and responsive. Drawing on insights shared by **Professor Shane Hearn** in his presentation at the 4th International Indigenous Health and Wellbeing Conference 2025 on Kaurna Country, along with his published work on ***cultural safety***, health equity and resilience (Hearn *et al.*, 2025), this section examines how continuous cultural quality improvement (CCQI) and culturally safe assistive technology provision can help transform outcomes for First Nations people living with SCI.

Cultural safety in healthcare goes beyond cultural awareness and competence. It is a transformative approach that places the individual at the centre of care, acknowledges historical and ongoing injustices, and commits services to practices that are self-reflective, accountable, and co-designed with communities (Curtis *et al.*, 2019). This is a revolving concept. In fact, in 2025, Curtis and colleagues revisited their original 2019 definition of *cultural safety* and recommended that it be redefined as:

> *"Cultural safety requires healthcare professionals and their associated healthcare organisations to examine themselves and the potential impact of their own culture on clinical interactions and healthcare service delivery. This requires individual healthcare professionals and healthcare organisations to acknowledge and address their own biases, attitudes, assumptions, stereotypes, prejudices, structures and characteristics that may affect the quality of care provided. In doing so, cultural safety encompasses a critical consciousness where healthcare professionals and healthcare organisations engage in ongoing self-reflection and self-awareness and hold themselves accountable for providing culturally safe care, as defined by the patient and their communities, and as measured through progress towards achieving health equity. Cultural safety requires healthcare professionals and their asso-*

ciated healthcare organisations to influence healthcare to reduce bias and achieve equity within the workforce and working environment".

In the context of SCI, cultural safety requires more than physical rehabilitation or equipment provision. It must include the understanding of cultural obligations, family responsibilities, language barriers and the trauma caused by dislocation from Country and culture. Health services often approach SCI care through a biomedical lens, which does not account for the holistic, social and spiritual dimensions of wellness (social and emotional well-being, SEWB) so vital to First Nations worldviews.

Professor Shane Hearn's story: Culturally safe assistive technology provision in Australia

"In my presentation on 'Culturally Safe Assistive Technology Provision in Australia' (Hearn et al., 2025), I highlighted how assistive technology can either enhance or hinder independence depending on how it is delivered. First Nations clients report that assistive devices provided without cultural consultation often go unused. If, however, cultural protocols are respected and devices are introduced in collaboration with Elders, community-based health workers and family members, the technology is welcomed and integrated into everyday life.

For example, in one patient scenario shared during the presentation, a young Wiradjuri man with SCI was reluctant to use his new wheelchair due to shame and visibility within his small community. Through community-led discussions and role-modelling by other local men with disabilities, he embraced the assistive technology and regained mobility and confidence. This outcome was possible only because the service provider recognised the cultural dimensions of disability and partnered with the community to co-create the intervention."

The authors followed up their article with a blog for the Global Observatory of Long-term Care, Assistive Technology Provision – perspectives on cultural safety from Australia, in which they provide first-hand experiences of First Nations people and assistive technology.

Jaru woman, **Natasha Short**, has also written about accessibility, based on the research above: Barriers and solutions to AT access for First Nations people.

Video: Disability and culture in First Nations history

This short video from the FPDN submission to the Disability Royal Commission provides historic evidence of a one-legged man's footprint in Lake Mungo. It would appear that he was able to keep up with the hunt. The narrator makes the point that 'disability' was not considered a deficit by Aboriginal people. It was colonisation that introduced this.

8.6.3. Continuous Cultural Quality Improvement (CCQI) in SCI services

In 2022, iLA engaged CultureLink, a First Nations enterprise, in partnership with positive change agency, Think HQ, to undertake qualitative research with LiveUp's First Nations audience, to understand current attitudes and preferences toward information about assistive products. Yarns were conducted with 20 older First Nations people and 16 service provider staff. The research unearthed a significant opportunity for LiveUp to lead better practice in the provision of information about assistive products and to offer the mainstream sector a way forward in meeting the longer-term care needs of older First Nations people. Cultural safety in SCI services requires more than audits or one-off training sessions. It requires systemic change guided by performance indicators co-developed with First Nations stakeholders. These include community engagement and co-design practices, being:

- Cultural safety training and reflection for all SCI service providers
- Integration of cultural protocols into care planning
- Feedback loops with Aboriginal and Torres Strait Islander clients, and
- Culturally responsive outcome measures beyond biomedical metrics.

Such tools enable health services to self-assess, adapt and be accountable for how they support First Nations people. The research resulted in a 55-page guide that describes nine guiding principles for culturally safe information about assistive products, which include being trauma-

informed, strength-based, holistic and goal-oriented: LiveUp Better Practice Guide for Culturally Safe information about assistive products.

8.6.4. Pain management in SCI for First Nations people

As discussed in **Chapter 2**, pain may be a constant for many years after sustaining SCI.

Important resource: Our Mob's Pain Management Network

The **Pain Management Network** has a tab relevant for First Nations peoples, called Our Mob. The story of health and fresh food, including bush tucker, in dealing with pain, is told through animated artwork designed by Danielle Sullivan. The website includes videos, stories and fact sheets that are culturally appropriate for good health and holistic well-being.

Key recommendations: Culturally safe SCI care for First Nations people

Thus, in providing healthcare for First Nations peoples, **Professor Shane Hearn** recommends the following:

- *"Cultural safety is not a destination. It is a continuous, reflective practice grounded in partnership and respect*
- *First Nations people living with SCI require services that are not only clinically competent but also culturally congruent*
- *Assistive technology, when delivered in culturally unsafe ways, can perpetuate exclusion; when co-designed, it can transform lives*
- *Continuous Cultural Quality Improvement (CCQI) tools provide a good pathway for embedding cultural safety within SCI services, and*
- *Investing in local, culturally competent service ecosystems in rural and remote Australia is essential for achieving equity."*

8.6.5. Services and support for First Nations people living rurally, regionally and remotely

This section begins with a personal story from **Jemma**, a FIFO (fly-in-fly-out) podiatrist.

Jemma's story: Experiences as a FIFO podiatrist in remote Australia

"Specific barriers for First Nations people living in Remote Communities: access to Podiatrists. From my experience, I visit some Communities in the Northern Territory only four to six times a year. Some Communities have no services visiting due to inaccessibility, conflicts, workforce shortages, and a lack of funding for specialised care. There are few people living with SCI in remote communities due to the lack of support, along with difficulty with mobility due to unsealed roads and pathways. The other impacts, such as family, community, support, socio-economic constraints, housing, available resources, medical facilities… the list continues. Most First Nations people who have SCI relocate to larger cities with hospitals that can provide ongoing healthcare and support."

As noted at the start of the Chapter, finding health services in some parts of RRR Australia is not easy. It would be even more difficult to find culturally appropriate services for First Nations people, particularly if they have a physical disability such as SCI. Below are some examples of services and supports available to First Nations people.

Important information: NDIS 2025 launch (First Nations)

Seven years ago, the**First Peoples Disability Network (FPDN)** produced a video, Time to get NDIS ready. In July 2025, the NDIS changed how it delivers services and released its First Nations Strategy (2025-2030), co-developed with a First Nations Working Group. The associated video about this Strategy describes the four priority areas:

1. **Fair and equitable access and support:** Making the NDIS pathway more equitable and culturally safe for First Nations people
2. **NDIS 'our way'- transformation for power-sharing:** Building First Nations governance into the NDIA's decision-making, co-design and operations
3. **Working together within and across sectors:** Building better systems within the NDIS and across sectors to deliver a better journey and outcomes for First Nations participants, and

4. **Gathering, sharing and revisiting knowledge about meaningful change:** Tracking change in the experiences and outcomes of First Nations participants and using these learnings to continue improving.

Important information: Medical Outreach Indigenous Chronic Diseases Program

The Medical Outreach Indigenous Chronic Diseases Program (MOICDP) helps Aboriginal and Torres Strait Islander people who have chronic conditions to access health care. It does this by covering some costs, such as travel and accommodation, for health professionals who provide outreach services. It supports medical specialists, general practitioners, Aboriginal and Torres Strait Islander health workers, allied health workers and other health professionals. It also supports:

- Multidisciplinary teams
- Coordinating and administering these teams
- Cultural awareness and cultural safety training upskilling, and
- Professional support associated with outreach services.

This ensures Aboriginal and Torres Strait Islander people with chronic conditions can access the culturally appropriate health care they need, wherever they live.

Below is a series of resources and key information, beginning with services for First Nations people generally, followed by resources specific to First Nations people and carers.

Important resources: Outreach and community health services for First Nations families

- The Outreach Program's Service Delivery Standards indicate that, in addition to the **MOICDP**, three other programs – Healthy Ears – Better Hearing and Better Listening, Eye and Ear Surgical Support (EESS) and the Visiting Optometrists Scheme (VOS) – are available.
- Townsville Aboriginal & Torres Strait Islander Health Service offers a range of services, including family and youth programs, accommodation, dentistry (see below) and sexual health, among others.
- MYTOOTHDOCTOR has a strong focus on paediatric dentistry, First Nations oral health and special needs dentistry. There are several branches across Townsville and in North-West Queensland Out-

back (Hughenden, Richmond, Julia Creek). Below is an extract from CheckUp's Access for All document (p. 28-29):

> *"As a part of our accessible service,MYTOOTHDOCTOR™ provides a compact mobile bariatric chair for people who require it. The bariatric chair can be removed, leavinga platform allowing a wheelchair user to remain in their chair while receiving dental treatment without the added stress of transferring to a standard dental chair. This is particularly helpful for people who would otherwise require a hoist to mobilise from their wheelchair. The wheelchair-friendly dentist chair is the only one available from a private dental clinic in Australia."*

- In **Chapter 1**, the listed services provided nationally by Neuromoves, which is linked to the NDIS, were described. In 2025, Neuromoves opened a facility in Orange, located in the **Orange Aboriginal Medical Service at the Walu-Win Centre**. This new site features state-of-the-art equipment and offers hydrotherapy through the nearby Orange Aquatic Centre. The following programs appear to be available in Orange:
  - Activity-based Therapy
  - Exercise Physiology
  - Functional Electrical Stimulation – Cycling
  - Gym (link currently broken)
  - Home Visit
  - Hydrotherapy
  - Locomotor Training
  - NeuroMoves Kids
  - Physiotherapy
  - Small Group Training
  - Strength & Conditioning, and
  - Telehealth.

Important resources: Supporting First Nations individuals, families and communities

- The First Peoples Disability Network (FNDN), Australia, is a national human rights organisation of and for Australia's First Peoples with disability, their families and communities. FNDN is governed by First Peoples with lived experience of disability. FPDN won the Improving Advocacy and Rights Promotion Award at the 2014 National Disability Awards
- The Physical Disability Council of NSW provides quick links to the Aboriginal Legal Service of NSW, the FNDN Australia and the Sydney Region Aboriginal Corporation (SRAC)
- iLA: LiveUp Better Practice Guide for Culturally Safe Information about Assistive Devices. The Guide has nine guiding principles: First Nations-informed, Trauma-aware, Strengths-based, Person- or Family-centred, Holistic Goal-oriented, Place-based, Relevant and Contribution-focused.

- Speak My Language: Provides several Conversations with Indigenous Australians living well with a disability
- Support for Aboriginal and Torres Strait Islander people, including those from Stolen Generations (My Aged Care): Aboriginal and Torres Strait Islander people over the age of 50 may be able to get support with aged care services, if assessed as eligible. This can help you stay at home for longer or move into an aged care home, and
- 13YARN, a helpline where one can yarn with a First Nations Crisis Supporter.

Important resources: Aboriginal and Torres Strait Islander carers

- Considering that this statistic was provided earlier (In 2022, 102,500 or one in seven (14.1%) Aboriginal and Torres Strait Islander people were carers), Carers WA, for example, provides a First Nations Wellbeing Program, Gwabba Koort Yarning (Good Heart Talking), which the website describes as "healing time" for First Nations carers, and
- Carerhelp (with a video) provides three sets of resources for Aboriginal and Torres Strait Islanders' families who are caring for a sick family member:
    - Pathway 1- Getting prepared for caring for someone who is very sick
    - Pathway 2 – Caring for someone who is finishing up (coming to the end of their life), and
    - Pathway 3 – Grief and after caring.

Uncle Willie Prince's story: Disability in Aboriginal culture

This is a story extracted from the Access for All Cases for Inclusion about Uncle Willie Prince, a proud Wakka Wakka and Kalkadoon man and an **Access for All** advisory group member. Uncle Willie offers a unique perspective on disability within Aboriginal culture.

"The Aboriginal person doesn't know if they have a disability," he explains. *"If you can't walk around, you still have a job to do in your village, you don't have to stand to make fire."* This concept of disability as 'inclusion' rather than 'exclusion' stands in stark contrast to the Western view. *"In Aboriginal culture, it's hidden,"* he says. *"It's simply just another person who is part of the community."* This difference in perception creates significant barriers when accessing services like the NDIS.

"The Aboriginal person is at a disadvantage because they don't know what they're entitled to," Uncle Willie explains. *"Is it helpful to call oneself disabled? Or is it going to name and shame you in the community?"* Furthermore, the lack of cultural and disability awareness within healthcare can lead to frustration and feelings of alienation. Uncle Willie describes his experiences with medical professionals and said, *"They come out with all these questions, and I'm left thinking, What?... What?... What?... What! I came here for assistance, and I ended up getting a survey."*

Below are clinical resources designed to support health practitioners working with Aboriginal and Torres Strait Islander communities, as well as resources for patients and their families.

Clinical resources: Working with Aboriginal and Torres Strait Islander communities

- AMA's Access for All – Disability Awareness for Health Providers: Released in March 2024, this free 2.5–3 hour CPD course includes a companion resource, Access for All: Cases for Inclusion, featuring lived-experience stories from people with disability and health providers. Pages 16–19 focus specifically on disability and First Nations people.
- RACGP's Providing effective, culturally safe primary healthcare: This guide explains what culturally safe care means for Aboriginal and Torres Strait Islander peoples and supports GPs to reflect on bias, power dynamics and communication to ensure care is respectful, safe and shaped by patient experience
- RACGP's Aboriginal and Torres Strait Islander Health: The Faculty offers education, resources and advocacy to strengthen culturally safe, high-quality primary care, including a cultural awareness module. The six-hour Cultural Awareness and Cultural Safety Training module builds understanding of First Nations histories and cultures and helps clinicians reflect on attitudes that influence clinical interactions
- RACGP–NACCHO Good Practice Tables: These tables outline practical, culturally informed actions that general practices can take to deliver culturally safe, responsive care aligned with RACGP Standards
- RACGP's National Guide to Preventive Healthcare for Aboriginal and Torres Strait Islander People: Includes tools, such as the Emotional Wellbeing Toolkit, which explores cultural responsiveness when working with First Nations clients
- NSW ACI's My rehab, my journey – Gadjigadji: A resource supporting clinicians to create culturally safe, supportive rehabilitation environments for Aboriginal people by improving communication, cultural awareness, service design and staff training. Originally developed for rehabilitation wards, it is applicable across healthcare settings
- Rural Doctors Association of Australia (RDAA): The national peak body for rural and remote doctors, advocating for improved healthcare and a strong rural medical workforce across all states and territories, and
- Royal Commission's Listening to First Nations people with disability: Summarises what the Disability Royal Commission heard from First Nations people with disability and outlines required reforms to

ensure culturally safe, inclusive and equitable supports.

8.7. Impacts of a changing climate on RRR Australia, particularly First Nations communities

Reminder: Chapter 17 and climate change

Chapter 17 of this resource describes the impacts of a changing climate on Australia, with reference to the 2025 National Climate Risk Assessment (Australian Climate Service, 2025) and 2025 National Adaptation Plan. Key stakeholders in the development of these documents included representatives from the disability sector.

The National Rural Health Alliance's June 2023 Report, Evidence base for additional investment in rural health in Australia, provides evidence of greater environmental vulnerability among residents of RRR Australia. The effects of climate change are disproportionately severe across rural Australian communities, particularly smaller towns, which are highly vulnerable and have low resilience to disasters.

Australia's first National Climate Risk Assessment, published in September 2025, identified 11 Priority Risks, one of which is **Regional and Remote Communities**, with the risk assessment statement: Risks to regional and Aboriginal and Torres Strait Islander communities supported by natural environments and ecosystem services (**Figure 8.3)**. Several of the other Priority Risks are related, such as water security, health and wellbeing, emergency response and recovery and natural ecosystems. The nationally significant risks and their framing were co-developed with Aboriginal and Torres Strait Islander peoples.

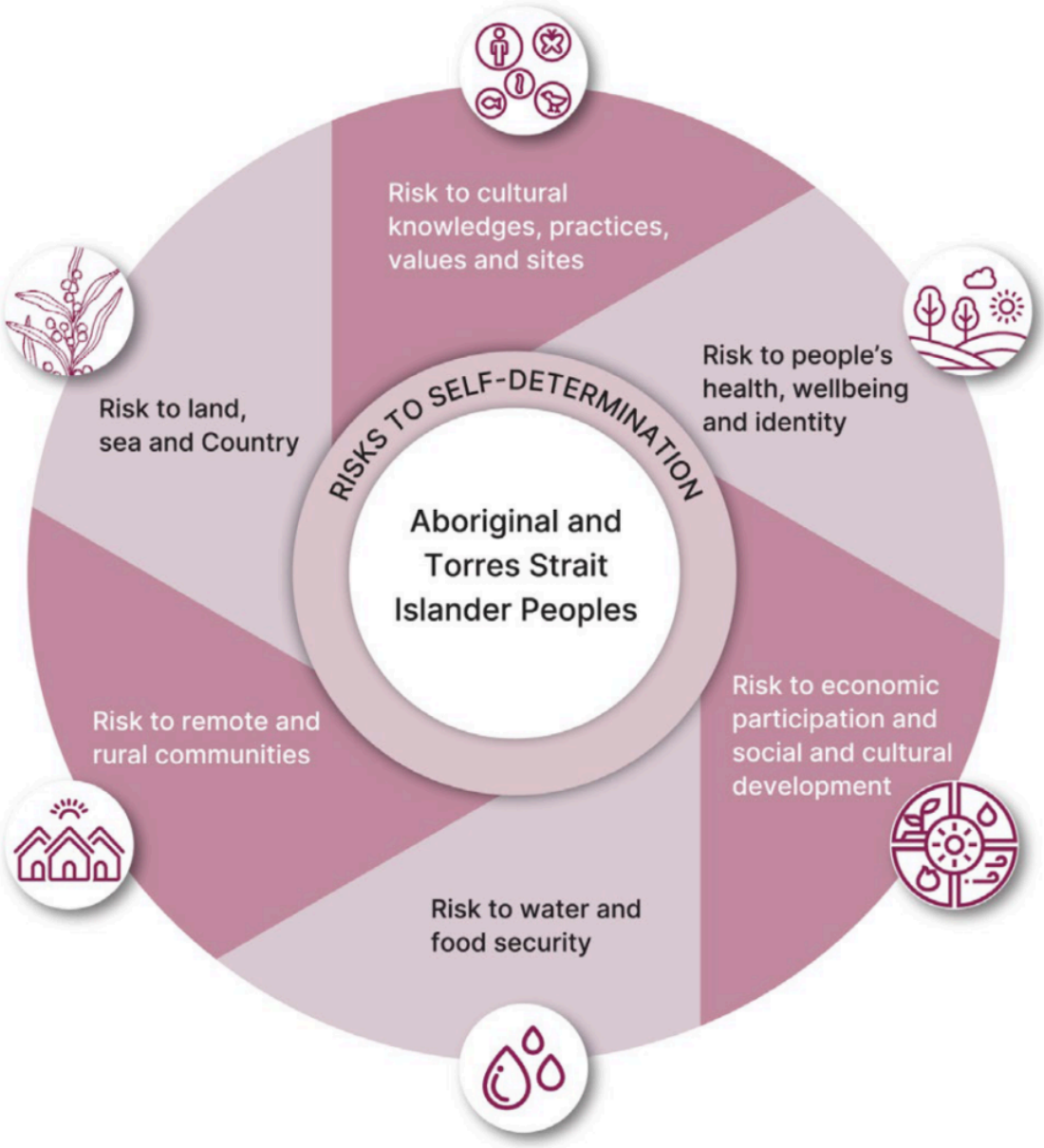


Figure 8.3. Major risks to Aboriginal and Torres Strait Islander people from the changing climate. *Source:* Aboriginal and Torres Strait Islander Peoples Technical Report. A technical report for the National Climate Risk Assessment, 2025. CC BY 4.0.

First Nations people's connection to Country is at risk because of the location of many communities. They will be affected by ocean warming, rising sea levels, droughts, higher temperatures and cyclones, amongst other risk factors (**Figure 8.4**).

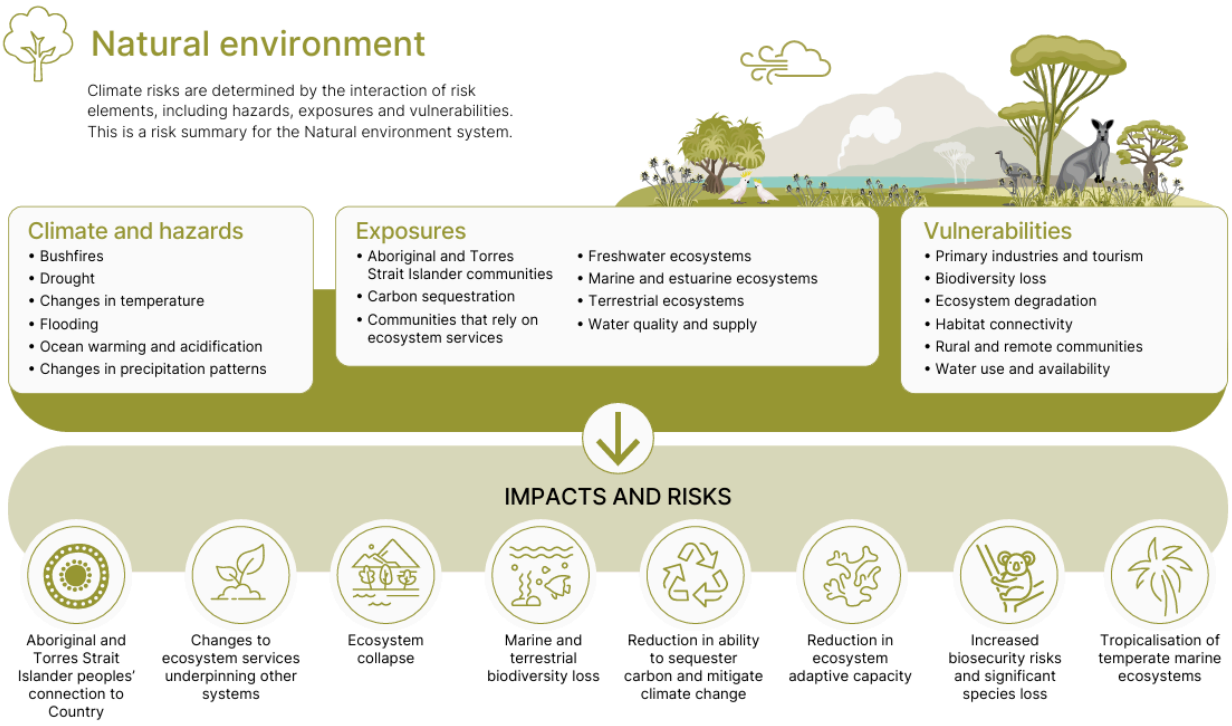
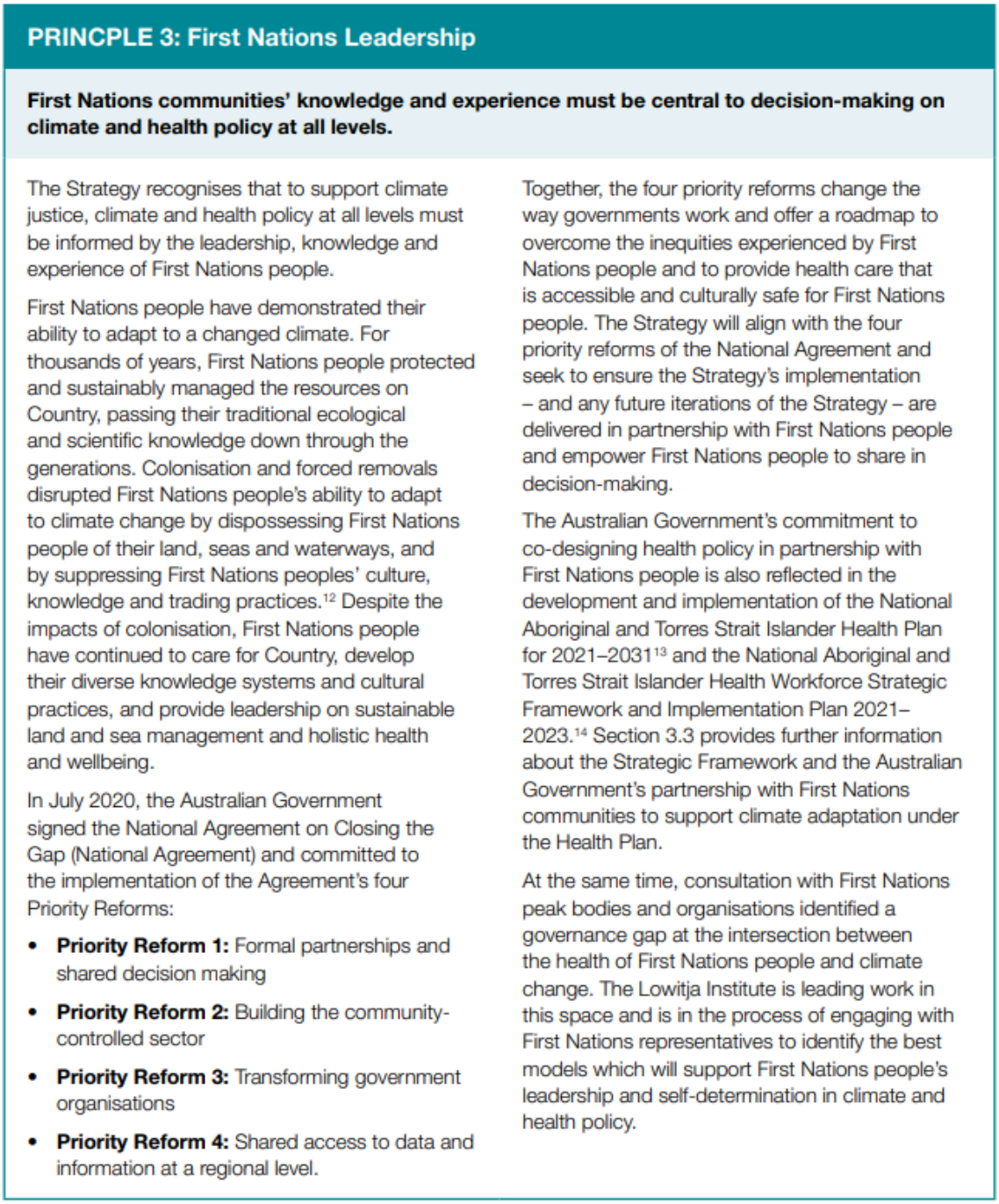


Figure 8.4. The impact of climate change on Australia's natural environment affects First Nations people's connection to Country. *Source:* Australia's National Climate Risk Assessment: An Overview, 2025, Australian Climate Service, p. 175. CC BY 4.0.

Importantly, First Nations leadership is one of the five Principles of the National Health and Climate Strategy 2023 (**Figure 8.5**). The national documents acknowledge First Nations people's long-standing ways of knowing, being and doing and the need to draw on their knowledge and stewardship to adapt and build resilience to a changing climate.



PRINCPLE 3: First Nations Leadership

First Nations communities' knowledge and experience must be central to decision-making on climate and health policy at all levels.

The Strategy recognises that to support climate justice, climate and health policy at all levels must be informed by the leadership, knowledge and experience of First Nations people.

First Nations people have demonstrated their ability to adapt to a changed climate. For thousands of years, First Nations people protected and sustainably managed the resources on Country, passing their traditional ecological and scientific knowledge down through the generations. Colonisation and forced removals disrupted First Nations people's ability to adapt to climate change by dispossessing First Nations people of their land, seas and waterways, and by suppressing First Nations peoples' culture, knowledge and trading practices.[12] Despite the impacts of colonisation, First Nations people have continued to care for Country, develop their diverse knowledge systems and cultural practices, and provide leadership on sustainable land and sea management and holistic health and wellbeing.

In July 2020, the Australian Government signed the National Agreement on Closing the Gap (National Agreement) and committed to the implementation of the Agreement's four Priority Reforms:

- **Priority Reform 1:** Formal partnerships and shared decision making
- **Priority Reform 2:** Building the community-controlled sector
- **Priority Reform 3:** Transforming government organisations
- **Priority Reform 4:** Shared access to data and information at a regional level.

Together, the four priority reforms change the way governments work and offer a roadmap to overcome the inequities experienced by First Nations people and to provide health care that is accessible and culturally safe for First Nations people. The Strategy will align with the four priority reforms of the National Agreement and seek to ensure the Strategy's implementation – and any future iterations of the Strategy – are delivered in partnership with First Nations people and empower First Nations people to share in decision-making.

The Australian Government's commitment to co-designing health policy in partnership with First Nations people is also reflected in the development and implementation of the National Aboriginal and Torres Strait Islander Health Plan for 2021–2031[13] and the National Aboriginal and Torres Strait Islander Health Workforce Strategic Framework and Implementation Plan 2021–2023.[14] Section 3.3 provides further information about the Strategic Framework and the Australian Government's partnership with First Nations communities to support climate adaptation under the Health Plan.

At the same time, consultation with First Nations peak bodies and organisations identified a governance gap at the intersection between the health of First Nations people and climate change. The Lowitja Institute is leading work in this space and is in the process of engaging with First Nations representatives to identify the best models which will support First Nations people's leadership and self-determination in climate and health policy.

Figure 8.5. Principle 3 of the 2023 National Health and Climate Strategy is First Nations Leadership. *Source:* National Climate and Health Strategy, 2023, p. 16. CC BY 4.0.

Clinical resource: Climate-related health impacts for First Nations communities

In terms of First Nations health and well-being, **Chapter 21** (Health impacts of climate change) from the RACGP-NACCHO National Guide to Preventive Healthcare for Aboriginal and Torres Strait Islander People provides invaluable clinical advice in a changing environment, considering the already high burden of disease amongst First Nations communities across Australia.

To close this Chapter, **Dr Jaclyn Szkwara**, a contributor to several chapters and a member of the editorial team, based on her physiotherapy experience working with patients with SCI, created this interactive summary of the challenges of living with SCI in RRR Australia (CC BY-NC (Attribution NonCommercial)).

An interactive H5P element has been excluded from this version of the text. You can view it online here:
https://bond.studium.pub/life-well-lived-with-spinal-cord-injuries/?p=166#h5p-8

Key Take-aways

- Australia is a large continent, with much of the country considered remote or very remote, making healthcare delivery challenging
- Spinal injuries, SCIs in particular, are challenges in RRR Australia because of limited access to service delivery and poor infrastructure, including public transport
- Coming home from transitional rehabilitation requires considerable adjustment for the individual, the family and the community, which leads to some individuals being motivated to take good care of their health, such as maintaining skin integrity
- While shortcomings in Australia's healthcare system and lack of resources can pose barriers for some First Nations peoples living in rural and remote communities accessing care, culturally appropriate resources are available
- Many of these resources have been developed by Aboriginal and Torres Strait Islander organisations for their communities to ensure they are culturally appropriate
- Colonisation has impacted how disability is viewed, making it important to align holistic care and well-being support with First Nations people's definition of health, and

- A changing climate will exacerbate the challenges in RRR Australia on many fronts, including health and well-being.

Reminder: Most relevant chapters

- **Chapter 1:** The resources provided in Chapter 1 are of a general nature and would be appropriate for the many people in rural and regional Australia, as well as First Nations people who work in cities and large towns. Living remotely or very remotely may be challenging
- **Chapter 2:** In terms of what is happening to the body, we hope that through the language used and the pop-up glossary, many people living rurally and regionally will be able to understand
- **Chapter 3**: The five pillars of good health and well-being, plus regular visits to a dentist and using the services of a podiatrist, are important, but as Chapter 9 has identified, the distances in RRR Australia may mean that some of the services may be mobile. While regional and rural Australia, which are often farming areas, may offer, for example, access to fresh fruit and vegetables, access becomes an issue in remote areas, especially for First Nations communities, where electricity supply cannot be guaranteed
- **Chapter 4:** Documenting health and well-being is important, especially if access to health services is limited. If electricity is not guaranteed, paper records would work, provided a family member can document
- **Chapter 5:** Studying, socialising and working
- **Chapter 6:** With age comes chronic conditions, exacerbating an underlying physical disability such as SCI. Older people need to access healthcare more often. Remoteness would be a barrier, with reliance on mobile services
- **Chapter 7:** This chapter on children and adolescents adds value in terms of a general discussion and reminds us that children are not just small adults.
- **Chapter 9:** Neurodiversity, LGBTQI+, migrants and CALD are considerations for any patient as we are all 'intersectional'
- **Chapter 10:** Discrimination, abuse, relationships and sexuality
- **Chapter 12:** Travelling to and from health services is important to stay healthy and well, but like so many other 'needs', remoteness reduces accessibility.
- **Chapter 13:** The chapter on surgery and anaesthesia provides detailed information about what happens before, during and after surgery. For those living in RRR Australia, this is likely to involve moving away from home
- **Chapter 14:** Spiritual health is part of good health and well-being. Chapter 14 offers some insight into what this might mean for those living with SCI.
- **Chapter 15:** Sport is an important part of life in many communities, with some individuals and teams with SCI advancing to the national and international level
- **Chapter 16:** Research into SCI provides hope that an individual's outcome may improve. Chapter 16 describes the many avenues of SCI research, including how one might become involved, and
- **Chapter 17:** Australia's changing climate is likely to have a considerable impact on communities in RRR Australia, as **Chapter 8** has indicated. Chapter 17 explores this in more detail in terms of rising sea levels, warming oceans and floods for those at the coast, particularly in the Far North of mainland

Australia and the Torres Straits. Those living more centrally will be impacted by heat, drought and bushfires. Just as children and older people are considered physiologically vulnerable, so too are people with higher-level SCI, as they may not be able to regulate their body temperature. In addition, during adverse weather events with strong winds and flooding, wheelchair mobility is likely to be impacted. It is therefore important to have an emergency plan relevant to local risks.

Acknowledgement

The editors would like to thank **Dr Janie Dade Smith** for providing feedback on an early draft of the Chapter.

References

Australian Bureau of Statistics (ABS). (2024). *5.5. million Australians have disability*. Media release. https://www.abs.gov.au/media-centre/media-releases/55-million-australians-have-disability

Australian Bureau of Statistics (ABS). (2025). *Aboriginal and Torres Strait Islander peoples with disability, 2022*. Australian Government. https://www.abs.gov.au/articles/aboriginal-and-torres-strait-islander-peoples-disability-2022

Australian Climate Service. (2025). *Aboriginal and Torres Strait Islander Peoples Technical Report. A technical report for the National Climate Risk Assessment.* Australian Climate Service, Australia. https://www.acs.gov.au/documents/af4c85634b8942e6b632bcc498ffabe0/about

Australian Government, Department of Health, Disability and Ageing. (2025). *Modified Monash Model.* https://www.health.gov.au/topics/rural-health-workforce/classifications/mmm?language=en

Australian Government. (2025). *National adaptation plan*. Department of Climate Change, Energy, the Environment and Water. https://www.dcceew.gov.au/climate-change/publications/national-adaptation-plan

Australian Institute of Health and Welfare (AIHW). (2021). *Spinal cord injury, Australia 2017-18.* Australian Government. https://www.aihw.gov.au/reports/injury/spinal-cord-injury-australia-2017-18/summary

Australian Institute of Health and Welfare (AIHW). (2025). *Rural and remote health.* Australian Government. https://www.aihw.gov.au/reports/rural-remote-australians/rural-and-remote-health

Australian Institute of Health and Welfare (AIHW). (2025). *Spinal injuries in Australia 2020-2021.* Australian Government. https://www.aihw.gov.au/getmedia/25e722fc-c00e-43c2-a9fd-ca902548bbf3/spinal-injuries-in-australia-2020-21.pdf.

Brabrook, C. (n.d). *How do individuals living with a spinal cord injury in a rural area prevent pressure injuries? The lived experience of intact skin.* HETI, NSW Health, Hunter New England Local Health District, NSW Spinal Outreach Service. https://www.heti.nsw.gov.au/__data/assets/pdf_file/0003/438825/Catherine-Brabrook-Final-Report.pdf

CheckUP Australia. (2024). *Access for all: Cases for inclusion*. https://checkup.org.au/wp-content/uploads/2024/11/Access-for-All-Cases-for-Inclusion.pdf

Curtis, E., Jones, R., Tipene-Leach, D., et al. (2019). Why cultural safety rather than cultural competency is required to achieve health equity: A literature review and recommended definition. *International Journal for Equity in Health*, 18(1), 174. https://equityhealthj.biomedcentral.com/articles/10.1186/s12939-019-1082-3.

Curtis, E., Loring, B., Jones, R. et al. (2025). Refining the definitions of cultural safety, cultural competency and Indigenous health: lessons from Aotearoa New Zealand. *International Journal of Equity in Health* 24, 130. https://doi.org/10.1186/s12939-025-02478-3

Gordon, W. & Harada, T. (2023). Mundane powered wheelchair journeys and embodied rural disability geographies of (not) belonging. *Journal of Rural Studies, 103,* 103106. https://doi.org/10.1016/j.jrurstud.2023.103106

Hearn, S., Langenberg, V., Harper, K., Callaway, L., O'Connell, H., Kennett-Smith, E., & Layton, N. (2025). Culturally safe assistive technology provision in Australia: Concept mapping perspectives from Aboriginal and Torres Strait Islander People. *Australian Journal of Social Issues*, https://onlinelibrary.wiley.com/doi/10.1002/ajs4.70085

Johnson, E. (2021). *An exploration of person-centred allied health supports with rural and remote families in the context of the rollout of the National Disability Insurance Scheme in Australia* [PhD thesis, University of Sydney]. Sydney Digital Theses. https://ses.library.usyd.edu.au/handle/2123/27208.

Johnson, E. (2025). The NDIA is changing how it pays for disability supports. What does that mean for rural communities? *The Conversation.* June 26. https://theconversation.com/the-ndia-is-changing-how-it-pays-for-disability-supports-what-does-that-mean-for-rural-communities-259148

Kendall, M., Harre, D, Schuurs, S., Hinchy, K. & Booth, S. (2021). Returning to rural communities following transitional rehabilitation after spinal cord injury. *The Australian Journal of Rural Health*, 29(4): 572-577. https://doi.org/10.1111/ajr.12772.

Lakhani, A., Townsend, R., & Smith, B. (2019). *Clarifying the geographic dispersion of essential health services for people with spinal cord injury in rural and remote Queensland: A spatial study. The Hopkins Centre*. https://www.hopkinscentre.edu.au/files/BIBS19/a_lakhani_bibs_19_poster_spatial_study.pdf.

National Rural Health Alliance. (2023). *Evidence base for additional investment in rural health in Australia.* https://www.ruralhealth.org.au/policy/position/evidence-base-for-additional-investment-in-rural-health-in-australia/

Queensland Health. (2024). *Spinal Cord Service Delivery Model for Queensland*. Spinal-Cord-Injury-Service-Delivery-Model-for-Queensland_Digital.pdf

Queensland Government Health Improvement Unit. (2025). *Statewide guideline for access to primary rehabilitation for new spinal cord injuries QH-GDL-987*. Queensland Health. https://www.health.qld.gov.au/__data/assets/pdf_file/0029/1444754/qh-gdl-987.pdf

Queensland Health. (2022). *Rural and Remote Health and Wellbeing Strategy 2022–2027*. https://www.health.qld.gov.au/__data/assets/pdf_file/0020/1142066/Rural-and-Remote-Health-and-Wellbeing-Strategy-2022-2027.pdf

Model Systems Knowledge Translation Centre. (n.d.). *Living with spinal cord injury*. https://msktc.org/

National Rural Health Alliance. (2023). *Evidence base for additional investment in rural health in Australia.* https://onlinelibrary.wiley.com/doi/10.5694/mja2.52175?msockid=2c16d98a012360f13802cc1b0026611e

National Rural Health Alliance. (2025). *Rural health in Australia snapshot 2025.* https://www.ruralhealth.org.au/wp-content/uploads/2025/02/NRHA-Rural-Health-in-Australia-Snapshot-2025.pdf

Probyn, E. (1996). *Outside belongings*. Routledge.

Royal Australian College of General Practitioners (RACGP) & National Aboriginal Community Controlled Health Organisation (NACCHO). (2024). *National guide to preventive healthcare for Aboriginal and Torres Strait Islander People.* RACGP. https://www.racgp.org.au/getattachment/ef5164d0-14ce-40b6-bd2e-7fe38922f7d4/National-Guide-to-preventive-healthcare-for-Aboriginal-and-Torres-Strait-Islander-people.aspx

Smith-Merry, J., Gilroy, J. & Watharow, A. (2023). The NDIS at ten years: designing an equitable scheme for the next decade. *Medical Journal of Australia, 218*(7). https://www.mja.com.au/journal/2023/218/7/ndis-ten-years-designing-equitable-scheme-next-decade

Quilliam, C., Wakely, L., French, L., Ellis, N., McNeil, R., Fallon, T., Kersten, M., Bagley, K., Spong, J., Doney, R., Stubbs, C., Devitt, A., & McKinstry, C. (2025). Placing rural in the National Disability Insurance Scheme review. *Australian Journal of Social Issues, 60*(4), 1077-1083. https://doi.org/10.1002/ajs4.70024

Vines, R. (2011). Equity in health and wellbeing: Why does regional, rural and remote Australia matter? *InPsych | The Bulletin of the Australian Psychological Society, October,* 11. https://groups.psychology.org.au/Assets/Files/InPsych%20Rural%20Issue%20index.php.pdf

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Chapter 9. Spinal Cord Injury and Marginalised Communities

Contributors: Richard Matthews, Michelle McLean and Belinda Craig

Reviewer: Tanisha Jowsey

Editors: Michelle McLean, Elmarie Stander and Tanisha Jowsey

> *"Disability is articulated as a struggle, an unnecessary burden that one must overcome to the soundtrack of a string crescendo. But disabled lives are multi-faceted – brimming with personality, pride, ambition, love, empathy, and wit."*
>
> **Sinead Burke**, writer, academic, activist and broadcaster.

Chapters 1-6 of this resource focused primarily on the 'average' person in Australia living with SCI who is transitioning home. By 'average', we mean individuals living close to amenities, with access to healthcare facilities and resources and being able to make decisions and who are also *cis-gendered*, so cis-male or cis-female. In reality, however, there are many individuals and communities who, for various reasons and circumstances, may not have access to resources or healthcare and for whom decisions about their health and life may not be in their hands. Some of the Special Topics chapters in this resource consider additional challenges some individuals living with SCI may face in Australia. In **Chapter 8**, we touched on Australia's distributed health-care system that sometimes does not reach those most in need because of their remoteness and the vast distances that need to be travelled, as is the case with First Nations people, which were discussed in **Chapter 8**.

This Chapter describes challenges faced by other groups and individuals who might be 'marginalised' in terms of a disability for various reasons in Australia, including in terms of accessing healthcare. Included in this Chapter are refugees and asylum-seekers, non-English speaking immigrants, the homeless and unhoused, incarcerated individuals (prisoners), those who have different neurotypes and the Rainbow (LGBTQIA+) Community.

Madeline's story: A homeless man discharged in a wheelchair

This podcast is by an American medical student, **Madeline Blatt** (2025), who reflects on her experience with a homeless man who has been discharged in a wheelchair. She highlights the need for greater inclusion: To Empty A Wheelchair – Academic Medicine Podcast – Apple Podcasts.

Madeline states:

> *"Throughout my medical training, I vow to make an effort to actively pursue each patient's full story. To cleave only the fragments of their existence that anchor them to the hospital room leaves behind parts of our patients, invisible and abandoned."*

The essay read in this episode was published in the Teaching and Learning Moments column in the July 2025 issue of *Academic Medicine*.

This Chapter will briefly explore the impacts of SCI on groups and communities that may already be marginalised and/or underserved.

Key Topics in this Chapter

This Chapter includes key topics about disability, including SCI, in terms of the following groups:

- The Rainbow (LGBTQIA+) community
- People with different neurotypes
- Homeless people
- Prisoners
- Migrants, and
- Refugees and asylum-seekers.

9.1. A primer on intersectionality, privilege and oppression

While we have 'grouped' people into 'communities' in this Chapter, each person is an individual with a unique history and self. As such, each person is likely to fit into many groups or may not identify with the umbrella terms we have identified. Multiple social, economic, cultural, ecological and other forces contribute to shaping human identity. These forces need to be taken into account in understanding health, health access and health behaviour. ***Intersectionality*** should thus be considered, which refers to the complex distributions of social, economic, cultural and ecological forces that shape the identity of individuals and groups such that unique individuals are produced. In particular, intersectionality is tied to issues of privilege and oppression, in which some groups are advantaged by virtue of their intersectional privilege, while other groups are oppressed by the same power dynamics. Most people carry at least some privilege and some oppression. Only a small proportion of the population carries privilege.

The bulk of the Australian population bears a mix of privilege and oppression. So, for example, a cis-gendered white male can suffer from class oppression and thereby be poor or homeless while benefitting from white and male privilege. A wealthy lesbian female of colour is exposed to misogyny and LGBTQIA+ oppression while benefitting from wealth privilege. It is here that the Diversity Council of Australia's definition of intersectionality is appropriate: "*Intersectionality refers to how different aspects of a person's identity expose them to overlapping forms of discrimination that greatly increase their marginalisation.*" Considering that one carries multiple oppression markers, individuals and groups can be excluded from access to power, lose control over the conditions of their lives and their voices are not heeded by dominant groups. Such individuals are discriminated against in numerous ways.

Privilege refers to unearned advantages, benefits or protections granted to individuals based on membership in dominant social groups, rather than personal ability or effort. In psychology, privilege is defined as unearned societal advantages linked to social identity and power. Privilege is embedded in social structures and institutions, often operating invisibly to those who benefit from it, while shaping unequal access to opportunities and resources. Importantly, privilege is not about individual intent or blame. It reflects how social systems consistently advantage some groups over others in everyday life (American Psychological Association (APA), 2023a; Brown, 2022). Examples of privilege include:

- **White privilege:** Reduced exposure to racial discrimination and greater positive representation in media, education and leadership
- **Male privilege:** Fewer barriers to authority and leadership and lower exposure to gender-based discrimination and harassment
- **Wealth (class) privilege:** Greater access to quality education, healthcare, secure housing and influential social networks
- **Citizenship privilege:** More reliable access to employment, healthcare, political participation and legal protections than non-citizens, and/or

- **Ability privilege:** The ease of navigating physical, social, and institutional environments without requiring accommodations.

These categories reflect how inequality is reproduced through structural means, even without explicit bias (APA, 2023a; APA2023b; Brown, 2022).

In Australia, privilege is generally afforded to white, wealthy, ***cis-gendered*** males. A much larger grouping of people, however, carries only oppression markers, which in Australia involves a combination of class or economic oppression with other markers of oppression. Included are, for example, homeless and unhoused women living with disabilities and homeless or unhoused racialised people or gender-diverse people. Indeed, depending on how one conceives oppression, attributions of disability are the universal feature of the oppressed, as Disability Studies scholar Gregor Wolbring (2008) argues.

This Chapter focuses on the problems of oppression, the access challenges and ensuing health harms of marginalised groups of people, particularly if they live with a disability.

9.2. Gender and sexual diversity

In Australia, individuals living with SCI may face unique challenges related to accessing appropriate care and support services due to their identification with one or more sexual and gender minority (SGM) groups (Rosendale & Singh, 2021). SGM refers to a broad umbrella encompassing diversities in sex characteristics, sexual orientation and gender identities. These include transgender, non-binary, gay, lesbian and bisexual identities, amongst others, as well as intersex variations. SGM may also be referred to as LGBTQIA+ and similar acronyms. In Australia, recent estimates indicate that around 4.5% of the population identifies as a member of an SGM, with 1 in 10 young Australians (aged 20-24) identifying under the LGBTQIA+ umbrella (Australian Bureau of Statistics, 2024). Below, we describe unique challenges faced by SGMs in accessing care and support, such as those living with SCI, as well as considerations for serving this community:

- **Stigma and discrimination:** SGMs are more likely to have experienced stigma and discrimination due to their identity, including in healthcare settings (Ayhan *et al.*, 2020). In combination with disability caused by SCI, they may face double discrimination, in terms of stigma related to both their SGM identity and their disability
- **Navigating support systems:** Related to past experiences of discrimination and stigma, people with SGM identities are more likely to have had negative experiences with health care systems with issues including encountering disrespectful attitudes, misgendering, and ignorance of services and supports relevant to SGMs (Haire *et al.*, 2021), posing a barrier to engaging with supports (Brener *et al.*, 2022). Finding support services that are both inclusive of SGM identities and understand the specific needs of individuals with SCI can be challenging

- **Mental health:** People with SGM identities are more likely to experience mental health challenges than heterosexual, cis-gendered people (Gmelin *et al.*, 2022). Acquiring an SCI can be distressing for many, with the prevalence of depression and anxiety higher amongst people living with SCI than in the general population (Schultz *et al.*, 2022). Already existing disparities in mental health in SGMs may be exacerbated by the addition of challenges adapting to life with SCI. The intersection between SGM identity, disability and mental illness statuses may exacerbate other forms of disadvantage, leading to a higher risk of poverty and unemployment or underemployment, which are also associated with poorer mental health (Paul & Moser, 2009), and
- **Sexuality and relationships:** Sexual health, romantic relationships and reproductive health are important aspects of life for most individuals. As we will describe in **Chapter 10**, individuals living with SCI may encounter unique challenges in these areas. Individuals living with SCIs can experience physical and sensory changes that can affect sexual experience and function (Zizzo *et al.*, 2022). Individuals who identify with SGMs may benefit from tailored support in navigating intimacy, relationships and reproductive health (Rosendale & Singh, 2021). If health providers assume hetero- and cis-normativity, they may rupture their relationship with patients and/or provide unhelpful support and advice. If an individual living with SCI does not receive appropriately person-centred, tailored and affirming care and support, this may have an ongoing impact on their quality of life (Anderson, 2004).

Podcast: Rachael Hosking, an LGBTQIA+ nightclub and accessible queer spaces

Feros Care Growing Bold with Disability podcast: Fostering diversity and inclusion by Rachel Hosking, co-founder of My Lover Cindi, Adelaide's queer utopian nightclub.

Rachel Hosking and co-founder Kate Toone (she/they) opened **My Lover Cindi** in May 2021 with a clear vision: To create a venue that is inclusive, intersectional and accessible. In this episode, Rachel discusses:

- Creating a nightlife space that is purposely designed to be inclusive
- Prioritising visibility and employment of people with disability and other marginalised communities
- Building a culture where community feedback is welcomed and valued, and
- The importance of accessibility in queer social spaces.

My Lover Cindi stands as a community-driven safe space focused on belonging, empowerment and celebration of diversity.

Important resources and information: LGBTQIA+

- Spinal Cord Injuries Australia (SCIA) recognises these challenges and is actively working to create more inclusive and welcoming environments for LGBTQIA+ individuals with SCI as a proud member of ACON's Welcome Here Project. This video explains the Welcome Here Project

- ACON developed the Welcome Here Project, which has a Queerability Toolkit. Included in this toolkit is a Disabled, Queer, Visible and Proud video, information about a Disability Community Leadership Project and a dropdown menu in the NDIS Guide for LGBTQIA+ People
- SCIA's Overcoming barriers for LGBTQ people with disability, which has a link to the Got Pride! Identity, discrimination and overcoming barriers for queer people with disability (Episode 1) podcast
- SCIA also provides peer support programs in which individuals living with SCI can connect with others who have similar experiences, including those who identify as LGBTQIA+
- People with Disability Australia's (PWDA) Advocating for the rights and inclusion for LGBTQIA people with disability page, and
- Spinal Injuries Association (SIA), For Life after SCI, has the Parapride and prejudice blog.

Personal stories: Sex, disability and LGBTQIA+ identity

Explore these powerful personal stories from people discussing their experiences at the intersection of sex, disability and LGBTIQ identity from SCIA's Have the Nerve Podcasts:

- Voices from the Sydney Mardi Gras 2023 (Episode 24, 3 March 2023): Features the perspectives and experiences of people with disability at Mardi Gras
- Ground Zero at Brand X – Voices from #SydneyWorldPride (Episode 27, 31 January 2024): High-

lights queer disabled voices during Sydney WorldPride

- Disability and the Performing Arts (Episode 32, December 21, 2023): **Jaclyn** shares her story as a queer, disabled emerging playwright navigating the arts, and
- Andrew Gurza – Queering and Sex (Keynote, 28 November 2019):**Andrew** explores how inaccessibility, ableism, prejudice and access barriers shape queer disabled experiences. He speaks candidly about loneliness, sexuality and disability, using personal stories to challenge assumptions and give audiences tools to create more inclusive, welcoming LGBTQIA+ spaces for disabled community members.

Clinical resource: Sexuality and ageing

icare: Form FSP034 for staff and service providers can be used by Lifetime Care and Workers Care to support participants ageing with SCI. The six-page form systematically addresses factors that promote good health and well-being, such as sleep and exercise. The Sexuality section checks whether the individual has LGBTQIA+ needs (**Figure 9.1**). Historically, in terms of Ageing with SCI, with questions to check as previously assumed, older people were heterosexual.

Sexuality

Each LGBTIQ+ community (lesbian, gay, bisexual, transgender, intersex, queer or otherwise diverse in gender, sex, or sexuality) has its own experiences and needs, as do the individuals within these communities. Traditional aged care service models may have previously assumed that their clients are heterosexual. As a result, the historical discrimination and stigma faced by older LGBTIQ+ Australians have led to a fear of disclosure and/or failure to access aged care and health services.

Consider:

- ☐ if the person identifies as a member of LGBTIQ+ community? Is it important to them that this is known to their service providers and supports?
- ☐ if the person is connected to LGBTIQ+ ageing and disability services and supports?
- ☐ reviewing rehabilitation, care and support programs - is there a need for education for service providers and supports, such as those available through Silver Rainbow: Ageing and Aged Care?
- ☐ is there anything else that the person wants their service providers and supports to know about their sexuality and gender identity?

Figure 9.1. Form FSP034 (Ageing with a Spinal Cord Injury) has a Sexuality section to check if the individual identifies as LGBTQIA+. *Source:* Insurance and Care NSW, © Insurance and Care NSW.

Important resources and information: Older individuals identifying as LGBTQIA+

Figure 9.1 has a link to LGBTQIA+ Health Australia's website relating to ageing people who identify as LGBTQIA+, called Silver Rainbow: Ageing and Aged Care. LGBTQIA+ Health Australia provides several fact sheets, including topics such as:

- Coming out and disclosure of LGBT older people
- LGBT people and dementia, and
- LGBT older people and social isolation.

This Chapter primarily caters for the individual living with SCI. We need to remember that carers may also identify as part of the LGBTIQA+ community. Carerhelp provides a range of ***LLEs*** (including videos) and resources from LGBTIQA+ carers.

9.3. Neurodiversity

The Neurodiversity paradigm recognises the natural variability that exists in human brains, cognitions and ways of experiencing the world. Captured under this umbrella are a range of neurocognitive differences or neurotypes, including autism, ADHD, dyslexia and giftedness, to name a few. People who are different from the neurodevelopmental or neurocognitive average in some way are referred to as ***Neurodivergent (ND)*** in contrast to someone who is Neurotypical (NT). The neurodiversity movement seeks to promote acceptance of difference as natural variations on the human experience with their own strengths and challenges rather than taking a deficit approach. For this reason, within some communities, there is a preference for identity-first language (Autistic person or ADHDer) rather than person-first language (person with Autism or ADHD). SCI is more common with certain neurodivergences, such as ADHD (Merrill *et al.*, 2009), so considering the intersection between neurodivergence and SCI is important. In reviewing existing literature and resources, there was limited work focused on providing care for ND individuals with SCI. Given the breadth of ways that one can be considered ND and limited work in this space, we will focus on a few of the most common neurocognitive differences that may present unique challenges or require special considerations in delivering care for individuals living with SCI in these communities:

- **Sensory processing differences:** Some types of neurodivergence involve sensory differences (American Psychiatric Association, 2022). Neurodivergent people can be hyper- or hyporesponsive to sensations across different domains, such as touch, hearing and sight. These sensory processing differences may make accessing regular treatment or support

in traditional settings undesirable or inaccessible. When treatment involves or targets the sensory system, sensory differences in the neurodivergent person may affect the treatment's effectiveness or their pain experience (Brown *et al*., 2020). In relation to making treatment more accessible, asking about and identifying ways to accommodate a person's sensory needs and preferences, such as adjusting sensory aspects of the environment, like lighting, incorporating use of fidgets and other tools that help the person to meet their needs, may reduce or remove barriers to accessing treatment and other supports for the SCI (Petty *et al.*, 2023)

- **Social and communication differences:** Some types of neurodivergence involve differences in social and communication preferences and approaches (American Psychiatric Association, 2022). These differences may pose a challenge to delivering care or support in the 'standard' way, as the clinician's or support provider's social and communication preferences may be misaligned with the neurodivergent person's preferences. Asking about and identifying ways to accommodate a person's social and communication preferences, such as accommodating preferences for reducing or having no eye contact, use of augmentative and alternative communication and using different types of questioning or explanation, can make accessing treatment and other supports for the SCI more accessible (Paynter *et al.*, 2025)
- **Information processing and attention differences:** Neurodivergence can also involve differences in these domains (American Psychiatric Association, 2022). For example, some types of neurodivergence, such as dyslexia and auditory processing disorder, involve difficulties with certain types of information (written, auditory). Providing information in a different modality to accommodate this difference can make care more accessible, for example, providing verbal information and visuals or diagrams, which can assist a person with dyslexia to access information more readily. Integrating the use of executive functioning supports such as schedules, lists and routines into the provision of treatment can support those with attentional and executive functioning differences, such as ADHD, and
- **Stigma, discrimination and mental health:** The Neurodiversity paradigm is relatively new. Many of the differences represented under this umbrella are still viewed as disabilities, disorders or deficits through a medical lens (American Psychiatric Association, 2022). As such, a neurodivergent person may face stigma (Kim *et al*., 2023), which is compounded by the stigma and disadvantage they may face relating to their SCI. Providing non-judgmental, neuro-affirming care can remove barriers to accessing SCI care for the neurodivergent person.

Personal stories: Being neurodiverse

- Feros Care Growing Bold with Disability, Paralympian **Chelseann Osborne** on Autism Spectrum Disorder: **Chelseann Osborne** shares her personal journey as a Paralympian and discusses her experiences living on the autism spectrum, and
- Speak My Language – In Conversations with Indigenous Australians Living Well with Disability, Thriving with Neurodiversity: Listen to Gomeroi man, **Mat Fink**, who was diagnosed later in life with ADHD and autism, as he speaks about navigating identity, culture and neurodiversity.

Important resources: Autism

- Griffith University's Focus Therapy Accommodations For Autistic People: Developed for providers of psychotherapies for autistic people, but may be of use to providers of other types of therapy, interventions and supports as a starting point for tailoring inclusive service provision
- NSW Government Agency for Clinical Innovation's Neurodivergent people: This resource outlines evidence-informed guidance for aftercare services to support neurodivergent individuals following suicidal crisis or attempt, highlighting risk factors, barriers to care, and practical adaptations to deliver inclusive, person-centred, and accessible support.
- Reframing AUTISM's Professional's Guide to Supporting Autistic Clients and Patients: This resource is an autistic-led, neurodiversity-affirming guide for professionals, providing practical, evidence-informed advice on understanding autistic experiences, communicating respectfully, and supporting autistic clients and patients in ways that prioritise lived experience, empathy, and inclusion over pathologising approaches
- Organization for Autism Research's (OAR) AASPIRE Healthcare Toolkit: This online resource supports autistic adults and healthcare providers to improve healthcare experiences by offering practical guidance, worksheets, and a personalised accommodations tool to help make medical appointments more accessible, respectful, and effective, and
- In co-operation with the Australian Government, Children and Young People with Disability Australia (CYDA) co-developed Take Charge of Change with young people and families with lived experience of autism, intellectual, physical or psychological disability, including those from rural areas, culturally diverse communities and LGBTQIA+ communities to help build confidence, knowledge and skills. There are resources for parents with children with disability aged 0-12 and resources for young people (aged 13-25).

9.4. Homeless individuals

The AIHW (2024) reported that about 9.5% of Specialist Homelessness Services clients had a disability. More were females, and most of the clients with disabilities were in the 45–54-year age group. Main reasons for homelessness for those with a disability seeking support related to issues with accommodation, such as inadequate availability (42.9%), followed by interpersonal relationships (20.4%), financial issues(18.6%) and health problems (6.1%).

Homeless and unhoused people living with a disability such as SCI may be intersectionally harmed in increasingly complex ways as oppressions interact, but the experience of facing interpersonal and structural ableism in accessing accommodation of any kind is shared by homeless people with disabilities regardless of which other oppressions they may share.

All homeless and unhoused people have challenges getting shelter, whether rental properties, social housing or crisis accommodation. But those living with SCI face compounding difficulties. Specialist Homelessness Services identifies the following populations as homeless:

- **Primary homeless:** Those forced to sleep rough through having to live on the streets, sleep in parks, squat in temporarily unoccupied buildings, cars or railway carriages, in improvised dwellings and those living in long grass or bush.
- **Secondary homeless:** Those living in short-term or emergency accommodation, including refuges, crisis accommodation, couch-surfing, temporarily living with friends or relatives, or in insecure accommodation such as hotels, motels, or boarding houses.
- **Tertiary homeless:** Those living in accommodation that falls below a minimum standard, for example, lacking bathrooms, kitchens or security of tenure (AIHW, 2025).

The experiences of homeless people living with SCI will vary depending on which form of homelessness has been imposed on them, with the primary homeless most at risk of severe morbidity and mortality. Below, we describe challenges faced at the intersection of homelessness and the experience of SCI:

- **Physical and mental health sequelae:** Those who are homeless experience higher mortality rates than the rest of the population and are disproportionately killed by violence and suicide, as well as by under-treated or untreated illnesses. Those living with SCI, along with others living with disabilities, are still more at risk of such structural violence. Morbidity rates for a wide range of conditions, including SCIs, are significantly higher than those in the housed population, also markedly higher than for those homeless people who do not live with disabilities (Aldridge *et al*., 2018; Glymour *et al*., 2014)
- **Access to housing:** All homeless people face disproportionate mental and physical health sequelae, and they all find it difficult to access decent and secure housing. But these health impacts and accessibility challenges are exacerbated when the individuals have SCI. The health sequelae are compounded when an individual has SCI, as accessibility issues make it harder to access secondary and tertiary options, such as crisis accommodation, the houses of friends or family or other housing. For example, accessing both

social housing and crisis accommodation is a significant problem. According to the final report of the Royal Commission into Violence, Neglect and Exploitation of People with Disability (the Commission), private rental properties tend to be inaccessible due to landlords failing to plan for people with disabilities. When they do provide accessibility modifications, this tends to result in rent increases, which thereby compounds the financial inaccessibility of properties. The average wait time for public housing in 2020-2021 for a person living with a disability was 413 days. 'Claudia' reported to the Commission that she had been on a wait list for five years and that she had been told it might take an additional five years before a ground-floor apartment could be found, and

- **Access to required accessibility modifications:** Those who are homeless and living with disability routinely face the following challenges: Long wait times, mismatches between accessibility needs and the housing offered and barriers to getting necessary modifications. In the Commission's Report (p. 555), one woman is described as having lived for six years in a house where her walker prevented her from using the shower, and her commode did not fit within the space. The same problems obtain for those with SCI who flee domestic violence and require crisis accommodation. Shelters may lack inclusive toilet, kitchen and showering facilities, be on the wrong floor with no elevator, and be otherwise inaccessible. Indignities are imposed upon unhoused people living with disabilities in how they are treated by the broader population, such as in their experience of interpersonal ableism and classism. But such indignities are also imposed through these different forms of structural violence. Each factor interacts with the others to compound the access problems and the attendant harms to physical and mental health.

Important resources: Federal, State and Territory services

- Australian Government Disability Gateway: Links people with disabilities, their carers, and families to the supports and services they need.
- Queensland Government Housing supports for People with Disability: Offers advice and support for people with disabilities seeking housing. It has sections on crisis housing, housing accessibility, understanding discrimination and other valuable information
- NSW Government Specialist Homelessness Services: Help and support are available for people experiencing homelessness, plus information, tools, and resources for specialist homelessness service providers
- Shelter Tasmania: Advocates for people experiencing or at risk of experiencing homelessness. It helps access services
- South Australia Department of Human Services: Provides housing support for those experiencing, or at risk of, homelessness in South Australia. It links to other housing support agencies in South Australia, including the Adelaide Zero Project and the SA Housing Trust
- Western Australia Homelessness Services: Provides support for those experiencing or at risk of homelessness in Western Australia. It links to crisis support and other agencies and institutions

- Northern Territory ShelterMe Website: Supports people experiencing or at risk of homelessness. It links to crisis accommodation, legal aid, food and other core support groups, and
- ACT's Woden Community Service: Provides a range of supports to the ACT, including mental health and housing supports for those in need.

Important resources: Non-governmental organisations and homelessness

Below are some of the many Australian organisations supporting individuals who find themselves homeless. While the organisations offer physical support, many are also advocates for ending homelessness:

- Australian Federation of Disability Organisations: AFDO is a national voice representing people living with disabilities across Australia. It provides policy advice on matters impacting people with disabilities in Australia. The site has reports and publications on contemporary concerns for people living with disabilities
- Homelessness Australia: Provide advocacy for the homelessness sector and work to strengthen the impact of homelessness services. We work with a large network of organisations and people with lived experience to provide a unified voice when it comes to preventing and responding to homelessness
- UnitingCare: Homelessness shelters and hubs: Services & Support is Gold Coast and Townsville-specific, offering services and support to the homeless and those at risk of homelessness in both communities
- Salvation Army: Homelessness Services provides case management, housing support and outreach support, financial assistance and connection to other support organisations
- Micah Projects (Brisbane): Help people in the community to access foundational human rights, such as housing, healthcare, domestic violence, safety, justice and meaningful connections, and
- Australian Alliance to End Homelessness: An independent champion and catalyst for ending homelessness in Australia. Supports and amplifies community efforts through driving the Advance to Zero movement, building a series of allied networks and working in partnership with people with lived experience to demonstrate that it is possible to make homelessness rare, brief and once-off.

9.5. Prisoners living with a disability

According to the AIHW's 2022 report on the health of people in Australia's prisons, as of 30 June 2022, there were about 40,600 people in prison, with First Nations people over-represented (32% of the prison population, but only 3.2% of Australia's population). Fifty-two per cent (%) of prison entrants reported chronic physical health conditions, such as arthritis, asthma, back pain, cancer, cardiovascular disease, kidney disease, diabetes, osteoporosis and pulmonary disease. Almost two in five (39%) reported that a long-term health condition or disability

affected their participation in everyday activities (30%), in education (16%) or in employment (21%), particularly amongst women.

Australian principles governing the management of prisoners assert that individuals are supposed to be supervised in ways that respond to their particular needs. It should recognise the impacts of trauma and victimisation, provide access to appropriate services, including health, interpretation and disability supports. Prison care is supposed to be culturally safe and respectful (Queensland Government, 2018). The reality for people living with a disability, including those with SCI, is, however, rather different. People living with disabilities, especially those with cognitive disabilities, are over-represented in prisons, yet the prisons are not designed for them. In 2020, Human Rights Watch published Australia: Deaths of Prisoners with Disabilities, which provided information on a report, *"He's never coming back"*, on people with disabilities dying in Western Australia's prisons. Below, we identify additional challenges that prisoners living with SCI may face in prison:

- **Systemic violence:** Systemic violence is the overarching problem for all prisoners, let alone prisoners with disabilities. Those prisoners with cognitive and psychosocial disabilities experience the worst violence and health sequelae. However, those with physical difficulties, including prisoners with SCI – whether in wheelchairs or dealing with other mobility challenges – are also disproportionately victimised in prisons, whether systemically or interpersonally (Human Rights Watch, 2020).
- **Inappropriate design:** Architecture is the dominant mode of systemic violence. Few prisons are designed to be accessible. By way of example, in 9 of the 14 prisons investigated by Human Rights Watch, there were no accessible toilets, showers, or kitchen facilities. Commonly, there were no shower chairs for people with physical disabilities. Conditions were often unsanitary, especially for those with disabilities. Some prisoners reported being left lying in their own faeces and urine for hours while waiting to access toilets. They also describe the humiliation of having to wear adult nappies. Prisons were often not supplied with the equipment necessary to support people with disabilities. Insufficient staffing and staff untrained in the needs of prisoners with disabilities further contribute to poor conditions of life. The result is that even simple tasks such as using the toilet or going to bed become painful and humiliating. In those prisons, prisoners and staff remarked that they either had to wait or else to shower, urinate or defaecate in humiliating conditions.

  One Aboriginal man who required a wheelchair reported that his chair could not fit into toilets and so he had to urinate into a bottle. Another commented on how hard it was to get into and out of bed because the beds are so low, and that *'Nothing is set up for a person in a wheelchair.'* At a prison farm, one inmate with a physical disability had to struggle uphill with his cane twice a day to get his medications. Each walk took 40 minutes.

- **Poor access to disability supports in prison:** In 2022, Doyle and colleagues (2022)in *'There's not just a gap, there's a chasm': The boundaries between Australian disability services and prisons'* report, which investigated NDIS support, wrote:

"This study provides important insights into the experiences of people with disability during their interactions with the Australian criminal justice system. It reveals that individuals with disability in prison are often largely invisible to correctional authorities due to inadequate identification processes. Even when people with disability are identified, prisons are not designed to accommodate this cohort and staff are often untrained on how to provide the necessary accommodations to support these individuals. Our study also shows that while the relevant NDIA policy makes clear that some NDIS disability supports may be provided while a person is incarcerated, there remains confusion and inconsistent practices regarding what types of support are possible or permissible. Finally, our findings confirm that a functioning NDIS plan is important not just for the support it provides to individuals, but also because provision of support can help prevent some people encountering the criminal justice system in the first place. Despite this, some individuals, including formerly incarcerated people, experience issues in accessing the scheme, navigating its complex processes, and using their plans" (p. 24).

Anna's story: Ableism and violence in prison

"Anna,' a woman living with a physical disability, was placed in solitary confinement for seven days and was left bed-ridden, unable to raise herself without assistance. Prior to confinement, she used both crutches and a wheelchair, but without daily exercises, she quickly lost her ability to use the crutches and thereby experienced further loss of mobility, in addition to mental health sequelae such as insomnia and nightmares.

In addition to systemic violence, interpersonal violence disproportionately affects people living with disabilities in prisons. They experience verbal humiliations, contempt and a variety of stigmatising behaviours from prison staff and other prisoners. They are at much higher risk of beatings, rapes, sexual assaults and a variety of other forms of sexual harassment and violence due to perceptions that they are weaker than the rest of the prison population.

In the prison systems, structural and interpersonal ableism intersect with ageist, racial and gendered oppressions to produce considerable avoidable physical and mental morbidity, along with disproportionately high mortality rates, for prisoners living with spinal cord injuries and other disabilities."

"He's Never Coming Back": People with Disabilities Dying in Western Australia's Prisons (HRW)

According to the NDIS website (accessed in 2025), some progress has been made. Anyone with a disability who becomes involved in the justice system has the same rights as anyone to

become or remain a NDIS participant. To this end, 'being involved in the justice system' includes the following circumstances:

- In custody in a correctional facility, such as a prison, remand centre, youth detention centre or secure mental health facility on remand, awaiting or following sentencing
- Required by a court order to regularly report to a correctional or community correctional agency when on bail, probation or parole
- Serving a community-based order or are on a leave of absence order or therapeutic leave, and
- Under forensic orders, which may include restrictions on your movements or other requirements, such as drug testing or attending prescribed treatment.

The NDIS is responsible for providing disability-related supports to help meet an individual's needs while someone is involved in the justice system. State justice systems are, however, responsible for:

- Imposing conditions on any individual who may be considered a risk while in the community
- Law enforcement and ensuring any participant released from a justice setting complies with any supervised orders or conditions that may be in place
- Taking action if someone re-offends or is considered a risk of re-offending
- Protecting others if a participant has a known criminal history, and
- The NDIS provides a guideline on the justice system that explains what we consider and how we make decisions in accordance with the legislation. The NDIA Justice Liaison Team has a network of Justice Liaison Officers (JLOs) who work collaboratively with state and territory government agencies to support people with a disability in custody and to transition back into the community.

Important resources and information: Prisoner support groups

- Sisters Inside: Supports criminalised women, girls, children and families
- Pivot Support Services: Prisoners, disability and the NDIS
- Myway Disability and Aged Care: Supports NDIS participants in the justice system
- New South Wales Government: Corrective Services NSW, and
- Queensland Government Prisoners of Concern: Custodial Operations Practice Directive.

- **Additional considerations for intersections of First Nations identity, disability and the justice system:** Although **Chapter 8** addressed First Nations people and disability in general, including spinal injuries, it did not consider individuals in the justice system. Information on this topic is scant (Walsh & Puszka, 2021). While exact statistics are difficult to obtain, it is recognised that those who are incarcerated and who have contact with the criminal justice system, particularly Indigenous people, have high rates of disability, including cognitive disability, hearing loss and mental health issues.

Research: Supporting incarcerated Indigenous people

Research recommends that Indigenous people with disabilities in contact with the criminal justice system would benefit from the following (Walsh & Puszka, 2021):

- Be Indigenous-designed, led and owned
- Identify a person's disability and needs using culturally appropriate definitions and tools
- Court models that are not only culturally appropriate but also disability or needs-focused
- Offer disability-appropriate and culturally appropriate diversionary options
- Facilitate connection to Indigenous country, culture and community
- Be person-centred and build agency, strengths and positive identity
- Protect human rights

- Break down communication barriers
- Provide mentors and support personnel
- Offer education and training for those working in the justice system and provide support upon release from prison.

According to Walsh & Puszka (2021), the sources within this review highlight the overall inadequacy of the justice systems in the Western settler states of Australia, Canada, New Zealand and the USA in responding to the needs of Indigenous people with disabilities. The 'tough on crime' attitude appears to be failing and harming these people. There have been numerous calls for corrective legislative, policy and system reform.

In conclusion, a sustained focus on treatment, care, connection, healing and community-based rehabilitation, rather than isolation, deprivation, rectification, punishment or mistreatment, is strongly recommended. Youth, women and Indigenous people with disability or complex needs, particularly those who are victims or witnesses of crime, experience significant and compounding disadvantage. Effective, culturally safe and disability-informed responses for these groups remain limited and are urgently needed.

9.6. Migrants

The next few sections consider migrants, refugees and asylum-seekers with disabilities in the Australian context. Before proceeding, it might be useful to explore the legal status of each of these categories of individuals in the Australian context.

Important information: Refugee, asylum-seeker or migrant?

What is the difference between a refugee, asylum-seeker and migrant?

Understanding these terms is important because people often use them interchangeably, even though they describe very different experiences and legal realities.

This resource clearly outlines how refugees are people forced to flee their country due to persecution or danger, asylum-seekers are individuals waiting for their protection claim to be assessed, and migrants are people who move by choice to improve their life circumstances. It highlights why using the correct terminology is essential to ensuring rights, protections and compassionate public understanding.

The same intersectional considerations that shape the experiences of life and access to public services of marginalised populations in the community also apply to migrants, asylum-seekers and refugees. The differences between these populations, however, generate other issues. Some additional considerations for a person living with SCI who is also a migrant include:

- **Language barriers and considerations:** There is no formal legal definition of an international migrant, but there is general agreement that this is someone who changes their country, irrespective of their reason for migration or legal status. The experiences of migrants vary considerably. A migrant from English-speaking countries, such as Canada, the UK, the US and New Zealand, has a dramatically different experience from an immigrant from China, Bangladesh, Sudan, Iraq, Russia or Colombia. Having English as a native language is an advantage, as is having origins in relatively similar legal and cultural traditions. As challenging as it is, navigating bureaucracies and accessing social and economic services is made markedly easier if one can converse in English
- **Changes in support networks and culture shock:** When one is an immigrant and a member of a culturally and linguistically diverse (CALD) community, while also having a disability such as SCI, the experiences are more difficult. Immigration involves leaving behind social and family support networks and problems, at least initially, of social isolation for the immigrant. CALD individuals thus need to navigate the tensions between their cultural identities and the norms, expectations and demands of Australian culture(s), and
- **Stigma and discrimination:** This is especially the case when individuals carry perceptible stigma, such as skin colour, dress, language, or gender; a person may experience more or less intense discrimination, both systemic and interpersonal (Agency for Clinical Innovation, n.d.). Those living with SCI experience additional stigma and are also subjected to the discriminatory effects of Australia's migration laws. On one level, they may be excluded from the country altogether. At the time of a visa or permanent residency application, their disability may be grounds for outright exclusion from the state. People with disabilities may not be accepted into Australia since they do not meet the health requirements for immigration. For example, if the condition imposes significant healthcare and community service costs on Australia, the visa application is likely to be denied. Immigration and Citizenship Australia currently defines the 'Significant Cost Threshold' as a cost that is 'higher than the average health and community services cost for an Australian,' and sets this threshold currently at $86,000 for five years. Such a refusal is grounded in the idea that the asylum-seeker, refugee or migrant must not 'prejudice access' to healthcare or community services that are already in short supply. According to the National Ethnic Disability Alliance (NEDA), if an asylum-seeker, migrant or refugee with SCI is perceived to be too expensive, their application will be refused.

Important information: Australia's migration health requirements

National Ethnic Disability Alliance (NEDA): Factsheet: An overview of Australia's migration health requirements and how they impact people with disability and/or health conditions. As the NEDA Factsheet notes,

> Australian health requirements for immigration and visas are discriminatory since they set standards for health which those living with a disability either do not or cannot meet.'

On another level, immigrants may be marginalised in Australia. In addition to the formal legal requirements, they face the same ableist stigma that Australians living with disabilities face, which may then be compounded by racist and poor-bashing stigma and other discriminatory attitudes and behaviours. These can result in the denial of visas, but can also intensify their difficulties in accessing healthcare, food, housing, and other necessities once they have been processed and accepted in the Australian system.

As the NDIS is aimed at Australian citizens, permanent residents, and New Zealand citizens who hold a Protected Social Category Visa in Australia, the services can be used by migrants and refugees who have attained permanent resident status. It cannot, however, be accessed by asylum-seekers, nor is the NDIS available for refugees or migrants in Australia on other visas. Nonetheless, those with disabilities from CALD communities who are permanent residents and citizens have access to the NDIS scheme, subject to the limitations that accompany poverty, i.e. those who are poor, homeless or prisoners, as noted in the prior description of the challenges for incarcerated people with difficulties. Disability advocates and experts say cultural stigma and migration laws leave migrants living with disabilities further excluded and marginalised.

Media stories: Migrants and disability

- What's Australia Really Like for Migrants with Disability? (24 March 2025): SBS English explores the experiences of migrants with disability, highlighting the challenges they face in navigating support systems, employment and inclusion, and

- "Almost Double the Rate of Hostility and Violence", How Ableism Impacts People with Disability (29 September 2025): SBS English examines how everyday ableism contributes to higher rates of discrimination, violence and exclusion for people with disability across Australia.

Podcast: Poverty and disability

SCIA's Have the Nerve's Continence Poverty, the cost when you can't afford (Episode 30, 20 October 2023): It investigates the cost of catheters and how some groups of people may not receive funding for this necessity. This can lead to catheter reuse, which has health implications, including kidney failure.

9.7. Refugees and asylum-seekers

According to the United Nations High Commissioner for Refugees (UNHCR), the UN Refugee Agency, a refugee is someone who has been forced to flee his or her country because of persecution or violence. A refugee has a well-founded fear of persecution for reasons of race, religion, nationality, political opinion or membership in a particular social group. Most likely, they cannot return home or are afraid to do so. War and ethnic, tribal and religious violence are leading causes of refugees fleeing their countries.

Important information: Refugees

- The Australian Government's Settle in Australia website provides support for refugees and migrants in terms of transport, education, healthcare (including disability) and language services. There is a MyAus App that can be set up in one of 20 languages
- Refugees are provided with a visa and are entitled to live, work and study in Australia. They may apply for permanent residency and, ultimately, citizenship. While refugees living with SCI on Temporary Protection and Safe Haven Enterprise Visas are not entitled to NDIS benefits, those on Perma-

nent Humanitarian Visas can access the NDIS, and
- Refugee Council of Australia: Barriers and exclusions: Support needs of challenges of newly arrived refugees with a disability. People with a disability from a refugee background have rights not only under general human rights law, but are also protected under the Refugee Convention and the CRPD. Newly arrived refugees with a disability are entitled to full and equal participation in Australia, not just equal to other people with a disability, but ultimately in line with the whole community.

Research: Disability and culture in Australian refugee communities

King and colleagues' (2016) research, Disadvantage and disability: Experiences of people from refugee backgrounds with disability living in Australia, explored how disability is culturally constructed in the family context for people of refugee backgrounds. Key issues raised by participants (either those living with a disability or their carers), which, in many instances, led to social isolation and unmet healthcare needs, included:

- The lived experiences of stigma in their country of origin, as disability in many Asian and African countries is seen as *'karma'* or a curse. For some, this continued within their community of origin in Australia
- Difficulty navigating the government and non-government services (knowledge gap and lack of support), with communication and language barriers contributing to delays and service gaps and access barriers, and
- Not understanding the transport system, as well as its expense.

Media story: Australia's one millionth refugee

In late 2025, Australia welcomed its one millionth refugee.

According to the UNHRC, an asylum-seeker is someone who is seeking international protection. In Australia, it is someone who has entered the country (legally or otherwise) and applied for protection. Just like people who are considered refugees, there are two main pathways for asylum-seekers in Australia:

- **Onshore protection applications:** For those who apply for asylum after arriving in Australia, either by air or by sea, and
- **Offshore processing:** For those who arrive by boat without a valid visa, they are often transferred to an offshore processing centre in Nauru or Papua New Guinea while their claims are processed. Asylum-seekers are not guaranteed refugee status. They must go through a lengthy application and assessment process. During this time, their legal status is uncertain. This means these people have restricted access to work, education and social services compared with recognised refugees. Australia, like many countries around the world, has 'illegal immigrants'. Some are students who overstay their study visas, while others who arrive by boat are sent to Nauru.

Personal injury claims by immigration detainees have documented physical and psychological injuries among approximately 17,000 refugees who sought asylum in Australia after arriving by boat over a 12-month period (O'Connor, 2013). In Australia, a Protection (subclass 866) visa allows a person who faces a real risk of significant harm or persecution in their home country to live permanently in Australia. To be eligible, an individual must be physically present in Australia, have arrived on a valid visa, and have cleared immigration upon arrival.

Asylum-seekers commonly have a range of challenges related to their forced displacement from their home country. They have never left voluntarily and have often either personally experienced torture or violence. Alternatively, they may have witnessed torture, sexual violence and murder inflicted on family members, friends or wider community members. Physical and psychological trauma commonly accompany the experiencing and witnessing of such violence. Having escaped their country of origin, they experience a sense of disconnection from family, friends, and their larger communities. The journey to their current country is often highly dangerous, with deaths and further physical and sexual violence accompanying it.

In addition to this trauma, they arrive in a foreign country and may be subjected to additional distress related to:

- The asylum-seeking or migration process
- Possible time spent in immigration detention or processing centres
- Accessing services and supports, including the NDIS and Medicare
- Finding employment, particularly if any professional qualifications are not recognised in Australia, and
- Language and communication issues.

Video: Asylum-seekers and protection visas

Watch this video from the Australian Department of Home Affairs to understand Australia's Protection Visa process for asylum-seekers.

Refugees and asylum-seekers, however, share the challenges experienced by CALD migrants. Below, we provide additional challenges faced by this group relevant to individuals with SCI:

- **Negative or traumatic experiences with health and social care systems:** A distinguishing feature of asylum-seekers' experiences, however, is that they may fear police, immigration and customs officials and healthcare workers due to their experiences either in their home country, in transit, or upon arrival in Australia. Such fears can compound their access difficulties and function as an additional barrier beyond any structural or interpersonal challenges. If asylum-seekers have entered Australia unlawfully, they are required to be held either in immigration or community detention. Some are transferred out of the detention systems on bridging visas, but others may be detained indefinitely, and
- **Limited access to healthcare:** As asylum-seekers, unlike refugees, have not yet been processed through Australia's immigration system, they have fewer possibilities of access to healthcare. For example, they are not entitled to Medicare, education or other important benefits and cannot yet work. It may take years as an asylum-seeker before one is recognised as a refugee. According to the Australian Human Rights Commission, common health needs of asylum-seekers and refugees include: *"torture and trauma counselling, access to family tracing services, access to legal and migration advice, interpreting and translation, health and mental health care, and access to educational and recreational activities."* SCI would exacerbate these needs, both to the greater likelihood of the denial of a visa due to the health costs of supporting asylum-seekers with SCI, as well as due to the interaction of stigma and inaccessible architecture and transportation. Despite their needs being high, asylum-seekers are not entitled to access NDIS benefits.

Important resources: CALD

- Amparo Advocacy Inc: Supports people from CALD backgrounds with disabilities who are being treated unfairly, abused, or discriminated against by speaking, acting, and writing on their behalf to protect their basic needs
- Amparo Advocacy – NDIS CALD Strategy 2024–2028: Aims to make it easier for CALD communities to participate in the NDIS, ensure NDIS plans better reflect the needs of CALD participants, and improve the overall NDIS experience. The Strategy is available in more than a dozen languages
- Refugee Council of Australia: Provides a broad range of resources, including fact sheets on housing, renting and living in Australia, education for refugees and support for international refugee programs
- Asylum Seeker Resource Centre (ASRC): Offers comprehensive support, including a foodbank, community meals, a Healthcare Centre in Victoria with GPs, immunisations, pharmacy support, eye care, a women's clinic, mental health services, Legal Aid and other advocacy programs. Also provides updates on law changes affecting migrants, refugees and asylum-seekers
- My Aged Care – Support for CALD Communities: Information and services for people from culturally, ethnically and linguistically diverse backgrounds, and
- My Aged Care – Support for Aboriginal and Torres Strait Islander People: Resources for First Nations people, including members of the Stolen Generation.

Santiago Martinez's story: Love for sport and others

Speak My Language: Listen to the stories of individuals from diverse communities living with a disability, including **Santiago Martinez,** who is wheelchair-bound and loves his sport.

Clinical resource: Healthcare for CALD individuals and refugees

- Culturally and linguistically diverse (CALD) communities, including refugees, humanitarian entrants

and other permanent migrants, need to be recognised as priority populations for suicide risk, with rates reported at 1.7 times higher than other permanent migrants, and
- Delivering healthcare to refugee communities in regional NSW provides guidance on supporting them through culturally responsive, trauma-informed care.

Key Take-aways

- While ***intersectionality*** is part of everyone's life and is part of our identities, it is particularly important in terms of the health and well-being outcomes of many of Australia's 'communities' who, for one or other reason, may be marginalised or underserved. Failure to understand why certain populations are excluded from healthcare means we cannot envision workable strategies for the inclusion of people living with SCI, whether they be part of the LGBTIQ+ community, neurodiverse, homeless and unhoused, prisoners or refugees and asylum-seekers
- Being 'different' often results in discrimination. Even today, this is true for the LGBTQIA+ community and neurodiverse individuals who are known to face numerous challenges, such as stigma, leading to poor psychological well-being. Having a disability can add another layer to stigma and discrimination. Support comes in many forms, particularly from their own community, but also from legislation
- Australian prisons are not sufficiently geared to recognise or accommodate prisoners with disabilities. It would appear, however, that those who qualify for the NDIS should receive support
- The status of migrants, asylum-seekers and refugees differs in terms of disability. Despite Australia having a Discrimination Act that includes no discrimination against people living with disabilities, a migrant may not be granted a visa if it is deemed that their disability will result in high healthcare costs. For refugees who have often fled war, conflict and violence, accommodation is made for disability, including SCI. They have access to the NDIS. Asylum-seekers with SCI, on the other hand, who are often held in detention offshore, have no access to the NDIS and so will receive minimal support, if any, for their disability
- The experiences of migrants and refugees with a disability in Australia can be isolating, depending on the stigma associated with the disability, such as the notion of karma, and
- Refugees and many migrants, many of whom may be CALD, have reported unmet healthcare needs because of communication and language barriers, as well as difficulty navigating government services and transport systems.

In the next chapter, **Chapter 10,** we explore factors such as discrimination, abuse and violence that may contribute to poorer health and well-being outcomes for some members of the groups or 'communities' we described in this Chapter who live with a disability, including SCI.

Reminder: Relevant chapters

- **Chapter 1:** The Australian resources provided in this chapter would be useful for anyone who is able to return 'home' after SCI
- **Chapter 2:** The impact of SCI on the body, including complications, is important for anyone who has not studied the body. There are hopefully explanations and Australian resources that are easy to understand
- **Chapter 3:** Five pillars of good health and well-being are universal but may be difficult for some groups of people to access, such as prisoners who may not have control over what they eat, the quality of their sleep and exposure to sunlight. For refugees and migrants, cost may be a factor
- **Chapter 4:** Documenting health and well-being may be difficult for some, particularly if English is not their first language
- **Chapter 5:** Studying, socialising, and working would certainly be priorities for many marginalised groups or communities. Their intersectionality might hinder inclusion
- **Chapter 6:** Ageing with SCI would be relevant to all marginalised groups described in **Chapter 9**
- **Chapter 7:** Age is part of the diversity of the groups discussed in Chapter 9. Many migrant families arrive with young children, some of whom may have a physical or cognitive disability
- **Chapter 8:** Many migrants and refugees move to rural or regional areas where health services are more distributed, and so, as minorities, with the added layer of disability, they may become further marginalised
- **Chapter 10:** Cultural and ethnic differences, sexual orientation and being cognitively different may lead to discrimination for those with a physical impairment.
- **Chapter 12:** For many, public transport is not always safe, plus this chapter also discusses wheelchair-assisted taxis (WATs) and the trials and tribulations of flying with SCI
- **Chapter 13:** Most people need surgery and anaesthesia at some stage of their lives, but are more likely to have a chronic condition. Consent is required, so there may be language issues or not wanting to disclose certain 'things' through mistrust or unfamiliarity
- **Chapter 14:** Spiritual health is part of good health and well-being for most individuals
- **Chapter 15:** Many communities, including migrant and LGBTQIA+ communities, share a love of sport, which may become part of their identity
- **Chapter 16:** As diversity among research participants improves health outcomes for everyone, Chapter 16 provides information about participating in SCI clinical trials
- **Chapter 17:** Impact of a changing climate, as children are vulnerable to heat, as are those living with CSI, particularly if the person cannot regulate their body temperature or has mobility issues during adverse weather events. Having an emergency plan is crucial, and
- **Chapter 18:** Health professions education needs to be inclusive of Australia's diversity if everyone is to have access to healthcare and a decent quality of life. This includes admission to health professional programs to ensure that health professionals working in the community reflect this diversity.

References

Agency for Clinical Innovation. n.d. *Culturally and linguistically diverse communities.* https://aci.health.nsw.gov.au/projects/universal-aftercare/priority-populations/cald.

Aldridge, R. W., Story, A., Hwang S. C., Nordentoft M., Luchenski, S. A., Hartwell, G, Tweed, E. J., Lewer, D., Katikireddi, S. V., Haywards, A. C. (2018). Morbidity and mortality in homeless individuals, prisoners, sex workers, and individuals with substance use disorders in high-income countries: a systematic review and meta-analysis. *Lancet, 391*(10117), 241-50. http://dx.doi.org/10.1016/S0140-6736(17)31869-X.

American Psychiatric Association. (2022). *Diagnostic and statistical manual of mental disorders* (5th ed., text rev.). https://doi.org/10.1176/appi.books.9780890425787

American Psychological Association. (2023a). *Privilege. In APA dictionary of psychology*. https://dictionary.apa.org/privilege

American Psychological Association. (2023b). *Inclusive language guide* (2nd ed.). https://www.apa.org/about/apa/equity-diversity-inclusion/language-guide.pdf

Anderson, K. D. (2004). Targeting recovery: Priorities of the spinal cord-injured population. *Journal of Neurotrauma*, *21*, 1371-1383. https://doi.org/10.1089/neu.2004.21.1371

Australian Bureau of Statistics (ABS). (2024). *Estimates and characteristics of LGBTI populations in Australia.* https://www.abs.gov.au/statistics/people/people-and-communities/estimates-and-characteristics-lgbti-populations-australia/latest-release.

Australian Institute of Health and Welfare (AIHW). (2018). *Sleeping rough: A profile of Specialist Homelessness Services clients*. https://www.aihw.gov.au/getmedia/96b4d8ce-d82c-4149-92aa-2784698795ba/aihw-hou-297.pdf?v=20230605173201&inline=true.

Australian Institute of Health and Welfare (AIHW). (2022). *The health of people in Australia's prisons* https://www.aihw.gov.au/reports/prisoners/the-health-of-people-in-australias-prisons-2022/contents/human-function-and-disability

Australian Institute of Health and Welfare (AIHW). (2024). *People with disability in Australia. Homelessness Services.* https://www.aihw.gov.au/reports/disability/people-with-disability-in-australia/contents/housing/homelessness-services

Australian Institute of Health and Welfare (AIHW). (2025) *Health of people experiencing homelessness*. https://www.aihw.gov.au/reports/australias-health/health-of-people-experiencing-homelessness

Australian Government Immigration and Citizenship. (n.d.). *Refugee category visas*. https://immi.homeaffairs.gov.au/visas/getting-a-visa/visa-listing/refugee-200

Australian Human Rights Commission. (n.d.). *Asylum Seekers and Refugees*. https://humanrights.gov.au/our-work/rights-and-freedoms/publications/asylum-seekers-and-refugees

Ayhan, C. H. B., Bilgin, H., Uluman, O. T., Sukut, O., Yilmaz, S., & Buzlu, S. (2020). A systematic review of the discrimination against sexual and gender minority in health care settings. *International Journal of Health Services*, *50*(1), 44-61. https://journals.sagepub.com/doi/10.1177/0020731419885093

Blatt, M. (2025). To empty a wheelchair: Looking beyond the hospital doors. *Academic Medicine, 100*(7), 871. DOI: 10.1097/ACM.0000000000006016. https://www.ingentaconnect.com/content/wk/acm/2025/00000100/00000007/art00026

Brener, L., Broady, T., Cama, E., & Treloar, C. (2022). The impact of sources of stigma on health care avoidance among gay and bisexual men in Australia. *AIDS Care*, *35*(5), 663-671. https://doi.org/10.1080/09540121.2022.2057410

Brown, C. O., Uy, J., & Singh, K. K. (2020). A mini-review: Bridging the gap between autism spectrum disorder and pain comorbidities. *Canadian Journal of Pain*, *4*(4), 37-44. https://doi.org/10.1080/24740527.2020.1775486

Brown, J. (Ed.). (2022). Privilege and power. In Introduction to social psychology. Maricopa Open Digital Press. https://open.maricopa.edu/socialpsychology/chapter/privilege/

Diversity Council Australia. (n.d.). *Intersectionality*. https://www.dca.org.au/resources/di-planning/intersectionality.

Doyle, C., Dodd, S, Dickson, H., Yates. S., & Buick, F. (2022). *'There's not just a gap, there's a chasm'. The boundaries between Australian disability services and prisons.* UNSW Canberra, Public Services Research Group, Australian Catholic University. https://www.unsw.adfa.edu.au/sites/default/files/documents/The_boundaries_between_Australian_disability_services_and_prisons_report_1.pdf

Glymour, M. M., Avendano, M., & Kawachi, I. (2014). Socioeconomic status and health. In: L. F. Berkman, I. Kawachi I., & M. M. Glymour. (Eds). *Social epidemiology* (pp. 17-62). Oxford University Press. https://www.researchgate.net/publication/281596223_Socioeconomic_Status_and_Health

Gmelin, J. H., De Vries, Y. A., Baams, L., Aguilar-Gaxiola, S., Alonso, J., Borges, G., Bunting, B., Cardoso, G., Florescu, S., Gureje, O., Karam, E. G., Kawakami, N., Lee, S., Mneimneh, Z., Navarro-Mateu, F., Posada-Villa, J., Rapsey, C., Slade, T., Stagnaro, J. C., Torres, Y., ... WHO World Mental Health Survey collaborators. (2022). Increased risks for mental disorders among LGB individuals: cross-national evidence from the World Mental Health Surveys. *Social Psychiatry and Psychiatric Epidemiology*, *57*(11), 2319-2332. https://doi.org/10.1007/s00127-022-02320-z

Haire, B. G., Brook, E., Stoddart, R., & Simpson, P. (2021). Trans and gender diverse people's experiences of healthcare access in Australia: A qualitative study in people with complex needs. *PLoS ONE, January*. https://doi.org/10.1371/journal.pone.0245889.

Human Rights Watch. (2020). *"He's never coming back": People with disabilities dying in Western Australia's prisons*. https://www.hrw.org/report/2020/09/15/hes-never-coming-back/people-disabilities-dying-western-australias-prisons

King, J., Edwards, N., Correa-Velez, I., Hair, S. & Fordyce, M. (2016). Disadvantage and disability: Experiences of people from refugee backgrounds with disability living in Australia. *Disability and the Global South*, *3*(1):843-864. https://dgsjournal.org/vol-3-no-1/

Kim, S. Y., Song, D. Y., Bottema-Beutel, K., & Gillespie-Lynch, K. (2023). Time to level up: A systematic review of interventions aiming to reduce stigma toward autistic people. *Autism*, *28*(4), 798-815. https://doi.org/10.1177/13623613231205915

Merrill, R. M., Lyon, J. L., Baker, R. K., & Gren, L. H. (2009). Attention deficit hyperactivity disorder and increased risk of injury. *Advances in Medical Sciences*, *54*(1), 20-26. https://www.scirp.org/reference/referencespapers?referenceid=1106019.

New South Wales Government Agency for Clinical Innovation. (n.d.) *Culturally and linguistically diverse communities*. https://aci.health.nsw.gov.au/projects/universal-aftercare/priority-populations/cald.

O'Connor, C. (2013). Personal injury claims for immigration detainees. *Precedent*, *116*, 24-29. https://www5.austlii.edu.au/au/journals/PrecedentAULA/2013/38.pdf.

Paul, K. I., & Moser, K. (2009). Unemployment impairs mental health: Meta-analyses. *Journal of Vocational Behavior*, *74*(3), 264-282. https://doi.org/10.1016/j.jvb.2009.01.001

Paynter, J., Sommer, K., & Cook, A. (2025). How can we make therapy better for autistic adults? Autistic adults' ratings of helpfulness of adaptations to therapy. *Autism*, *29*(6), 1540-1553. https://doi.org/10.1177/13623613251313569

Petty, S., Bergenheim, M.-L., Mahoney, G., & Chamberlain, L. (2023). Adapting services for autism: Recommendations from a specialist multidisciplinary perspective using freelisting. *Current Psychology*, *42*(9), 7489-7500. https://doi.org/10.1007/s12144-021-02061-3

Queensland Government. (2018). *Guiding principles for corrections in Australia (Revised 2018).* Queensland Government. https://www.ics.act.gov.au/__data/assets/pdf_file/0009/1355805/guiding_principles_correctionsaustrevised2018.pdf

Rosendale, N., & Singh, V. (2021). Spinal cord injury in sexual and gender minority individuals. *The Journal of Spinal Cord Medicine*, *44*(5), 687–689. https://doi.org/10.1080/10790268.2021.1970886

Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. (2023). *Final report: Inclusive education, employment and housing. Part C.* https://disability.royalcommission.gov.au/system/files/2023-09/Final Report – Volume 7, Inclusive education, employment and housing – Part C.pdf

Schultz, K. R., Mona, L. R., & Cameron, R. P. (2022). Mental health and spinal cord injury: clinical considerations for rehabilitation providers. *Current Physical Medicine and Rehabilitation Reports*, *10*(3), 131-139. https://doi.org/10.1007/s40141-022-00349-4

United Nations High Commissioner for Refugees. (n.d.). *Who we protect: Asylum seekers*. https://www.unhcr.org/au/about-unhcr/who-we-protect/asylum-seekers

United Nations High Commissioner for Refugees. (n.d.). *What is a refugee?* https://www.unrefugees.org/refugee-facts/what-is-a-refugee/

Walsh, C. & Puszka, S. (2021). *Aboriginal and Torres Strait Islander voices in disability support services: A collation of systemic reviews*. Centre for Aboriginal Economic Policy Research (CAEPR), Australian National University. https://gecko.healthinfonet.org.au/uploads/resources/43636_43636.pdf

Wolbring, G. (2008). The politics of ableism. *Development*, *51*. 252-258. https://link.springer.com/article/10.1057/dev.2008.17

Zizzo J, Gater DR, Hough S, & Ibrahim E. (2022). Sexuality, intimacy, and reproductive health after spinal cord injury. *Journal of Personal Medicine*, *12*(12), 1985. https://doi.org/10.3390/jpm12121985

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Chapter 10. Dignity, Discrimination, Abuse, Violence, Relationships, Intimacy and Fertility

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> *"Too many of us see ourselves based on our wheelchairs. We have to see ourselves as complete people. All of us have been [judged] based on the color of our skin, or what we believe, or where we pray, or what we've done. Very few people are able to look into our eyes and see our heart and soul. Make a heartfelt commitment to never place that kind of judgment on someone else. When you encounter another, look into their eyes, acknowledge their humanity. That alone will make you feel better."*
>
> **Dan Gottlieb**, *TSCI*, psychologist, health educator

SCI can have far-reaching effects beyond mobility and sensation, deeply influencing a person's dignity, their confidence and capacity to engage in intimate relationships and affecting fertility. SCI also puts them at greater risk of discrimination, all forms of abuse and violence. For individuals living with SCI, navigating these aspects of life often involves confronting physical, emotional and societal barriers. Health professionals, carers and all individuals interacting with persons living with SCI need to understand the complex interplay between neurological injury and psychosexual health to provide compassionate, informed and respectful care. Promoting autonomy, legally safeguarding against abuse and supporting healthy relationships and reproductive choices are essential to preserving the dignity and well-being of individuals living with SCI.

Video: Misconceptions about driving

SCIA's Can You Ask That? "You can drive?" and other misconceptions (27 Jan 2025): In this episode of *Can You Ask That?,* **Dan, Heidz** and **Rob** discuss common misconceptions about wheelchair users, from "You can drive?" to assumptions about relationships or knowing every other wheelchair user. They encourage viewers to consider whether they would ask these questions of an able-bodied person.

Key Topics in this Chapter

- What does dignity mean for individuals living with SCI, particularly in the healthcare system
- Discrimination, abuse and violence statistics relating to disability in Australia
- Status of Australia's Disability Strategy 2021-2032 in terms of the Safety, Rights and Justice Outcome
- Risk of abuse, harassment and violence, including financial, physical, emotional and sexual, and
- Relationships, intimacy and fertility.

10.1. Being treated with dignity means being included

What does 'being treated with dignity' mean? In a recent scoping review that sought to determine the definition of dignity in relation to disability, including the extent to which the current definitions were inclusively developed, Chapman and colleagues (2024) identified diverse definitions of 'dignity', but did find that it was defined from a *utilitarian* perspective, emphasising affordances and barriers rather than offering robust theoretical constructs.

> *"From a human rights point of view, we refer to how the concept of Dignity is captured in the UN Convention on the Rights of Persons with Disabilities as a touchstone for this concept. The first general principle for Convention (outlined in article 3 a) is: 'Respect for inherent dignity, individual autonomy*

including the freedom to make one's own choices, and independence of persons'" **Siobhan Tierney** (Reviewer).

It is worth noting that in Chapman and colleagues' (2024) review, none of the studies they used mentioned inclusive research methods, indicating that the studies were not designed in collaboration with people living with disability. The authors concluded that:

> *"The absence of inclusive research methods hinders the development of a comprehensive definition of dignity that is accepted by and relevant to people with disability. Engaging with both theoretical and empirical perspectives of dignity is crucial to develop a meaningful and inclusive definition, which can inform interventions and policies that enhance dignity for people with disability across diverse settings and contexts"* (p. 5404).

The authors included the following implications of their findings:

- Inclusive research methods in disability research should be a priority to better shape research, study design and outcomes
- The absence of inclusive research methods hinders the development of a comprehensive definition of dignity that is accepted by and relevant to people with disability
- Dignity concerns in healthcare settings for people with disability need to be addressed
- Health professionals in rehabilitation should advocate for person-centred approaches, improved communication and increased accessibility to create dignified healthcare, and
- Rehabilitation researchers and practitioners can play a pivotal role in advocating for social justice and equity by supporting policies and interventions that foster inclusive practices, dignity and equitable opportunities for people with disability.

Research: What is dignity for people living with SCI?

In Chapman and colleagues' (2023) study on dignity and the importance of acknowledging personhood, the researchers used an inclusive approach called Extreme Citizen Science, in which people living with disability were not just participants. They helped design and lead the research. Data were collected through online surveys with 17 participants and focus groups with five participants, some of whom also did the survey. Participants shared personal stories about when they felt dignified or undignified, especially in healthcare and public settings. In their view, dignity comes from being seen and treated as a full human being, not just as a 'patient' or a 'disabled person', which means being listened to, having control over decisions and being respected for who they are. The following advice was offered, which could perhaps become the five 'cornerstones' of dignity in healthcare:

Five ways to support dignity

1. **Acknowledge personhood:** Treat people with disabilities as individuals with value and rights and do not ignore or talk over them
2. **Recognise people as decision-makers:** Let them make choices about their own lives and don't assume others, such as carers or doctors, know better
3. **Ensure access to information:** Provide clear, accessible information so people can make informed decisions and use formats, such as captions, plain language or assistive technology
4. **Respect privacy:** Avoid discussing personal or medical details in public and respect both physical and emotional boundaries, and
5. **Remove barriers to accessibility and inclusion:** Make environments and systems, such as transport, healthcare and education, accessible. Inclusion is not just physical. It is about feeling welcome and safe and not being marginalised.

Participants also provided examples of when dignity is denied, especially in healthcare, which can lead to feelings of shame, frustration and even avoidance of healthcare. Being:

- Talked about instead of talking to
- Ignored or dismissed, and
- Faced with inaccessible environments or services.

Chapman and colleagues (with **Dinesh Palipana** as a co-author) followed up on their 2023 work, publishing '*Understanding patient and staff perspectives on dignified rehabilitation care experiences*' in 2026, which explored the challenges of undignified care through the personal experiences of individuals living with SCI, both as patients and as staff, in an inpatient rehabilitation unit. The authors used a ***Generative Co-design Framework for Healthcare Innovation***, specifically reporting on the pre-design phase, semi-structured interviews were conducted with 18 patients and 20 staff members over about five months. Patient interviews were conducted while they were in the hospital and after discharge. The major findings included:

- Dignity was experienced through interactions influenced by people, infrastructure and policies
- Participants defined dignity as being acknowledged and respected as people or the acknowledgement of personhood
- While many patients reported positive, dignified experiences, others reported undignified, but necessary care activities, and
- Staff and patients highlighted the need for flexible, person-centred policies and identified practices that enhanced dignity, including validating patient choices, respecting privacy and ensuring informed decision-making. Despite some systemic challenges, staff showed a strong commitment to dignified care.

Research: Experiences of inclusion and recognition in different countries

In 2025, Leiulfsrud and co-researchers published a study comparing the experiences of inclusion and recognition amongst Norwegians, Dutch, and Australians living with SCI, using the core questionnaire of the International Spinal Cord Injury Community Survey (InSCI Community Survey). For their research, they

used two types of constraints (mobility limitations and negative societal attitudes to people living with a disability), with potential impacts on self-perceived inclusion and cognition. In terms of mobility, the researchers found that this was a substantially weaker predictor of self-perceived inclusion and recognition than experiences of negative attitudes towards them as people living with a physical disability. In both Norway and Australia, participants' sense of inclusion was dependent on their employment status. In the Netherlands, it was gender, in addition to mobility status and perceived negative attitudes from the environment, not employment, that explained differences in how people living with SCI perceive their inclusion in society. Overall, Norwegians reported higher perceptions of inclusion and recognition than the Australian and Dutch participants. The article confirms that there are significant physical barriers and obstacles for people living with SCI in all three nations to move around due to the degree of impairment, i.e. problems traditionally addressed in disability and equal access policy and in a vocabulary of accessible, usable and universal design, that is United Nations Article 9 on Accessibility as a mechanism to secure social inclusion in the UN Convention of Human Rights. At the same time, they found an even stronger social and cultural dimension, grounded in societal factors, shaping attitudes toward social recognition and perceptions of 'Self and Others'.

Research: Dignified care

Chapman and colleagues (2026) offered the following implications for dignified care in SCI rehabilitation:

- Although dignity can be subjective, patients in rehabilitation must be allowed to express their choices and exercise control, even when those choices cannot be realised
- Flexible, person-centred policies should be created to balance risk management, task-based care and improved patient outcomes
- Rehabilitation staff and executives must prioritise hiring staff with greater disability awareness and/or develop improved capacity-building and training, as these factors greatly influence patients' experiences of dignity, and
- Rehabilitation practitioners can play a pivotal role in advocating for policy changes and systemic reform that prioritise flexibility for their patients.

To conclude, the authors concluded that dignity is challenging to define and recommended that rehabilitation units and health systems cultivate more responsive care interfaces through flexible, person-centred policies, prioritise and hire staff with disability-aware attitudes, and embed dignity into organisational culture.

In his book,*Stronger*, **Dinesh** alludes to 'dignity' several times, particularly while in the healthcare system, such as when he was in hospital with just a sheet covering him, being showered naked and having a spontaneous erection while undergoing physiotherapy one day. The physiotherapist's response was dignified. In the video below, **Dinesh** also talks about vulnerability in hospitals and how easy it is to be sexually abused if one is unable to move.

Dinesh's story: Talking to Kurt Fernleigh about being a doctor and a patient

In this video, Dinesh Palipana on the challenges of being a doctor and a patient (One Plus One, ABC News), **Dinesh** chats to **Kurt Fearnleigh** (NTSCI) about loss of dignity and being vulnerable to potential sexual abuse in the early days of his SCI. He also talks about hope. In the video, **Kurt** comments about *"being born with an apology from the doctor".* By this, he meant that at his birth, the doctor apologised to his parents because he was not 'normal'.

When **Perry Cross** was asked what it means to be treated with dignity as a patient, he asked healthcare providers to communicate directly with the affected individual and to encourage the individual to become their own healthcare provider. He went on to say:

> *"Communication and shared decision-making should be a priority from the very start of our relationship".*

Additionally, below, **Perry Cross** reflects on what dignity and respect look like for health professionals who interact with people living with SCI. Many of his comments mirror the research findings summarised above:

Key recommendations: Perry's guidance for health professionals working with people living with SCI

"Please communicate directly with us: Talk to us, not about us

Please communicate directly with us, the individuals with SCI. Unless required for their healthcare role, we should be at the centre of all conversations, and be made aware of all aspects needed to manage our own health, independently, without having to rely on others to make any decisions

Good communication may take some time to develop. At the start, a patient is likely to be overwhelmed and not willing to discuss treatments or management plans. This [not being part of the decision-making] should be discouraged – Move slowly and help the patient develop a two-way conversation about their

treatment. Clinical consultations can be very 'matter of fact', such as "this is what has happened and this is how we will deal with it". Discussions are vital. It also takes time for the person to progress to become their own healthcare provider. Help them become experts on their health and management strategies and make decisions accordingly. Don't take "Yes, Doctor" as a response; encourage conversation, disagreement, questions and two-way communication.

Encourage us [those living with SCI] to be our own health providers through shared decision-making

We need to become our own healthcare providers. We need to manage our own health in a way that works for us. It is therefore not helpful to 'direct' us to something. Even if we say 'Yes' to all your suggestions, we should be encouraged to ask questions and provide our thoughts. The reason for this is that when the patient [us] does happen to disagree on a management strategy, it is not at all confrontational. The more items and plans are discussed, the more comfortable it will be when a disagreement arises.

Perry Cross provides the example of how he chose to avoid taking any medications early on after his SCI. This was (and still is) against the wishes, expertise and recommendations of his physicians and health teams. Yet, 30 years on, Perry remains healthy and happy. This type of decision is entirely the patient's choice, and even if it might be against best-practice guidelines, it should never be forced on patients. Work with SCI patients and decide what is best and most comfortable for them.

Encourage us to be hopeful and optimistic

It is appropriate to encourage us to be hopeful and optimistic. Talk to us about treatments and highlight potential research advances and innovation [such as the research described in **Chapter 16***]. Maintaining hope for a better future, better health and potential positive outcomes is vitally important, even in the most severe cases of SCI. With optimism and hope, the patient is more likely to maintain their strength, exercise, eat healthy and look after themselves. Linking up with groups, such as the* Perry Cross Spinal Research Foundation*, the* Christopher and Dana Reeve Foundation *and others, can bring those with SCI together as a community. People with hope are more productive and more willing to contribute to society. With the onset of AI and technology, those with SCI can become more integrated into society. This could even include full-time employment, such as editing articles and using AI to generate text. Remind patients that there are new opportunities each day. It is, however, difficult to begin these endeavours while in the hospital. Try to discharge us as soon as is feasible.*

In summary**,** dignity implies inclusivity, autonomy and active participation in decisions that impact their lives. That means recognising that an individual living with SCI is a person whose affliction does not define them. They are foremost a person who, through trauma (an accident or a fall) or through a non-traumatic event (a cyst or a tumour,) now has limited mobility and physiological changes in terms of how their body functions. Any decision about their body and their way of life requires consultation and shared decision-making. Their opinions matter when it comes to treatment options, regulatory frameworks and policies. Their voice and their lived and living experiences (LLEs) matter as they are the experts on their bodies and their lives.

Below are two examples of dignity. In the first video, dignity is personal, in the sense of not having to worry about bowel accidents.

Podcast: Listen to Emily's story

SCIA's Have the Nerve, I am more than my disability (Episode 19): In this episode, **Emily**, a wife, mum, PhD candidate, whose topic is about how to best support people with SCI as they transition from paediatric to adult SCI services, and a social worker running resilience programs talks about how hard it is for the broader community to see beyond a person's disability.

Video: Dignity with a colostomy

Dave Thraves – My dignity has been restored, Colostomy UK (15 May 2021): **Dave** shares how undergoing a colostomy helped him reclaim his dignity.

The next resource is about being included (having a 'voice') as part of quality assurance to improve service provision.

Important information: Having a 'voice' by getting involved in evaluation

Should you need or want to evaluate your experience of a new SCI-specific service at your local GP practice, you can consider key resources from the Australian Government's Disability Gateway evaluation toolkit to help determine how inclusive the evaluation process is:

- Part 1: Getting involved – evaluation as a person living with a disability: Explains how people with disability can take part in evaluations that affect them, emphasising their rights, the value of their lived experience, and the supports available to help them participate meaningfully
- Checklist for people with disability, families and allies: Provides a practical checklist to help people with disability, their families and allies prepare for an evaluation, covering planning, understanding roles, identifying supports, knowing how data will be collected and how findings will be used

- Disability-inclusive evaluation checklist for evaluators: Provides a detailed checklist to ensure evaluation processes are inclusive and accessible, covering planning, participation, supports, consent, data collection, analysis, cultural safety and equitable remuneration, and
- Part 2: For evaluators and evaluation commissioners: Outlines guidance on designing and running inclusive, accessible evaluations that meaningfully involve people with disability at every stage while upholding their rights throughout the process.

10.2. Discrimination, abuse and violence

Before exploring how the Australian Government is addressing safety, rights and justice for people living with a disability, the first section will address disability, and the second section will discuss the many forms of abuse that people living with disability can endure.

10.2.1. Discrimination and disability

The next chapter, **Chapter 11**, explores Australia's legal system, focusing on the various anti-discrimination Acts and Laws. If you want a sneak preview, these include:

- Australia's Anti-discrimination Laws 1992, Attorney-General's Department, the Disability Discrimination Act 1992, which is under review: Video DDA Review: Attorney-General's Department. Submissions closed on 24 October 2025, and
- Australian Human Rights Commission Act 1986, which gives effect to Australia's obligations in terms of the Declaration on the Rights of Disabled Persons and the Convention on the Rights of Persons with Disabilities.

Disability discrimination occurs when people with some form of disability are treated less fairly than others because of the disability. The Australian Human Rights Commission's preferred wording is *"Disability discrimination occurs when a person is treated less favourably, or not given the same opportunities as others in a similar situation, because of their disability."*

Podcast: Disability discrimination in Australia

"Almost double the rate of hostility and violence": How ableism impacts people with disability (SBS English): This podcast and article highlight that one in five people in Australia lives with a disability, with many facing disproportionate levels of discrimination and prejudice, ranging from verbal abuse, being mocked and being excluded. Mostly, this is due to an ableist culture, according to **Megan Spindler-Smith**, the CEO of People with Disability Australia, who also said that people living with a disability experience a disproportionate rate of violence. In many instances, their stories are not heard.

The following statistics were taken from the Australian Bureau of Statistics (ABS) website. In 2022, among people with disability aged 15 years and over (living in households):

- 9.9% had experienced discrimination
- 10.6% of females, with 9.1% having experienced discrimination
- 17.6% of young people aged 15-34 years experienced discrimination, compared with 3.9% of those aged 65 years and over, and
- 27.7 % of LGBTIQ+ people (compared with 8.7% of heterosexual individuals), making them almost three times more likely to experience discrimination.

Experience of discrimination varied by severity of limitation: 19.0% of people with a profound or severe limitation and 6.8% of people with a moderate or mild limitation experienced discrimination.

Of those with disability who experienced discrimination, the common sources of discrimination were:

- 38.6% by service and hospitality staff
- 30.3% strangers in the street
- 24.5% by their employer. Of those with disability in the labour force (aged 15-64 years) who experienced discrimination, common sources of discrimination were their employer (40.2%) and work colleagues (37.7%).

This led to avoidance of situations, as shown in **Figure 10.1.**

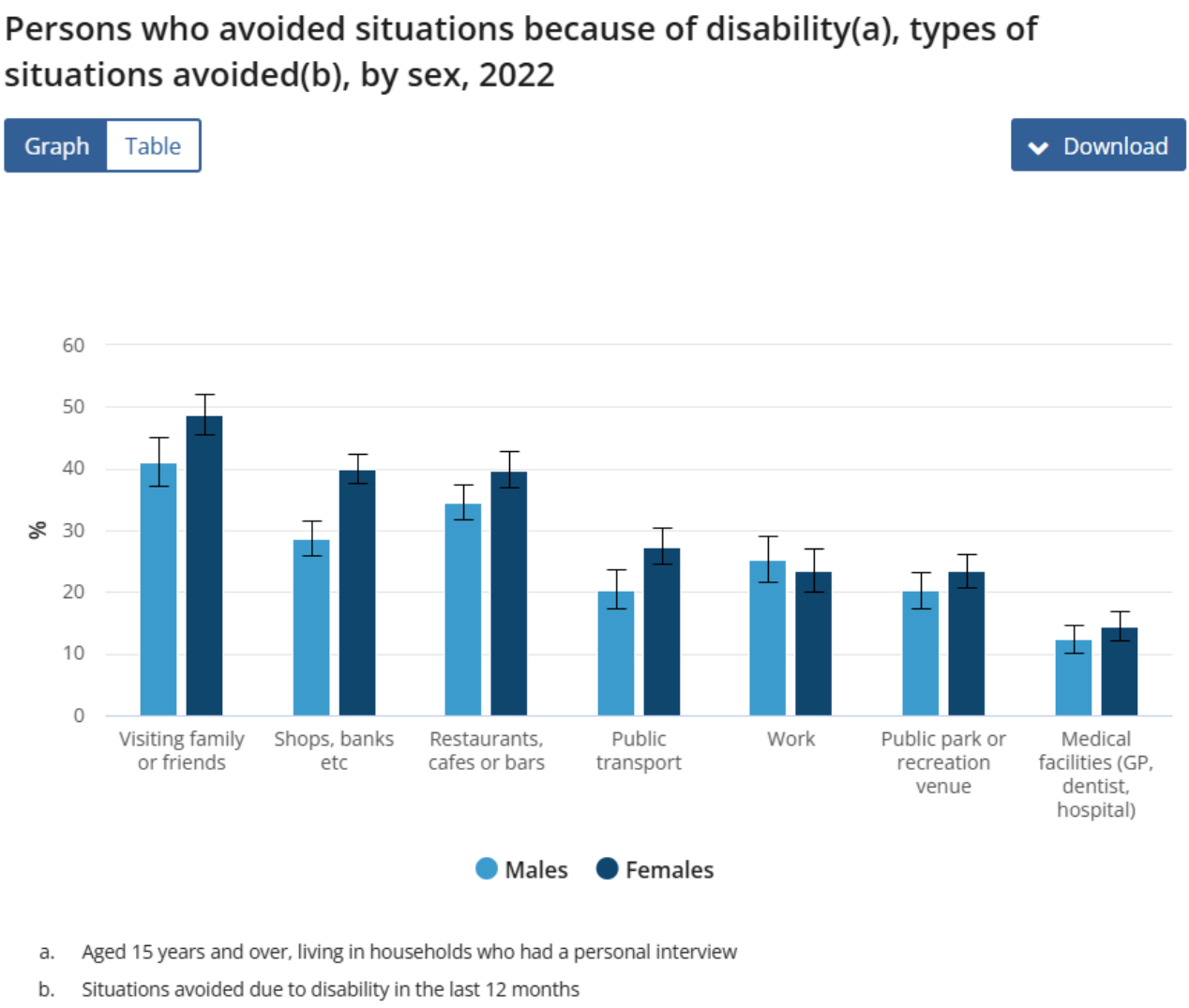


Figure 10.1. Discrimination led many people with disability to avoid situations, primarily family and friends, shops, banks, restaurants, cafes and bars and public transport. *Source:* ABS (2024), CC BY 4.0

Important information: 2023-2024 Disability discrimination complaints

Did you know that each year, the Australian Human Rights Commission (AHRC) receives more complaints about disability discrimination than about any other form of discrimination?

Of the **disability discrimination complaints (will download a file)** the AHRC (document) received in 2023-24, the Acts under which the complaints were lodged were:

- 43%: Disability Discrimination Act
- 22% of complaints were lodged: Sex Discrimination Act
- 16% of complaints were lodged: Australian Human Rights Commission Act
- 14% of complaints were lodged: Racial Discrimination Act
- 5% of complaints were lodged: Age Discrimination Act.

In terms of **employment**:

- 81%: Sex Discrimination Act
- 63%: Age Discrimination Act
- 39%: Disability Discrimination Act
- 39%: Racial Discrimination Act.

In terms of **goods and services**:

- 45%: Disability Discrimination Act
- 38%: Racial Discrimination Act
- 32%: Age Discrimination Act
- 15%: Sex Discrimination Act.

Video: ABC's *Can you ask that?*

S1 Wheelchair Users (ABC iview): In this video, several wheelchair users respond to frequently asked questions, some of which may be perceived as discriminatory. In this video, they answer questions such as *Can you shower yourself? Can you have sex?*

Note: You will probably have to open an ABC iview account if you don't already have one.

Podcast: Disabilities and equal opportunities

SCIA's Have the Nerve podcast, Something to Think About: Are We Given Equal Opportunities? (Episode 50): The episode explores whether students with disabilities in 2024 have fairer opportunities compared to those in 2000. Sixteen-year-old high school student **Lara Grimson** shares her experience seeking

work experience as a person with disability, and her story closely mirrors interviewer Susan's experience from 24 years earlier.

10.2.2. Abuse and violence, including domestic violence in Australia

Abuse comes in many forms, from financial, physical, psychological, to sexual. There is no doubt that those living with SCI are more vulnerable to all forms of abuse. A quick getaway will generally not be possible if they are being physically threatened. If the person is in an 'institution' or in a marriage, it may be difficult to inform someone of the abuse, as Nicole explains in her story below.

Media stories: Abuse comes in many forms

- **Transport:** Taxi driver caught abusing and defrauding disabled passengers (2025): A Melbourne taxi driver was exposed for assaulting disabled passengers, failing to secure their wheelchairs, and fraudulently overcharging them
- **Mobility equipment provider:** Remote Mobility takes payments, then disappears: A business called Remote Mobility allegedly accepted payments from vulnerable outback Queensland residents for mobility aids, then became unreachable and was later reported insolvent, leaving customers without the equipment they had ordered
- **Voluntary assisted dying:** Trio charged over alleged black-market operation (video): The Hope Island man referred to in the video was a 43-year-old living with quadriplegia who had allegedly paid the accused $9,200 before his death
- **Dodgy NDIS service providers:** $86 million in fraudulent claims blocked: The National Disability Insurance Agency rejected $86 million in fraudulent NDIS claims after scrutinising more than 100,000 submissions as part of a major fraud crackdown, and
- **Domestic violence: Nicole Lee's** experience of abuse: This story highlights a woman with disability who endured severe domestic abuse from her partner, and the additional systemic barriers she faced in seeking help or safely leaving the relationship. **Nicole** states:

"Even if ten people have ignored you, the eleventh might be the one to listen... It was the last time that I reached out after being ignored by so many ... it was that eleventh person who listened and took some action, and it saved my life."

Research: Abuse and violence for people with disability

The AIHW (updated in 2024 using 2022 data) explored the lived experience of abuse and violence for people with disability, providing descriptions of what is meant by violence and abuse:

- **Violence:** Can be sexual (behaviours of a sexual nature carried out against a person's will, such as sexual assault or threat of sexual assault), physical (incidents involving the use or threat of physical force with the intent to harm or frighten a person). Violence can be perpetrated by strangers or by someone the person knows, including an intimate partner
- **Partner violence:** Sexual and/or physical violence by a co-habiting partner. Co-habiting partners include the current partner with whom the respondent lives in a married or de facto relationship and the previous partner with whom the respondent lived. Violence is defined as any incident involving the occurrence, attempt or threat of physical or sexual assault. Sexual assault excludes unwanted sexual touching, which is defined as sexual harassment
- **Emotional and economic abuse:** When a person is subjected to certain behaviours or actions aimed at preventing or controlling their behaviour (emotional abuse) or access to economic resources (economic abuse), causing them emotional harm or fear. These behaviours are intended to manipulate, control, isolate or intimidate the person. They are generally repeated behaviours and include psychological, social, economic and verbal abuse. Examples of emotional abuse include:
    - Controlling or trying to control a person from contacting family, friends or the community
    - Constantly insulting a person to make them feel ashamed, belittled or humiliated
    - Shouting, yelling or verbally abusing a person to intimidate them
    - Lying to a person's children with the intent of turning their children against them, and
    - Threatening to take a person's children away from them.

Although 'neglect' is not defined on the website, a legal definition may be something along these lines:*"A disregard of duty resulting from carelessness, indifference or willfulness, especially a failure to provide a child (or any other person or perhaps animal) under one's care with proper food, clothing, shelter, supervision, medical care or emotional stability."*

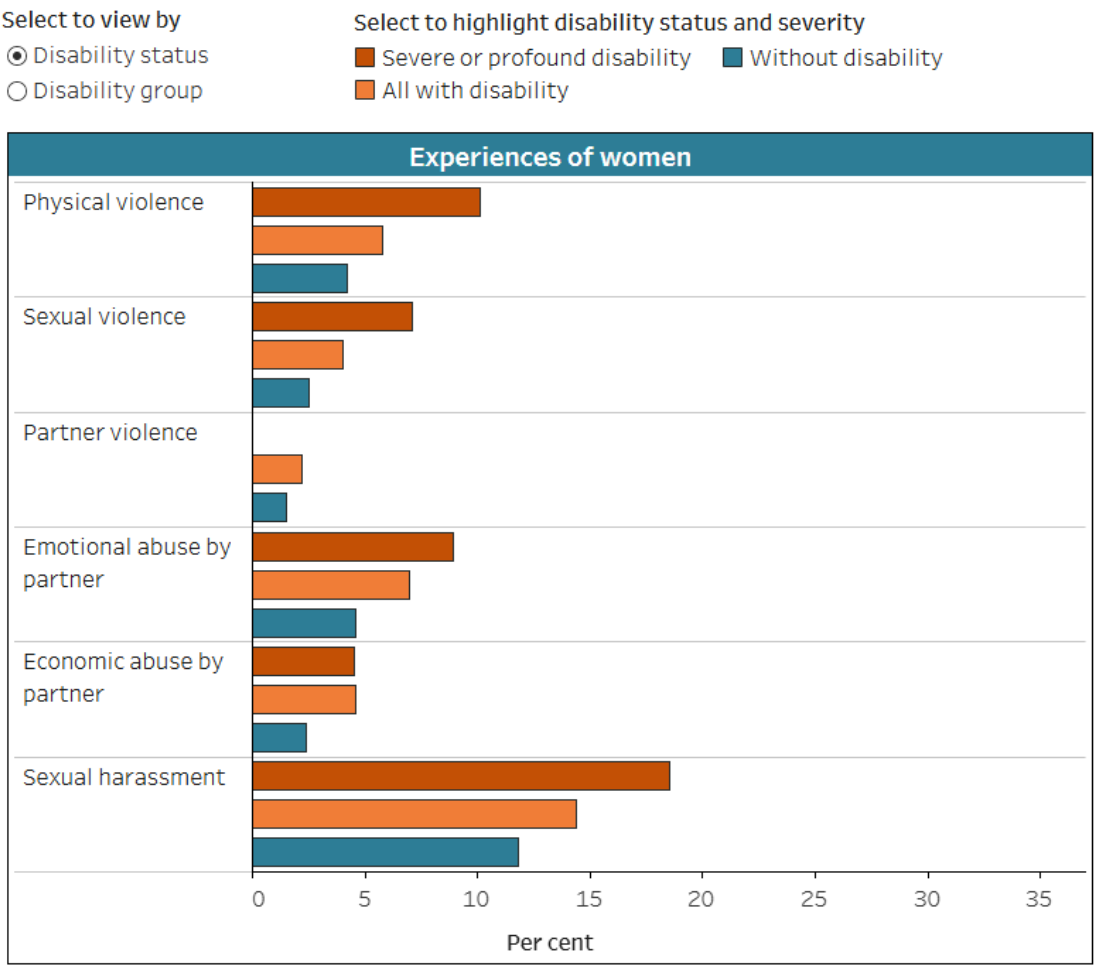
The Australian Bureau of Statistics (ABS) released its findings in relation to disability, ageing and carers on its website (2024). For the first time, the 2022 survey asked people about their experiences of physical abuse, emotional abuse and neglect in the 12 months before their interview. The new survey questions were asked of people aged 18 years and over who were living in households and who received a personal interview, which was answered by them and not by someone else on their behalf (via proxy). Data indicated:

- Abuse or neglect in the last 12 months: 11.4% (once) and 3.5% (twice or more)
- Emotional abuse: 9.1%
- Physical abuse: 4.5%, and
- Neglect: 1.5%.

The survey found that females living with a disability were more likely than males to report abuse or neglect overall (12.5% *vs*. 9.8%) and emotional abuse (10.4% *vs.* 7.4%). **Figure 10.2** below indicates that women over 18 years with a disability are more likely to experience abuse, violence and harassment compared with women with no disability. This violence increased with disability severity. Younger people were

more likely to report abuse or neglect than older people: 17.6% of those with disability aged 18-44 years, compared with 5.6% of those aged 65 years and over.

Figure VIOLENCE.1: Women's recent experiences of violence, abuse and sexual harassment, by disability characteristics, 2021–22



Source: ABS 2023b, ABS 2023c, ABS 2023d, ABS 2023e; see also Table VIOL2 to Table VIOL12.
https://www.aihw.gov.au

Figure 10.2. The comparison between women with and without a disability in terms of abuse, violence and harassment. *Source:* AIHW (2024). CC BY 4.0

Podcast: I will heal you with this miracle cream!

SCIA's Have the Nerve, Thoughts and Prayers (Episode 41, 30 June 2024): Several people recall their stories about people trying to 'heal' them. This might be a form of abuse as the individual with the disability may be a 'captive' audience.

Dinesh's story: Experiences as a doctor with SCI

When **Dinesh** was asked whether he had ever been 'abused' by a patient, he responded:

> *"Never. Not once in nine years. It's funny… I read a couple of studies that say that when a physician sits down, there is a better interaction with the person. But I wonder if there are some sort of subconscious things at play. Interestingly, while I have never ever had a problem with a patient, my female colleagues have. For them, the patient might say "Oh, where's the doctor?"* or *"I want a male doctor". Whereas for me, no-one has ever gone "Can I have an able-bodied doctor?", which is empowering. They accept me for what I am. But it is also damning on society [in terms of gender]. I just found it surprising….. I'm very grateful for the patients. They have been amazing, and I think society has advanced a lot, but I think it's fascinating that society better accepts on its face someone in a wheelchair who is a male to be the doctor."*

Reminder: Chapter 4

In **Chapter 4,** we discussed 'vulnerability' in terms of online scammers.

Importantly, Australia's Disability Strategy 2021–2031 identifies **Safety, Rights and Justice** as a core outcome area, recognising that many people with disability continue to face disproportionate risks of harm, discrimination and unequal treatment. The Strategy outlines six key priorities designed to address these risks and ensure that people with disability can live safely, exercise their rights and access fair treatment across all systems. These priorities are:

- **Safety from violence, abuse, neglect and exploitation:** Making sure services for people with disability are high quality and safe and that they are safe
- **Trauma-informed policy, processes and programs**: Improving access to services that support people with disability who have experienced trauma
- **Violence against women and their children:** Keeping women and children with disability safe from violence, abuse and neglect
- **Rights protected and upheld:** Protecting the rights of people with disability, decreasing discrimination and improving access to supports that help people with disability stand up for themselves and make their own decisions

- **Access to justice:** Supporting access to justice for people with disability, and
- **Equitable treatment in the criminal justice system:** Reducing the use of criminal justice interventions when responding to the needs of some people with disability.

These priorities highlight ongoing, systemic inequities. They matter because people with disability continue to be:

- more likely to experience violence or abuse
- more likely to be misunderstood in service, health and justice settings
- more vulnerable to discrimination
- less able to access justice or exercise autonomy, and
- disproportionately affected by punitive or inappropriate criminal justice responses.

In short, these priorities outline the minimum conditions required for people with disability to live safely, have their rights recognised and upheld, and be treated fairly across services, systems and communities. They lay the foundation for a society where safety, dignity, and justice are available to everyone.

Below, we provide research findings and statistics relating to abuse, harassment and violence experienced by individuals living with a disability generally. It is not always possible to find information specifically related to those living with SCI.

Research: Sexual abuse and SCI, Australia

New's (2020) Australian study used three survey tools (Spinal Cord Injury Secondary Conditions Scale, International SCI Quality of Life Basic Dataset, and the Physical Disability Sexual and Body Esteem Scale) to compare the prevalence and impact of sexual abuse in individuals with spinal cord damage (SCD) with able-bodied individuals in Australia (web and paper-based survey). Some of the findings included:

> *"Those who reported experiencing sexual abuse were more likely to be younger and female, with 7% of males and 44% of females reporting sexual abuse. There was no association between the reporting of sexual abuse and the following covariates: Sexual orientation, current partner, relationship status, disability, severity of secondary spinal cord conditions, chronic pain, quality of life, frequency of sexual activity with another person, enjoyment of sexual part of life, satisfaction with the sexual part of life, satisfaction with quality of the sexual part of their life, or their sexual disability and body esteem."* (p. 590).

The study concluded that:

> *"Even though there was no difference regarding the reporting of sexual abuse between respondents with SCD and able-bodied controls in this study, it is still important for rehabilitation clinicians to be aware of a number of factors that affect the vulnerability of people with SCD regarding sexual abuse. This includes: people who are significantly disabled may not be able to avoid contact with their abuser and be at*

> *increased risk of re-victimization; if the abuser is someone the person depends on for care this will impact the willingness and ability to report abuse; and myths that people with disabilities are asexual could impact the responses to victims' reports. Consideration should also be given to educating people with recent onset SCD regarding their vulnerability for being sexually abused, and strategies for dealing with this. Rehabilitation service providers need to ensure that there are appropriate systems in place to facilitate the reporting by people with SCD of sexual abuse, whether this abuse occurred prior to SCD and rehabilitation or afterwards, and to offer the necessary emotional support for these people, if requested."* (p. 591).

While this Australian study concluded that no significantly higher prevalence of sexual abuse was found among people with spinal cord damage (SCD) living in the community compared with able-bodied participants, the author acknowledged several limitations of the study, such as a biased control sample, the nature of the recruitment and the omission of some key considerations in the survey. The study did, however, provide data in an underresearched area of disability, but more robust research is required.

Podcast: Survivors of domestic violence

SCIA's Have the Nerve podcast, The overlooked victim: Survivors of domestic violence and sexual assault (Episode 20): **Nicole Lee** is a victim-survivor of domestic violence and sexual assault. She uses her first-hand experience as a person with a disability to help advocate for others who are also victim-survivors of abuse. She shares her journey and the cycle of coercive control and explains how the systems mostly work for someone able-bodied to escape violence.

The 2022 survey was followed by the Australian Government's Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. The SCIA website provides a 10-part series on the 2023 Royal Commission's findings, with full reports for the various aspects of the Commission, from abusive service providers to schools not supporting children living with a disability. **NOTE:** The videos are located on Instagram, so you may have to set up an account.

In January 2025, the AIHW released the fourth annual report of the Disability Strategy 2021-2030, **Figure 10.3** indicates some regression, an improvement in NDIS participants to self-advocate and that in 2022, 90% of people with disability had not experienced discrimination over the past year.

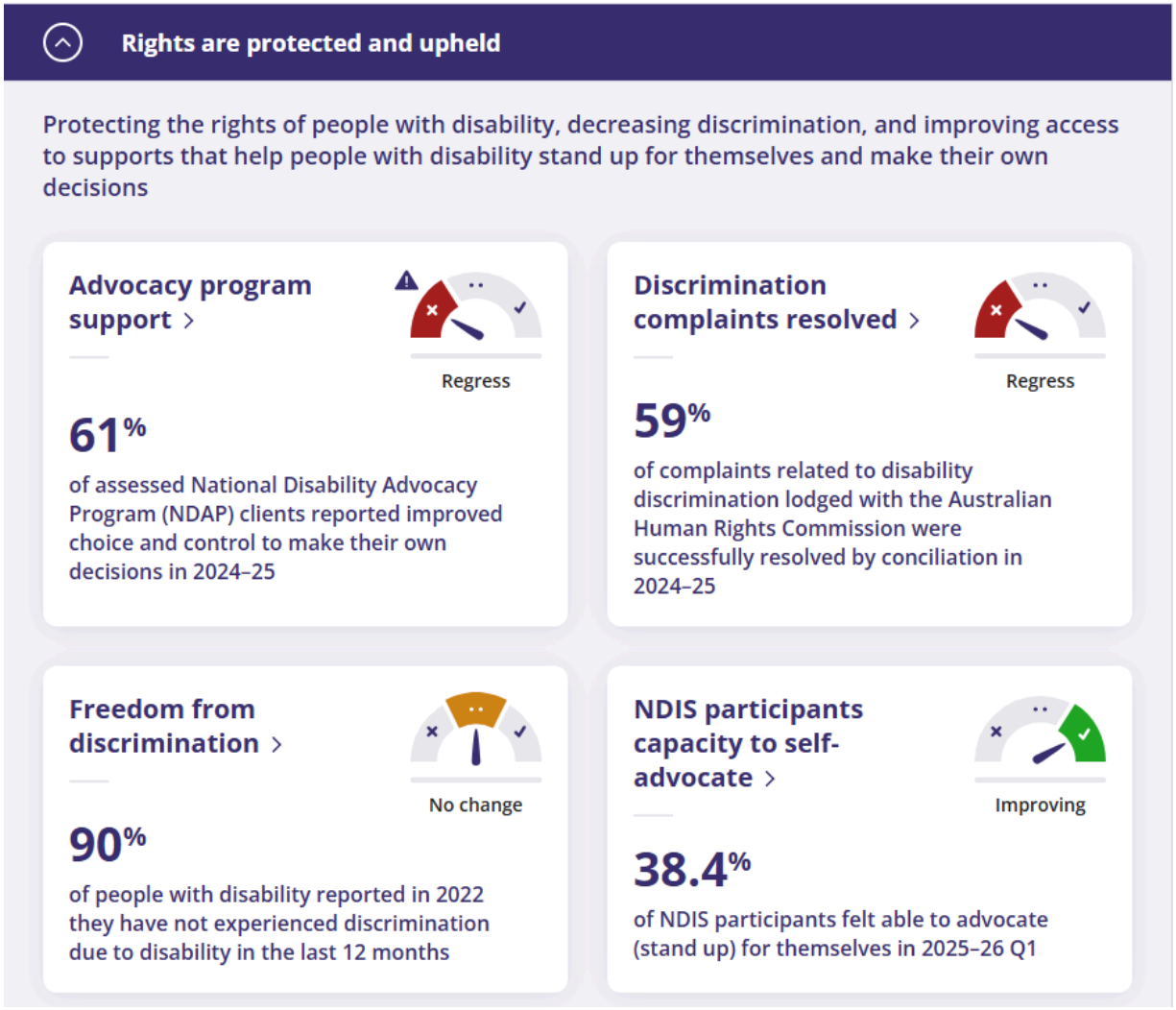


Figure 10.3. Statistics relating to the **Safety, Rights and Justice Outcome** of Australia's Disability Strategy 2021-2031. *Source:* AIHW (2024). CC BY 4.0

Important information: 2025-2027 Targeted Action Plan (TAP) for the Safety, Rights and Justice Outcome

In response to the lack of progress in this Outcome, the TAP is based largely on the recommendations from the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. People living with disability also identified these as priority outcomes in Australia's Disability Strategy 2021-2031. Safety, Rights, and Justice Targeted Action Plan (TAP) 2025-2027 sets out key actions to prevent people living with disability from experiencing harm and to improve supports for those at risk of harm. Thus, the TAP has been revised to include State and Territories contributing to national actions to ensure aligned approaches, more focused indicators that can measure improvement rather than arbitrary targets to reflect that States and Territories may be starting at different baselines and with different levels of resources, as well as an

acknowledgement that some actions may be extended or become ongoing services and therefore continue beyond the TAP end date.

The latest set of TAPs is a part of a broader network of disability reforms and actions. The following links highlight other work being undertaken in this area, including:

- United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)
- National Agreement on Closing the Gap (First Nations people)
- Disability Sector Strengthening Plan (DSSP) – Priority Reform 2 of the National Agreement on Closing the Gap
- National Strategy to Prevent and Respond to Child Sexual Abuse 2021-2030
- National Principles for Child Safe Organisations
- Working together to deliver the NDIS | NDIS Review
- Recommendations from the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability
- The National Plan to End Violence against Women and Children 2022-2032 | Department of Social Services, Australian Government, and
- Working for Women: A Strategy for Gender Equality.

Important resources: Domestic violence and disability

I'm a person with disability and experiencing domestic violence (Communities and Justice) offers many resources, including a video, particularly for women.

10.2.3. NDIS Code of Conduct

As the NDIS is the primary body for providing support for people with a disability, it recognises that these individuals have the right to be safe and the right to receive quality supports and services from NDIS providers and workers.

The NDIS Commission works to uphold the rights of people with disability, including the right to dignity and respect and to live free from abuse, exploitation and violence. The Commission does this by:

- Empowering people with disability to exercise choice and control in the supports and services they receive, while ensuring appropriate protections are in place
- Providing information that helps people with disability and their families or advocates to make informed decisions about NDIS providers

- Responding to and managing concerns and complaints, and
- Supporting a strong and viable market for disability supports and services.

Important information: NDIS Code of Conduct and hotlines

Below are videos and a website relating to the **NDIS Code of Conduct**:

- NDIS Code of Conduct video (English): Discusses individual rights to freedom and decision-making, respect for privacy and others
- NDIS Code of Conduct: Eliminating violence, exploitation, violence and abuse, with an example, and
- NDIS Quality and Safeguards Commission website: Addresses the rights of people with disability, providing information on provider and worker obligations to people with disability, including the use of unregistered providers and workers and human rights guidance.

Helplines:

- White Ribbon: A domestic violence helpline with links to others such as Lifeline, 1800Respect, KidsHelp Line and 13YARN
- National Disability Abuse and Neglect Hotline: 1800 880 052
- NDIS Family violence and mental health web page: Offers a range of hotlines, including for mental health.

10.3. Personal relationships and intimacy

"And also, relationships. I had a girlfriend for a little while, but actually managing relationships is really tough. People's sexual function changes. And you can't just hold someone's hand and go for a walk [...] I suppose reproduction is something we could cover as well. But all these factors go into creating a very difficult psychological state." **Dinesh Palipana**

Reminder: Chapter 2

In **Chapter 2**, we discussed the impact (physiology) of different levels of SCI on the male and female sexual response, indicating that these would be considered in more detail in this Chapter. Below, we provide further information on sexual dysfunction globally and resources and research on the topic.

10.3.1. Extent of sexual dysfunction post-SCI globally

According to the 2017-2019 International SCI Community Survey, sexual dysfunction was third on the list of self-reported health problems globally (22 countries, including Australia). These data suggest that while sexual dysfunction is a common health issue. But, compared with pain, spasticity and bowel dysfunction, it is a neglected health (and well-being) issue with only 14% of participants receiving treatment:

1. Pain (77.3%), with 66% reporting being treated
2. Spasticity (73.5%), with 61% being treated
3. Sexual dysfunction (71.3%), with only 14% receiving treatment, and
4. Bowel dysfunction (70.8%), with 58% being treated.

10.3.2. Research about the sexual response and sexuality following SCI

Talking about sexual dysfunction is not easy, even for individuals who have not sustained SCI. To overcome the awkwardness, below is a chronological summary of some of the research exploring individuals' lived experiences of relationships and intimacy following SCI.

Research: Sexual and reproductive health in women with SCI

Courtois *et al.* (2017) provided an evidence-based summary (at that time) of the impacts of SCI on women, with the view to educating women and their health providers to better understand their experiences of sexual and reproductive health. According to the authors, women living with SCI are sexually active and consider sexuality an essential part of their quality of life. In addition, sexual responses can be differentially preserved through psychogenic or reflexogenic (genital) stimulation, depending on the lesion level and extent. The approach to clinical management should be holistic, using ***Autonomic Standards*** to describe remaining sexual function, such as thoracolumbar ***dermatomes***, vulvar sensitivity (touch, pressure, vibration) and sacral reflexes and psychosocial factors, such as lower self-esteem, past sexual history, depression and dating habits. For women, self-exploration should include clitoral, vaginal, cervical and nipple stimulation. For pharmacological management, options include PDE5 inhibitors and flibanserin on an individual basis.

Clinical resource: PDE5 inhibitors CPD activity

The following is an important CPD resource for health professionals:

Dhaliwal, A., & Gupta, M. (2023). PDE5 inhibitors. In StatPearls. StatPearls Publishing.

It provides a comprehensive clinical overview of PDE5 inhibitors, explaining their uses, mechanisms, dosing, risks, contraindications and the role of healthcare teams in safely managing conditions, such as erectile dysfunction and pulmonary hypertension.

Research: Systematic review on sex, sexuality and relationships with SCI

Earle *et al.*'s (2020) systematic review of qualitative research explored the views and experiences of sex, sexuality and relationships of people who had sustained SCI from 15 countries across five continents. Four themes were discussed:

- **Sexual identity:** Sex and sexuality were an important part of identity post-injury. The literature suggests that SCI can have a profound effect on an individual's ability to feel masculine or feminine,

although it also suggests that there may be subtle differences in the way that this manifests according to gender. For men, a loss of independence was proportional to a loss of masculinity, with subsequent corollaries for sexual identity. Women's sexual identity was also connected to reproductive capacity and to their traditional roles as wives and mothers. **Note:** LGBTQIA+ perspectives were not included in this research

- **Significant and generalised others:** How individuals felt about themselves was often strongly influenced by 'significant others' (husbands, wives, partners, boyfriends or similar) and 'generalised others' (society in general). The attitudes of significant others were important, regardless of whether the relationship was positive or negative. Negative attitudes post-injury in terms of 'significant others' seemed to contribute directly to relationship breakdown, particularly for women. Some described the loss of sexual function as 'the beginning of the end'. In instances where the relationship had issues, relationship breakdown following SCI was sometimes retrospectively seen as a positive life change. In positive relationships with a significant other, being able to communicate openly and have an understanding partner was essential for managing sexuality post-injury. The 'generalised others' were perceived by participants as having negative attitudes towards SCI and the disabled body, positioning people living with SCIs as asexual, unwanted and unattractive, which could be internalised (called 'internalised othering'), as is exemplified in this short SCIRE video, I wasn't seen as a woman
- **Sexual embodiment:** Two narratives of embodiment focused on comparisons of sexuality before and after injury. In the first, post-injury embodiment, such as pain, lack of sensation and discomfort, constrained or prevented sexual activity or sexual pleasure. Men discussed not being able to achieve an erection, and men and women both talked about not being able to orgasm. Some research participants also talked about how their injury made it difficult to find suitable sexual positions. Also identified was the management of bladder and bowels as something that affected sex negatively. Some individuals had waited several years before engaging in sexual activity (if at all), despite sex being important to them. Reluctance to re-engage with their sexual lives was often attributed to bladder and bowel management. Loss of control over bladder and bowels was seen as embarrassing and something fearful in the context of all sexual activity, particularly in terms of a new partner. In the second narrative, post-injury sex focused more on physical forms of sexual embodiment and experimentation, with new types of sexual pleasure and techniques being used, which involved exploring elements of physical embodiment that had previously been less important or ignored, such as discovering new erogenous zones, and
- **Sexual rehabilitation and education:** The quality of sexual rehabilitation and sex education for people with SCI is generally low. Professionals who deliver sex education are regarded as poorly equipped, often finding it embarrassing or ignoring the subject altogether. When there is sex education and sexual rehabilitation is offered, it is often unhelpful and out-of-date, especially for women. The evidence is contradictory on whether it is always appropriate to deliver sex education in the early phases of recovery from injury. Many studies suggest signposting information about sex during all phases of rehabilitation.

To summarise, the research suggests that SCI can profoundly affect sexual embodiment. Pain, discomfort and a lack of sensation, including the inability to achieve an erection or orgasm, can seriously affect sexual expression. A fear of losing control of the bladder and bowels during sex is also an important factor in whether an individual feels able to engage in sexual activity. Despite accounts of sexual embodiment pre- and post-injury often focusing on loss, there were numerous accounts of positive sexual expression framed by new opportunities to rethink what it means to be sexual.

Research: Sexual function after SCI

Zizzo and colleagues (2022) reviewed the impact of SCI on sexual activity by addressing a range of topics, including anxiety-provoking questions and concerns of affected individuals. Questions regarding the ability to resume sexual activity, partner's satisfaction, as well as the ability to have children, are a few of the unknowns facing patients following SCI. While SCI can impair sexual function, libido, achieving and maintaining an erection, ejaculation and orgasm, can be addressed in an evidence-based and patient-centred approach as safe and effective treatments are available. Safe, effective methods of sperm retrieval maximise the chances of biological fatherhood in men with SCI. Finally, learning to redefine one's self-image, reinforce confidence and self-esteem and feel comfortable communicating are as important as understanding functionality in regaining quality of life after SCI. It is, however, important to re-emphasise that this recovery is characterised not just by understanding what remains but also by realising what can be gained. The pursuit of meaning, fulfilment and happiness contributes to an enriching life for individuals impacted by SCI.

Research: Psychosocial impact of an SCI on sexual function

In *"You feel a bit unsexy sometimes": The psychosocial impact of a spinal cord injury on sexual function and sexual satisfaction*, Barrett and colleagues (2023) interviewed people living with SCI in the UK. They describe their findings in terms of the psychosocial barriers to and facilitators of sexual function and satisfaction post-SCI:

- **Internalising societal views and stigmatisation:** Participants acknowledged that they faced a major barrier because of stereotyping, societal beliefs and stigmatisation about sexuality. Sexuality, whilst living with a disability, was felt to be under-addressed and misunderstood both within the media and wider society
- **Diminished sexual confidence:** Rebuilding confidence after SCI was difficult and elicited emotions such as feelings of rejection, guilt and uncertainty, which collectively negatively impacted sexual confidence. Low sexual confidence was particularly memorable during the early stages of re-engagement with sexual activity
- **Navigating communication:** The need for communication around sexual function post-injury in partner, professional and social capacities was of central importance and was thought to facilitate sexual satisfaction. Effective communication aided in the initiation of open discussion, which helped to develop, establish and sustain a sexually healthy relationship
- **Managing relationship dynamics:** In adjusting to life with SCI, partner involvement was a vital component of support, acting both as a barrier and a facilitator. Worries over partner satisfaction and the

impact of one's injury on the partner were highly salient. Physical changes and obstacles in relation to sexual functioning and performance led many individuals to question whether they were able to fulfil a partner's needs

- **Lack of sexual support provision:** All participants highlighted the lack of sexual rehabilitative services both within the inpatient and outpatient phases of recovery, which impacted sexual preparedness and reduced feelings of sexual competence and cognitive understanding. Health professionals were considered important figures in the delivery and provision of education and support, yet approachability, confidence in clinical competence, accessibility and aftercare following discharge were barriers, and
- **Intervention development recommendations:** Individuals varied in terms of their readiness to explore sex, yet collectively agreed that some form of increased sexual education should initially be offered during the inpatient rehabilitative phase, with further readily accessible after discharge into the community. Given the diversity of individual requirements, a group intervention format was deemed inappropriate.

To summarise, sexual function and satisfaction are highly challenging areas of rehabilitation for males and females living with SCI. Increased efforts are needed to educate others in society to overcome the negative stereotypical attitudes obstructing acceptance of sex despite disability. Countering sexual stigmatisation for people living with SCI would facilitate growth in sexual confidence. Techniques to enhance interpersonal sexual communication and involve the partner or spouse in regaining mutual sexual satisfaction are foundational. The study highlighted key outpatient-based recommendations for intervention development, clarifying primary targets for future SCI-focused sexual therapeutic work.

Research: Meta-synthesis of sexual health

Giurleo *et al.*'s (2023) meta-synthesis of qualitative evidence of sexual health amongst individuals living with SCI is important in terms of the clinical implications relating to sexual rehabilitation:

- Partnership concerns were identified most frequently, followed by sexual drive or interest, self-view or self-esteem and bowel or bladder concerns. This suggests that there should be a greater focus on supporting these specific areas of sexual health during rehabilitation
- Communication was particularly useful in building and maintaining partnerships for positive sexual health and facilitating acceptance of their injury. Thus, therapists could assist persons living with SCI in improving communication skills and supporting open communication between couples during rehabilitation, and
- Sexual function, which typically receives the most attention during rehabilitation, was a concern in about one-third of articles. Regaining sexual function was viewed as very important for some individuals, while others shifted their perspective of sexuality from a purely physical and penetrative experience to one focused on intimacy, feelings and partner satisfaction. This allows experiencing sexuality in new and satisfying ways.

Thus, rehabilitation professionals should consider encouraging patients to explore sexual avenues outside of a purely physical experience. From the perspective of those with lived experience, rehabilitation of sexual function after SCI is needed, yet support in this area is greatly lacking. Whether it be to help diminish problems related to faecal and urinary incontinence during sexual activity or to provide education on adapted sexual positioning, health professionals have an important yet underdeveloped role to play in all domains of the Sexual Rehabilitation Framework. Providers should seek to assist patients with sexual health issues unique to them and with tailored supports.

Other notable findings included:

- A consistent theme across the wide range of lived experiences was a flawed healthcare system. Lack of healthcare professional knowledge in sexual health, as well as negative attitudes, were common barriers standing in the way of positive sexual health outcomes. This underscores the need for rehabilitation centres to specifically educate and train staff, as well as embed positive, meaningful sexual health practices into standard SCI care. Evidence suggests that staff participation in sexual health workshops has been noted to improve clinician self-efficacy in addressing sexual health concerns of patients after SCI
- The availability of sexual health resources for staff and patients, such as pamphlets, posters, online websites and e-learning modules, can also be an effective tool in supporting sexual health practices in SCI rehabilitation, and
- Rehabilitation clinicians should not overlook the positive role of peer support from a person with lived experience on sexual health. This was especially true in supporting positive childbearing experiences and facilitating stable, intimate relationships. Peer support should be integrated into all rehabilitation programs to help establish connections.

Research: Sexual health amongst Australians living with SCI

Amongst Australian adults living with SCI, Allan and colleagues (2025) explored the sexual quality of life support experiences of nine adults living with varying levels of SCI (8 males; 1 female). While the findings of the study confirmed previous research on sexuality in SCI, noting an emphasis on physical aspects, such as erection and ejaculation ability, while neglecting the psychological and interpersonal, they identified that aside from the physical impact of SCI, one's identity and relational connection to others, in addition to socio-cultural discourse related to disability stigma, collectively impacted sexual well-being. Participants identified difficulties discussing sexuality with health professionals stemming from stigma, discomfort and pre-existing perceptions of disability equating to asexuality.

Equipping sexual health nurses, psychologists or occupational therapists in rehabilitation teams with skills to increase sexual positivity and provide individualised, tailored recommendations for resources and equipment might facilitate improved sexual adjustment and rehabilitation, supplementing the physical elements of sexuality. Likewise, mental health professionals may be better equipped to support the specific sexual quality of life support for people living with SCI. Addressing internalised stereotypes around disability and sexuality might be overcome by facilitating the adoption of a healthy attitude towards disability to advance a more open and tolerant perspective towards themselves and others.

Dylan, Danielle and Shane's stories: Sex and disability

People with disability share a wide range of experiences when it comes to intimacy, sexuality and dating. The following stories offer insight into how different individuals navigate these aspects of life.

- **Dylan Alcott** is one Australian who speaks openly about intimacy. In the Developing Australian Communities article How to Overcome Challenges When Dating With a Disability, Dylan provides candid dating advice. The article also includes other lived experiences, such as the 2021 ABC story Dating with disability can be challenging. So, when do you show someone who you really are?
- In her TEDx talk Everybody: Glamour, Dateability, Sexuality and Disability, psychologist **Dr Danielle Sheypuk,** who has used a wheelchair since childhood, shares her New York dating experiences and once described them as "Sex and the City, disability style." After being named Ms Wheelchair NY 2012, Danielle became a widely sought-after voice on dating, relationships and sexuality in the disability community, and
- **Shane Clifton** also reflects on love and intimacy through his characteristically engaging and thoughtful musings, including his piece Thinking About Sex?

For some, like **Dean Durman,** a husband and father of a five-year-old at the time of his accident, sexual intimacy became too complicated.

Dean's story: Sexual health and SCI

Below, **Dean** opens up about these difficulties, his and his wife's deep love and understanding and the mutual 'peace' with a different but fulfilling life.

> *"This is a very private and deeply emotional topic to share, but I will endeavour to do my best from lived experience. We have been assisted by specialist doctors in this field, however, sexual health does not rest solely on the individual who has suffered SCI. Both husband and wife are drastically affected — emotionally, mentally and physically. This is one of the areas that represents a colossal part of the loss.*
>
> *Education and enablement are unique to each couple facing these challenges. Both parties must engage in open and cordial discussions, reaching a point where they can even find comfort enough to joke about it. For my wife and me, like every couple, we shared a deep love for each other. We vowed*

to remain faithful for better or worse, in sickness and in health and until death do us part. This covenant stands as the primary value upon which we have built our marriage.

We experimented as advised by medical professionals, but the reality was that for neither of us would the experience ever be the same. With the recurrent bladder infection I was experiencing, and my wife having to care for our five-year-old son while also caring for me, her emotional capacity for lovemaking was far gone. We tried going on holiday, hoping a change of environment might help, but it never altered the reality of my inability to rise to the occasion.

So, we decided to make peace with that part of our lives and build on what we had — a foundation that would see us through the rest of our days with joy, peace and love. We literally put that part of our desires to bed and chose instead to pursue satisfaction in other creative avenues, rather than in sexual desire and fulfilment."

Below are a few more resources and personal stories relating to love, sexuality, and fertility after SCI.

Important resources and information: Love, sexuality and fertility after SCI

Since a finding from the research that has been described was that sexual health resources are an important source of information for health professionals and support staff, as well as individuals living with SCI, below are several resources from a range of sources:

- NSW AIC's Sexuality following spinal cord injury
- SpinalCord.com's Building Romantic Relationships After Spinal Cord Injury
- Mayo Clinic – Sexuality and Fertility After SCI
- Queensland Health – Sex and Fertility After SCI
- Physiopedia – Sexual Function and Reproductive Health After SCI
- Spinal Life Australia: Navigating sex and relationships with SCI, which offers a peer support program
- Intensive Love, a trauma-informed Sex & Relationship Therapy practice in Sydney. The website has some resources, such as this podcast: Awareness – Exploration – Liberation
- Assist Support Services' Finding love without limits: Disability and dating insights
- Disabled Singles Dating platform, where you can create a profile and find disabled singles in your area
- Model Systems Knowledge Translation Centre's (MSKTC) Sexuality and sexual functioning after SCI

- SCIA's Can you ask that? Disability and dating (20 October 20205), and
- SCIA's Assistive tech unveiled: Solutions for enhanced bedroom pleasure (18 December 2023).

Shaun Gash's story: Finding love after SCI

Finding Love After Spinal Cord Injury (Hollister): Read about how **Shaun Gash**, who was injured at a young age, overcame his doubts and insecurities to find love.

Podcasts: Sexual self-esteem and disability

- Episode 10: Psychosexual exploration, sexual self-esteem and disability: Listen to two experts talking about sexual identity, and
- A wheelie good sex chat with Care Rehab: A podcast with a psychosexual therapist and a specialist social worker.

Important resources and information: Sexual function and intimacy after SCI

Men's resources:

- Craig Hospital's web page on Sexual function for men after spinal cord injury
- Holloster's web page on How Spinal Cord Injury Impacts Male Sexuality, and
- The SCI Health Maintenance Tool on managing male-specific problems.

Women's resources:

- SCI Interest Group of the Academy of Neurological Therapy's factsheet on Female reproductive system and SCI
- Craig Hospital's web page on Sexual function for women after SCI
- Shepherd Center's Women with spinal cord injury: Intimacy (video, US)
- Mayo Clinic's web page on Sexuality and fertility management after SCI
- Mayo Clinic: Sexuality and fertility management after SCI, and
- The SCI Health Maintenance Tool on managing female-specific problems.

Videos: Sex after SCI series

SCIRE provides several Sex after SCI videos. This resource includes views of clinicians involved in sexual health rehabilitation:

- Sex after SCI: Sexual Health Framework
- Sex after SCI: Introduction to your sexual health
- Sex after SCI: Five guidelines for sexual health
- Sex after SCI: My need a shift to a new 'normal, but it could be better
- Sex after SCI: Sexual self-esteem

- Sex after SCI: Three sexual medicine principles for sexual health, and
- Everyone is a sexual being.

Some health professionals may feel unsure about how to support individuals with SCI when discussing sexuality and fertility. Below are a few relevant resources.

Clinical resources: Sexuality and fertility and SCI

The following are useful resources for health professionals:

- Agency for Clinical Innovation (ACI), Emotional Wellbeing Toolkit app: A clinician's guide to working with individuals with SCI, as they often present with complex medical and psychological challenges. The NSW State Spinal Cord Injury Service (SSCIS) established the Psychosocial Strategy to highlight the importance of psychosocial support for people adjusting to and living with SCI. In the section on sexuality, clinicians are encouraged to consider sexuality as a team issue and as a positive aspect of well-being. Go to Sexuality for helpful tips to consider, such as 'consider sexuality as a team issue and as a positive force'
- SCIA's Fertility Following SCI – Information for Health Professionals (8 September 2022): Provides health professionals with an overview of how SCI affects fertility in men and women, outlining key considerations, common challenges and available reproductive options for people living with SCI, and
- SCIA's Sex after SCI: Using the PLISSIT Model to address sexual health (12 October 2016): Reminds clinicians that sexual health is an important but often overlooked aspect of life after SCI and that people with SCI may need support to address sexual concerns. It introduces the PLISSIT model as a practical framework to initiate and guide conversations about sexual health. The model includes four levels: *Permission (allowing patients to discuss concerns), Limited Information (providing focused education), Specific Suggestions (offering practical strategies or interventions) and Intensive Therapy (referral to specialised sexual health or mental health professionals when needed).* While not all clinicians provide sexual health treatment, all can offer "Permission," creating a safe, open environment that validates concerns and helps patients access appropriate guidance and care.

Video: A sweet 7-minute fictional video

You are sure to recognise the lead male actor in Head over Wheels.

Note: You need to create an ABC account to access. It is part of the ABC's International Day of People with Disability 2025 collection.

Rachel Wotton's story: Disability and paying for sex

- SCIA's Have the Nerve, Sexual rights, sex work and disability (Episode 13): In this episode, **Dr Rachel Wotton (PhD)**, a sex worker, talks about individuals with disability engaging the services of sex workers. In some Australian states, sex work has been decriminalised.

  - **Rachel Wotton's** PhD presentation: The sexual rights of people with disability: Why some people pay for sex. Her PhD is accessible from this site, which also includes
  - Scarlet Road, an award-winning 2011 documentary following **Rachel's** journey as a sex worker whose clients are people living with a disability, can be watched at a small cost. You can view the trailer here. Below is **Rachel's** logo for her work on her research website:

10.3.4. Fertility and pregnancy

Following on from sexual health, the next topic of discussion is fertility, which may be affected for both men and women.

Clinical resource: Fertility following SCI

ACI offers a Guide, Fertility following SCI (Information for health professionals) (update due in 2026), which provides an overview of male and female fertility issues. It helps clinicians understand these issues and educate their patients about the different avenues and supports available. The website does state that: *"Female fertility is generally not as affected. However, women with spinal cord injury may still face challenges during pregnancy related to self-care and daily functioning, as well as labour and delivery."*

Important resources: Male infertility and pregnancy in women with SCI

- On the SpinalCord.com website, the Male infertility after SCI infographic discusses assisted reproductive techniques, such as penile vibratory stimulation (PVS), electro-ejaculation (EEJ) and surgical sperm retrieval (another infographic). Be sure to download the infertility infographic, as it has statistics, such as *"the average per cent of motile sperm in men with SCI is 20% compared with 70% in non-disabled men."*
- MSKTC's Pregnancy and women with SCI: This factsheet provides clear guidance for women with SCI on planning for pregnancy, managing health considerations during pregnancy and working with healthcare providers to ensure a safe pregnancy, labour and delivery.
- Pearls and Perspectives: Reimaging fertility and sexual health after SCI (12 October 2016): This episode features **Dr Emad Ibrahim**, a leading expert in male fertility after SCI, who explains the distinct sexual-health and fertility challenges men face post-injury and the specialised, stepwise techniques his program uses to achieve ejaculation and support family-building without surgery. He also discusses his cutting-edge research on treating sperm dysfunction, the importance of clinician awareness, and the broader reproductive, counselling and technological considerations essential to providing hope and effective care for this often-overlooked population.

Podcast: Fatherhood after SCI

SCIA's Have the Nerve podcast, The lived experience of fatherhood (Episode 53): This episode explores what three Australian men's experience of fatherhood is. One had just been through a successful IVF procedure, one had a six-month-old daughter and the third had two daughters in their 20s who were 4 and 6 when his spinal cord was injured because of a spinal tumour (NTSCI).

In terms of female fertility, Courtois *et al.* (2017) write that pregnancy is possible for women with SCI, with younger age at the time of injury and at the time of pregnancy being significant predictors of successful pregnancy, along with marital status, motor score, mobility and occupational scores. Pregnancy may decrease the level of functioning, such as self-care, ambulation and upper-extremity tasks, may involve complications such as pressure injuries, weight gain and urological complications and must be monitored for postural hypotension and AD. Taking into consideration the physical and psychosocial determinants of sexuality and childbearing allows women living with SCI to achieve positive sexual and reproductive health.

Kristen, Casey and Dani's stories: Being a mother with SCI

- **Kristen** shares the challenges she faced breastfeeding her premature newborn while living with a SCI
- **Casey** talks about working hard to shape her future, and
- **Dani** highlights the barriers women with SCI face in healthcare and calls for better support for mothers with SCI.

10.3.5. Management of and support relating to sexual health and fertility

Based on an exploration of the research on the lived experiences of adults living with SCI, the following would contribute to a life well-lived with SCI in terms of sexual health and fertility:

- **Good communication with an understanding significant other:** Having open conversations with an understanding partner leads to heightened self-esteem and confidence around sexuality
- **Multidisciplinary informed care:** Involves well-informed, trained and empathetic health professionals, including GPs, psychologists and fertility specialists
- **Education and counselling:** Essential for addressing emotional, relational and practical aspects of sexual health and well-being
- **Assistive devices and positioning:** Can help facilitate sexual activity and intimacy, and
- **Pharmacological options:** Options like Viagra may help with erectile dysfunction, although side-effects should be monitored.

Key Take-aways

- Individuals with SCI have the right to be treated with dignity by their health providers, their co-workers, their friends and their family

- Having SCI potentially makes these individuals vulnerable to all forms of abuse at home, at work and by 'general others'
- Sexual dysfunction is common amongst men and women who have SCI, usually S2-S4 (reflex erections) and T11-12 (psychogenic (psychological) arousal). This dysfunction can be impacted by stereotyping and stigmatisation
- While global surveys suggest that most do not receive treatment, opportunities do exist, but for many people, healthcare and transport costs mean it may not be a priority. Seeking help for sexual dysfunction may also relate to cultural contexts
- There appears to be a general need for upskilling of rehabilitation health professionals in terms of managing sexual health for people living with SCI, many of whom view being sexual as part of their identity, and
- Fertility may be impacted by SCI, particularly in men, but again, opportunities can be explored for men and women.

The next chapter, **Chapter 11**, discusses the legal issues relating to SCI in Australia, some of which we have touched on in this Chapter.

Reminder: Most relevant chapters

- **Chapter 1:** As it addresses SDA, the NDIS, and other support streams, it also discusses associated issues. There is a section on carers, but more in terms of carers being family members, many of whom do it tough, and so it is more about their support than carers being abusive
- **Chapter 2:** The discussion of the physiological changes in the male and female sexual responses, as well as in bowel and bladder function, is important for Chapter 10
- **Chapter 5:** Disability discrimination happens in all aspects of life. Since Chapter 5 is about studying, working and socialising and since the statistics show that discrimination and sexual abuse happen in the workplace, Chapter 5 is relevant
- **Chapter 6:** Ageing with SCI may mean that people living with SCI may have to move to care and aged care facilities, where abuse triggered a royal commission. Chapter 6 also discusses voluntary assisted dying
- **Chapter 7:** Children and adolescents may be subject to bullying at school and on public transport by peers. They may also be accosted by strangers. Just as partners can be abused, so too can parents
- **Chapter 8:** Discrimination and abuse can happen anywhere, but in rural, regional and remote Australia, it may be that there are fewer opportunities to report it. The Chapter also discusses First Nations and disability, where, for many reasons, there may be heightened abuse from a range of people and organisations
- **Chapter 9:** The stigma that is still associated with being neurodiversity, identifying as LGBTQIA+ or speaking another language may result in unintended, and in some instances, intended discrimination and abuse
- **Chapter 11:** This legal chapter is highly relevant to Chapter 11
- **Chapter 12:** As has already been discussed in Chapter 10, travelling by taxis and using the public transport system have been reported to be activities in which some people with disability have been

abused. The Chapter also explores flying with SCI, which may be internationally. Again, there are many opportunities for unintended and intended discrimination and abuse before flying, during the flight, as well as at the final destination

- **Chapter 15:** While sport is encouraged and for many people living with SCI, it has become part of their identity, there is a dark side to sport, even for those with no SCI. Children are particularly vulnerable
- **Chapter 17:** Our changing climate, especially the increase in heatwaves and adverse weather events, may lead to heightened psychological distress and anxiety, which in turn could result in discrimination and abuse, and
- **Chapter 18:** This chapter on health professions education explores inclusivity in medical education for applicants and patients, as well as curriculum content addressing disability in general. As in several other chapters, there may be unintended discrimination against students and patients.

References

Allen, A., Heck, M., Doig, C., Cudmore, T., Lawrence, K., & Mason, J. (2025). Sexual rehabilitation support experiences of Australian adults living with a spinal cord injury. *Journal of Spinal Cord Medicine*, 1-10. https://doi.org/10.1080/10790268.2025.2496567

Australian Institute of Health and Welfare. (2024). *Disability, ageing and carers, Australia: Summary of findings.* https://www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/latest-release#disability

Australian Institute of Health and Welfare (2026). *Australia's Disability Strategy 2021–2031 Outcomes Framework: 4th annual report*, catalogue number ADS 7, AIHW, Australian Government. https://www.aihw.gov.au/getmedia/7936ac1f-cf99-4212-89e3-69338e0b7d96/aihw-ads-7.pdf?v=20260212142411&inline=true

Barrett, O.E.C., Mattacola, E. & Finlay, K.A. (2023). "You feel a bit unsexy sometimes": The psychosocial impact of a spinal cord injury on sexual function and sexual satisfaction. *Spinal Cord, 61*, 51-56. https://doi.org/10.1038/s41393-022-00858-y.

Chapman, K. (2023, October 30). *Dignity means seeing the whole person: Why this matters for people with disability.* Inclusive Futures, Griffith University. https://inclusivefutures.griffith.edu.au/dignity-means-seeing-the-whole-person-why-this-matters-for-people-with-disability

Chapman, K., Dixon, A., Kendall, E., & Clanchy, K. (2024). Defining dignity at the intersection of disability: a scoping review. *Disability and Rehabilitation*, *46*(23), 5404-5414. https://doi.org/10.1080/09638288.2024.2302582.

Chapman, K., Dixon, A., Palipana, D., & Kendell, E. (2026). Understanding patient and staff perspectives on dignified rehabilitation care experiences. *Disability and Rehabilitation, 48*(1). https://doi.org/10.1080/09638288.2025.2496780

Courtois, F., Alexander, M., & McLain, A. B. (Jackson). (2017). Women's sexual health and reproductive function after SCI. *Topics in Spinal Cord Injury Rehabilitation, 23*(1): 20-30. https://doi.org/10.1310/sci2301-20.

Earle, S., O'Dell, L., Davies, A., & Rixon, A. (2020). Views and experiences of sex, sexuality and relationships following spinal cord injury: A systematic review and narrative synthesis of the qualitative literature. *Sexuality and Disability, 38,* 567-595. https://doi.org/10.1007/s11195-020-09653-0.

Giurleo, C., McIntyre, A., Harnett, A. *et al.* (2023). Sexual health among individuals with spinal cord injury: A meta-synthesis of qualitative evidence. *Sexuality and Disability, 41*, 713-737. https://doi.org/10.1007/s11195-023-09804-z

Leiulfsrud, A. S., Ellinggard, K. B., Post, C., W. M., Arora, M., & Leiulfsrud, H. (2025). Experienced inclusion and recognition amongst people with spinal cord injury: A comparative study in Norway, The Netherlands, and Australia. *PLOS One,* April 2025. https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0306231.

New, P. W. (2020). Sexual abuse in people with spinal cord damage. *The Journal of Spinal Cord Medicine, 43*(5), 586-593. https://doi.org/10.1080/10790268.2019.1621730

Zizzo, J., Gater, D. R., Hough, S., & Ibrahim, E. (2022). Sexuality, intimacy, and reproductive health after spinal cord injury. *Journal of Personalized Medicine*, *12*(12), 1985. https://doi.org/10.3390/jpm12121985

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Chapter 11: Legal Considerations Relating to Long-term Spinal Cord Injury

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Reviewer: Bruce Arnold

Editors: Michelle McLean, Elmarie Stander and Jaclyn Szkwara

One of the most important things to bear in mind is that an individual with SCI has the same legal status as any other person, rather than being legally deficient or diminished in any way. Much of the law governing healthcare is informed by human rights and bioethical principles. From a legal perspective, people with physical disabilities enjoy the same rights and protections as everyone else, grounded in the same principles of autonomy, dignity and respect for persons, as discussed in **Chapter 10**. Understanding these rights is critical to ensuring equitable access to healthcare and safeguarding the quality of life for individuals living with SCI.

This Chapter will mostly explore legal considerations related to SCI in Australia.

Key Topics in this Chapter

- Disability and human rights protections
- Medical decision-making, capacity and consent in healthcare
- Confidentiality and privacy related to healthcare, and
- Complaints about healthcare providers and services.

Individuals living with long-term SCI in Australia experience the legal system differently across a range of issues. For some people, the legal system is the last line of defence for their human

rights, including the right to autonomy. For others, it provides a pathway to decision-making in the event they are unable to exercise that autonomy. Some people will use the law to claim compensation for their injury or seek access to social welfare systems, including disability and carers' pensions, that protect them from job loss or defend them against discrimination on the basis of disability.

These issues are not unique to people living with long-term SCI. They can, however, be a significant source of stress for these individuals. In the sections that follow, some of the more common legal issues faced by people living with SCI, particularly those arising in the context of treatment, are identified. Clearly, it is beyond the scope of a document of this scale to provide comprehensive personalised legal advice. The experiences of people living with SCI vary, and so do their requirements for legal advice and support. By introducing some of the more commonly encountered legal issues, we hope to provide people living with SCI with an idea of the kinds of issues they may face and support them in identifying the right issues to raise and the right questions to ask their personal legal advisors.

11.1. Disability and human rights protections

Although Australian law offers some human rights protections for people living with disabilities, these protections are weaker compared with those provided in other jurisdictions, such as in many European countries. Generally, people living with a disability enjoy the same human rights protections as those without, particularly if the disability is physical. The majority of those rights, such as the right to life (Article 10), the right to equality before the law (Article 12), the right to liberty and security of the person (Article 14), the right to protection of the physical and mental integrity of the person (Article 17) and the equal right to the highest attainable standard of health (Article 25) are found in international law, including the Convention on the Rights of Persons with Disabilities, to which Australia is a signatory.

Important information: Understanding your legal rights

Disability Gateway Rights and Legal: This webpage provides clear, up-to-date information on legal rights, protections and available resources for people living with disability in Australia.

Some, but not all, of those rights are reflected in Australian federal laws, including the Disability Discrimination Act 1992 (Cth). Under Section 12, the Disability Discrimination Act applies broadly to the Commonwealth and its authorities, and, under Section 13, it operates alongside State and Territory law, ensuring consistency rather than replacing them. The Disability Discrimination Act makes it unlawful to discriminate against people with disabilities in key areas,

including employment, education, access to premises and the provision of goods and services, including healthcare. Many healthcare providers are bound by the Disability Discrimination Act and by related state and territory anti-discrimination laws. In addition, three Australian jurisdictions – Victoria, the Australian Capital Territory (ACT) and Queensland – have Human Rights Acts that prohibit discrimination on grounds including disability. Pathways for responding to human rights complaints, including those on the grounds of disability discrimination, and for reinforcing rights to equality before the law. Complaints under these legislative frameworks typically proceed through alternative dispute resolution and ***restorative justice*** measures, rather than litigation. This means outcomes often involve formal apologies and policy changes rather than large monetary compensation.

When the person's disability is cognitive or psychological in nature, rather than purely physical, the law may authorise different treatment to protect against exploitation of perceived vulnerability. These laws have been widely criticised for being overly paternalistic. Recent reforms have limited their application to exceptional circumstances where the statutory presumption of decision-making capacity is displaced. Such laws, particularly in the context of medical decision-making, will be discussed in further detail below.

11.2. Medical decision-making, capacity and information

Under Australian law, adults are presumed to have decision-making capacity. This means the law assumes they are capable of making their own decisions, even if those decisions are perceived as 'bad' or 'unwise', unless there is clear evidence to the contrary. By extension of this principle, adults who have decision-making capacity are entitled to make their own decisions regarding medical treatment, including choosing not to receive medical treatment. Those decisions must be respected. A doctor or healthcare professional who provides treatment against a patient's wishes may potentially commit a criminal offence and could be liable in a civil claim for ***battery***.

Providing treatment without the patient's consent is, however, permissible in some circumstances. For example:

- If the treatment must be provided quickly to prevent loss of your life or serious further injury or harm,
- If provision of the treatment without consent is expressly authorised by legislation, or
- If consent to provide the treatment is provided by another person who is authorised under law to make decisions on the individual's behalf, typically because the person is unable to.

A valid decision to receive or refuse medical care must be made by a person who has all the information necessary to make that decision and decision-making capacity for it.

11.2.1. Decision-making capacity

Under Australian law, decision-making capacity means a person understands the nature and effect of decisions about a matter, can use those decisions freely and voluntarily, and can communicate them in some way. These three elements of understanding, voluntariness, and communication are essential for a person to be considered capable of making decisions (see e.g. Schedule 4, Guardianship and Administration Act 2000 (Qld) and Schedule 3, Powers of Attorney Act 1998 (Qld)). Provided someone can demonstrate that they can retain and evaluate information to support their decision-making and communicate that decision in some way, they will have decision-making capacity for that particular decision.

Capacity is context-dependent, meaning that it applies to the particular decision the person is being asked to make. People with some cognitive impairment may, for example, be able to make fairly straightforward medical decisions without too much difficulty, particularly if the risks and benefits of the proposed treatment can be explained to them in an easily understandable way. The same person may, however, lack the capacity to make a decision regarding a more complex form of treatment, particularly if it entails a broader range of risks and benefits.

Capacity also fluctuates. No one has the capacity to make decisions while they are asleep or unconscious, for example. In addition, medication, pain, grief, shock and fatigue can also affect a person's ability to retain and evaluate information and risk, compromising their decision-making capacity. For most of us, these losses of capacity are only short-lived. When we wake up, or the medication wears off, our decision-making capacity will return, and the decision can wait until then.

If decisions related to medical care need to be made before the person's capacity to make the decisions returns – or if loss of decision-making capacity is prolonged or permanent – the law provides pathways which permit others to make decisions on behalf of the person. These pathways operate by creating a hierarchy of decisions and decision-makers.

The preferred form of consent is a decision made by the person the decision directly affects, made at the time the decision is required. If that is not possible, the law establishes ways for people to record their healthcare wishes in anticipation of a future loss of capacity. They can do so either by recording their specific wishes regarding particular forms of treatment or by appointing decision-makers to act on their behalf.

A person can document their wishes regarding future healthcare needs in anticipation of a future loss of capacity through a formal document known as an Advanced Care Directive (see e.g. Part 3, Powers of Attorney Act 1998 (Qld)) Common examples of wishes that people might choose to document include a refusal to receive cardiopulmonary resuscitation in the event they suffer a heart attack or a refusal to receive a blood transfusion. In some jurisdictions, people can also record their wishes regarding future treatment for established mental health issues.

Other legal instruments, known as Enduring Powers of Attorney (EPA) or 'Guardianship', depending on the state or territory, enable a person – the principal – to appoint specific named individuals to make decisions on their behalf if they lose decision-making capacity in the future (see, for example, Part 2, Powers of Attorney Act 1998 (Qld)). Although traditional powers of attorney cease if the principal loses capacity (S18, Powers of Attorney Act 1998 (Qld)), an appointment made under an enduring Power of Attorney or Guardianship instrument survives once the principal loses decision-making capacity, hence the 'enduring' in the title.

Appointments made under an Enduring Power of Attorney or Guardianship can be broad or specific. Some principals may appoint a person to make any health or welfare decisions permitted under legislation, either on their own or in consultation with other identified appointees. Other instruments may restrict appointee decision-making powers to specific issues or decisions. It is important to note that there are some decisions the law does not permit an Enduring Power of Attorney or Guardian to make. Typically, these decisions include voting, changing a will, marrying or divorcing, donating tissue, sterilisation, abortion or electroconvulsive therapy (Schedule 2, Ss 3 and 7, Powers of Attorney Act 1998 (Qld)).

If a person loses capacity without having formally recorded their wishes in advance through an Advance Care Directive, an Enduring Power of Attorney or a Guardianship appointment, legislation typically identifies other people who may be appointed to make decisions on their behalf.

In acute or short-term situations, legislation permits healthcare providers to seek consent from the Senior Available Next of Kin, who are typically close family members identified hierarchically by legislation, often starting with the person's spouse, adult children, and parents and progressing to other relatives or close connections (S62-3, Powers of Attorney Act 1998 (Qld)).

If the person is likely to be unable to make decisions on their own behalf permanently or for an extended period and they had not previously either appointed someone to act as their decision-maker or the person they appointed is unable to act as their decision-maker, under an EPA, it may be necessary for the guardianship tribunal of the relevant jurisdiction to appoint a guardian to make decisions on the persons behalf (Part 1, Guardianship and Administration Act 2000 (Qld)). Guardianship tribunals typically form part of the Civil and Administrative Tribunal of each jurisdiction (see S81, Guardianship and Administration Act 2000 (Qld)).

On receiving an application to appoint a guardian to act as a decision-maker on behalf of a person, the Tribunal will hear evidence from the person's doctors and healthcare providers, family members and other interested parties before appointing someone to act as a guardian on their behalf. The application is often lodged by a family member or a healthcare provider rather than the government. The Tribunal, by appointing a guardian, authorises that person to make any decisions specified under the Tribunal orders appointing them. Those decisions must be permitted under the relevant legislation.

Guardianship tribunals also hear applications relating to any disputes about how a guardian is exercising their decision-making powers as well. In the event there is no suitable person to be appointed as a guardian, the tribunal can appoint the Public Trustee, who is appointed under

statute to act as a guardian in the event no one else can do so and to make decisions on behalf of the person (S27, Public Trustee Act (Qld)).

For any decisions that fall outside the scope of decisions a guardian or EPA is authorised to make under legislation or the EPA instrument, the Civil and Administrative Tribunal or the Supreme Court of the relevant jurisdiction remains the decision-maker of last resort. Ultimately, the law operates to ensure that no decision regarding a person's health lacking capacity can be made without an authorised decision-maker.

11.2.2. Consent for medical treatment

Ensuring the decision-maker has all the information required to make their decision is also critical. The High Court decision in *Rogers v Whitaker* (1992) established that provision of incomplete or insufficient information regarding risks associated with a proposed course of treatment amounts to negligence on the part of the doctor or healthcare provider, rather than battery, for which the provider may still be liable to the patient in the event the risk arises. Legislative reform in most Australian jurisdictions now requires that doctors and healthcare providers warn patients of any risks associated with treatment that the reasonable professional practitioner would warn them of, as well as any risks they know – or ought to know – about which the patient has particular concerns (S21, Civil Liability Act 2023 (Qld)). The expectation is that information will be conveyed in a way that the patient can understand, thereby enabling meaningful consent consistent with both the law and the emphasis on autonomy and dignity noted above.

Although it is widespread practice to record consent in writing, often with a standard form, it is neither necessary nor sufficient that consent be recorded in that way. A person who is unable to write can still provide legally valid consent, for example, by oral consent. Simply obtaining a patient's signature at the bottom of a pre-prepared consent form does not necessarily mean that the patient or decision-maker has sufficient understanding of the potential risks and benefits of the proposed treatment to constitute valid consent. The written form may be a summary of consent discussions and may record the risks reasonable practitioners would ordinarily disclose. It will, however, often be insufficient to reflect any concerns specific to the individual patient or the person providing the consent, as required under legislation, or to demonstrate that the patient understands the implications and significance of those risks.

11.3. Confidentiality and privacy

Along with the right to have one's healthcare decisions respected, one also has the right to confidentiality and privacy with respect to one's medical information, as any other patient does. With the exception of people appointed to make decisions on a person's behalf when they lack decision-making capacity, healthcare providers are generally not permitted to discuss or dis-

close the person's health status or information to other people outside of the treating team without consent. There may be some circumstances in which that information is required to be disclosed under legislation or by court order. For example, instances of notifiable infectious diseases and certain types of cancer must be reported to public health authorities for public health reasons, to facilitate investigation of crimes by police or to support gathering of evidence for litigation.

A person is also entitled to have some say over who can be present when they are treated or examined. The person can refuse to have a medical student present during the examination, for example, or request a chaperone during treatment or examination. This may be particularly important if a person comes from a particular cultural or religious background or has previously experienced trauma. Everyone, however, is entitled to exercise these rights without needing to provide a reason.

11.3.1. Confidentiality

Confidentiality refers to information a person shares with their healthcare providers within the context of their relationship with them. Most discussions between a person and their doctor regarding a person's health are generally regarded as confidential. A person can choose to waive that confidentiality by simply discussing the information with others. The doctor, however, requires their consent to share the same discussions with others outside the treating team. A person may bring a friend, relative, or support person to medical appointments and is entitled to do so. Increasingly, some patients and some doctors choose to record consultations. This should only occur if all parties to the conversation are happy to be recorded and are aware of the purpose for which the recording will be used. Recording a consultation or discussion without the knowledge and agreement of all concerned may constitute illegal surveillance, potentially a crime in some Australian jurisdictions.

11.3.2. Privacy

Privacy refers to the protection of information (both personal and health) held by others, including insurers, NDIS providers and health service providers, that relates to an individual. Health records contain an abundance of health and personal information, including details about other people, such as family members, next of kin, and others. It includes all types of information, including images, pathology results, referral letters and patient records and notes.

Collection, use, storage and destruction of health and personal information is governed by a complex array of Commonwealth and State and Territory legislation, including the Privacy Act 1988 (Cth) and health sector-specific Acts, such as the Health Records (Privacy and Access) Act 1997. The Privacy Act establishes the Australian Privacy Principles (APPs), the foundational principles governing the protection of private information in Australia. In the event that health

information privacy has been breached, a person can lodge a complaint with the Office of the Australian Information Commissioner or the relevant state or territory health privacy regulator.

It is important to note that under Australian privacy law, a person is entitled to inspect and access their health information, regardless of who holds it, and to have any errors or inaccuracies contained in that information corrected. A person can also request that the information in their health record be transferred to a new practitioner if they decide to change providers, although they may be required to provide a written authorisation for the transfer. A healthcare provider is not permitted to withhold health information simply because a person chooses to seek a second opinion or transfer it to a different provider. There are, however, limits on how long a provider is required or permitted to retain records of previous patients before they are destroyed.

11.4. Complaints about healthcare

Before making a formal complaint, one needs to check whether the healthcare provider has an internal complaint process. Many hospitals and large health services have internal pathways that can resolve issues more quickly and with less formality.

If internal processes have no satisfactory outcome, a person can decide whether to lodge a formal complaint and with which body. As part of natural justice, the complaint body must notify the health practitioner or service and give them a chance to respond. A person will be identified and will need evidence to support the complaint. It is advisable to seek legal advice because the process can be lengthy and may take years to complete. This, however, should not discourage a person from standing up for their rights.

Important information: Making a complaint about discrimination or healthcare quality

- Individuals who believe they have experienced disability-based discrimination can lodge a human rights complaint with the Australian Human Rights Commission or with the relevant State or Territory

human rights body. Complaints involving one or more healthcare providers regulated by the Australian Health Practitioner Regulation Agency (Ahpra) may be submitted directly to Ahpra. In New South Wales and Queensland, this function is carried out by the Health Care Complaints Commission or the Office of the Health Ombudsman

- Complaints to Ahpra and other health regulatory bodies may address a wide range of issues, including quality of care, practitioner conduct, clinical skills and professional behaviour, and do not need to involve human rights matters. Concerns relating to a healthcare institution rather than an individual practitioner can be directed to the appropriate regulatory authority for that organisation, and
- The Australian Commission on Safety and Quality in Health Care provides accessible guidance on the complaints process.

11.5. Other common legal issues

Depending on how the SCI was sustained, it may be possible to claim against statutory compensation schemes, such as WorkCover or ComCare, the Department of Veterans' Affairs (for military veterans) and Compulsory Third Party motor vehicle accident or other statutory insurance schemes.

Alternatively, a person may be seeking to claim against someone else's insurance, such as professional indemnity or public liability insurance. They may also seek a claim under a policy operating for their own benefit, such as an income protection insurance policy, or be reliant on social welfare supports, including the NDIS, disability benefits, or carers benefits, to support their medical and living costs. A person may even find themself having to sue for compensation through a civil law claim for damages or trespass against the person, which will ordinarily be assault and battery.

Disputes arising in any of these settings are often highly specific to the facts and circumstances of a particular case and, accordingly, are beyond the scope of this resource to canvas in detail. If a person finds themself in dispute with a government department or an insurance provider, the department or insurance provider is required to provide you with information about their reasons for disallowing or rejecting a claim and how you can appeal against their decision if there are grounds to do so.

Depending on the organisation involved, these processes may be relatively straightforward or complex. If unsure about the processes or need assistance in determining how best to proceed, a person may be able to access some initial legal advice about their options through organisations such as community legal centres or pro bono legal advice clinics. The law society in a person's jurisdiction may be able to assist in identifying support services of this type. Alternatively, a person may wish to directly engage with a solicitor or law firm to act on their behalf, particularly if the claim or dispute is complex or high-value. Depending on the circumstances, some firms offer 'no win no fee' legal services. Clients should be aware that these arrange-

ments do not mean they are no cost. Clients who lose may still be liable to pay the costs of the other party and may still be liable to pay compensatory damages if the other party countersues, for example, in the context of a motor vehicle accident in which both parties suffer injury or damage and both are at fault.

Video: Understanding 'no win–no fee' legal arrangements

Understanding "No win – no fee": Avoid the pitfalls (Victorian Legal Services Board and Commissioner, 15 May 2023): This video explains what "no win-no fee" legal arrangements mean. It highlights that while a person may not pay legal fees if the case is unsuccessful, they could still be responsible for other costs, such as disbursements or the opposing party's expenses. The video provides practical tips to avoid common misunderstandings and to ensure that a person makes informed decisions before entering into such agreements.

Key Take-aways

- People living with SCI have the same legal status and human rights protection as any other Australian
- The legal system is important for people living with SCI for a range of reasons, including as their last line of defence for their human rights, such as autonomy. For others, it is a pathway for decision-making if they are unable to exercise that autonomy
- As people living with SCI are more likely to use the healthcare system than non-SCI Australians, medical decision-making, capacity, consent, confidentiality and privacy become important, and
- Decision-making depends on capacity, which can fluctuate.

The next chapter, **Chapter 12**, is about getting around and travelling locally and abroad. Judging by the experiences of some individuals travelling with wheelchairs, there is certainly scope for legal action.

Reminder: Relevant chapters

- **Chapter 6:** Not included in this Chapter were the legalities of voluntary assisted dying (VAD). This was discussed in detail in **Section 6.14** in Chapter 6. Chapter 6 also discusses dementia, which would have legal implications
- **Chapter 10:** Relevant sections are discrimination and abuse, and
- **Chapter 13:** For surgery and anaesthesia, consent would be required.

Reference

United Nations. (2006). *Convention on the Rights of Persons with Disabilities.* United Nations Treaty Series, 2515. https://www.un.org/disabilities/documents/convention/convoptprot-e.pdf.

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Chapter 12. Getting Around and Travelling with Spinal Cord Injury

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Reviewer: Lindsay Nott

Editors: Michelle McLean, Elmarie Stander and Jaclyn Szkwara

"Don't let the little things stand in your way, how you deal with situations in life depends on you and what drives you to achieve." **Lindsay Nott**, myc5life.com

Returning home from the hospital or rehabilitation after SCI brings exciting changes. One of the biggest steps towards independence is getting out and about locally. Mobility is not just about moving from A to B. Mobility is key to connecting with community, keeping up with friends, getting to doctors' appointments, going to the gym, pursuing education or returning to work. In short, being able to get around reliably is essential for a good quality of life. The next step would be to travel either locally or abroad, which requires considerable planning, including completing the necessary airline forms.

The primary purpose of this Chapter is to support individuals living with SCI and their carers in getting around. It is also intended to inform health professionals to better understand some of the challenges of travelling with SCI. Hopefully, it also assists those who offer travel services for the SCI community.

As in other chapters throughout this resource, this Chapter integrates personal stories (***LLEs***) detailing the potential barriers faced when travelling with SCI. These honest, real-world accounts are critical for understanding how complicated travelling might be for individuals living with SCI.

The Chapter is divided into two sections. **Section 1** focuses on essential mobility planning, covering both local and long-distance journeys and accessible tourism. **Section 2** provides specific information for individuals managing more complex care requirements, such as travelling with a catheter, bowel or ostomy bag or a ventilator.

Key Topics in this Chapter

Section 1: Preparing individuals with SCI for general travelling, such as

- Getting around locally, using public transport, modified taxis or being able to drive
- The State and Territory regulations for the process relating to being certified to drive with SCI
- Requirements for short- and long-haul flights, and
- Being a tourist with SCI.

Section 2: Travelling with complex needs, such as with

- A catheter
- A bowel or ostomy bag
- A ventilator, and
- Other medical conditions, such as ***deep vein thrombosis (DVT)***.

Section 1: Preparing for general travel

This section focuses on essential mobility planning, addressing both local and long-distance journeys and tourism.

12.1. Introduction to general travel

The ability to travel and participate fully in society is not a luxury, but an equity issue. Transport must be safe, reliable and affordable to ensure that everyone can access essential aspects of life, such as healthcare, education and employment (Spinal Life Australia, 2020). It can, however, be challenging, as the media stories below highlight. But, as some of the LLEs indicate, travelling internationally is doable.

Media stories: Travelling with disability

- These horror stories show how transport systems 'fail' Australians with disability (ABC News, 25 February 2024)
- Transport services are 'failing' Australians with disability. It shouldn't – and doesn't have to – be that way (ABC News, 24 February 2024), and
- Travelling with a disability in Australia (ABC Listen podcast).

Section 1 addresses the spectrum of general travel needs, from daily local mobility to planning significant national and international trips. Integrating into community life requires taking local flights for special occasions such as weddings and birthdays or for medical appointments, as well as maintaining daily access to school, vocational pathways, university or work. Some of these topics, such as taxis, were discussed in **Chapter 1.**

To travel independently with SCI, several transport options are available, depending on the individual's specific needs, such as mobility and geographic location:

- **Public transport:** Depending on where you live, you may have access to modified buses and trains, but physical barriers and consistency remain challenging (Spinal Life Australia, 2020)
- **Specialised taxis and private hire:** In many instances, specifically modified taxis or accessible private hire are available, and
- **Personal transport:** Options include using your own vehicle with a driver or, in some instances, driving a modified car yourself.

Regardless of the mode of transport, every journey requires careful planning to ensure that you arrive at your destination and return home safely. The extent of this preparation will depend on the level of your injury and the complexity of the assistive devices you need for the journey.

The necessity for accessible transport is underpinned by core principles detailed in Spinal Life Australia's (2020) Advocacy Position Statement Transport. These principles recognise that:

- For people with disabilities to live independently and take part fully in life, proactive steps need to be taken to make sure they have equal access to safe, reliable and affordable transport
- Accessibility is essential to everyday life, and for many people, transport makes that access possible

- Without accessible transport, people cannot access health care, education or employment
- All transport options, including public transport, courtesy transport and ride-booking services, should be accessible for people with disability
- Governments are responsible for subsidising wheelchair-accessible taxis (WATs) and personalised transport for people who cannot use public transport, and
- Removing social and physical barriers to movement and access can improve the lives of people with disabilities by enabling the use of passenger transport services and supporting real participation in the community.

Spinal Life Australia's advocacy position statement also highlights the ongoing difficulties people living with SCI face in accessing public transport due to physical barriers such as steps and inconsistent ramp availability. As a result, many rely on family and friends for transport.

12.2. Getting around locally

As identified in **Chapter 1**, there is a range of transport options for getting around locally, including public transport (buses, trains, trams), utilising modified taxis, having a dedicated driver, and, for some, self-driving in a suitable modified vehicle.

12.2.1. Public transport

Public transport would include buses, trains and trams, depending on the location. Australia has disability standards for public transport, which can be accessed below.

Videos: Disability transport resources

- Disability Transport Standards for Accessible Public Transport (Department of Infrastructure, Transport, Regional, Communications, Sport & Arts) to ensure an accessible public transport system that meets the needs of people living with disabilities, to ensure equality and independence. To learn more about the Standards, visit this website.
- Transport (Disability Gateway): It can be tough getting around if your mobility is limited in any way. There are several options for you to help you get to where you need to go. The Australian and State and Territory governments subsidise some transport options.

Important resources and information: Different transport options

The following are useful pages on the Australian Government's Disability Gateway website. Each link has an interactive map of Australia to locate services in the States and Territories:

- Public Transport
- Community Transport
- Taxis and Rideshare Services, and
- Driving and parking your own car.

Dean Durman's story: Public transport

"Travelling to Brisbane City presents significant challenges for wheelchair users. The terrain is often not conducive to moving around freely, and even when using public transport, many pathways and sidewalks remain unsuitable for those in a manual wheelchair.

I used the train system extensively for six months, travelling from Varsity Lakes [Gold Coast] to Brisbane. The staff were consistently helpful and always willing to make things easier. Like all passengers, however, I was still subject to delays. On several occasions, the elevators were out of service, creating significant inconvenience. With no alternative access to the correct platform, I was directed to catch a train on a different line and then return to the original station. This added stress and frustration to an already challenging journey."

12.2.2. Wheelchair-accessible taxis (WATs)

Most cities and towns in Australia offer Wheelchair-Accessible Taxis (WATs) as a transport option. However, accessibility remains inconsistent, as not all taxi and ride-share providers are keeping pace with demand. For instance, according to Blue Badge Insurance Australia (n.d.), while ride-share services like Uber offer a Wheelchair-Accessible Vehicle (WAV) service in countries such as Canada and the US, they currently do not provide this option in Australia.

Important information: Taxi information

- A list of some WAT options available in Australia:
  - 13 Cabs Australia-wide
  - 13 Maxi Cabs Sydney
  - Black and White Cabs Melbourne, Perth
  - Zero 200 Sydney
  - Silver Top Melbourne, and
  - Service NSW Book a WAT Sydney.
- Forward: Fact Sheet for travelling safely in a taxi: This resource provides essential information regarding wheelchair requirements and the legal need for a passenger to be properly restrained during the journey. WAT providers have a duty of care to ensure a safe service. Drivers must be able to demonstrate competence in the safe loading, restraint, carriage and unloading of a person in a wheelchair. The Factsheet also provides contact details for lodging a complaint in the event of a safety concern or inadequate service.
- Taxi subsidy for wheelchair and mobility scooters: You might be eligible for a taxi subsidy for wheelchairs and mobility scooters. Different State contacts are provided. Leap in! has provided details for

each State and Territory. Chapter 12 reviewer, **Lindsay Nott**, reminded us that in Queensland, the Taxi Subsidy Scheme covers 20 interstate taxi vouchers every 12 months. Check if your State or Territory offers similar vouchers.

- NDIS taxis are essential for people with disabilities: Ahsan Care is an example of an NDIS provider that arranges NDIS taxis.

Personal safety should always come first when using transport services, especially WATs. Unfortunately, people living with SCI often report poor treatment or neglect from some transport providers. Advocacy groups have recently raised these concerns. In a media release titled "Safe taxis critical to full participation", National Disability Services (NDS) said it was shocked and distressed by reports of taxi drivers and companies abusing, neglecting or defrauding people living with disabilities (National Disability Services, 2025). Of note, the NDS emphasised that access to safe and quality services must be guaranteed for people with disabilities, stating: *"Safe and affordable taxis are critical to enabling people to fully participate in our community."*

The organisation also highlighted that fraudulent behaviour is particularly harmful because it takes funding away from vital disability services. The NDS is committed to working with governments and industry to strengthen quality and safeguarding measures and better protect people with disabilities who rely on transport services.

12.3. Driving

For individuals who can drive, independent travel is arguably one of the most important skills one can acquire, serving as a powerful step towards social and community integration.

Dean Durman's story: Journey back to driving

"For people living with a SCI, driving represents more than mobility. It is independence, dignity, and the ability to contribute fully to family and community life. I had already enjoyed this independence in Johannesburg, South Africa, and after a year of settling in Australia, we decided to bring my adapted vehicle over.

This became another learning process, especially applying for approvals from agencies in both Benoni, South Africa and NSW, Australia. It demanded patience, a clear understanding of requirements, and careful compliance with each step. Once approvals were obtained, the next challenge was arranging a container to transport the vehicle. It took three months to reach Sydney, where it was placed in quarantine until cleared by customs. I was then notified to collect the vehicle and pay the stamp duty for release.

Afterwards, the vehicle had to undergo stringent roadworthy testing and receive a personal import certificate to qualify for registration with Transport and be operational on Australian roads. This final stage was completed over the course of a month. Achieving this milestone meant I could once again contribute to the family, easing the pressure on my wife, who had been solely responsible for transporting us wherever we needed to go.

I also had to undergo a driver's test to ensure I understood the road laws and was fit to drive. On an annual basis, the Department of Roads requires me to submit a fitness-to-drive evaluation from my GP to confirm that I remain competent and safe behind the wheel. While these checks can feel demanding, they are essential for balancing safety with independence. For me, regaining the ability to drive eased the burden on my family and restored a sense of freedom that public transport alone could not provide."

12.3.1 Driving: Assessment and vehicle modification

For individuals with sufficient residual function, returning to or learning to drive a modified vehicle offers the highest degree of independence. This process is structured and regulated for safety.

12.3.1.1. The return to driving process

The process of driving a modified vehicle requires specialist clinical input, and state authority approval involves the following:

- **Clinical assessment:** This must be conducted by a specialist occupational therapist (OT), often working in conjunction with a certified driving instructor. The OT assesses the individual's physical, visual and cognitive capacity to drive safely and determines the necessary vehicle modifications
- **Vehicle modification:** Modifications vary significantly based on the level of injury and functional capacity, such as hand controls for braking and acceleration, steering aids or complex electronic joystick controls for high-level quadriplegia, and
- **Licensing and approval:** The final stage requires approval from the relevant State or Territory licensing authority, which then imposes conditions on the driver's licence specific to the required vehicle modifications.

12.3.1.2. Innovation and safety

Tools, such as driving simulators, are increasingly being used in rehabilitation settings to safely assess a person's capability to operate controls and manage complex driving scenarios before they get into a modified vehicle.

Media story: Simulation and driving

Driving simulator assists people with disabilities to get behind the wheel (ABC News, 26 October 2025): Twenty clients with disability in South Australia now have their 'L' plates after learning to drive through simulation.

12.3.2. Driving standards

Individuals living with SCI, their carers and health practitioners should consult the relevant national standards and State or Territory requirements (**Figure 12.1**) for detailed procedural information, as specific forms and assessment requirements vary:

An interactive H5P element has been excluded from this version of the text. You can view it online here:
https://bond.studium.pub/life-well-lived-with-spinal-cord-injuries/?p=193#h5p-9

Figure 12.1. Interactive map with a State- and Territory-based resources or guidelines relating to driving with SCI. Created by Jaclyn Szkwara using Canva and HP5, licensed under a CC BY-NC (Attribution NonCommercial).

Important information: National standards for driving

- The Austroads and National Transport Commission's 2022 Medical Standards, Assessing fitness to drive for commercial and private vehicle drivers, are the foundational guidelines used in Australia.

The relevant sections for SCI are Part B. Medical Standards, Fitness to drive, Numbers 5 (Neurological) and 6 (Musculoskeletal conditions).

- SCIA's The Ultimate Guide to Driving with Disability (27 April 2023)
- Total Ability provides links to features such as 'Find an Installer' and 'Love to Drive Stories'.

12.3.3. Ethical considerations: Parking access

While accessing transport is challenging, the misuse of designated disability parking spaces by non-disabled people remains a significant frustration and disrespectful barrier to independence. These spaces are often the only places where a person in a wheelchair can safely and fully deploy a ramp or lift to enter or exit their vehicle.

Watch this video: Parking etiquette and disability

SCIA's Can You Ask That? – Accessible Car Parks (5 November 2024): What do people with disabilities think when someone without a disability parks in an accessible space and says, *"I'll just be quick"* or *"I won't be long"?* Unsurprisingly, it is incredibly frustrating. In this episode of *Can You Ask That?*, SCIA's Peer and Family Support team tackles this common issue, answering questions that many people hesitate to ask openly.

12.4. Short- and long-haul flights

Air travel can be a stressful and challenging mode of transport for individuals living with a SCI, as **Dean Durman** and **Perry Cross** describe in their LLEs below.

Dean's story: Advice when flying

"I have had numerous opportunities to fly locally and overseas for both business and pleasure with and without my family. Flying with SCI is all about preparation, such as calling ahead, notifying the airline and arranging the required assistance at airports. This can be done, but each airline has its own process and it often differs every time a person with a SCI travels.

The best advice is to remain calm, exercise patience and expect the unexpected. Don't set high expectations. Instead, work with the staff and they will usually be more supportive. I have observed that some people with SCI or mobility challenges can feel a sense of privilege or entitlement. My approach is different: Let go of pride, remain humble and be flexible. Things will work out smoothly and you will experience far less stress."

Perry's story: Experiences with flying!

"Interestingly, "What is air travel like?" is one of the most common questions Perry is asked when he meets new people. It is clearly a curiosity for those meeting with SCI patients, and as such, could be discussed quite early-on. Unfortunately, air travel remains a challenge for people with disabilities. Qantas Airlines are the only Australian airline to have a "specialist handling department", making them the sole viable carrier in many cases. Qantas, alongside PWDA, offer a concession card which provides discounted flights for both the patient and carer. Patients wishing to travel should directly contact the airline and discuss options well before the flight. Nonetheless, something will always go wrong and the SCI patient should be well-aware of this. No two flights are the same and there is no easy way to prepare oneself for the challenges that will most certainly arise at some stage during the trip.

Perry Cross and support worker, Dan Boardman, agree that the only way to travel is to be resilient, and to just "go with the flow". The people you are directly dealing with, the airline policies, and the airport regulations do not always match up with their plans for the patient, and there is often confusion, lack of support or incompatible procedures. The support crew, including families, carers and workers, all need to be aware of this. Rather than be frustrated, if everyone is on-board with the sentiment that something will go wrong, it can alleviate frustrations and help the group deal with whatever challenge presents next. There is rarely a good flight experience, and there is little hope of this changing in the

near future. While buses, trains, taxis can all be navigated quite easily by those with disabilities, air travel remains 'stuck in the past'.

The length and time of the actual flight makes little difference to the journey. Instead, a big consideration is the size of the plane. Domestic travel tends to use smaller planes. In most cases, the chair (with ventilator, etc) will not fit in the cargo hold and needs to be folded down. This requires special tools to be brought along, with the carer or support worker spending15-30 minutes at the airport working on this at both ends. This requires additional planning, arrival times and workload for both the individual and the support worker or carer. International flights, with their larger planes, can often fit the chair straight in. Meaning that it is much simpler, easier and quicker to accommodate. As such, the size of the plane and its availability of cargo space, not the location or distance, is a major contributor to the ease of travel.

At the airport, the public will stare. Airport staff will stare. Other passengers will stare. The whole journey is awkward, even to the point of being dehumanising. You may be forgotten about, left in one place for long periods. You may miss the flight despite having arrived many hours early. You may delay the whole plane and hear people complaining loudly. This can not only impact the individual, but also the comfort of the attending carers and support workers. There is no easy way to do it. One has to adapt and be flexible."

Thus, air travel can be a source of considerable anxiety, as it involves temporarily relinquishing control over personal equipment and mobility routines. Successful short- or long-haul travel hinges on meticulous pre-planning, clear communication and self-advocacy (Spinal Life Australia, 2020). For individuals living with SCI, the journey is often complex, involving unique risks such as equipment damage and potential pressure injuries.

12.4.1. Pre-flight protocol and booking

Effective management begins at the time of booking:

- **Mandatory notification:** It is crucial to notify the airline of mobility needs immediately upon booking and then confirm details at least 48 hours before travelling. Airlines use standardised codes, such as WCHR (wheelchair required), to communicate the need for special assistance.
- **Powered wheelchairs and batteries:** This

is the most complex aspect of pre-flight preparation. A passenger must declare the type of battery, such as dry cell, gel or lithium-ion, as regulations require specific handling. For safety, the battery must often be disconnected and terminals insulated to prevent short-circuiting in the cargo hold (International Air Transport Association, n.d.). The individual or carer must carry the chair's instructions, detailing the battery type and disconnection procedure, for the ground crew.

- **Pressure management:** Customised pressure-relieving cushions, such as Roho and Vicair, are essential and must not be checked in with luggage. These items should be carried into the cabin to mitigate the high risk of pressure injury during prolonged fixed seating.
- **Dangerous goods:** Most airlines have a list of 'dangerous goods'. This is an example of the Qantas Dangerous Goods website.

12.4.2. The airport and the boarding process

The physical process of boarding an aircraft poses risks to both the individual and their equipment and so needs to be carefully 'navigated'.

- **Check-in and transfers:** Passengers must request 'Meet and Assist' services. At the gate, the individual will transfer from their personal chair to the airline's aisle chair, a very narrow device used to transfer passengers down the aircraft aisle. This transfer is the most physically demanding part of the journey. Carers or the individual must ensure that ground staff are trained in safe lifting techniques to prevent injury to the passenger and staff.
- **Equipment damage:** Damage to personal mobility aids, particularly powered wheelchairs, is a perennial and costly risk during baggage handling. Experts recommend taking photos or a video of the wheelchair immediately before it is transferred to the cargo hold to document its condition. Also, remove all breakable items, such as controllers, armrests and foot plates, and carry them as hand luggage. This prevents damage, cost and delays.
- **Cabin seating:** Request a bulkhead or aisle seat to facilitate the easiest transfer and to have room to move for pressure relief.

12.4.3. Managing the journey and medical needs

Long-haul flights require careful planning for ongoing medical and practical needs. According to experts and individuals with LLE, including the SCIRE Community (2022) and the American Spinal Injury Association (2022), key considerations include:

- **Bladder and bowel:** Manage fluid intake before and during travel. If using indwelling catheters, ensure collection bags are appropriately sized and that all catheter supplies and bowel care equipment are packed in carry-on luggage.

- **Pressure relief:** Even with a suitable cushion, prolonged immobility increases risk. Release pressure every 15-30 minutes or request assistance from a companion or flight attendant.
- **Self-advocacy:** Be prepared to advocate for your needs, as airline staff may have limited experience with SCI care requirements.
- **Planning:** When choosing a destination, assess sitting tolerance, accessibility and transportation. Pack spare wheelchair parts. Flight planning should include decisions about layovers, transfer methods and washroom access.
- **Medication:** Include an extra 2-3 weeks of spare medication and incontinence products in case there is a delay on the return journey.

Important resources: Travelling with SCI

- SCIRE Community's Travelling with a SCI (16 November 2022): This 13-page resource covers numerous topics when travelling, and
- Incontinence tips for travelling (Ideas, 3 October 2024): This resource provides plenty of travel tips.

Below, **Dinesh** shares a personal story about travelling.

Dinesh Palipana's story: International travel

Read **Dinesh**'s responses to the following travel-related questions:

Who travels with you?

> *"I travel with some of the guys [support workers] and my mom usually. The guys can't be with me 24/7 so I need a couple of people and they do shifts. Qantas and Virgin have carer travel schemes for those who can travel independently."*

Do you need a special seat?

"No, but I try to travel business class. You can stretch out so if you need care, then you can do whatever you want."

What are some of your particular issues with international travel?

"Travel insurance actually. You have to find the right travel insurance that will cover your SCI and the complications. The other thing is understanding the health system at the other end [another country]. Most countries will not be equipped to expertly care for someone with this one injury.

And then there is the disability framework in your destination. The transport system, like the ground transport system. What are the taxi services like? *Some countries are not going to have one, like Sri Lanka. I always wanted to go to Egypt and Africa.* Will I be able to visit?

Also damaged equipment and lost equipment. What do you do if your wheelchair doesn't turn up? It has happened to people. Again, I'm lucky that I travel with these guys who will 'throw' me into a car. They are strong. But, if you don't have access to someone who can physically lift you, you can't travel to some places. So, lost or broken wheelchairs are an issue. Invariably, they'll damage it, so I travel with manual wheels".

Emergency supplies, such as a spare catheter, are important. In the worst-case scenario, we can change a catheter and then we keep some medications for autonomic dysreflexia. The problem with all of that is getting through security. You need a doctor's certificate. And if you're in pain and you have opioids... It's very complex."

Based on **Dinesh**'s advice, below is information on travelling by air with a carer on Qantas and Virgin.

Important information: Qantas and Virgin Airlines

- Qantas – Fare Reductions for Travel with a Carer: If you need assistance and travel with a carer, you may be eligible for reduced fares on Qantas flights within Australia and international flights departing Australia. Eligibility requires one of the following:
  - Carer Concession photo ID card (People with Disability Australia)
  - Centrelink Pensioner Concession Card with blind entitlement
  - Travel pass for vision impairment issued by an Australian State or Territory

    - For more info about the PWDA Qantas Carer Concession Card:
        - Call: 1800 422 015 (toll-free within Australia)
        - Email: qccc@pwd.org.au
- Virgin – Travelling with a Carer: Virgin also offers support for passengers travelling with a carer. To notify Virgin in advance of your condition, you can:
    - Make a request online by submitting a Special Service Request form
    - Call the Guest Contact Centre on 1300 139 303 (within Australia) or +61 7 3295 3941 (outside Australia)
    - Medical Clearance Guide, and
    - Special Service Request Form.

12.5. Being a tourist with SCI

For individuals living with SCI, becoming a tourist, whether locally or internationally, is the ultimate expression of independence and a powerful tool for re-integrating into community life. Travel planning for a wheelchair user moves beyond booking tickets. It becomes a complex logistical exercise focused on accessibility, safety and personal care management. The goal of accessible tourism is to ensure that individuals with physical disability can have the same experiences as able-bodied people, fostering a sense of inclusion and agency (Greenwood *et al.*, 2025; SCIA, 2021).

12.5.1. Importance of inclusion and accessibility

Successful tourism for people living with SCI depends on meaningful inclusion, which can only be achieved when accessibility is guaranteed. Accessible transport, infrastructure, accommodation and public spaces enable people with SCI to travel safely, independently and with dignity.

Research: Accessible tourism and well-being

In a small study in which four men aged 32 to 63 living with SCI (two with C6/7, two with T8/9), who were also co-researchers in the study, toured the Gold Coast for two to three days. Three travelled with their

partners and/or a friend and one travelled with family and friends. One person used a power wheelchair as their primary means of mobilisation. Two people used a manual wheelchair, while the fourth person used both power and manual wheelchairs.

They were asked to take photographs to illustrate their experiences, which they then discussed in a focus group. They reported feeling valued and experiencing a greater sense of agency and control when able to participate with their family and/or friends. This ability to share experiences, such as dining out or visiting a landmark, made the tourist experience meaningful, demonstrating that accessibility is not merely a matter of compliance, but of vital social and psychological well-being (Greenwood *et al.*, 2025). This emphasises the critical importance for local councils and city planners to consider access, as it impacts all aspects of infrastructure, from footpaths to public facilities.

The importance of inclusion and accessibility extends beyond individuals with SCI and their families, friends and support networks. Policymakers, local councils and town planners need to consider accessibility when designing and developing tourist destinations. Inclusive planning helps ensure tourist spaces are accessible to everyone, supports wider community participation and contributes to more sustainable and socially responsible tourism outcomes, as discussed in the podcast below.

Podcast: Tourism, accessibility and city planning

SCIA's Have the Nerve podcast, Tourism, Access and City Planning with Access Bondi (Episode 11, 1 December 2021):**Susan Wood** examines why universal accessibility is crucial for local councils, using Bondi Beach as a case study. The discussion focuses on the requirements for city planners to integrate comprehensive access measures into infrastructure to ensure visitors with mobility issues can fully participate in tourism and community life.

12.5.2. Specialist travel agents and organised tours

Given the extensive logistical planning required for accessible travel with physical disability, including securing accessible accommodation, coordinating flights, managing transfers and arranging care, many individuals or their families opt for specialist assistance, particularly if a carer or support worker also needs to travel. If the financial means are available, specialist travel agencies can arrange personalised itineraries, with some expenses for supported travel covered by the NDIS.

Below are a few useful resources for planning the next trip.

Important resources: General travel and transport

- SCIA's Accessible Travel and Transport Tips for People with SCI (17 November 2021): This resource provides a brief, foundational overview of travelling with an SCI. It is recommended as a first read to inform initial travel planning before delving into more detailed, complex logistics.
- Ideas' Travelling with a SCI (3 October 2024): This page has many useful links on general travel.
- NDIS Support Lists: For Australian residents, the NDIS offers lists of registered providers and resources to assist with travel support needs, including finding carers, coordinating specialist equipment hire and funding transport-related goals.
- Wheelchair Users' Guide to Air Travel (Wheelchair Travel): This comprehensive guide offers detailed, practical information on the entire air travel process, including how to book flights, required preparation the night before, procedures at the airport and managing mobility once on board. It also often includes user-generated blogs and tips on essential topics like protecting your wheelchair from damage.
- WheelchairTraveling.com: This website provides extensive information about international destinations. The current link is for travelling with a wheelchair on Australia's long-distance train journeys, such as the Ghan, Indian Pacific, Great Southern and the Overland. For other destinations, use the dropdown menu.

These agencies often cater specifically for individuals with complex support needs, offering tailored services, such as cruises with carers and fully supported day trips. With so much to organise to travel locally and even more so internationally, if you have the financial means, you can always get a specialist travel agency to arrange personalised travel.

Important information: Personalised and specialised travel

- Supported Travel eXperiences (STX): Provides organised and supported holiday packages
- Disability Specialist Travel (Aspire Hub & STX): Provides integrated travel planning and support services
- ISCREAM Travel: A specialist accessible tour operation
- Amplify: Accessible Travel Specialists: Provides tailored tours and travel consulting, and
- AccessibleOz: A disability inbound tour operator specialising in creating accessible and inclusive travel experiences for people with disabilities and special needs.

The next story (**Fletcher** and **Lachie**) appeared on Channel 9's Today show (March 2026). It is a heartwarming story about mateship.

Lachie and Fletcher's story: Four continents, two months, two friends and a wheelchair

Man in wheelchair 'speechless' at best mate's commitment to their travel. Read and watch how **Fletcher**'s friend, **Lachie**, took him on a trip of a lifetime after his SCI.

12.6. LLEs and the role of advocacy in inclusive tourism

The push for improved accessible tourism often involves individuals with SCI moving into advocacy roles, influencing policy and industry standards. This shift in individuals with LLE from consumers to influencers is contributing to creating an inclusive tourism sector.

Belinda Harris' story: An accessibility advocate for sport, recreation and tourism

Belinda plays a key role in driving inclusivity in sport, recreation and tourism – Carers Queensland (Carers Queensland, 2023): **Belinda Harris** is an accessibility advocate, former Paralympic athlete (Boccia), and the founder of the consultancy, The Access Journey, which works to improve accessible tourism in Australia. Her professional journey included championing inclusivity in sport, recreation and tourism, demonstrating the powerful impact LLEs can have on the industry's best practices.

From 3-5 November 2022, the Disability Royal Commission engagement team hosted two online workshops focused on the experiences of violence, abuse, neglect and exploitation of persons with disability using domestic air travel and in airports as part of the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability.

Key issues they identified included:

- People with disability are often treated as an afterthought when flights are cancelled or

changed
- Passengers who use assistance dogs experience discrimination, including being refused travel
- There are very few accessible flight options in regional and remote areas.
- Many aircraft limit the number of wheelchairs allowed in the cabin, often to only two per flight
- Many aircraft do not have onboard wheelchairs
- Long wait times are common when trying to confirm accessibility needs before flying
- Information and support before a flight are often unclear or insufficient, and
- Airlines are often slow to respond, with some participants reporting that their concerns as passengers are ignored or dismissed.

As was pointed out earlier, there are 'issues' with flying, and sometimes, accidents happen. Below are some of these stories.

Media stories: Disability advocates and airline failures

- Heartbreaking: Airline's Negligence Led to Wheelchair User's Death: In November 2021, disability advocate **Engracia Figueroa** died after her custom power wheelchair was destroyed by an airline.
- Advocates Express Fear and Rage at Latest Wheelchair User's Death-by-Airline: **Gaby Assouline**, 25, became quadriplegic after a jet bridge accident in February 2022, after the airline failed to assist her in boarding. Sadly, she died in Jan 2023.
- Calls for Change After Qantas Refuses to Fly British Woman with Mobility Scooter: **Dr Jurai Darongkamas** faced a six-month dispute after Qantas classified her mobility scooter as a personal device, sparking calls for consistent standards.

Section 2: Travelling with complex needs

This section provides specific, detailed information for individuals managing complex medical requirements, such as bladder management and ventilatory support, while travelling. This level of planning is critical for ensuring personal safety and continuous health management away from familiar environments.

A common anxiety among travellers with mobility aids is equipment loss or damage. As **Dinesh Palipana** noted earlier in this Chapter, there are lots of issues with air travel, particularly inter-

nationally. It is therefore important to minimise dependence on complex equipment, as far as is reasonably possible.

Below are a few important resources to consider when travelling with complex needs and equipment.

Important resources: Practical travel guidance

- Travelling with a SCI -The Back Up Travel Guide (Back Up Trust): Provides general guidance and support information, focusing on confidence and managing expectations while travelling with an SCI
- Tips for flying for people with a SCI (Urology Awareness Week) (Back Up Trust): Focuses specifically on air travel challenges related to urology, offering practical tips for managing catheters on flights
- Travel Checklist for SCI Survivors (SpinalCord.com): A straightforward, actionable checklist to ensure you have not forgotten critical medical items, back-up equipment or necessary documentation, and
- Coloplast Care: Travel: A useful resource providing specific advice on managing essential routines, such as bladder and bowel care and ensuring you have the necessary supplies packed and managed effectively while away from home.

12.7. Travelling with a catheter

Managing bladder care while travelling demands meticulous preparation regarding supplies and hygiene. Infection and blockages are significant risks during extended travel (Health Experience Insights (Hexi), University of Oxford, n.d.). Below are some key recommendations.

Key recommendations: Travel preparation for catheter users

- **Supply management:** Always pack more supplies than necessary, such as catheters, lubricant, leg bags and drainage bags. A general rule is to carry at least two days' worth of extra supplies in carry-on luggage to protect against checked baggage loss. For long trips, consider having supplies delivered to your destination in advance (Back Up Trust, n.d.; SCI BC, 2025; Spinal Cord.com, 2020).
- **Hygiene protocol:**
    - Maintaining strict hygiene is essential, especially when using intermittent catheters in unfamil-

iar or public restrooms.
    - Using sterile, pre-lubricated catheters is advisable in environments where the cleanliness of facilities or water quality is uncertain (SCI BC, 2025).
    - Carry disinfectant wipes for surfaces and always wash hands with soap and water or use hand sanitiser before the procedure.

- **Airport security:** Individuals must carry a medical letter from their health practitioner explaining the need for catheters and associated supplies. Having documentation simplifies security screening (Coloplast Care, n.d.).
- **During long flights and journeys:** Use larger night bags for long flights to minimise the need to empty. For those with indwelling catheters, secure the tubing to prevent kinks and ensure free drainage during transfers and sitting (Hexi, n.d.).

Important resources: Travel resources for managing bladder and catheter needs

- Tips for flying for people with a SCI (Urology Awareness Week) (Back Up Trust): Focuses specifically on urology-related air travel challenges, offering practical tips for managing catheters on flights
- Travelling with a catheter user (SCI BC): Offers simple, practical advice specifically focused on managing catheter routines and supplies while away from home, and
- Travelling Long Distance with an Indwelling Urinary Catheter by Hexi (Oxford Health NHS): Offers specific, medical guidance for managing indwelling catheters on long journeys, including securing the device and hygiene protocols.

12.8. Travelling with a bowel or colostomy bag

Travelling with SCI often involves accessibility challenges, fatigue and disruptions to established care routines. The need to manage an ostomy during these situations can increase anxiety and planning demands. Understanding these added pressures is important when preparing for travel. Regardless, travelling with a bowel or colostomy bag is achievable, as **April**, an American, explains below.

April's story: Navigating airport security with an ostomy

Airport security tips with an ostomy: **April** provides a short video about how she gets through airport security in the US with an ostomy bag.

Travelling with a bowel (stoma) or ostomy bag is thus achievable with good preparation and the right support. It is important to pack more ostomy supplies than normally needed, as travel delays or changes in routine can occur. Essential items such as spare bags, skin barriers, wipes and disposal bags should be kept in carry-on luggage, so they are always accessible. Carrying a medical letter or travel card explaining the ostomy can also be helpful when passing through airport security or customs (Coloplast, n.d.b).

Lastly, when flying, keeping ostomy products in their original packaging may assist during security screening. Maintaining regular eating, drinking and bag-changing routines can support comfort and confidence while travelling (Coloplast, n.d.c).

12.9. Travelling with a ventilator

Travelling with a ventilator requires extensive planning and mandatory communication with carriers to address power requirements and safety.

12.9.1 Medical clearance

Airlines universally require passengers using medical oxygen or mechanical ventilation to submit a Medical clearance form. This documentation is necessary if there is any reasonable doubt that the passenger can complete the flight safely without requiring extraordinary medical assistance during the journey or if the medical device itself poses a safety risk.

Key recommendations: Medical clearances

The requirement for medical clearance typically applies if the passenger meets any of the following criteria:

- Medical oxygen during the flight
- A medical condition such that there is a reasonable doubt they can complete the flight safely without requiring extraordinary medical assistance
- A communicable disease or condition that could pose a direct threat to the health or safety of others on the flight.

Completing the medical clearance process well in advance is crucial as airlines usually require the form to be submitted and approved at least 48 hours prior to departure (Virgin Australia, n.d. a & b).

Important information: Key contacts for Virgin Australia

An example of arranging medical clearance at **Virgin Australia within Australia** will require you to:

- Make a request online by submitting a Special Service Request form
- Call their Guest Contact Centre on **1300 139 303** (within Australia) or **+61 7 3295 3941** (outside of Australia), or
- For more information, visit Flying with medical conditions.

12.9.2. Power and battery compliance

The safe and successful transport of a ventilator requires rigorous pre-planning focused on power, battery compliance and contingency. The device must be powered by portable battery packs that adhere to the Federal Aviation Administration (FAA) standards (FARs) and the International Air Transport Association (IATA) regulations. IATA provides essential guidance for the transport of mobility aids and medical equipment, which is critical for consistent handling across the aviation industry. Specifically, lithium-ion battery capacity is strictly limited by its watt-hour (Wh) rating. A single lithium-ion battery or a battery system designed to provide 300 Wh or less may be carried. If the battery exceeds 300 Wh, two spare batteries that are not more

than 160 Wh each may be carried. Crucially, all spare batteries must be protected from short circuiting, typically by placing them in a protective pouch or container (Home Mechanical Ventilation in Partnership (HMVIP), 2025; IATA, 2023; Newcastle Hospitals NHS, 2025).

12.9.3. Battery life and oxygen calculations

Meticulous calculation of power reserves is crucial to managing potential flight delays and unexpected circumstances. Passengers are typically required to carry sufficient battery reserves to cover 150% of the maximum flight time to account for potential delays. For example, a 10-hour flight requires 15 hours of certified battery life. These batteries must be stored in carry-on luggage and are not permitted in the cargo hold due to fire risk. If supplementary oxygen is required in-flight, a separate Medical Clearance Form is mandatory and must be submitted to the airline in advance (Virgin Australia, n.d. a).

12.9.4. Backup plan and equipment safety

A comprehensive backup plan is mandatory to address equipment failure or power loss during the journey, as reliance on the device is absolute for many users. This includes carrying all spare parts, tubing and masks in carry-on luggage. For individuals who rely entirely on the device, a manual resuscitation bag (ambu bag) must be immediately accessible to the travelling companion or carer for use during emergencies or power failure. Furthermore, carrying the official instruction manual for the ventilator and a detailed medical letter is necessary as airline staff and foreign medical professionals may need its specifications and operating procedures (Medical Repatriation, n.d.; Medical Air Service, n.d.).

12.9.5. Destination planning and contingency

Planning for reliable power and support at the destination is essential for maintaining continuous ventilation and safety. Individuals must ensure their destination accommodation has reliable, compatible power outlets. You may need voltage converters or plug adaptors specific to the country you are visiting. If the ventilator is life-sustaining, ensure the destination has an emergency power plan, such as a generator to cover regional power outages. Researching local medical assistance, repair facilities and home ventilation services before departure is vital to establish a support network in case of equipment malfunction or medical need (Home Mechanical Ventilation in Partnership (HMVIP), 2025; Newcastle Hospitals NHS, 2025).

Important resources and information: Travel guidance for people with ventilation

- Medical Conditions and Specific Needs Assistance (Virgin Australia): Official source for the airline's rules. It details when a Medical Clearance Form is required (including for oxygen and ventilators) and provides links to necessary documentation for travel approval.
- Travelling with Home Mechanical Ventilation (HMVIP): An excellent guide from the UK's Home Mechanical Ventilation Information Portal, offering practical steps for planning and managing ventilation equipment abroad.
- Travel and Holidays: Advice for Home Ventilation Service Patients (Newcastle Hospitals NHS): Provides specific, detailed advice from a major health service on pre-travel preparation, managing power and coordinating care at your destination.
- Flying Intubated Patients (Medical Repatriation): Offers essential information on the critical aspects of air travel with life-sustaining devices, covering battery life calculations and backup emergency protocols.

12.10. Other medical considerations

As we discussed in **Chapter 2,** muscle contractions and the sympathetic nervous system promote blood return to the heart (venous return), but muscle control and sympathetic activity are impaired after injury. Blood can pool in the legs. This increases the risk of blood coagulating and so clots forming in the veins. This can disrupt blood flow throughout the body, particularly in the legs or lungs. There is a significantly increased risk of stroke by 300-400% (Badur *et al.,* 2025).

Deep vein thrombosis (DVT) is caused by the formation of a blood clot in a deep vein, most often in the legs. Often, clots will dissolve on their own. It is, however, possible that a clot can dislodge and travel to the lungs, causing a pulmonary embolus, which can be fatal. The risk of DVT increases with long-distance travel of four or more hours (with risk increasing the longer you sit without moving) for those with underlying risk factors, such as decreased mobility. Talk to your doctor about the risk of blood clots before your trip and whether you would benefit from preventive treatments, such as medication and compression stockings.

Key recommendation: Circulation support

During long journeys, complete seated pressure lifts or weight shifts every 15-30 minutes to support circulation. Avoid crossing your legs and, if possible, gently move your ankles and feet regularly to promote blood flow and reduce pressure-related risks.

Key Take-aways

Section 1: Preparing individuals with SCI for general travelling

- Mobility after SCI contributes to a life well-lived. The ability to get around is an equity issue for connecting with the community and accessing essential services
- Access is, however, inconsistent. Despite official standards, public transport remains challenging due to physical barriers, such as ramps and elevators
- Driving is the goal for those who can as driving a modified vehicle provides independence. This requires a formal Return to Drive Process with specialist clinical assessment, and
- Safety is a priority. Users of wheelchair-accessible taxis (WATs) face safety and quality concerns. Personal safety depends on adhering to restraint protocols.

Section 2: Travelling with complex needs

- Flying is stressful. It involves temporarily relinquishing control and carries a high risk of equipment damage and pressure injury
- Meticulous preparation and timely notification are required. Success hinges on mandatory notification to the airline upon booking and confirmation and carrying custom pressure-relieving cushions in the cabin
- A Medical Clearance Form is mandatory for anyone requiring oxygen or mechanical ventilation in-flight
- Ventilator battery compliance is crucial. Powered wheelchair batteries must comply strictly with FAA/IATA watt-hour (Wh) limits and be protected from short-circuiting. Passengers must carry a battery with a capacity covering 150% of the maximum flight time
- A comprehensive backup plan is essential. For life-sustaining devices, this includes an accessible manual resuscitation bag (ambu bag) and carrying spare medical supplies in carry-on luggage, and
- Long-haul travel increases the risk of DVT. Preventive measures must be discussed with your doctor.

The next chapter, **Chapter 13**, will discuss in detail the preparation required should you need to undergo surgery.

Reminder: Relevant chapters

- **Chapter 1:** As the first chapter discussing coming home, it covers getting out and about and travelling locally
- **Chapter 2:** You can always revert to Chapter 2 to refresh your knowledge on what could happen to your body when physiologically stressed
- **Chapter 3:** To stay healthy and well, including being physically strong, is important. This will require transport to doctors, the pharmacy, the supermarket, to name a few. If you are a traveller, you need to be in reasonable physical fitness as you never know what awaits you on the other side
- **Chapter 5:** This chapter deals with socialising, studying, working and perhaps volunteering. You will need transport to be able to undertake these activities
- **Chapter 10:** There is always the possibility that you might experience discrimination and abuse while travelling, either from the ground staff, the airline staff or other passengers Best be prepared, and
- **Chapter 17:** Impact of a changing climate, as children are vulnerable to heat, as are those living with SCI, particularly if the person cannot regulate their body temperature or has mobility issues during adverse weather events. Having an emergency plan is crucial.

References

American Spinal Injury Association. (2022). *The SCI traveler: A guide to navigating barriers to domestic and international travel.* https://asia-spinalinjury.org/scitraveler22/

Badur, N.B., Winkle, M. J., & Leslie, S.W. (2025). Autonomic Dysreflexia. In: StatPearls. Treasure Island (FL): StatPearls Publishing. https://www.ncbi.nlm.nih.gov/books/NBK482434/

Back Up Trust. (n.d.). Urology awareness week: *Tips for flying for people with a spinal cord injury.* https://www.backuptrust.org.uk/blog/independence/urology-awareness-week-tips-for-flying-for-people-with-a-spinal-cord-injury

Blue Badge Insurance Australia. (n.d.). *Wheelchair taxi options in Australia.* Blue Badge Australia. https://www.bluebadgeinsurance.com.au/blog/wheelchair-taxi-accessible-transport-australia/

Carers Queensland. (2023). *Belinda plays key role in driving inclusivity in sport, recreation and tourism*. https://carersqld.com.au/belinda-plays-key-role-in-driving-inclusivity-in-sport-recreation-and-tourism/

Coloplast Care. (n.d.a). *Travel.* https://www.coloplastcare.com/en-CA/continence/lifestyle/travel/

Coloplast. (n.d.b). *Travelling with a stoma*. https://www.coloplast.com.au/ostomy/people-with-a-stoma/living-with-a-stoma/travelling-with-a-stoma/

Coloplast. (n.d.c). *Packing and planning for travel*. https://www.coloplastcare.com/en-AU/ostomy/lifestyle/travel/l5.2-packing-and-planning/

Greenwood, J., Gustafsson, L, McShane, M, Mackereth, C., Greenfield, N., Fernandes, J., & Walder, K. (2025). Tourism experiences of people with a spinal cord injury: a photovoice study of the Gold Coast. *Disability & Society. 40,* 12, 3419-3440*.* https://www.tandfonline.com/doi/pdf/10.1080/09687599.2025.2492658?needAccess=true

Health Experience Insights (Hexi) (n.d.). *Travelling long distance with an indwelling urinary catheter*. University of Oxford, Nuffield Department of Primary Care Health Sciences. https://hexi.ox.ac.uk/living-urinary-catheter/travelling-long-distance

Home Mechanical Ventilation in Partnership (HMVIP). (2025). *Travelling with home mechanical ventilation – Air travel guidance*. https://hmvip.co.uk/travelling-with-hmv

International Air Transport Association (2023) (n.d. a). *New guidance to improve the transportation of Mobility Aids.* https://www.iata.org/en/pressroom/2023-releases/2023-02-08-01/

Medical Air Service. (n.d.). *Traveling while on mechanical ventilation.* https://www.medical-air-service.com/blog/traveling-while-on-mechanical-ventilation_9793.html

Medical Repatriation UK. (n.d.). *Flying intubated patients: Traveling safely when on mechanical ventilation*. https://www.medical-repatriation.uk/repatriation-services/blog/flying-intubated-patients-traveling-safely-when-on-mechanical-ventilation_9532.html

National Disability Services (NDS). (2025). Safe taxis are critical to full participation. Media release, 18 February 2025. https://nds.org.au/news/safe-taxis-critical-to-full-participation

Newcastle Hospitals NHS (2025). *Travel and Holidays: Advice for Home Ventilation Service Patients*. https://www.newcastle-hospitals.nhs.uk/services/home-ventilation-service/travel-and-holidays/

Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. (2022). *Workshops find people with disability an afterthought in domestic air travel.* https://disability.royalcommission.gov.au/news-and-media/workshops-find-people-disability-afterthought-domestic-air-travel

Spinal Cord Injuries Australia (SCIA) (2021). *Accessible travel and transport tips for people with SCI.* https://scia.org.au/resource-hub/travel-and-transport/

Spinal Cord.com (2020). *Travel checklist for spinal cord injury survivors.* https://www.spinalcord.com/blog/travel-checklist-for-spinal-cord-injury-survivors

SCIRE Community. (2022). *Travelling with a spinal cord injury.* https://community.scireproject.com

Spinal Cord Injury BC (SCI BC) (2025). *Travelling as a catheter user*. https://sci-bc.ca/travelling-as-a-catheter-user/

Spinal Life Australia. (2020). *Advocacy Position Statement: Transport.* https://www.spinal.com.au/wp-content/uploads/2020/02/Position-Statement-Transport-new-2020.pdf

Virgin Australia. (n.d. a). *Flying with medical conditions.* https://www.virginaustralia.com/au/en/travel-info/specific-travel/specific-needs-assistance/medical-conditions/

Virgin Australia. (n.d. b). *Medical clearance guidelines and form*. https://www.virginaustralia.com/content/dam/vaa/documents/specific-travel/medical-clearance-guide.pdf

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Chapter 13. Surgery and Anaesthesia for Individuals with Spinal Cord Injury

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From time to time, individuals with SCI will need to undergo a surgical procedure. Anaesthesia for these procedures requires special care that considers each patient's specific needs. This is because SCI can affect many body systems, especially the autonomic nervous system, which controls blood pressure, heart rate, breathing and body temperature. As no two people are the same, you can be assured that the anaesthesia is tailored, depending on the SCI level and its impacts on a person's body, as well as the type of surgery being performed.

This Chapter is divided into two sections: **Section 1** focuses on preparing individuals living with SCI for surgery, while **Section 2** provides information for health professionals.

Key Topics in this Chapter

Section 1: Preparing for surgery

- Important considerations for anaesthesia in individuals with SCI
- Common surgeries for individuals living with SCI: Urological, orthopaedic, dermatological (skin, wound), respiratory, neurosurgical and neuro-rehabilitative procedures
- Steps to take once surgery is scheduled
- Increased risks before, during and after surgery for individuals with SCI
- Pre-surgery bowel and bladder management
- Guidelines for pre-operative fasting
- Special considerations for patients with high-level spinal injuries who are ventilated
- What to expect on the day of surgery
- Types of anaesthesia commonly used
- Hospital stays and recovery
- Returning home after surgery, and
- Resuming usual activities or physiotherapy.

Section 2: Information for health professionals

- Evidence-based guidance for GPs
- Post-operative monitoring and rehabilitation
- Special considerations for anaesthesia during childbirth and children living with SCI, and
- Additional anaesthetic considerations for paediatric patients with SCI.

Section 1: Preparing for Surgery

13.1. Important considerations for anaesthesia in individuals living with SCI

As we already know, SCI can disrupt communication between the brain and the body, leading to complications such as *autonomic dysreflexia (AD)*, blood pressure fluctuations and heart rate and respiratory issues. Therefore, administering anaesthesia in individuals with a long-term SCI requires careful planning, as physiological changes depend on the injury level (Rizk *et al.,* 2022; Vaidyanathan *et al.,* 2012).

Higher-level injuries, such as those in the neck or upper thoracic region, generally cause more serious problems than the lower injuries. **Table 13.1** summarises the factors that anaesthetists need to consider for individuals living with SCI who must undergo surgery.

Table 13.1. Factors anaesthetists consider when an individual with SCI undergoes surgery (Rizk *et al.,* 2022; Umamaheswara Rao, 2008; Vaidyanathan *et al.,* 2012).

SCI level	Respiratory function	Autonomic dysreflexia (AD) risk	General anaesthesia (GA)	Neuraxial (spinal or epidural)	Peripheral nerve or regional blocks
Cervical (C1-C8)	Above C4: diaphragmatic paralysis (ventilator-dependence). C5-C8: diaphragm intact, intercostal muscles are weak, poor cough.	Complete loss of sympathetic tone; chronic hypotension and bradycardia. AD risk if a high (lesion ≥T6).	Airway protection is essential; intubation and ventilation are usually needed. High risk of hypotension (use vasopressors). AD may still occur under GA.	Neuraxial at the cervical level is rarely used. A low SCI could theoretically prevent AD reflexes, but it is uncommon.	Useful for limb procedures, such as a brachial plexus block. Does not block visceral stimuli. AD is still possible, so sedation is required.
High thoracic (T1-T6)	Intercostal muscle weakness (diaphragm largely preserved).	Partial sympathetic loss; baseline hypotension or bradycardia. AD risk if a high lesion (≥T6).	GA feasible, expect haemodynamic lability. Monitor for AD-induced hypertension or severe hypotension.	Spinal or epidural can block AD and provide excellent analgesia. Muscle relaxation helps with surgery. Must manage hypotension carefully.	Peripheral nerve blocks, such as upper- or lower-extremity blocks, provide analgesia; visceral or traction pain may still trigger AD if not otherwise blocked. Often used with GA.
Low thoracic (T7-T12)	Minimal respiratory effect.	The sympathetic chain is mostly intact above the lesion. AD risk is low.	GA is generally safe; standard intra-operative monitoring.	Spinal or epidural blocks are straightforward and used for analgesia.	Peripheral nerve blocks are effective. Standard practice of limb surgery.
Lumbar, sacral (L1 and below)	No respiratory compromise.	Sympathetic outflow is intact. AD risk is negligible.	GA is the same as that of non-SCI patients. No special airway or haemodynamic issues due to the SCI.	A spinal or epidural can be easily placed below the injury. Valuable for lower limb or obstetric surgery.	Peripheral nerve blocks are effective. Standard practice of limb surgery.

13.2. Common surgeries for individuals living with SCI

People living with SCI often undergo surgeries for complications related to immobility, AD and associated conditions (Dalal & DiMarco, 2014; Petsas & Drake, 2015). Common surgeries are described below.

13.2.1. Urological surgeries

Bladder control is often affected following SCI, leading to urine retention, incontinence, infections and kidney damage. Surgeries that can ensure safe urine drainage, prevent kidney damage and improve continence include:

- Suprapubic catheter insertion
- Bladder augmentation (enlargement, called *enterocystoplasty*)
- Insertion of an artificial urinary sphincter
- Stone removal (bladder or kidney), and
- Urethral or bladder neck surgery.

Note: If your injury is at T6 or above, surgeries involving the bladder may trigger AD during surgery. Your anaesthetist will use special precautions to manage this.

13.2.2. Orthopaedic surgeries

SCI often leads to spasticity, contractures, bone loss and mobility issues. Orthopaedic interventions improve function, posture, or prevent complications. Some of the commonly performed surgeries include:

- Tendon and muscle releases
- Tendon or nerve transfers
- Fracture fixation or joint stabilisation, and
- Heterotopic ossification resection.

13.2.3. Dermatological (skin or wound) surgeries

Patients with SCI are at increased risk of pressure ulcers due to immobility and sensory loss. Healing may be slower. Infection prevention is the key. Surgeries include:

- Pressure ulcer debridement and flap reconstruction, and
- Minor skin procedures for the removal of cysts, warts or trauma-related wounds.

13.2.4. Gastrointestinal surgeries

Bowel dysfunction is common post-SCI, leading to constipation or incontinence. Surgeries include colostomy or ileostomy, gallbladder removal (cholecystectomy) and insertion of a feeding tube (gastrostomy).

13.2.5. Respiratory surgeries

Respiratory impairment is a major concern in high-level SCI (especially C1-4). Some of the procedures performed to support breathing include *tracheostomy* and *diaphragm pacing.*

13.2.6. Neurosurgical and neuro-rehabilitative surgeries

These surgeries target the spinal cord itself or help manage the chronic effects of SCI. Some of the procedures performed include:

- *Intrathecal baclofen pump (ITB)*
- *Spinal cord stimulator* implantation
- *Syrinx or tethered cord* surgery, and
- Acute spinal decompression and/or fusion: In early injury, surgeons remove pressure over the spinal cord and stabilise the spine to preserve function.

13.3. Steps to take once surgery is scheduled

After your surgery has been scheduled, there are a few steps to help you get ready and ensure everything goes smoothly and safely. You will be contacted by the hospital for a pre-admission clinic visit or a telephonic consultation, often 2-4 weeks before surgery (described below), and you will receive clear instructions on how to prepare for surgery (Petsas & Drake, 2015; Rizk *et al.,* 2022).

As the date of your surgery nears, the surgical and anaesthetic team will contact you or provide information about:

- When to stop eating and drinking (called fasting)
- Which medications do you need to stop taking, and
- How to manage feeding tube, bowel preparation and other special care routines.

13.3.1. Confirmation the day before surgery

Someone from the hospital will invariably call you the day before surgery to confirm:

- What time to arrive
- Where to go
- Any last-minute instructions, and
- Any personal items or equipment you need to bring.

You should then:

- Let your care team or support worker know what is planned and how they can help
- Pack any essential items (medications, pressure-relieving cushions, equipment or care notes), and
- Contact the hospital beforehand if you are unwell, have a pressure injury or sore, a urinary tract infection or if anything has changed. They may need to reschedule.

13.3.2. Tests and assessments required before surgery

If you are living with SCI, your body may respond differently to surgery and anaesthesia. To ensure your safety and well-being, you will need to undergo routine tests and assessments before your operation.

Your **GP and allied health team** will probably review your overall health by:

- Assessing your daily routines and any special equipment you use, such as a ventilator or pressure cushion
- Ordering routine blood tests, urine tests, an ECG or an X-ray, as required, and
- Checking your medications and coordinating with the hospital team.

The **surgical and anaesthesia team** (at the pre-assessment clinic) will:

- Review your overall health and all test results
- Assess the level of SCI
- Assess your risk of complications (like AD and breathing problems)
- Plan your anaesthesia, positioning and post-operative care, and
- Request other tests, such as a lung function test or refer to specialists if needed.

Additional specialist teams (if required) may include:

- **Urology:** If bladder care is complex or you are having a urological procedure
- **Respiratory:** If SCI affects breathing or you use a ventilator

- **Cardiology:** In cases where you have cardiac disease, such as coronary artery disease, and
- **Dietetics:** If you are at risk of poor wound healing or weight loss.

These assessments and reviews help your**surgical team**:

- Understand your general health
- Identify any SCI-specific risks, such as infection or pressure injury, and
- Plan anaesthesia and aftercare.

You will be supported throughout this process by your surgical team, and, if needed, a specialist or anaesthetic team. You should not hesitate to ask questions. Because every person is different, their care needs to be personalised. Your surgical team will thus tailor a plan based on your injury, health history and the type of surgery.

13.4. Increased risks before, during and after surgery for individuals living with SCI

Individuals with SCI face higher rates of complications around the time of surgery and post-operatively than the general population. SCI affects many body systems, and the level of SCI can influence how an individual's body responds to surgery and anaesthesia (Khan *et al.,* 2007; Petsas & Drake, 2015; Rizk *et al.,* 2022).

If your **SCI is at or above T6 (high-level SCI)**, you are at risk of AD. You may need deep anaesthesia or specific medications to prevent AD during surgery.

If your **SCI is cervical (C1-C8)**:

- Your breathing muscles may be weak, and you may need breathing support or even a ventilator
- You might have trouble coughing up mucus after surgery, increasing your risk of a chest infection, and
- The anaesthesia team may plan extra respiratory support and monitoring after surgery.

Other risks related to SCI and their management during surgery are outlined in **Table 13.2**.

Table 13.2. Other risks related to SCI and their management.

Risk during surgery	How risk is managed during surgery
Skin breakdown or pressure sores	Careful positioning and padding of potential pressure areas in the operating room
Poor wound healing	Nutritional support and wound checks
Bladder or bowel issues	Pre-operative catheter care and bowel preparation
Temperature control problems	The operating room is kept at ambient temperature, warm blankets are used, and fluids are managed carefully.

13.5. Pre-surgery bowel and bladder management

People living with SCI often need an individualised plan for managing their bladder and bowel function before surgery. This preparation usually happens 1-2 days before your surgery. The healthcare team will:

- Review your usual bladder and bowel routine
- Provide you with specific instructions based on the type of surgery, and
- Coordinate any changes or support needed, such as home preparation or inpatient preparation if admitted early.

Bowel preparation is important, as general anaesthesia slows gut motility. A clean bowel helps prevent complications like constipation, ileus, or accidental soiling during surgery. You may be given a mild bowel preparation the evening before surgery, such as a laxative or enema, especially if you are having abdominal or pelvic surgery. In addition, your usual bowel care routine (suppositories, digital stimulation or manual evacuation) may need to be done earlier or adjusted before surgery.

Note: A high-level SCI can increase the risk of AD during bowel preparation, so it must be done gently and with continuous monitoring.

Bladder management is also important. If you use a Foley or suprapubic catheter, it typically remains in place for surgery but may need to be changed or flushed one day before if needed. If you do intermittent catheterisation (self-catheterisation), you will need to undertake a final catheterisation just before hospital arrival. A temporary Foley catheter may be inserted for surgery and remain in place during the post-operative period.

You should let your GP or surgical team know if you have ever had AD, urinary tract infections, or trouble with bowel preparation. If you are managing the bowel preparation at home, ensure you have clear written instructions about when to take the medications.

If you are prone to urinary tract infections, make sure the anaesthetic team know so they can consider prophylactic antibiotics.

13.6. Guidelines for pre-operative fasting

Before an anaesthetic, all patients, including those with SCI, are usually asked to stop eating and drinking (fast) for a certain time before surgery. This is to reduce the risk of aspiration (food or fluid entering the lungs) during anaesthesia.

13.6.1. General fasting guidelines

- **Solids:** Stop eating six hours before surgery
- **Clear fluids (like water, clear juice):** Allowed until two hours before surgery unless told otherwise, and
- **Feeding tubes:** If you have a *percutaneous endoscopic gastrostomy (PEG)*, nasogastric or jejunostomy tube, your team will tell you when to stop feeds (often 6-8 hours prior). Tube feeds may be paused earlier than oral diets, especially if anaesthesia risk is higher.

13.6.2. Special considerations for SCI undergoing surgery

There are several special considerations for individuals with SCI who are undergoing surgery. These include the following:

- Some individuals with SCI experience delayed stomach emptying or gastro-oesophageal reflux, which increases the risk of aspiration during anaesthesia. For this reason, the surgical team may recommend a longer fasting period or prescribe medicines to reduce stomach acid
- If you are prone to AD, hunger or gastrointestinal discomfort during fasting may trigger an episode. It is important to inform your healthcare team if this has happened to you in the past, and
- If you rely on a carer, nurse, or live in residential care, they can assist by tracking fasting times and supporting you throughout the preparation process.

13.7. Special considerations for SCI patients with high-level injuries already requiring ventilation

If you use a ventilator due to high-level SCI (C1-C4), your breathing needs before, during and after surgery have to be planned (Cotton *et al.*, 2025).

13.7.1. Before surgery

The pre-operative meeting typically takes place well before surgery, often during your pre-operative assessment or consultation. Ideally, it is scheduled a few weeks in advance to ensure all necessary preparations are made. In urgent cases, it may be scheduled closer to the surgery date, but earlier planning allows time for adjustments, especially if special ventilator arrangements are needed.

During this meeting, you will meet with your healthcare team, including the surgeon, anaesthetist, ICU or respiratory physician, respiratory therapist or physiotherapist, and biomedical or technical staff, to discuss your care and ensure everything is ready for the procedure. At this meeting, you should share details about your ventilator, such as:

- Type (invasive or non-invasive)
- Mode (pressure or volume control)
- Usual settings (breathing rate, oxygen levels, pressure)
- Alarm limits, tubing, humidifier, battery life
- Airway clearance needs, and
- Airway devices, such as a ***tracheostomy***.

Reminder: If you use a ventilator

Bring a written summary of your ventilator settings to assist staff. The team will decide if you can use your own ventilator or switch to a hospital one. Hospitals have compatible ventilators, but yours may be used as a backup. Carers or support workers familiar with your routine should attend this meeting to assist staff.

When **preparing your breathing equipment**, keep the following in mind:

- If you are bringing your breathing equipment, label each item with your name
- Verify in advance with the hospital which items you should bring
- Pack sufficient backup supplies (such as batteries and filters) for your ventilator, and
- If in doubt, having your own portable ventilator on hand is safer. Hospitals can switch devices if needed.

13.7.2. During surgery

The **anaesthetic team** will:

- Monitor your breathing closely at all times.
- Adjust the ventilator settings as needed and provide ventilation via the hospital system.
- Ensure staff are aware of the risk of AD and take precautions.

A high-level SCI and anaesthesia carry the risk of aspiration and infection. Because lung function is reduced, you have a higher chance of pneumonia. The anaesthetist will use techniques (nasogastric tube or fast intubation) to lower the risk of aspiration.

13.7.3. After surgery (recovery on the ward)

You are likely to go to the intensive care (ICU) or high dependency unit (HDU) for at least 24 hours, as there are specialised nurses, doctors and therapists who will watch your breathing closely. After surgery, ICU staff will follow strict precautions to prevent pneumonia. Your bed head will remain elevated, oral care will be performed regularly, and breathing circuits will be kept sterile. Nurses trained in tracheostomy and ventilator care will be involved to monitor for signs of respiratory infection or distress, ensure suctioning needs are managed, and resume your routine as soon as it is safely possible.

If you were using non-invasive support (*BiPAP* or*CPAP*), it will be resumed once awake, often with your personal machine. A respiratory physiotherapist will assist with chest physiotherapy and breathing exercises.

13.8. What to expect on the day of the surgery

You may be asked to shower with a special antiseptic wash in the morning and/or the night before the surgery to reduce the risk of infection. On the day of surgery, you will follow a structured process from arrival at the hospital to being taken into the operating room. The process is likely to include the following:

- You will check in and complete the administrative steps
- Meet the nursing and anaesthetic teams for final assessments
- The anaesthetist will re-explain the anaesthetic plan and discuss the risk

- You will be asked to sign a consent form for both surgery and anaesthesia (if not done previously)
- Change into operating room clothing and be escorted to the pre-operative holding area
- In the pre-operative holding area, your blood pressure, heart rate, temperature and oxygen saturation are recorded, and an IV line is placed (if not already placed)
- Have your identity and procedure confirmed
- Finally, you will be wheeled into the operating room on a bed
- You will be positioned carefully on the operating table. The anaesthetist will reconfirm your identity, attach the monitors and administer the anaesthetic agent, and
- Once the anaesthesia is administered, the surgery begins. You will remain under deep anaesthesia, with your safety and comfort vigilantly monitored throughout by the anaesthetic team.

13.9. Types of anaesthesia commonly used

Your anaesthetist will discuss the options, for example, general versus regional (spinal or epidural) versus sedation. The choice will depend on your injury level, remaining sensation, type of surgery, risk of AD and your wish (Petsas & Drake, 2015; Rizk *et al.,* 2022). You will receive clear explanations of the chosen method, its benefits, and possible side effects.

Considerations:

- Higher-level injuries (above T6) need extra measures against AD, favouring deeper blocks or general anaesthesia
- Lower abdominal, pelvic or leg surgeries often suit regional blocks, while more extensive operations usually need general anaesthesia, and
- If your chest muscles are weak, a breathing tube under general anaesthesia keeps you safe; if your breathing is strong, regional techniques let you breathe on your own.

If you develop AD, your anaesthetist will:

- Deepen anaesthesia or optimise epidural or spinal anaesthesia to reduce nerve stimulation
- Elevate the head of the bed
- Remove triggering stimuli, such as draining the bladder and loosening tight garments
- Administer fast-acting anti-hypertensives if needed, and
- Ensure adequate analgesia and anxiolysis (Hambly & Martin, 1998; Rizk *et al.,* 2022).

13.10. Hospital stays and recovery

Individual stays vary by procedure type, your overall health and any complications, but data from SCI populations provide helpful benchmarks (Biglari *et al.,* 2014; Hagan *et al.,* 2022; Nööjd *et al.,* 2023; Whiteneck *et al.,* 2011). In individuals with chronic SCI, the number of days in hospital after undergoing major elective surgeries, such as reconstructive flap or bladder augmentation, is 10-30 days. Less extensive procedures, such as urological or minor orthopaedic operations, are 7-14 days.

Factors that can extend your stay include:

- Complications during or after surgery
- Medical co-existing conditions, such as heart disease and diabetes mellitus
- Social factors, such as arranging home care or equipment, and
- If the surgery is followed by inpatient rehabilitation, the length of stay increases by 4-6 weeks.

13.11. Returning home after surgery

Once you are home after surgery, you and your carer will need to watch for:

- Sudden high blood pressure, pounding headache or sweating, especially if you have SCI at or above T6
- Fever of 38 °C or higher
- Red, painful, or leaking wound, which could mean infection
- New redness or swelling in your legs, which might be a blood clot, and
- Low oxygen (SpO_2 below 92%) or severe shortness of breath (Burns *et al.,* 2024).

If you see or experience any of these, call your surgeon or GP immediately or go to the nearest emergency department. Your surgical team will provide you with a personalised checklist, depending on the type of surgery and level of SCI, about what to watch for after surgery.

13.12. Resuming usual activities or physiotherapy

After your surgery, your surgical team and physiotherapists will guide you when it is safe to resume your usual routines and rehabilitation activities (Rizk *et al.,* 2022).

In the hospital: You may start gentle movements or breathing exercises early on, sometimes even the day after surgery, depending on the procedure and your overall health. The hospital

physiotherapy team may show you how to move safely, help you plan transfers or modify your usual exercises.

At home: You will likely restart your physiotherapy gradually. This might be:

- After 1-2 weeks, light activities, such as stretching or bed exercises
- After 4-6 weeks, more involved activities, such as sitting balance, transfer or wheelchair mobility, depending on your surgery type.

Ask your surgical or rehabilitation team before resuming:

- Weight-bearing or strenuous activity
- Using mobility aids or standing frames, and
- Aquatic therapy or community physiotherapy.

You will usually have a post-operative follow-up appointment (within 1-4 weeks) during which your recovery will be reviewed and your activity plan adjusted. Every person's recovery is different. Go at your own pace and always check with your healthcare team before making changes to your routine.

Section 2: Information for healthcare professionals

People living with SCI often face unique health challenges that can significantly affect their surgical outcomes. Thorough pre-operative planning addressing bowel and bladder management, skin integrity, and respiratory function, is essential to ensure patient safety during surgery and minimise the risk of post-operative complications, such as infections, pressure injuries and AD.

Following hospital discharge, GPs are often the first point of contact in the community and play a key role in ensuring a smooth transition back. GPs should monitor closely for early signs of post-operative complications, including wound healing, infection, deep vein thrombosis, and respiratory difficulties. Patients living with SCI are often highly aware of their baseline health and can detect subtle changes that may indicate a problem. GPs should encourage patients to report any concerns, even if they seem minor. GPs should remain alert to these subtle shifts, ensure continuity with rehabilitation services and address any psychosocial or equipment-related needs that may arise during recovery.

By maintaining close communication, providing timely interventions and coordinating with multidisciplinary teams, GPs can significantly enhance recovery and reduce the likelihood of hospital readmission.

13.13. Evidence-based information for GPs

Managing patients living with chronic SCI who are scheduled for elective surgery requires a comprehensive, multidisciplinary approach; as a GP, your role is central to pre-operative optimisation, risk mitigation and coordination of care, and what should be considered at this stage is a thorough history and examination that explicitly screens for SCI-related complications likely to influence anaesthesia and peri-operative management (for example, respiratory compromise, cardiovascular instability, including autonomic dysreflexia, neurogenic bladder and bowel, pressure injuries/skin integrity, spasticity and pain, thermoregulatory dysfunction, bone health and fracture risk and psychosocial factors) (McKinley *et al.,* 2002). Building on this foundation, the following systems-based review outlines practical checkpoints to guide your assessment and shared planning with the surgical and anaesthesia teams.

- **AD:** Before surgery, assess any previous episodes of AD, what triggered them, and the treatment methods used. Prior anaesthesia and surgical experiences should also be considered.
- **Heart disease:** Individuals living with SCIs also have a higher risk of *heart disease* and may require extra heart tests before major surgery (Myers *et al.,* 2007). Their blood pressure and heart rate are often lower than normal. They may need adjustments in anaesthesia or medications to prevent hypotension whilst under anaesthesia. Orthostatic hypotension can persist beyond the initial injury phase, making sudden movements or changes in body positioning risky.
- **Breathing problems**, such as impaired diaphragm and respiratory muscle function, risk of pneumonia, lung collapse and respiratory failure. In patients with cervical and high-level thoracic SCIs, lung function may also be weakened, increasing the risk of pneumonia and breathing difficulties. This can make anaesthesia induction more challenging, as they may experience rapid oxygen desaturation (Cotton *et al.,* 2005). Thus, it is important to assess their lung functions and respiratory infections before surgery.
- **Psychological disorders**, such as depression, anxiety or post-traumatic stress disorder. Screen for psychological disorders and provide appropriate referrals.
- **Implanted neuro-modulatory devices:** Individuals with intact *phrenic nerve* function may sometimes rely on implanted pacing devices to assist breathing (Dalal & DiMarco, 2014). Also, patients may have an implanted spinal cord stimulator for chronic pain (Jacques & Safaee, 2016). As a GP, you may have to collaborate with the patient's respiratory specialist, the centre managing the phrenic nerve stimulator and the patient's pain management specialist, respectively, to determine if the device should be adjusted or deactivated during surgery. Subsequently, pass on this information to the surgical team.
- **Understand the patient's support network:** Assess the patient's support system and coordinate with social services as needed.

13.14. Post-operative monitoring and rehabilitation

As the first point of contact, GPs are well-positioned to detect early signs of postoperative complications. The key areas to monitor include:

- **AD:** Monitor for signs of AD (Hambly & Martin, 1998; Rizk *et al.*, 2022).
- **Blood clots (venous thromboembolism):** Individuals living with SCI are at high risk of blood clots in the early post-operative period (Rizk *et al.*, 2022). If a patient presents with new-onset leg swelling, redness, pain or calf tenderness, it could be a clot. Clarify with the patient whether prophylactic anti-coagulation was given and if it is ongoing. If deep vein thrombosis is suspected, do not delay referral. It might be prudent to request a D-dimer test and Doppler ultrasound of the affected limb. Refer to the emergency department or the patient's surgical team urgently for confirmation and initiation of treatment. Notify the patient's surgical and rehabilitation teams, as this may affect their recovery plan
- **Pressure ulcers:** Immobility can lead to skin breakdown, requiring frequent repositioning, special mattresses and skin checks (Rizk *et al.*, 2022), and
- **Infection**: Patients with SCI are prone to develop UTIs, pneumonia and surgical site infections. Proper hygiene and monitoring help prevent these (Rizk et al., 2022).

13.14.1. Multidisciplinary support and care co-ordination

Immediately after surgery, hospital teams manage the recovery, while long-term care is generally overseen by GPs. The key aspect of ongoing care is rehabilitation, which is important in restoring function, maintaining health and improving quality of life. GPs play a central role in facilitating this multidisciplinary collaboration, ensuring that patients have access to the right support at the right time:

- **Physiotherapy and occupational therapy:** Initiate range-of-motion exercises early to prevent contractures. Develop individualised mobility and strengthening programs based on the level of injury
- **Psychosocial support and education:** Educate patients and carers about the prevention of AD, pressure sore care and bowel and bladder management. Provide emotional support and counselling when necessary, and
- **Coordination with specialist services:** Engage spinal rehabilitation specialists early to plan ongoing care. Plan transitions to subacute rehabilitation facilities or outpatient programs as needed (Rizk *et al.*, 2022).

Some patients may need extended recovery or intensive care support to stabilise vital signs and prevent serious complications. With careful planning, patients can achieve the best possible recovery and quality of life. Genuine collaboration between GPs and hospital teams helps

ensure that people living with SCI receive safe, well-coordinated care throughout the surgical journey and recovery.

13.15. Special considerations: Anaesthesia during childbirth and for children with SCI

Pregnant individuals with a high-level SCI are at risk of AD during labour, triggered by the stretching or irritation of the cervix, vagina, bowel or bladder. Those with SCI below T11 typically feel labour pain, while those with injuries between T5 and T10 may experience a painless delivery. In cases of a high-level SCI, AD, dangerously high blood pressure might be the only indication of labour. If not managed properly, AD can lead to serious complications, including brain haemorrhage, reduced blood flow to the placenta and potential harm to the baby (Robertson & Ashworth, 2022).

Consulting an anaesthesiologist during pregnancy is crucial for developing a pain management plan. Epidural anaesthesia should be started early or even before labour begins, though it may be difficult to administer due to muscle spasms or prior spinal surgeries. Techniques like continuous spinal, combined spinal-epidural and epidural anaesthesia have all been successfully used in individuals at risk of AD (Robertson & Ashworth, 2022).

For Caesarean delivery, individuals with SCI above T6 should receive either general or regional anaesthesia to prevent AD. After delivery, regional anaesthesia should be maintained until the blood pressure stabilises, as post-partum uterine contractions can still trigger AD (Robertson & Ashworth, 2022). If AD occurs during labour, it should be managed as previously outlined, with additional considerations:

- Some drugs, such as nitroprusside, should be avoided due to potential risks to the baby, and
- In cases of dangerously high blood pressure that cannot be controlled, an emergency Caesarean delivery under general anaesthesia may be required.

By carefully planning pain management and monitoring the patient's condition, healthcare teams can reduce complications and ensure a safer labour and delivery for both mother and baby.

13.16. Other anaesthetic considerations in paediatric patients living with SCI

Children living with SCI require careful management before, during and after surgery. While SCI is less common in children than adults, it often presents with unique challenges due to developmental differences in the spine and autonomic nervous system. Guidelines for fasting vary, with some institutions allowing children to fast for shorter periods. Individuals with SCI, however, face a higher risk of delayed gastric emptying due to pain, medications and their injury. To minimise aspiration risk, stricter fasting rules, such as avoiding food after midnight or fasting for at least eight hours, may be more effective. In addition to standard paediatric anaesthesia practices, SCI presents distinct neurological, respiratory and haemodynamic challenges that require specialised adjustments, much like those seen in adult SCI patients (Drum, 2000).

Key Take-aways

If you are an individual living with SCI and undergoing surgery:

- Be assured that the anaesthetist in attendance at your surgery will have thoroughly reviewed your medical history and tailored the anaesthetic plan to your specific needs. This includes considerations for AD, respiratory function and other SCI-related complications
- Your surgical and rehabilitation teams have prepared a personalised plan for resuming activities and physiotherapy to ensure a safe and effective recovery process, and
- Open communication with your healthcare providers is crucial. Don't hesitate to ask questions or express concerns about anaesthesia, recovery or any other aspect of your post-operative care.

If you are a health professional, especially a GP, and have a patient with SCI undergoing surgery:

- Ensure any necessary investigations, such as bloods and ECGs, are up to date. Help clarify medication management, pressure care needs and bowel and bladder plans
- Communicate proactively with the patient's surgical and rehabilitation teams, especially if you are aware of complex needs, such as a history of AD, spasticity and equipment dependence
- Watch for complications, such as pressure injuries, respiratory issues or changes in neurological function. You may be the first point of contact after discharge
- Stay involved in the patient's rehabilitation goals, liaise with community physiotherapy or rehabilita-

tion providers and ensure timely referrals if the patient's needs change, and
- Help reinforce key recovery instructions and ensure carers understand signs of complications and how to seek help.

Next, in **Chapter 14**, we discuss spirituality, spirit and spiritual health.

Reminder: Relevant chapters

- **Chapter 2:** The impact of the level of your injury needs to be considered during anaesthesia and surgery.
- **Chapter 3:** Following the five pillars of good health and well-being should keep you in good physical and psychological shape for surgery.
- **Chapter 4:** Having a personal health record and documenting your health and well-being will be useful for the clinical team preparing you for anaesthesia and surgery.
- **Chapter 6:** Age is always a consideration for anaesthesia and surgery.
- **Chapter 7:** Children and adolescents require additional attention when it comes to surgical procedures.
- **Chapter 8:** Living rurally, regionally and remotely will have travel and recovery implications.
- **Chapter 10:** There are a few resources about being pregnant with SCI.
- **Chapter 11:** Consent will need to be taken from you for the procedure, and the risks need to be thoroughly explained to you and your family. You need to know your legal rights in case you want to take action against a health professional or the hospital for any reason, and
- **Chapter 14:** Having surgery is an anxious time for everyone, and sometimes we need to speak to someone, such as a spiritual leader, to put our minds at rest.

References

Biglari, B., Büchler, A., Reitzel, T., Swing, T., Gerner, H. J., Ferbert, T., & Moghaddam, A. (2014). A retrospective study on flap complications after pressure ulcer surgery in spinal cord-injured patients. *Spinal Cord*, *52*(1), 80-83. https://doi.org/10.1038/sc.2013.130

Burns, K. K., Bhatia, Z., Gill, B., van der Nest, D., Knox, J., Mouneimne, M., Buck, T., Charbonneau, R., Aiello, K., Loyola Sanchez, A., Kamran, R., Olayinka, O., & Ho, C. (2024). Measures for persons with spinal cord injury to monitor their transitions in care, health, function, and quality of life experiences and needs: A protocol for co-developing a self-evaluation tool. *Healthcare*, *12*(5), 527. https://doi.org/10.3390/healthcare12050527

Cotton, B. A., Pryor, J. P., Chinwalla, I., Wiebe, D. J., Reilly, P. M., & Schwab, C. W. (2005). Respiratory complications and mortality risk associated with thoracic spine injury. *The Journal*

of Trauma: Injury, Infection, and Critical Care, *59*(6), 1400-1409. https://doi.org/10.1097/01.ta.0000196005.49422.e6

Dalal, K., & DiMarco, A. F. (2014). Diaphragmatic pacing in spinal cord injury. *Physical Medicine and Rehabilitation Clinics of North America*, *25*(3), 619-629. https://doi.org/10.1016/j.pmr.2014.04.004

Drum, E. (2000). Perioperative care of the pediatric patient with a spinal cord injury. *Topics in Spinal Cord Injury Rehabilitation*, *6*(Supplement 1), 54-67. https://doi.org/10.1310/KDXK-7GBH-5X98-LBL7

Hagan, M. J., Pertsch, N. J., Leary, O. P., Sastry, R., Ganga, A., Xi, K., Zheng, B., Kondamuri, N. S., Camara-Quintana, J. Q., Niu, T., Sullivan, P. Z., Abinader, J. F., Telfeian, A. E., Gokaslan, Z. L., Oyelese, A. A., & Fridley, J. S. (2022). Influence of sociodemographic and psychosocial factors on length of stay after surgical management of traumatic spine fracture with spinal cord injury. *World Neurosurgery*, *166*, e859-e871. https://doi.org/10.1016/j.wneu.2022.07.128

Hambly, P. R., & Martin, B. (1998). Anaesthesia for chronic spinal cord lesions. *Anaesthesia*, *53*(3), 273-289. https://doi.org/10.1046/j.1365-2044.1998.00337.x

Jacques, L., & Safaee, M. (2016). Epidural spinal cord stimulation for recovery from spinal cord injury: its place in therapy. *Journal of Neurorestoratology*, *4*, 63-67.

http://dx.doi.org/10.2147/JN.S61824

Khan, S., Plummer, M., Martinez-Arizala, A., & Banovac, K. (2007). Hypothermia in patients with chronic spinal cord injury. *The Journal of Spinal Cord Medicine*, *30*(1), 27-30. https://doi.org/10.1080/10790268.2007.11753910

McKinley, W. O., Gittler, M. S., Kirshblum, S. C., Stiens, S. A., & Groah, S. L. (2002). Spinal cord injury medicine. *Archives of Physical Medicine and Rehabilitation, 83*(3, Suppl. 1), S58-S64. https://doi.org/10.1053/apmr.2002.32159

Myers, J., Lee, M., & Kiratli, J. (2007). Cardiovascular disease in spinal cord injury: an overview of prevalence, risk, evaluation, and management. *American Journal of Physical Medicine & Rehabilitation*, *86*(2), 142-152. https://doi.org/10.1097/PHM.0b013e31802f0247

Nööjd, M., Wyckman, A., Steinvall, I., & Elmasry, M. (2023). Flap survival after reconstructive surgery for pressure ulcers: A cohort study. *Plastic and Reconstructive Surgery – Global Open*, *11*(12), e5451. https://doi.org/10.1097/GOX.0000000000005451

Petsas, A., & Drake, J. (2015). Perioperative management for patients with a chronic spinal cord injury. *BJA Education*, *15*(3), 123-130. https://doi.org/10.1093/bjaceaccp/mku024

Rizk, A. A., Saad, M., Singh, M., Schaller, B., Venkatraghavan, L., & Chowdhury, T. (2022). Perioperative complications and anesthesia practices in managing patients with quadriplegia undergoing surgery: A systematic review. *Frontiers in Medicine, 9*, 852892. https://doi.org/10.3389/fmed.2022.852892

Robertson, K., & Ashworth, F. (2022). Spinal cord injury and pregnancy. *Obstetric Medicine*, *15*(2), 99-103. https://doi.org/10.1177/1753495X211011918

Umamaheswara Rao, G. S. (2008). Anaesthetic and intensive care management of traumatic cervical spine injury. *Indian Journal of Anaesthesia, 52*(1). https://journals.lww.com/ijaweb/full-text/2008/52010/anaesthetic_and_intensive_care_management_of.2.aspx

Vaidyanathan, S., Soni, B., Selmi, F., Singh, G., Esanu, C., Hughes, P., Oo, T., & Pulya, K. (2012). Are urological procedures in tetraplegic patients safely performed without anesthesia? A report of three cases. *Patient Safety in Surgery*, *6*(1), 3. https://doi.org/10.1186/1754-9493-6-3

Whiteneck, G., Gassaway, J., Dijkers, M., Backus, D., Charlifue, S., Chen, D., Hammond, F., Hsieh, C.-H., & Smout, R. J. (2011). Inpatient treatment time across disciplines in spinal cord injury rehabilitation. *Journal of Spinal Cord Medicine*, *34*(2), 133-148. https://doi.org/10.1179/107902611X12971826988011

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Chapter 14. Spirituality and Spinal Cord Injury

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"To live is the rarest thing in the world. Most people exist, that is all." **Oscar Wilde**

This is a personal narrative and perspectives chapter, centred on lived experience and contributor reflections, combining the author's first-person narrative with supplementary testimonies from others.

This Chapter explores the role of spirituality in life after SCI, framed through the profoundly moving experiences of **Denis Bartrum**, **Dean Durman**, **Cheryl Selvage** and **Adrienne Graham**. Together, they offer different yet heartfelt testimonies and insights into how spirituality can sustain individuals through profound upheaval. Dean's story, for example, describes how a near-fatal accident led to a deep spiritual transformation that reshaped his understanding of meaning, faith and resilience. His reflections show how, in the face of trauma, spiritual grounding can provide clarity, hope and a renewed sense of purpose, becoming a stabilising force throughout recovery and adaptation. Complementing his narrative, the Chapter weaves in the clinical and pastoral perspectives of the authors, highlighting how spirituality, although distinct from religion, can support emotional well-being, identity, connection and coping for people living with SCI, as well as for their families and carers. Together, these insights introduce the Chapter's broader exploration of spiritual health, the role of pastoral care, the evidence of spirituality's influence on recovery and quality of life and the various practices, including meditation, prayer and humour, that can nurture the human spirit in the aftermath of a life-changing injury.

Dean's story: A spiritual journey

The Chapter opens with **Dean Durman's** spiritual journey following a motor vehicle accident that left him with paraplegia.

"Through the horrific motor vehicle accident, I faced death head-on. It felt as though we had endured a tsunami, a hurricane, and an earthquake all at once. The destruction reverberated through the lives of all our loved ones. Everything in my life was shaken, stirred and turned upside down — right to the core of who I am, my faith and what I believed.

In that moment, everything artificial and false was incinerated, and only truth stood the test of time. Through this journey, I count myself blessed to have experienced an extraordinary spiritual encounter that sparked a ***metanoia*** *— a profound transformation spiritually, mentally, emotionally, physically and socially.*

On my deathbed, the doctors gave my family little hope of survival. They said the next 24 hours would be critical. Think of that: I was given 24 hours, yet here I am 15 years later and counting. In that moment, the only One who could deliver me from death, the One who defeated death, reached into this world of destruction to rescue me. The Lord Jesus lifted me out of the mess I had made and gave me a second chance at life, not only to survive, but to thrive through the same power that raised me back to life.

Therefore, I can boldly and unashamedly declare: "If it had not been for the Lord, whom I met personally, I would never be alive. I would not have the courage, determination, and tenacity to endure and thrive through all the challenges, while still standing and smiling, through it all."

My spiritual grounding is built on the Rock that remains forever. Whatever storms I may face, I know I will never be alone. He stands with me, before me, behind me, and by my side, through all of time and eternity.

Living my life on this solid foundation with SCI makes each day more bearable, and even joyful — filled with love, peace, and hope, despite the challenges that may come. I may not be walking, but I am healed. My wheelchair has become an instrument to reach those in lonely places, caught in despair, gripped by depression, or surrounded by the shadow of death. I have been there, and I stand as a testament to a Heavenly Father who still performs miracles.

My approach is not rooted in religion, but in a living relationship with my Heavenly Father, my Big Brother, and the Holy Spirit who dwells within me. This is the hope upon which my life is built, not fleeting, but an anchor to my soul."

Dean's story: At a crossroad

To Die Or Not To Die (One To The Power 3, Ep # 1, 3 December 2025): Listen to Episode 1 of **Dean Durman's** recent podcast series, where he talks about his first experiences in the hospital after his SCI, when a nurse told him the worst was over.

Personal perspectives: Notes from contributors

*"I (**Denis**) write this Chapter as a retired GP obstetrician, emergency medicine consultant, and, finally, a retrieval medicine specialist with the Royal Flying Doctors. I was deployed five times with the Australian Defence Force. I have an Anglican background and was ordained as an interfaith minister through One Spirit Interfaith Seminary in New York, USA. Although I no longer work clinically, I am engaged as an adjunct associate clinical professor with Oceania University of Medicine and an adjunct assistant professor with Bond University Medical School. I am also an authorised volunteer chaplain at Ipswich Hospice and Ipswich Hospital in Queensland.*

*We (**Cheryl** and **Adrienne**) reviewed this Chapter as the Pastoral Care Coordinator at Brisbane's Princess Alexandra Hospital (PAH) (**Cheryl Selvage**), Anglican Priest, managed by Anglicare Southeast Queensland and PAH and **Adrienne Graham**, a past Pastoral Carer from PAH for about 30 years, during which time Adrienne sustained an SCI. I (Adrienne) was treated at the PAH as an acute patient and then as an inpatient at the PAH SCI Unit for over 12 months, eventually returning to the Pastoral Care Department as a paid worker, under Anglicare for the Anglican Team."*

*As the primary contributor, I (**Denis**) prefer the appellation 'SCI survivor' to describe people living with SCI. From the spiritual aspect, at the very least, the descriptor of 'SCI' may suggest a static state, as the neurological damage is often permanent from the time of the injury. The addition of the epithet 'survivor' emphasises the growth, determination, and struggle the person has invested in their adjustment from the time of their injury to their discharge and beyond. This Chapter is primarily geared towards the person with SCI following discharge from the healthcare system, but the spirit, spirituality and spiritual health can be applied to all stages of the SCI journey.*

*The use of the term 'survivor' sparked wonderful dialogue amongst **Cheryl**, **Adrienne**, **Michelle** and **I**. I see now that it can be construed as contentious, yet I struggle to find a better term that captures the often emotional journey from the moment of injury or damage to discharge. I am relieved that this is an open document and would welcome feedback from people living with SCI and their carers."*

This Chapter will discuss a range of topics relating to spirituality and how spiritual support might assist those living with SCI, as well as their carers and family.

Key Topics in this Chapter

- Definitions of spirituality, spirit and spiritual health
- Attributes of religion and spirituality
- The spiritual care team
- Evidence that spirituality can make a difference
- A rationale for discussing spirituality in the context of SCI
- How spiritual health can be fostered and eroded
- The role of meditation and prayer, and
- How humour can lift the spirit.

A good place to start this Chapter on spirituality is to provide definitions for 'spirituality', 'spirit' and 'spiritual health', followed by a discussion about the attributes of religion and spirituality.

14.1. What is spirituality, spirit and spiritual health?

Ask 100 people to define spirituality, and there will likely be 100 different answers. Offering a single, universal definition is challenging because spirituality is deeply personal and shaped by emotion, experience and culture. This invites exploration of spirituality from multiple perspectives, much like the word love, which resists simple definition unless considered through different lenses. Love can be almost as unique as a fingerprint, expressed and experienced in countless ways. Spirituality shares this quality. It is not easily captured in a single definition, yet its meaning becomes clearer when approached from different angles that reflect the diversity of human experience.

Denis' perspective: Spirituality

"Below is my definition of spirituality, but it is imperative to note that there is no one definition that does spirituality full justice. In Oscar Wilde's words, "To define is to limit". I view spirituality from a somewhat reductionist perspective. To this end, if a discussion or interaction cannot be explained by physiology, philosophy or psychology, then it is probably spiritual, at least in part.

Some define spirituality as a positive experience that elicits awe. Others might say that it is something far bigger than the 'self' that provides meaning, but at the same time makes one realise how small they are on the cosmic stage. It could just as easily be construed as something to which we are drawn, solid, wholesome and unchanging, an entity ostensibly unchanging but capable of responding and growing in relation to life experiences and interactions.

The list of what is spiritually sustaining might include something along the lines of these examples:

- *The night sky and the cosmos*
- *Nature in all her glory*
- *Pets or animals*
- *A baby is being born for the parents and the obstetrician*
- *Bees gather pollen and make honey*
- *Walking in the forest*
- *Uluru at dusk*
- *Flying and gliding*
- *Beautiful music*
- *Art*
- *Painting*
- *Meditation, and*
- *Singing.*

Rumi, a poet, reminds us that we do not need to explain all events, Sell your cleverness and buy bewilderment", and Ionesco, a philosopher, expands on this, saying: "Explanation separates us from astonishment, which is the only gateway to the incomprehensible".

In 2009, participants discussing the quality of spiritual care in palliative care developed the following definition of spirituality, intended to be broad and inclusive of religion: "Spirituality is the aspect of

humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred." (Puchalski *et al.*, 2009)."

Shane Hilton's story: The spirituality of surfing

Shane Hilton, an ethicist and (ex)theologian, Honorary Associate Professor at the Centre of Disability Research and Policy, The University of Sydney and Assistant Director, Research and Policy, at the Royal Commission into Violence, Abuse, Neglect, and Exploitation against People with Disability, sustained a C5 SCI in 2010, leaving him with quadriplegia. In his blog, The Spirituality of Surfing, Shane describes his and his brothers' almost ritualistic love of surfing. Not long after spending three hours of exhilarating joy in the waves with his son, he broke his neck riding a bicycle into what should have been a safe landing in a foam pit. In reminiscing about surfing, he wrote:

"I certainly miss the surf – and golf and all the other things that go with a body that works. Perhaps more significantly, I regret that I did not make the most of my former opportunities. In the busyness of life I didn't surf enough. I didn't pursue the fullness of the spiritual connection with the waves and nature and God at work in and through these things. More than just finding God at church, I think we experience life in the Spirit when we find beauty and when we take the opportunity to glory in its wonder. I found that beauty in surfing, but I just didn't surf enough. Of course I did other things of greater value – loved my wife and raised kids – but I still think I failed to make the most of the blessings of the ocean. And now the time has passed. Such is life for each one of us at some point, so don't feel sorry for me. Instead, examine your own life. Slow down. Discover your passion and enjoy its wonder with friends".

14.1.1. What then is 'spirit' as it relates to those living with SCI?

With acceptance, adjustment, adaptation, and perseverance, many individuals living with SCI go on to become champions on the sports field, have careers in academia, politics, law, finance and other professions and become partners, parents, grandparents and friends. Disabled sportspersons of this world are admired not because of their disability but for their spirit, which has enabled their triumph over adversity. The Invictus Games, in which veterans move from the battlefield to the world's sports stage, is a great example of spirit. These Games have given many disabled veterans of the Iraq and Afghanistan wars a purpose and an iden-

tity, potentially preventing numerous suicides. The Invictus Games 'motto' is *"Through sport, we change lives, and save lives."*

Serious injury or illness can significantly affect a person physically, psychologically and socially. For those who have served, these injuries or illnesses, whether sustained during conflict or otherwise, can have the additional impact of dramatic and sudden changes to their chosen career or lifestyle, placing pressure on their family or home life.

The Invictus Games Foundation offers a recovery pathway for international wounded, injured and sick (WIS) servicemen and women. We collaborate to provide opportunities for post-traumatic growth: enabling those involved to reclaim their purpose, identity and future, beyond injury.

'Spirituality' and 'spirit' are intertwined. Our spirit is demonstrated in our attitude, integrity, determination and resilience, along with many survival attributes. If spirit is our battery, then spirituality is what keeps it charged and recharged. Many courageous souls throughout history have been comforted by the realisation that captors can inflict deplorable damage on their bodies, but do not have control over their spirit.

In the introductory text to **Part A** of this resource, we extracted the definition below from Jenkins and Cosco's (2012) discussion on the three elements of resilience, one of which was spirituality:

> *"A universal and fundamental human quality involving the search for a sense of meaning, purpose, morality, well-being, and profundity in relationships with ourselves, others, and the ultimate reality."*

14.1.2. What is spiritual health?

Spiritual health demands an acknowledgement of the existence of 'spirit' as an entity that can be galvanised to provide support and acceptance. Spiritual health allows us to positively interact with all wholesome forms of spirituality, so that energy flows effortlessly where and when it is most needed.

While personality and psychological attributes are in the mix to underpin resilience and determination, spiritual health allows us to see through the present chaos and pain. Paradoxically, many 'survivors' later in life indicate that their injury and survival opened their eyes to what is really important in the world and in life. Some SCI 'survivors' evolve to the point of accepting their injury somewhat as a matter of fate. In reviewing this Chapter, **Adrienne** commented that her life now after SCI was not better or worse, just 'different'. When pushed for a preferred descriptor, she enthusiastically opined that she felt "blessed" – blessed and full of gratitude for her family and friends who supported her on her arduous journey to a 'different' life. This

says as much about Adrienne's attitude and determination as it does about the support she received.

We thus hope that this Chapter provides information and reassurance that resonates with everyone, so that they, too, can feel blessed in their own way, through new ways of doing things and living their lives as valued members of the community, as parents, siblings, children, friends, and employees or employers.

14.1.3. Can spiritual health be measured?

The answer is 'probably'. There are tools and instruments designed to 'measure' spiritual health. This measurement, in itself, would, however, be almost meaningless unless there were proven interventions known to improve and support spiritual health.

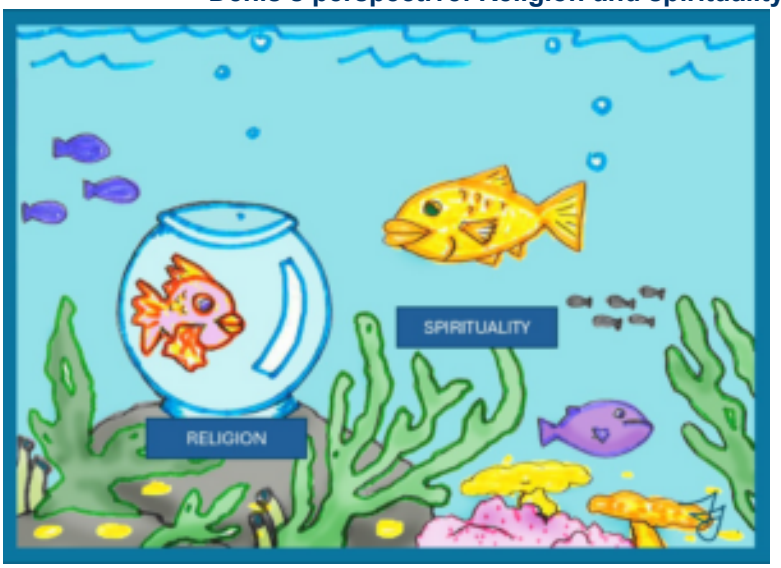
Denis' perspective: Measuring 'spiritual health'

"I am most familiar with Fisher's (2010) SHALOM (Spiritual Health And Life-Orientation Measure) acronym. This questionnaire examines spiritual health in four domains: personal, communal, environmental and transcendental. The elegance of the design is that it can detect inconsistencies, and if these elements are handled delicately with the affected individual, the outcome may provide a nidus for further enquiry. For example, the questionnaire may uncover a discordance in the domain of forgiveness, which can be tactfully explored. In fact, the questionnaire can be a relatively hands-off, objective approach to a topic that can be hard to broach with individuals, some of whom may have rejected religion or spirituality. Importantly, because it is a scored instrument, it can be re-administered to measure progress after an intervention."

14.2. Religion and spirituality: Not quite the same thing

It should be made clear that any distinction between religion and spirituality is not intended to diminish the value of either. Providing clear definitions can help guide conversations with individuals who may state from the outset that they do not believe in God or do not identify as religious. Framing spirituality as a broader, more flexible concept allows it to serve as another supportive tool, offering sustenance to people with SCI who may feel disconnected from religion, have experienced disillusionment, or have never held a particular faith tradition.

Denis's perspective: Religion and spirituality



There is considerable overlap between the use of the terms 'religion' and 'spirituality' in conversations. Below are Denis' thoughts on the difference between religion and spirituality. The image on the right, drawn by **Associate Professor Tanisha Jowsey**, highlights the difference between religion and spirituality.

> *"I am aware that this goldfish analogy can be interpreted in several ways. Some critics have indicated that it puts religion in a poor light, comparatively. My (Denis) take is that, like any good analogy, it allows someone who is new to the discussion of spirituality to find a way in. Clearly, this cartoon is not perfect. If it were, there would be no need for an analogy. For me, this image highlights that the religious goldfish essentially occupies the same water as the goldfish outside the bowl. Both can change places, and, in fact, nothing is stopping the fish in the bowl from swimming out of the bowl and re-entering at will. The glass walls of the bowl represent some of the more rigid and dogmatic parts of religion.*
>
> *Religion is therefore included in the broader concept of spirituality. Although both deal with spiritual aspects, religion tends to be more structured and is predicated upon the existence of an all-powerful creator or God and in some instances, gods. Religion tends to have rules, practices and observances. Religions commonly have a rank structure of their ministers or clergy. Historically, religions have sometimes felt the need to impose belief upon individuals rather than allow them to make up their own minds. In reality, many people have a mixture of organised faith and various other spiritual practices. Adrienne rightly points out that it does not need to be one or the other, and many people have a background faith but find spiritual sustenance outside the faith.*
>
> *So, what does this mean for the person living with SCI? Essentially, if you subscribe to a major faith group that provides you with support and hope, that is terrific. As an in-patient, I am sure that a Pastoral Care team will have called on you, offering support, and, if it was your wish, arrange someone*

from your denomination to visit. If, however, your spiritual sustenance comes from one or more of the awe-inspiring descriptions and events provided earlier, that too is valued, respected and supported.

Fortunately, there is increasing collaboration amongst various faiths. Annually, I present as an inter-faith minister at The Vedanta Centre (2 Poppy Crescent, Springfield Lakes, Qld, 4300). In the ashram, permanently displayed are symbols of all world religions, and a member of each faith presents on the same topic or takes part in a panel discussion.

This does not mean that Vedanta Hinduism is better than any other major faith. It is simply that they make a considerable effort to demonstrate and practice what they preach in terms of the acceptance of religious diversity. As an interfaith chaplain relating to people of any religion or especially none, I find 'Namaste' useful and universal, either as a verbal statement or as a simple greeting by pressing my palms together in front of my chest.

This wonderful Hindu term has several definitions. My favourite is "The evolving spirit in me salutes the evolving spirit in you". There is immense power in this greeting because the person saying or forming Namaste with their hands is basically saying: "I accept and respect you with my growing spirit irrespective of your beliefs."

Buddha reminds us that our religion is essentially a boat to carry us across the river of life to enlightenment on the other side. We must be careful to view religion as a conduit and not start worshipping the boat rather than the goal. Just to add to the beautiful complexity of spirituality is the realisation that Buddha never intended to start a religion per se. Although some followers of Buddhism acknowledge it as their religion, many others, including Buddha, view it as a philosophy."

14.3. What's in a name? Minister, chaplain, pastoral carer?

Just as there is a wide range of religions and spiritual practices, there is also a variety of titles used for hospital and rehabilitation staff who provide religious or spiritual support, both during admission and after discharge. This raises a common question: *"What do we call these individuals?"* The terminology can indeed be confusing, as these professionals may be known as ministers, chaplains, priests, rabbis, imams or pastoral carers.

Contributors' perspectives: What's in a name?

"All of us involved in this Chapter discussed this at length to make it clearer for the reader. This has not been easy. Although I (**Denis**) *view myself as a minister or chaplain, I can see how* **Canon Cheryl**, *an ordained Anglican priest, sees more credence in being able to offer 'pastoral care'. Historically, 'pastoral care' was mainly used in a Christian context, but is now more widely used for someone who is 'there' for a person on their journey. Pastoral invokes images of a shepherd who tends to their flock and guides them to take cover in bad weather. In essence, the '**Pastoral Care Team**', which is what exists at many Australian hospitals, best describes the care provided whilst in the spinal unit and in the community. This team will be able to facilitate the continuation of spiritual care following discharge."*

For individuals with SCI and their immediate family, friends and support workers, it is helpful to be aware that many different terms are used for people who provide spiritual or religious support. Although individual spiritual carers may have preferred titles, most are approachable and comfortable being addressed by their first name.

Additional information, if interested: Spiritual care *vs*. pastoral or chaplaincy care

- This article on the Christian Reformed Church website was written following queries from readers about the different terminology relating to spiritual care: 'Spiritual versus Pastoral or Chaplaincy care', and
- Interestingly, RACGP training has 'pastoral support' for trainees in its Standards:

"Pastoral care is care that assists an individual in maintaining their intellectual, emotional, physical, social, and psychological well-being. Such care respects individuality, diversity and dignity. Supervisors are expected to provide pastoral care to registrars within the clinical environment (refer to Outcomes 2.2 and 2.3). Pastoral care is also the responsibility of the training program and be extended to all involved in the program including registrars, supervisors, medical educators, cultural mentors and administrative staff. Pastoral support refers to the institutional supports and services that are put in place to provide that care."

In the United States, military chaplains in hospitals can accompany an injured soldier from one appointment to another and serve as a spokesperson. More importantly, they can follow up while in the community. Because the chaplains have officer status and rank, they can be a 'godsend' when accompanying the veteran to an appointment. Not only can the chaplain cut through most of the bureaucracy, but because they know the veteran's history, they can do a handover, obviating the need for the veteran to repeat the whole sad saga each time they meet someone new in the healthcare system.

Shane Clifton's story: Talking about faith and God

SCIA's Have the Nerve podcast, Faith, God, Diversity and the Journey (Episode 40): **Shane** makes the point that we generally inherit our religion from our parents and that as we develop, we either remain committed to the same religion or start to explore other options.

Exploring other options is good, as it will expose us to different belief systems and world views. Critically, our spiritual growth occurs because of all the interactions we have with people and life in general. Essentially, spiritual growth is a work in progress rather than being static.

Chithrani Palipana's story: Always having faith

In **Chapter 1**, we provided a link to **Dean Durman**'s interview (March 2026) with **Dr Dinesh Palipana**'s mother, **Chithrani**, about her life as his mother and carer. In the second half of the video, **Chithrani** talks about her strong faith and how that has gotten her through tough times, from **Dinesh**'s accident, her divorce and her recent breast cancer.

For those who believe in God, sustaining a SCI may test their faith. *"Where was God?"* and *"How could God let this happen to me?"* are common questions and difficult to answer. **Denis**, in his role as a chaplain, approaches these questions with sensitivity and compassion, recognising that the most meaningful and satisfying answer is ultimately the one each person discovers for themselves when the time is right.

14.4. Exploring spiritual care

Spiritual care involves taking the time to truly get to know a person through active, attentive listening, allowing their story to unfold at its own pace. Once a person's spiritual outlook or needs are understood, the role of the carer is to validate, support and empower whatever is present, while gently helping those who feel they are "not spiritual" to recognise the inner resources and sense of meaning that everyone carries. For those who are more cynical, it can sometimes be helpful to begin with something simple and relatable, such as their bond with a beloved pet, and explore whether they perceive a sense of spirit there. If their only companion happens to be a goldfish, a light-hearted shift in conversation, perhaps even to the weather, may help open the door to a deeper connection.

14.4.1. Spiritual care in the Australian healthcare system

Chaplains in hospitals and the community have a vital yet obvious role in 'ministering' to individuals. Not well known in the hospital environment, either generally or in palliative care, is that much of the spiritual care is provided by the service providers and nursing staff who spend time with people. Sadly, as doctors, we (meaning health professionals, with **Denis**, a retired GP) do not spend enough time with patients. We would do well to spend more time listening attentively to provide spiritual care alongside clinical care, as they are inextricably intertwined.

Research: Best practice in spiritual care in healthcare (Australia and New Zealand)

The Spiritual Health Organisation (Australia) and the Spiritual Care in Aotearoa New Zealand (SCANZ) published a 2022 scoping review on the elements of best practice in terms of spiritual care in healthcare. The researchers conclude that *"Research affirms that spiritual care improves patient health outcomes and patient satisfaction."* The quote was used at the start of the report (Tan *et al.*, 2022).

In medicine, from Osler onwards, it is well known that 'taking a history' from a patient contributes considerably to the diagnosis and effective management. Even a patient's silence means something. Silence should be encouraged but managed carefully, as it can be construed as disapproval. Although silence can be therapeutic, it is not always so. The ministering person, whether it is their doctor or pastoral carer, should be like a mirror – non-judgmental and reflecting to the individual, who can then make their own judgment. This empowers people to

examine their issues. The chaplain can then challenge them if they are being too hard on themselves or blame others inappropriately.

The person delivering daily care is ideally positioned to notice changes in demeanour. This 'ministry' is neither structured nor theological, but may take the form of a familiar, caring, smiling face who addresses the person by their name. It may be a word of encouragement or the plumping of a pillow. Caring, non-judgmental attention that reassures the person that they are accepted. The grieving, distressed SCI 'survivor' is often harder on themselves than the people around them, and this level of acceptance by staff is unconditional. These valuable 'soft' carers may not seem as threatening as an unknown chaplain and can break the ice.

Authorised chaplains in the hospital and the community are usually skilled at talking to anyone about pretty much anything. Part of our authorisation process is the understanding that we take people as we find them, listen intently, and at no time try to convert them to our spiritual way of thinking. Having asked the person if this is a good time, the minister should listen and assess where the patient is spiritually. If it is not a good time, another time can be suggested.

If they have a recognised faith that they find supportive, we (as spiritual carers) can facilitate attendance by an ordained or lay minister of that faith. Personally, I still keep in contact if they so desire, as there can be matters such as gender identity, homosexuality, IVF (*in vitro fertilisation*) or VAD (voluntary assisted dying, **Chapter 6**) which some ministers of certain faiths may not be comfortable discussing. Additionally, there are some matters that the individual may not want to discuss with a minister of a known faith.

Identifying the person's spiritual base is essential because only then can we facilitate and support it. If it is church-based, we can facilitate connecting them to services and singing. If it is nature-based, such as the connection to Country for First Nations people, we can get them back into nature as soon as possible. If they are indisposed, we bring nature to them, such as plants and pets. If they are missing their pet cat, we can work with the nursing staff to facilitate contact, as there is always at least one staff nurse who loves cats. The 'minister' does not need to be an expert in all religions. They just need to actively listen to the person in front of them with respect.

Clinical resource: Top 12 Standards for Spiritual Care

The recommended Standards of Spiritual Care below emerged from a conference on providing the spiritual dimension of whole-person care. Deliberations were based on evidence that spiritual care is a fundamental component of high-quality, compassionate healthcare, and it is most effective when it is recognised and reflected in the attitudes and actions of both patients and healthcare providers (Puchalski *et al.,* 2014).

Recommended Standards for Spiritual Care

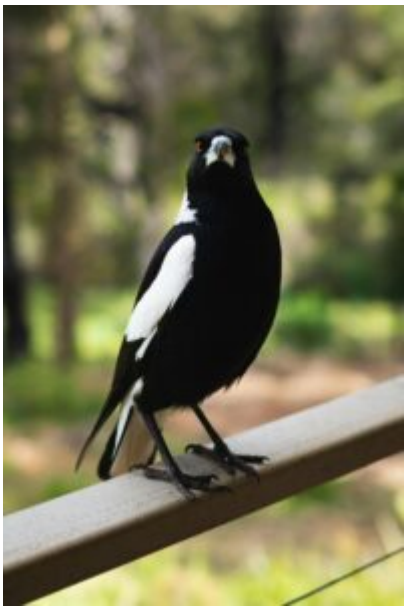
1. Spiritual care is integral to compassionate, person-centred healthcare and is a standard for all health settings
2. Spiritual care is part of routine care and is integrated into intake and ongoing assessment policies for spiritual distress and spiritual well-being
3. All healthcare providers are knowledgeable about the options for addressing patients' spiritual distress and needs, including spiritual resources and information
4. Development of spiritual care is supported by evidence-based research
5. Spirituality in healthcare is developed in partnership with faith traditions and belief groups
6. Throughout their training, healthcare providers are educated on the spiritual aspects of health and how they relate to themselves, others, and the delivery of compassionate care
7. Healthcare professionals are trained in conducting spiritual screening or spiritual history as part of routine patient assessment
8. All healthcare providers are trained in compassionate presence, active listening, and cultural sensitivity, and practice these competencies as part of an interprofessional team
9. All healthcare providers are trained in spiritual care commensurate with their scope of practice, in line with a spiritual care model, and tailored to different contexts and settings
10. Healthcare systems and settings offer opportunities to develop and sustain a sense of connectedness with the communities they serve; healthcare providers work to create healing environments in their workplaces and communities
11. Healthcare systems and settings support and encourage healthcare providers' attention to self-care, reflective practice, retreat and attention to stress management, and
12. Healthcare systems and settings focus on health and wellness rather than just disease.

14.5.2. The healing power of furry and feathered companions

In **Chapter 3**, we identified the role companion dogs and horses can play in the psychological well-being of individuals living with SCI. About pets and spirituality, who can argue about the important role played by support dogs, be they for the blind or those with other disabilities? I (**Denis**) was recently informed about an excellent autobiography and film about an SCI 'survivor', Penguin Bloom: The Odd Little Bird Who Saved a Family. This is a true story of a neurology nurse and mother, Sam Bloom, who sustained an SCI while holidaying in Thailand in 2013, leaving her paralysed from the chest down. She travelled the well-known nightmare path and was depressed despite considerable family support. Her son found a young, injured magpie, which they named **Penguin**. Sam admits that the little bird ignited the nurse and mother in her, and her focus on keeping the bird alive was therapeutic. Sam and Penguin become inseparable. Sam said that she could have seen Penguin as an angel, but would wonder what sort of God would send an angel that pooped all over the place!

Video: Penguin Bloom trailer

Penguin Bloom: A true story about the enabling relationship between a disabled mother and an orphaned magpie. Sam's book is available in hard copy with great photographs by Sam's husband, Cameron, a professional photographer. I (**Denis**) found the user-friendly audiobook deeply moving and inspirational.



Penguin Bloom contains many appropriate reflections that will resonate with everyone. Sam reflected that *"her soul became allergic to affection".* She describes herself in the early stages as feeling like a dependent lump of meat. For Sam, physically able and attractive 'carers' were a sad reminder of a previous life rather than support. Penguin facilitated Sam's outward gaze when she had understandably become preoccupied with her condition and altered family situation.

Finally, Sam, with Penguin's help, moved through the dark cloud so that she could see that life is a precious but fragile commodity and that it was not over when she thought she was 'damaged' (just different, as Adrienne said). One is never too damaged to experience the spirit of joy! Sam thus learned to be motivated by need rather than by outcomes. Sam reconnected with her love for the ocean and returned to surfing. In August 2018, she was selected for the Australian Adaptive Surf Team and won Gold for Australia at the 2018, 2020, and 2023 World Para Surfing Championships. Sam has written a second book, *Sam Bloom, Heartache & Birdsong*.

During her recovery following SCI, **Adrienne** too found the need to interact with her pets:

"I wanted to be in contact with my own pets, Whilst I love all animals, it was important for others to organise for me to interact with my own pets. Arrangements were made for them to visit with me at times."

14.5.3. Peer support is invaluable

As identified in **Chapter 5**, peer support or mentoring is invaluable. SCI 'survivors' can and do 'minister' to each other. There are always people who have been injured chronically who can be of immense support to acutely injured people. This manner of support works well for all types of maladies, including cancer and veteran support. The power of the support group is that a new member knows the other members share something in common, so there is no need to start from the beginning. As discussed later, helping others gives a person a huge spiritual buzz. Once past the initial chaos, it becomes easier to help peers and advocate for others' care. The person who has lived with a long-term SCI has credibility and has navigated the path over several years. Below are four links to peer support programs in Australia.

Important resources and information: Peer support networks

- SCIA's Youth Peer Support: Has a peer and family support team, including youth (12-24) support (NSW, Victoria) launched in late 2025, as well as Have the Nerve podcast series and Can you ask that? short videos
- Forward's blogs from peers, such as **Joel Sardi** and **Dinesh Palipana**
- Pbf Australia's Peer Support Program: You need to be a member and then submit your details, and
- Estera's Spinal Cord Injury Peer Support: In partnership with Lifetime Support Authority, Estera's team of peer support mentors provides free support to people living with SCI.

Adrienne explained that she does not view herself as having a 'disability', because her inner essence has not changed. Her focus is therefore not on what has been lost, but on what remains intact and meaningful.

Pastoral care can play an important role in nurturing this sense of inner strength and identity, providing nourishment for the soul during times of challenge. There is often a creative tension

between the realities of injury and the enduring qualities of the person. Individuals like Adrienne can be seen as valiant and courageous, much like soldiers who receive medals for bravery but seldom consider themselves brave. They are often grateful to be alive.

14.6. Evidence that spirituality does make a difference

Despite the ongoing quest for evidence-based clinical practice, spirituality remains a neglected research topic. Appropriate, statistically valid studies are the gold standard, allowing scientists to generate tables and figures and epidemiologists to generalise findings. Matters of the spirit, however, centre on individuals. Some studies have confirmed that spiritual perspectives and ministering do make a difference as part of a holistic approach to care in SCI and other tragic physical maladies (Jones *et al.*, 2018). This influence, however, is hard to quantify. In their meta-analysis on spirituality and SCI, Jones and colleagues (2018) concluded that spirituality can have a profound impact on recovery from and acceptance of having SCI. Impacts were observed in the domains of life satisfaction, quality of life, mental health and resilience.

Mercifully, the obsession with evidence is gravitating to the centre and accepting traditionally considered 'lower order' evidence such as case studies and qualitative research, giving the stories individuals tell the credit they have always deserved. The ability to learn from anecdotes, storytelling and case studies does not belong in the pages of history. They are the ***LLEs*** from which we can learn. In many cultures, including among Indigenous peoples, storytelling has long been the way knowledge is passed on from one generation to the next.

In addition to this research, numerous anecdotal accounts add credence to the role of spirituality in survival and resilience, such as those of Viktor Frankl, a Holocaust survivor and psychiatrist who lost his wife and family:*"In some way, suffering ceases to be suffering at the moment it finds a meaning, such as the meaning of a sacrifice."* Interestingly, in a number of these studies and anecdotes, the particular brand of spirituality does not seem to make a significant difference to the outcome. The adherence to an idea or concept that there is something bigger and longer-lasting than self seems more relevant than a particular brand of religion or spirituality. In the case of Frankl, there were several spiritual 'carrots' which helped him survive Nazi concentration camps: His Jewish faith, his love for his wife who was interred nearby and the future of his new psychoanalytic theory called 'Logotherapy'. Sadly, his wife died in the camp and Logotherapy did not take off, but they did the trick for him and gave him reasons to keep going when others, quite reasonably, decided to give up.

14.7. A discussion of spirituality in the context of SCI

SCI is a catastrophe, and for an able-bodied person, it is hard to imagine a more devastating injury, regardless of age. Spirituality involves the meaning of life and existential matters, so it

can influence adjustment even in the absence of its acknowledgement. SCI, on the other hand, threatens the existence and *status quo* of the SCI 'survivor' directly and the family indirectly.

These injuries rarely happen to couch potatoes but more often to adventurous, courageous, fun-loving people. The young are more likely to embrace risky behaviour and, although aware of the risk, they are more likely to discount it in favour of the excitement. Thus, it takes spirit to have the courage to pursue these endeavours. This spirit should be admired and encouraged. Post-injury, this spirit remains, but sometimes it needs to be uncovered and validated.

Research: Spirituality and SCI

- Magalhães and colleagues (2015), using Quality of Life instruments, wrote that, *"SCI people who rely on personal beliefs and spirituality accept their physical appearance better and maintain self-esteem leading to better focus on recovery."*
- Jones *et al.* (2018) concluded that more effort needs to be expended to determine the spiritual status of SCI and family spirituality, as some spiritual beliefs can act as a block to attitude to and attendance at rehabilitation, such as ' it is God's will' or 'let go and leave it in God's hands'.
- In a comprehensive examination of the psychosocial aspects of SCI, Budd and colleagues (2022) stress the importance of post-traumatic growth. It is such a compelling insult to the body to have SCI that, although the anatomical damage may be permanent, the affected individual needs to realise that, holistically, they themselves are not frozen in time but are capable of infinite growth in other domains. Importantly, the SCI has not damaged their 'spirit'. That 'system' is intact.

Moral injury, a term coined after the Vietnam War, is also a consideration with respect to injury and 'survivor' guilt, which can have a considerable impact unless examined from the psycho-spiritual aspect. Guilt can arise when the young person looks back on the traumatising incident. They may carry guilt for performing the dangerous activity against parental advice or feel guilty for the effects their injury has had on their family, or if someone else was killed or maimed in the accident. Guilt never has a constructive long-term purpose. Guilt is a high-order response in primates, especially humans, that tells us we have messed up. Generally, its only purpose is to allow us to question our behaviour and should lead to self-examination, sharing, apologies, making up, where possible, and a determination not to repeat the same hurtful activity or behaviour. If something is really playing on their minds, it may help to confess this to a minister, not because the minister has magic powers but because it is their job to listen attentively and objectively and help them regain the right perspective with their God, if applicable. Additionally, a minister in a person's chosen faith has a nominal and spiritual authority in their eyes.

Grief has many definitions, which can be viewed as the reaction and adjustment to loss. Although usually attributed to the death of someone, it can logically be related to the loss of limbs or loss of function. Grieving is a very personal event, and despite all the books and

experts, it can only be alleviated with time. The sense of integration and perspective essentially does not make the injured person feel happier about losing function, but it does dramatically foster acceptance of permanently changed functions and gratitude for what remains.

Finding a person's 'spirit' and spiritual affiliation may require several interactions when they are receptive to this discussion. There may well be some initial awkwardness, but this usually dissipates as the person and the 'minister' get to know and trust each other. Sometimes the match does not work. That should not pose a problem, and consultation with another chaplain may well be in order.

The best place to start is by asking the person to share something about their past and, if comfortable, how their injury occurred. The pathological anatomy of the spine defines the neurological deficits, but the pre-morbid history and anatomy of the incident also help the minister, pastoral worker, spiritual carer or chaplain to get their bearings. Discussion of the traumatic event and subsequent adjustment can enable the survivor to ventilate, but can also bring negative aspects such as guilt and shame to the surface. These aspects, once surfaced, acknowledged and addressed, can lead to spiritual healing.

If, for argument's sake, the young female equestrian expresses remorse and guilt that she went riding on that occasion, and now she is in this predicament along with her family. This is the time to listen to her, then ask her if she loves horses... *Does she still?* Remind her that she loved the activity and that she knew at the time that there was some risk, as there is for anything enjoyable in life. Mention then that intention is key and ask her if she intended to injure herself that day (knowing, of course, that she did not.) If she did not intend harm, then she should not feel guilty. If she still likes horses (which is highly likely), she may be an ideal candidate for equine therapy and mentoring. Depending on the severity of her injury, she may become a para-athlete.

We need to differentiate between disappointment and guilt. It is perfectly reasonable to be disappointed with the changed status post-injury, but it is in no way helpful to be guilty and blame-ridden. If being 'spiritual' relates to art, music or anything else listed at the start of the chapter, then that can be facilitated. Once more mobile and assimilated to the new normal, groups can get together to jam, paint or indulge in spiritual services and singing.

As we described in **Chapter 5** (getting back into the community and perhaps volunteering) and **Chapter 16** (being a participant in research trials), *service to others* is a great way to boost the spirit, and, as mentioned, as adjustment occurs, SCI 'survivors' can themselves become peer mentors and support others. We all seek meaning and purpose in life, as they affirm our intrinsic goodness. Some may aspire to be ministers and chaplains for others with SCI. *Who could have more credibility?*

For sporty types, **Chapter 15** describes how to become involved in sport, which can be an excellent channel for their energy and frustration as well as an opportunity to socialise with others who have literally been to hell and back. The initially loathed, feared wheelchair, with time, may be seen for what it is – a badge of triumph over great adversity and a sign of

resilience and perseverance. The affected individual could easily have given up trying, but guess what? Against all odds, they didn't.

So, the spiritual system is probably the only system in the body that is not permanently damaged by the injury. It is the same spirit that gave the patient the courage to reasonably undertake the injuring activity, which is not going to desert them now.

Adrienne spoke with deep conviction about the way her faith and trust in God supported her throughout her journey. In her role as a pastoral carer, she encountered many people who felt spiritually abandoned after their injury, expressing sentiments such as, *"If there really was a God, this wouldn't have happened to me,"* and who, even years later, declined to engage in any conversations about faith. Yet she observed that spiritual beliefs often persist beneath the surface, even when a person feels disillusioned or disconnected. With gentle, patient support, these beliefs can sometimes be rekindled, helping individuals reconnect with meaning, hope and a sense of inner healing.

14.9. Spirit can also be diminished

Deception, betrayal and guilt-loading are potent destroyers of spirit. No person living with SCI relishes their disability. But many triumph over the adversity with the same spirit that may have got them into the predicament. They can handle the truth if it is delivered sensitively and appropriately. Hope springs eternal, but it must be reasoned, so realistic optimism is far preferable to blind, positive thinking. The desire for scientific breakthroughs is a completely understandable incentive, but it must be balanced with current medical technology. 'Never say never,' but the advent of a cure is far in the future, and the focus needs to be on the here and now. Unbalanced spiritual advice can be damaging, as can pity, blame, derision and patronisation.

Denis' story: Supporting spiritual healing

"I will not forget a patient who had adjusted well to his medical predicament. He came in very distressed one morning. Enquiry revealed that a minister had told him that his disability was due to his sin and that if he truly repented, he would be healed. I remember strenuously reassuring him that this was clearly not true, and then rang the minister (with consent) and told him that unless he could be supportive, he should stay away from my patient. If SCI is truly and sincerely perceived by the individual as a punishment from God, which distresses the individual, then the minister can gently and sensi-

tively tease out why the person holds this perception of God's will and help them establish that there is no shred of evidence to that effect. So yes, we can and should be advocates for our patients if the need arises."

Military veterans with SCI are often diagnosed with PTSD. Moral injury, like PTSD, tends to manifest some years after a stressful deployment. Once the fanfare, medals, and processions are over, the veteran is often not adequately supported, though this is better now than immediately after the Vietnam War. Once the dust settles, the veteran can react to public opinion, arguably implying that their government tricked them into an unnecessary and unjustified war. Guilt begins to creep in, not only for fellow combatants that they may have injured, but especially for the civilians who were killed and injured. These issues require careful handling as the person deals with guilt and betrayal. Often release is found in forgiveness, especially self-forgiveness.

So, spiritualities can be of mixed support, but again, it is so necessary for us not to judge. If a person is convinced that 'God gives and God takes away' and it is working for them, no problem. If, however, it is advice from the sidelines, it can make adherence to rehabilitation more challenging. Acceptance is not resignation. Acceptance involves dealing with the conditions a person cannot change. Acceptance often leads to gratitude for what was and for what remains.

14.10. Meditation and prayer

Meditation has been practised with good effect for millennia (Meditation Association of Australia). It is not necessary to sit in a lotus position dressed in a loincloth to meditate. Meditation has been shown to affect mental health and physiology. In its simplest form, it is the emptying of the mind and basically 'rebooting' the brain. It is easy to do in concept but challenging in practice. Close your eyes, look towards the root of your nose and focus on your breath to the exclusion of all thought. It does work and when you inevitably wander back to the day-to-day humdrum of life, it is important to gently pull yourself back to emptiness.

Meditation is not a fantasy or dreamland. Fantasy is fine too, whether of a physical or sexual kind and can take the person to another place other than the here and now. Meditation is cheap, portable and needs no electricity! Many people throughout history have relied on meditation to find the strength to cope with adversity or imprisonment. Many people have practised meditation while sitting around a campfire, captivated by the flames. Purists would argue that it is not genuine meditation as the mind is not stilled and can still wander from subject to subject. Good for entry-level meditators coming in from the cold. **Rumi**'s take on this relates to deep listening: *"The branches of your intelligence grow new leaves in the wind of this listening."*

In a fantasy state, the person may or may not assume full physical functioning of limbs. They may be able to go to a peaceful place by following a meditation sequence, repeating a mantra or engaging in guided imagery.

SCI may physically impact one's meditation routine. Adrienne spoke of not being able to engage in meditation as it was impossible to find a comfortable position because of her pain, which created 'noise' in her head. She also commented that in the initial stages of her recovery, she often felt completely numb and unable to interact meaningfully.

Denis' advice: Prayer

"Prayer can be a difficult concept to define. At its heart, prayer is simply a conversation with God or with a source of spiritual guidance. Many spiritual teachers note that while the act of praying is valuable, the listening that follows is often where insight and comfort emerge. Speaking a prayer or petition, especially aloud, can help bring concerns to the forefront of the mind, and the quiet that follows allows space for reassurance or potential solutions to arise from whatever source feels meaningful.

For those who follow an organised religion, set prayers or psalms can offer structure, direction and familiarity. But prayer does not need to be formal. You can pray if you feel drawn to, or simply speak your thoughts into the cosmos. There is nothing to lose; at the very least, it can help organise and calm the mind.

For those who are interested, the following is the Pueblo Prayer:

Hold on to what is good, even if it is a handful of earth.
Hold on to what you believe, even if it is a tree that stands by itself.
Hold on to what you must do, even if it is a long way from here.
Hold on to your life, even if it is easier to let it go.
Hold on to my hand, even if someday I will be gone away from you."

14.11. Humour: Laughter can be the best medicine

Adjusting to life after SCI can leave little to laugh about in the beginning. The physical changes, emotional challenges and shifts in relationships can make humour feel out of reach. Over time, however, many people find that humour, when used with sensitivity and respect, can ease tension, build connection and lighten difficult moments. Laughter must always be shared with a person, never at their disability.

Forms of dark or gallows humour are common among emergency responders, military personnel and others who routinely face confronting situations. This style of humour is not intended

to offend. It is often a coping strategy for dealing with experiences that are otherwise overwhelming. People living with SCI may find themselves in circumstances that echo this need for emotional release, and a sense of humour can offer relief and perspective. Of course, humour can also create awkward situations, and even well-meaning jokes can fall flat.

History provides many examples of individuals who used humour to navigate adversity. The **Reverend Sydney Smith** (1771-1845), celebrated for his wit, once contrasted his own career with that of his more solemn and successful brother by remarking, *"My brother seems to have risen through the ranks because of his gravity, and I have fallen in mine due to my levity."* His observation highlights how humour can comfort, challenge or disrupt, depending on the context.

Oscar Wilde also demonstrated the power of humour in hardship. Despite being unjustly imprisoned for his sexuality, he retained a sharp and playful outlook. His well-known twist on the "glass half full or half empty" question is particularly relevant for people finding their way after SCI: *"The optimist will tell you the glass is half full; the pessimist half empty; and the engineer will tell you the glass is twice the size it needs to be."* For some, the wisest response may simply be to withhold judgment until they know what is in the glass.

Humour related to disability often appears in cartoons, imagery and comedy performances, even when "stand-up" is not literally possible for some of the comedians. Used thoughtfully, humour can encourage resilience, help people reframe their experiences and affirm that joy and connection remain possible, even in the wake of life-changing injury. Below are three examples of successful disabled comedians in Australia:

- **Maddie Stewart** on how she is 'accessibilifying' the Aussie comedy world
- **Alexandra Hudson** on growing up as the only triplet with a disability
- **Steady Eddy**, whose website has video of his shows.

14.12. Conclusion and recommendations

Ultimately, as the various stages of reaction and recovery are experienced, at some point, there needs to be acceptance of the SCI. This will happen in its own time and cannot be rushed or made to fit the timeframe of staff or family. As **Alan Watts** (author and philosopher) wrote: *"Things are as they are. Looking out into the universe we make no comparisons between right and*

wrong stars, nor between well and badly arranged constellations." For **John Donne**, *"No man is an island, entire of itself; every man is a piece of the continent, a part of the main."*

We strive to be independent, but in reality, humans are destined for and defined by interdependence. We need to accept that we help others at times, and at other times, they help us. Most people love to help someone in need. Spirit and spiritual health are, by their nebulous nature, difficult to pin down with evidence, but such evidence is emerging.

Jones *et al.* (2018) published evidence for the importance of spiritual health and have advised that more studies are needed (which is true about just about anything academic). What is so charmingly valuable about spirituality is that it thumbs its nose at the scientific method.

So, the SCI 'survivor' starts as a whole person and tragically becomes an inpatient, but by the time of discharge, they become impatient! From here, they may still visit 'Outpatients', but they are survivors who return to what they have always been: whole people. I am yet to meet a fully able human being with or without SCI, so they are among friends.

For me (**Denis**), people living with SCI are 'survivors' and veterans of an intense, protracted battle. Their wheelchair is a chariot which bears testimony to their resilience, not dependence. Hope springs eternal, and in the words of **Seamus Heaney**, "*Hope is not optimism, which expects things to turn out well, but something rooted in the conviction that there is good worth working for."*

Finally, inarguable wisdom from **Fernando Sabino**,*"In the end, everything will be OK. If it is not OK it' s not yet the end."* **Henri Nouwen**, Professor of Psychology and Theology at Notre Dame University, reminds us that,*"In solitude we become aware that our worth is not the same as our usefulness."*

Key Take-aways

- There is a difference between spirituality and religion, with spirituality being a broader concept of a belief system
- SCI is an acronym, not a life sentence
- Spiritual health means there is spirit and this is what drives us to continue
- Physical injury can maim the body, yet counter-intuitively strengthen the spirit
- For humans, there will always be SCIs, and there is no one better qualified than the SCI 'survivor' (a peer) to help an injured person navigate their recovery. When the time is right, this support of others can boost the spirit, and
- Independence is good, but interdependence is better. We have all helped others. At some stage, we have to graciously accept help when it is needed. Many triumphs appear to have been performed solo, but invariably, there is assistance from a team of supporters.

The next chapter, **Chapter 15**, explores different levels of assisted sport, from community sport to the Paralympics.

Reminder: Relevant chapters

- **Chapter 4:** Documenting one's health and well-being is a way of tracking progress on achieving personal goals, whether these be returning to work, studying or getting involved in the community in some way. In terms of 'spiritual health', recording one's psychological state is important
- **Chapter 5:** Getting back into the community and finding purpose and meaning is good for one's well-being. Becoming a peer mentor is likely to be good for the soul
- **Chapter 6:** The chapter on ageing with SCI, discusses VAD. Some people may discuss this with a person of faith
- **Chapter 15:** Sport is where many individuals who have SCI find purpose and achieve personal goals, and
- **Chapter 16:** Research into SCI has clinical trials. Participating may be a way of 'giving back'.

References

Fisher, J. (2010), Development and application of a spiritual well-being questionnaire called SHALOM. *Religions, 1*(1), 105-121. https://doi.org/10.3390/rel1010105

Budd, M. A., Gater, D. R., & Channell, I. (2022). Psychological consequences of spinal cord injury: A narrative review. *Journal of Personalized Medicine*, *12*(7), 1178. https://doi.org/10.3390/jpm12071178

Ernstmeyer, K., & Christman, E., (Eds.). (2021). Chapter 18 Spirituality. In Nursing Fundamentals [Internet]. Eau Claire (WI): Chippewa Valley Technical College. https://www.ncbi.nlm.nih.gov/books/NBK591821/

Jenkins, H. T., & Cosco, T. D. (2021). Spinal cord injury and aging: an exploration of the interrelatedness between key psychosocial factors contributing to the process of resilience. *Health Psychology and Behavioral Medicine*, *9*(1), 315-321. https://www.tandfonline.com/doi/full/10.1080/21642850.2021.1911656

Jones, K., Dorsett, P., Briggs, L., & Simpson, G. K. (2018). The role of spirituality in spinal cord injury (SCI) rehabilitation: exploring health professional perspectives. *Spinal Cord Series and Cases*, *4*(1), 54. https://www.nature.com/articles/s41394-018-0078-3

Margalhães, S.R., Carvalho, Z.M.F., Andrade, L.M. Pinheiro, A.K.B. & Studart, R.M.B. (2015). Influence of spirituality, religion, and beliefs in the quality of life of people with spinal cord injury. *Text Context Nursing*, *23*(3), 792-800. https://doi.org/10.1590/0104-07072015000620014.

Puchalski, C. M., Vitillo, R., Hull, S. K, & Reller, N. (2014). Improving the spiritual dimension of whole person care: reaching national and international consensus. *Journal of Palliative Medicine, 17*(6), 642-656. https://journals.sagepub.com/doi/full/10.1089/jpm.2014.9427

Tan, H., Arnison, C., & Venter, N. (2022). *Spiritual care in health care: elements of best practice. A scoping review.* Joint Project: Spiritual Health Association (Australia), Spiritual Care in Aotearoa New Zealand (SCANZ) Healthcare. https://spiritualhealth.org.au/wp-content/uploads/2024/06/Elements-of-Best-Practice_A-Scoping-Review-of-the-Literature_Final-Report-2022.pdf

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Chapter 15. Engaging in Sport with Spinal Cord Injury

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"I've been able to get back to playing sports and being active, which was and still is one of the most important parts of my rehab journey, and the rebuilding of my life."

Rubie, Wheelchair Rugby Athlete (C5/C6 SCI) (AQA)

The sudden impact of SCI can cause significant emotional distress for the individual, as well as their family and friends. Feelings of loneliness, loss of autonomy and diminishing sense of purpose can be overwhelming. Engaging in sport following SCI can provide a range of physical, social and psychological benefits, including fostering resilience (Kornhaber *et al.*, 2018). Sport for people with impairments or disabilities can offer inclusive and competitive opportunities for a wide range of abilities and interests, from local grassroots community sport to high-performance levels. For health professionals and carers supporting people living with SCI, understanding the opportunities, structures and systems in parasport is essential to facilitating access and long-term engagement. In addition to the benefits of sport participation, it is also important to be aware of the potential risks for individuals living with SCI, such as pressure injuries, autonomic dysreflexia, soft tissue injuries and thermoregulation issues. Proper preparation, including risk management and ongoing monitoring, is key to ensuring participation remains safe and beneficial for people living with SCI.

This Chapter will provide an overview of topics related to sport participation and its relevance to those living with SCI. It introduces the evolution of sport for people with disability, including a brief history and the development of the Paralympic Games, the pinnacle of elite sport for people with disability. There are several ***LLEs*** across various sports.

Key Topics in this Chapter

- Benefits of exercise and sport
- Sport terminology and pathways
- Competitive sport pathways in Australia
- Classification in para-sport
- Potential risks of sport participation and management strategies, and
- Practical considerations for health professionals and carers.

15.1. Benefits of exercise and sport for individuals living with SCI

Support workers and health professionals are uniquely positioned to guide individuals living with SCI along various sporting pathways, ranging from rehabilitation to elite participation. Encouraging engagement in physical activity and recreational or competitive sport can be an important aspect of holistic care that promotes long-term health, social connection and well-being.

15.1.1. Physical benefits

Regular participation in physical activity and sport can lead to positive physiological adaptations. The body becomes stronger, fitter, and better able to meet not only the demands of the sport but also those of everyday life.

15.1.1.1. Muscular strength and endurance

Individuals with SCI who engage in moderate-to-high-intensity activity at least three days per week for 30 minutes per session can increase muscular strength, muscular endurance and fatigue tolerance. Each sport offers a unique combination of specialised movements and goals that promote specific strength and coordination in the upper-limb and trunk musculature. These skills and improvements in strength can carry over into daily function, such as transfers and bed mobility (Chieffo *et al.*, 2024).

15.1.1.2. Body composition

Disuse and atrophy of skeletal muscle post-injury lead to a reduced ***resting metabolic rate (RMR)***, the amount of energy the body uses at rest. Coupled with a relatively more sedentary lifestyle and reduced energy expenditure, weight gain can be a significant challenge post-SCI (Madigan et al., 2024). Exercise and sport can counteract these effects by maintaining or increasing muscle mass and strength as well as promoting more regular physical activity and energy expenditure. Studies have also shown that athletes who use a wheelchair have significantly lower fat mass in the trunk region compared with non-athlete wheelchair-users (Rayes *et al.*, 2022).

15.1.1.3. Fitness

Any type of exercise can improve heart health, but endurance sports in particular can lead to changes in the heart structure and function for athletes with SCI (Rayes *et al.*, 2022). Those with higher-level or complete SCI injuries often have lower capacity for high-intensity exercise and a lower baseline***VO_2 max*** (maximum amount of oxygen the body can use during intense activity). While improvements in VO_2 max vary depending on the level of injury, research shows that cardiorespiratory fitness can increase by 10-70% after participating in exercise programs spanning 8-16 weeks. These improvements happen because the heart and blood vessels become healthier and more efficient. Exercise can increase blood flow to the muscles, strengthen the heart (including the left ventricle), boost cardiac output and reduce inflammation throughout the body (Vivodtzev & Taylor, 2021).

Athletes living with SCI have a higher risk of respiratory illnesses compared with those with other injuries and impairments, mainly due to changes in the autonomic nervous system (ANS) after SCI. Respiratory muscle training, such as Inspiratory Muscle Training (IMT) using resisted breathing devices, can significantly improve lung function and help prevent illness. Research shows that training at higher intensities and more frequently can lead to significant improvements in aerobic fitness, lung function and other respiratory benefits (Rayes *et al.*, 2022).

15.1.2. Psychosocial benefits

Beyond physical benefits, participating in sport can promote psychological well-being, confidence and independence, which are key outcomes for many individuals with SCI (Beacom *et al.*, 2016; Gold & Gold, 2007). Individuals living with SCI often experience higher levels of anxiety and depression (Gioia *et al.*, 2006). Taking part in sport regularly has been linked to overall better mental health for these individuals, including a reduction in depression and anxiety and increased energy (Muraki *et al.*, 2000).

This is mainly because taking part in and competing in sport can increase feelings of self-satisfaction and give athletes with SCI a chance to reconnect with their pre-injury identity or transform their identity beyond their disability. These experiences can lead to greater acceptance of their injury, as well as improved self-efficacy and self-reported quality of life (Rayes *et al.*, 2022). Adaptive sports should be introduced early in an individual's journey with SCI because they can help ease the transition from pre- to post-injury life. It can also provide a sense of belonging and purpose, feelings of freedom and autonomy and motivation at a time when they may feel like all of that has been lost. These all support the development of resilience (Kornhaber *et al.*, 2018).

After SCI, it is easy for individuals to become isolated and withdraw from their community. Sports can help by creating opportunities to build relationships, socialise, and develop a strong social network. These interactions also make it easier to connect with others who have similar experiences and reintegrate into the community. These social interactions also create opportunities to connect with others who have had similar experiences, ask questions and talk openly about disability. Through these conversations, individuals gain insights from others with first-hand experience of living with their injury.

Despite these well-documented benefits, national data show that people with disability, including those with SCI, remain underrepresented in sport and physical activity participation. While the Paralympic Games have grown exponentially in scale and visibility, participation in para-, adapted, and inclusive sport at the grassroots level in Australia has not kept pace. For example, in 2017, 52% of people with a disability reported participating in sport or physical activity at least three times per week, compared with 64% of people without a disability (Australian Sports Commission, 2017). This disparity highlights the need for targeted interventions and inclusive practices that reduce barriers to participation and ensure equitable access to sport for all individuals. Health professionals who support individuals with SCI can play an important role in addressing this gap by promoting sport and physical activity, providing tailored guidance and connecting individuals with inclusive programs and opportunities.

15.2. Sport terminology and pathways

For people living with SCI, there are multiple avenues to engage in sport and physical activity, ranging from recreational participation to elite international competition. The terminology used across the sports landscape, however, can be confusing. Understanding the distinctions between terms such as *inclusive, adaptive, para-sport* and *Paralympic* sport is essential for health practitioners and others who want to make informed referrals and empower people with SCI to pursue sport participation that aligns with their goals and interests (**Table 15.1**).

Table 15.1. Key characteristics of inclusive, adaptive, para-sport and Paralympic sport.

Elements/ Sport	Inclusive sport	Adaptive sport	Para-sport	Paralympic sport
Participant	Mixed (people with and without impairment or disability)	People with an impairment or disability	People and athletes with an impairment or disability	Elite athletes with an impairment or disability
Setting	Local or community, integrated	Local or community, rehabilitation, or disability specific settings	Local or community, state, national, and international programs and competitions	Paralympic Games sports and events
Modifications	Minimal, for inclusion, such as rules	Rules, individualised equipment	Individualised equipment, structured rules and classification systems	Highly formalised, IPC-governed sport with strict classification and qualification
Classification	None	Some adaptive sports	Formal classification systems	Formal classification systems
Focus	Social inclusion, participation	Accessibility, participation, skill development	Competitive sport pathways for people with impairments or disability	Sporting excellence, international recognition and social change through elite-level competition
Governance	Community organisations	Local or community, state, disability or national sport organisations	International federations and national sport organisations	International Paralympic Committee

15.2.1. Inclusive sport

Inclusive sport refers to programs and environments where people with and without disabilities participate and compete together. The emphasis is on removing barriers to participation, with adaptations to rules, equipment or the environment as needed to ensure everyone can take part. Inclusive sport is often found in community, school or grassroots club settings, where

it promotes social inclusion, engagement and peer interaction (Darcy & Dowse, 2013). For people living with SCI, inclusive sport can offer valuable opportunities to re-engage in life roles and participate in community-based recreation or fitness. Another related term is reverse inclusion, which involves people without impairments or disabilities joining disability-specific formats, such as wheelchair basketball.

15.2.2. Adaptive sport

Adaptive sport is a broad term that refers to any sport developed or modified to meet the needs of individuals with impairments or disabilities. This includes changes to rules, equipment, such as racing wheelchairs and sit-skis, playing surfaces or game structures. Adaptive sport can be recreational or competitive and may take place in disability-specific settings or integrated into mainstream environments (DePauw & Gavron, 2005).

15.2.3. Para-sport

Para-sport is part of the wider spectrum of adaptive sport and refers specifically to sports included in the Paralympic Games, governed by their international sport federations recognised by the International Paralympic Committee (IPC). Para-sport spans recreational to high-performance competition and includes summer disciplines, such as swimming and athletics. and winter disciplines such as snow-based sports. Most para-sports use classification systems that group athletes based on how their impairment affects sport performance, ensuring fair competition (Tweedy & Vanlandewijck, 2011).

15.2.4. Paralympic sport

Paralympic sport refers specifically to the sports included in the Paralympic Games and is used only to describe their involvement at this level. Paralympic sports are for elite athletes with impairments or disabilities and require rigorous classification and qualification processes. Participation at this level typically involves progression through local and national competition, talent identification and development programs, and adherence to international standards of training and performance (International Paralympic Committee).

The Paralympic Games represent the highest level of sport for athletes with an impairment, including those with SCI. While the Paralympic Games are high-performance, their origins are rooted in rehabilitation. Following World War II, Dr Ludwig Guttman, a neurosurgeon at the Stoke Mandeville Hospital's National Spinal Injuries Unit (UK), recognised the potential of sport to enhance both the physical and psychological recovery of individuals with SCI. This innovative work led to the first competitive sporting event for athletes with SCI in July 1948, an archery

competition held in conjunction with the London Olympic Games. This event laid the foundation for what would become the Paralympic Movement (Blauwet & Willick, 2012; Gold & Gold, 2007).

This historical connection reinforces the integral role of sport beyond the clinical setting. Initially used as a therapeutic intervention, sport has evolved into a global platform for excellence, empowerment and social inclusion. The first official Paralympic Games were held in Rome in 1960, featuring 400 athletes from 23 countries. Since then, the Paralympic Games have grown significantly, with Paris 2024 hosting over 4000 athletes from 168 countries competing in 549 medal events across 22 summer sports.

The Paralympic Games focus on athletes' achievements rather than their impairments or disabilities and aim to shift public perceptions and reinforce the idea that high-performance sport is accessible to all abilities (Dehghansai *et al.*, 2017; Kavanagh, 2012; Purdue & Howe, 2012). For people with SCI, this representation highlights the potential for sport to be a pathway to high-performance competition and long-term engagement.

Founded in 1989, the IPC carries the vision to *"enable Paralympic athletes to achieve sporting excellence and inspire and excite the world."* It is therefore responsible for organising and delivering the Paralympic Games and supports ten para-sports internationally, advocating for increased participation, equality and inclusion (Brittain, 2012).

15.3. Competitive sport pathways in Australia

While the Paralympic Games represent the pinnacle of elite sport for people with an impairment or disability, there are several competitive opportunities and structured sport pathways available to those with SCI. These pathways provide important opportunities for skill development, social connection and potential progression toward high-performance competition, such as the Paralympic Games. For health professionals and carers, understanding these pathways helps them provide informed referrals, increase awareness of sport opportunities and support broader engagement in sport and physical activity, which may contribute to improved overall well-being.

15.3.1. Entry-level and grassroots competitions

Para-athlete pathways are highly individual, so there is no single 'right' amount of time to start sport after SCI. Sport may be introduced during inpatient or community rehabilitation programs, or individuals may begin later through local inclusive or adaptive sport programs. These programs often focus on developing foundational skills, promoting social participation and improving fitness, while also offering competitive opportunities at local, regional and State-level events. Even in larger cities, people may face challenges identifying accessible sports options for someone living with SCI.

Video: Challenges in identifying accessible sports options

Professor Sean Tweedy, a world-leading Paralympic classification researcher based at the University of Queensland, discusses some of the challenges in identifying accessible sport options for people living with SCI.

One or more interactive elements has been excluded from this version of the text. You can view them online here: https://bond.studium.pub/life-well-lived-with-spinal-cord-injuries/?p=217#video-217-1

In Australia, State-based organisations play a key role in providing access to a range of adaptive or inclusive sports, offering regular competitions for people with SCI who want to explore available opportunities. Interactive **Figure 15.1** below highlights key contact organisations in each State.

An interactive H5P element has been excluded from this version of the text. You can view it online here:
https://bond.studium.pub/life-well-lived-with-spinal-cord-injuries/?p=217#h5p-10

Figure 15.1. Map showing the location of various adaptive or inclusive sport organisations. Click on the information icon. Created by Jaclyn Szkwara using Canva and HP5, licensed under a CC BY-NC (Attribution NonCommercial).

Nationally, Disability Sport Australia's Abilities Unleashed program provides an important entry point into adaptive sport and active recreation for individuals with disability, including those with SCI. This program offers experiential 'come and try' events where participants can engage with a variety of inclusive and adaptive sports in a supportive environment. These events aim to increase awareness of local opportunities, break down perceived barriers to participation and build confidence in engaging in physical activity. For individuals living with SCI, Abilities Unleashed can serve as a valuable first step in their sport journey, allowing them to explore different activities suited to their interests and functional capacities. These events also offer an opportunity to connect with local clubs, coaches and peers, which can be particularly beneficial during the transition from rehabilitation to community participation.

Paralympics Australia, the National Paralympic Committee for Australia, offers another centralised and supportive entry point to para-sports (those with a pathway to the Paralympic Games) through its initiative, The Start Line. This program helps individuals with disabilities, including those with SCI, explore participation options in para-sport regardless of their prior experience or current functional level. A key feature is the 'Get Involved' enquiry process, which provides tailored information on sporting opportunities based on individuals' impairment type, interests, and geographical location. For those aspiring to compete at the Paralympic Games, the 'Get Involved' enquiry process can help identify para-sports that offer a potential pathway to elite-level competition based on impairment and likely classification.

Alongside this, Paralympics Australia's Play Para-sport webpage offers a practical tool for exploring sport-specific pathways. The site includes information on a wide range of para-sports, including sport-specific details on eligibility requirements, basic rules, and how impairments such as SCI are classified within each sport. This resource is especially useful for individuals motivated to pursue a specific sport and seeking guidance on getting started. Health professionals and carers can use this resource to help individuals with SCI to identify local opportunities, understand competitive pathways and connect with national sporting organisations through the provided contact details.

15.3.2. National and international competitions

Beyond grassroots community levels, many state and national sporting organisations offer pathways, competitions, and talent development opportunities that support athletes in pro-

gressing toward high performance. Competitions, such as the Wheelchair Rugby National League and the National Wheelchair Basketball League (NWBL) and the Women's National Wheelchair Basketball League (WNBL), are examples of domestic elite competitions that are feeder systems for national teams.

Additional information, if interested: Sports Directory

For more information on Australia's national sporting organisations, including their contact details, visit the Australian Sports Directory.

Internationally, sport-specific federations, such as the International Wheelchair Basketball Federation, host world championships and ranking events. These competitions provide opportunities for international representation and serve as stepping stones to selection for Paralympic representation, the ultimate competition for athletes living with SCI.

15.3.3. Talent identification and development programs

High-performance para-sport pathways often begin with talent identification initiatives led by national sporting organisations, state institutes or academies of sport, Paralympics Australia or the Australian Institute of Sport. These programs assess athletes' characteristics and guide them toward sports where they have the greatest potential for high-performance success. Athletes may be invited to join development squads, attend training camps or work with specialist coaches and support teams.

Previously, Paralympic Talent Search programs have played a significant role in identifying and supporting aspiring Para-athletes across Australia. Since 2005, more than 1,000 individuals have been recognised as having the potential to succeed in sport and have been encouraged to pursue competition or join athlete development pathways. At the London 2012 Paralympic Games, 43 of the 161 Australian team members (27%), including 23 medallists, had been identified through the Talent Search initiative. Current programs, such as the Australian Institute of Sport's (AIS) Future Green and Gold Talent Search, are actively seeking athletes with a disability, including SCI, who have the potential to compete at an international level, such as the Paralympics and world championships.

15.3.4. University and college sport

For individuals living with SCI pursuing sport at a competitive level, many Australian universities offer a range of scholarships and support programs designed specifically for elite athletes, including those competing in para-sport. These programs recognise the dual demands of academic study and high-performance training and aim to reduce financial and logistical barriers to participation in both. It often provides financial assistance (scholarships and bursaries), academic flexibility, mentoring and support, and access to high-performance support such as physiotherapy, strength and conditioning. To be eligible, athletes typically need to be competing at a national or international level and be recognised by a relevant sporting body such as a National Sporting Organisation. University equity or disability support scholarships may also be available, offering additional financial and academic support to students with disability. Practitioners can play a valuable role in supporting athletes through the application process by helping them navigate eligibility requirements, prepare documentation, or connect with university sport coordinators. These scholarships can significantly enhance opportunities for both sporting and academic success.

Internationally, in some regions, particularly in the United States, college sport offers another structured pathway for individuals with SCI. Many colleges and universities have dedicated adaptive sports programs that actively recruit athletes with disabilities, including international students. These programs provide competitive opportunities alongside academic study, supported by coaching, scholarships and rehabilitation staff. To pursue a scholarship, athletes typically need to demonstrate competitive performance through national or international events, maintain academic eligibility, and connect with university coaches or program coordinators. Prospective students can start by researching universities with adaptive sports programs and reaching out directly to these programs or coaches. If the prospective student can provide performance history, classification details and video footage, this can often support the recruitment process. Carers and health professionals can assist by encouraging participation in sport, supporting exposure to competition and increasing awareness of collegiate opportunities abroad.

15.4. Classification in para-sport

To compete in adaptive sports and all para-sports, athletes must undergo classification, which is pivotal to ensuring fair and equitable competition. Classification is the process used to determine which athletes are eligible to compete in para-sport and then group athletes based on their functional abilities. To compete in para-sport, athletes must have one of the following eligible impairments:

- Limb deficiency
- Impaired muscle power

- Co-ordination impairments
- Restricted joint movement
- Short stature
- Leg length difference
- Intellectual impairment, or
- Vision impairment.

Classification aims to minimise the impact of an athlete's impairment on the outcome of a competition by grouping athletes whose impairments affect them similarly within their sports. The core principle behind the IPC classification is that the competition outcome should be determined by factors such as fitness, training and performance rather than the athlete's level of impairment. Para-sport classification is similar to that of other sports, which groups athletes by age, gender or weight.

Video: Para-sport classification process

Professor Sean Tweedy describes the advice he provided to his son, **Conor Tweedy**, who sustained an SCI during a collapsed scrum in a schoolboy rugby match in 2018, on what to expect regarding the classification process for his entry into para-sport and the rationale for the classification.

One or more interactive elements has been excluded from this version of the text. You can view them online here: https://bond.studium.pub/life-well-lived-with-spinal-cord-injuries/?p=217#video-217-2

The classification process involves assessing athletes' physical and functional capabilities and grouping them into classes. Generally, classification may include providing supporting medical documents, physical and technical assessments, and observation during competition (Paralympics Australia, n.d.). In Australia, the classification system operates at three levels:

1. **Provisional classification** is typically the first step for athletes new to para-sport. It provides a temporary class that allows individuals to participate in local or introductory competitions and is often conducted by trained sport professionals at club or entry-level events or by an allied health practitioner
2. **National classification** is a more detailed assessment conducted by accredited classifiers and is required for participation in national-level competitions. It offers a more sta-

ble and validated classification status based on sport-specific protocols, and

3. **International classification** is required for athletes competing in sanctioned international events, including the World Championships and the Paralympic Games. This process follows strict international guidelines set by the relevant International Federation and usually involves a panel of classifiers with expertise in both the sport and impairment type.

James' story: The classification process

Australian Steelers Wheelchair Rugby representative, **James McQuillan**, discusses his experiences with the classification process for wheelchair rugby after his SCI and how this differs from individual para-sports such as cycling, running and swimming (11:40-12:48).

While classification is essential to ensuring fairness in para-sport, classification may present significant challenges for athletes. The classification process can be stressful, as athletes often worry about the timing of assessments, perceived fairness and the risk of incorrect or inconsistent classifications. Some athletes report feeling that the classification process is too rigid or that it fails to account for the nuances of their impairment (Arnold *et al.*, 2017; Molik *et al.*, 2017). These stressors can be compounded by a lack of understanding of the classification system.

Beyond impairment-based classification, gender and sexuality intersect with disability to shape athletes' experiences and representations, often reinforcing stereotypes and influencing access to resources and visibility in para-sport (Pullen *et al.*, 2020; Pullen *et al.*, 2025; Weiller-Abels *et al.*, 2021).

By understanding the classification process and the stressors associated with it, health professionals and carers who work with athletes with SCI can better support them to navigate the complexities of para-sport. Providing athletes with clear information about classification, advocating for transparency and fairness and offering emotional support during this process can help reduce anxiety and improve their overall experience in competitive sport.

Not every impairment type is eligible to compete in every para-sport. For example, an athlete with SCI will be ineligible for Blind Football, Para-Judo or Goalball, which are sports for athletes with impaired vision.

Additional information, if interested: Paralympics Australia Mapping Tool

The following are resources for those wanting to learn more about the Paralympics Australia Mapping Tool:

- Paralympics Australia has created this resource for those involved in supporting athletes and their well-being around para-sport classification
- More information on which impairment types are eligible for para-sports can be found here, and
- The Paralympics Australia Impairment Mapping Tool for Para-sport is designed as a general guide to help identify which para-sports may offer a competitive pathway, including toward the Paralympic Games, based on impairment types. It is important to note that this is not a formal classification, and athletes must undergo a more formal process to determine their eligibility for competition.

Before moving to the next section on adaptive equipment, below is **Professor Shean Tweedy** talking about sampling sports to find a sport that suits you. This is followed by several LLEs on the importance of sport in people's lives.

Video: Does your classification suit you?

Prof Sean Tweedy also provides additional suggestions for individuals who may not feel their classification suits them and wish to win gold medals at Paralympic competitions. He also mentions that they may need to sample a variety of para-sports and undergo different classification assessments until they find a sport that meets their high-level aspirations.

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Personal stories: What sports mean to individuals

Several SCIA Have the Nerve blogs and podcasts that involve individuals involved in adaptive sport:

- SCIA's Louise Sauvage – Paralympic Gold Medalist and Coach, Wheelchair Racing (Episode 8, 16 November 2021)
- SCIA's Nazim Erdem – Paralaympic Gold Medalist, Wheelchair rugby (Episode 9, 16 November 2021)
- SCIA's Aimee Fisher: Adaptation and Determination (11 December 2022)
- SCIA's Have the nerve podcast, Something to Think About – What does my sport mean to me? (Episode 47, 17 October 2024): **Tamsin**, **Gerry** and **Daira** talk about what sport means to them as international athletes and a coach, and
- I thought I hated basketball. Now it's given me an amazing life (ABC News,11 November 2025): Katherine wanted to be a veterinarian but sustained an SCI at 19: *"As it turned out, I didn't hate wheelchair basketball. Less than 3 months later, before I'd even left rehab, I had caught the bug and had a new life goal."*

15.5. Adaptive equipment

Adaptive equipment is critical to enabling individuals living with SCI to fully participate and excel in both recreational and high-performance sport. Whether in summer or winter disciplines, the use of specialised equipment, such as sport-specific wheelchairs, sit-skis or handcycles, distinguishes sport by tailoring participation to athletes' functional capabilities. These adaptations facilitate inclusion and seek to optimise safety, efficiency and performance.

Technological innovation in this space has been significant; advances in materials, biomechanics, and sport-specific customisation have allowed athletes to train and compete at increasingly higher levels. For example:

- Streamlined racing wheelchairs designed with carbon fibre frames improve speed and aerodynamics
- Basketball and rugby wheelchairs are reinforced for agility and impact resistance, and
- Sit-skis used in para-alpine skiing are built to maximise control and shock absorption on variable terrain (Burkett, 2012).

Access to this technology, however, remains a critical challenge.

High-performance adaptive equipment can be expensive, and for athletes with SCI, the financial burden can be a significant barrier to entry and progression. Costs can range from AUD $5,000 to more than $20,000, depending on the equipment type, with additional ongoing costs for repairs, modifications and upgrades. Research has shown that limited access to appropriate equipment can hinder talent identification, athlete retention and overall development (Dehghansai *et al.*, 2021).

Video: Modifying equipment

Prof Sean Tweedy provides advice on how an individual living with SCI can work with their friends and families to develop innovative solutions to modify equipment, such as wheelchairs, to enable initial participation.

One or more interactive elements has been excluded from this version of the text. You can view them online here: https://bond.studium.pub/life-well-lived-with-spinal-cord-injuries/?p=217#video-217-4

Important resources and information: Funding sources

Below are links to useful information to understand the funding sources available to athletes with disabilities:

- State-based wheelchair sports associations: See **Figure 15.1** in this Chapter
- Sport Australia's Local Sporting Champions program, and
- Para-sport Equipment Enhancement Program (via Paralympics Australia).

Unlike standard sporting gear, adaptive equipment must be tailored to each athlete's specific functional needs and the demands of their chosen sport. Health practitioners and carers, along with coaches and support staff, play an essential role in helping athletes navigate equipment decisions and access appropriate resources. Several key considerations should guide the equipment selection process:

- **Functional capacity and level of injury:** The type and configuration of equipment should align with the athlete's neurological level and the completeness of the SCI. For example, athletes with higher-level cervical injuries may require additional trunk support, stabilising straps or modified control mechanisms, while those with lower-level injuries often benefit from lighter, more agile equipment
- **Sport-specific design requirements:** Each para-sport has distinct performance and safety demands that inform equipment design.
- **Customisation:** Equipment must be carefully measured and fitted to minimise the risk of pressure injuries, optimise biomechanics and enhance performance. Factors such as seat depth, cushion type, wheel position and backrest angle must be tailored to the athlete's body and sport requirements. Collaboration with specialised technicians or manufacturers is often necessary to ensure precision
- **Adaptability and progression:** Particularly for younger athletes or those with recently acquired injuries, equipment should accommodate growth, physical changes, and skill development over time. Modular designs or adjustable features can accommodate progression along the sport pathway, avoiding the need for frequent complete equipment replacement
- **Practicality and transport:** Considerations such as portability, durability and storage requirements of the equipment are important, especially for athletes travelling for training or competition. Equipment that can be disassembled or stored easily can reduce barriers to consistent participation
-
Costs and access to funding: Due to the cost of adaptive sports equipment for individuals with SCI, it is important to explore funding options early, including the NDIS, Paralympics Australia's Para-Sport Equipment Enhancement Program and other organisations that offer grants to support appropriate and sustainable equipment choices, and
- **Athlete involvement and autonomy:** Ensuring the athlete is involved in decisions about their equipment promotes a sense of control, improves satisfaction and leads to better long-term outcomes. Health professionals should support a collaborative approach, recognising that the athlete is the expert in their own experience.

15.6. Potential risks of sport participation and management strategies

To ensure an individual living with SCI can enjoy the benefits of adaptive sports and safely participate, it is important to be aware of several risk factors. These include internal and external risk factors. Internal risk factors relate to impaired bodily processes, while external risk factors relate to the environment, its demands and potential dangers associated with sport participation. Some common internal and external risk factors are outlined below. **Chapter 2** describes many of these risks in detail.

15.6.1. Physiological risk factors

Physiological risk factors are internal factors resulting from impaired bodily processes caused by the individual's SCI. The severity of the injury determines which functions have been affected and which strategies are needed to mitigate risk when participating in sport.

Reminder: Understanding your body and its limitations after SCI

Chapter 2 focused on the implications of SCI on the body, including the physiological and psychological impacts of SCI, injury levels, effects on different organ systems, types of pain and related management strategies.

15.6.1.1. Inability to regulate body temperature

During physical activity, the body's temperature rises, triggering thermal receptors that signal the brain to initiate cooling mechanisms. This includes redistributing warm blood from the core to the peripheries (arms and legs), where it is pushed to the skin's surface to allow for evaporation of heat through sweating. Individuals with injuries at T6 and above SCI are not able to regulate their body temperature, so they cannot redistribute blood in the manner described above. They also have an impaired ability to sweat below the level of the SCI. Excessive sweating may occur above the injury site as a compensatory mechanism. This increases the risk of heat-related illnesses during sports and exercise.

15.6.1.2. Managing body temperature

Sanchez-Jimenez and colleagues (2022) offer a range of strategies to manage this impaired thermoregulation for sports participation:

1. Consider a sport played in temperature-controlled environments, such as indoor sports or swimming. Also consider the timing of sport participation in colder seasons.
2. Wear lightweight, breathable clothing that wicks moisture
3. Use ice packs or vests, water sprays and cooling gels. Drinking ice-cold water quickly lowers body temperature. Cooling towels mimic sweating, allowing evaporation to cool the body, and
4. Incorporate long warm-ups and cool-downs to allow the body to gradually adjust to avoid overexertion and overheating.

As described in **Chapter 2**, the *autonomic nervous system (ANS)* comprises the *sympathetic nervous system* and the *parasympathetic nervous system,* which, in turn, influence the *enteric nervous system (ENS)*. This complex system is responsible for maintaining *homeostasis* in the body, the process by which a stable environment is regulated so the body can function at its best. After SCI, these pathways are impaired, causing autonomic dysfunction of almost all physiological systems, resulting in poor blood pressure control and *autonomic dysreflexia (AD)*, bowel and bladder dysfunction and poor thermoregulation.

15.6.1.3. Poor blood pressure (BP) control and AD

As mentioned in **Chapter 2**, those who have sustained SCI of T6 or above are at risk of experiencing AD, a marked and sudden increase in blood pressure. AD can be elicited by noxious (harmful or unpleasant) stimuli below the level of injury, such as catheter blockage, bowel obstruction, injury to the lower limbs (legs) or pressure injuries. Individuals engaging in sport are at risk of triggering AD via musculoskeletal injuries, such as a muscle tear or strain or a bone fracture or break and pressure injuries, such as those caused by contact or from inappropriate or ill-fitting equipment.

15.6.1.4. Acute management of AD

If left unmanaged, AD can cause a rise in systolic BP to values above 200 mmHg. Early recognition and intervention are critical. Several things can be done to counteract AD, as listed below. If an individual has persistent symptoms, Emergency Services must be called.

1. BP should be monitored every 2-5 minutes to ensure it is returning to the individual's normal levels

2. Identify and immediately remove the noxious stimulus
3. Position the individual upright and lower their legs
4. Remove all restrictive clothing and compression aids such as abdominal binders
5. Check the catheter tube for any kinks or blockages and empty the bladder or bag
6. Check for any signs of constipation or impaction, proceed with manual or pharmacological disimpaction and evacuation if required, and
7. Administer medication, if prescribed and under guidance from your GP or specialist, such as glyceryl trinitrate (GTN).

15.6.1.5. Preventing AD when participating in sport

To mitigate the risk of sports-related AD and to attend to it if it develops, consider the following before participation:

- Empty bowel and bladder
- Check catheter equipment for any blockages, kinks or defects
- Check skin for any irritations or pressure sores
- Loosen any tight clothing or compression aids, and
- Ensure anti-hypertensive medication is readily available and inform the coach where it is located.

15.6.1.6. Bowel and bladder function

Individuals with SCI at T12 or above can have a reflexive (tight) bladder and bowel. There is no voluntary control of the bladder and bowel. When they become full, they empty automatically. The bladder and bowel will also empty when stimulated, which can occur at the least expected times, such as when laughing or during spasms. Those living with SCI at T12 or lower can have a flaccid (loose) bladder and bowel. Lower lesions can damage the reflex pathways, meaning they no longer contract to empty automatically and will not fully empty even when stimulated. These impaired nerve pathways can lead to increased risk of constipation, incontinence and urinary tract infections, all of which can trigger AD.

15.6.2. Injury risk

There are many potential external risk factors for injury in sport, including collisions, falls, and overuse or pressure injuries. The risk is higher for contact sports, such as Wheelchair rugby or basketball.

15.6.2.1. Soft tissue injuries

Soft tissue injuries are common in sports. Individuals with SCI participating in sports are more likely to sustain an upper-limb (arm) injury than a lower-limb (leg) injury (Rayes *et al.*, 2022). This is due to ill-fitting equipment, such as chairs that are not tailored to the body and level of function, as well as collisions, overuse and muscular deconditioning. Many individuals who use their arms daily to mobilise in manual wheelchairs suffer overuse injuries, particularly in the shoulders.

Key recommendation: Preventing soft tissue injuries

Preventing soft tissue injuries is therefore important. Regular exercise is essential for both general health and sport-related conditioning in individuals living with SCI. To reduce the risk of overuse and soft tissue injuries, athletes should engage with a physiotherapist and/or an exercise physiologist to develop a prehabilitation program to help ensure the body can manage the physical demands of daily wheelchair use, such as pushing and transfers, as well as the added demands of sport. A key focus of the prehabilitation program should be improving the range of motion and strength of the upper limbs.

15.6.2.2. Skeletal health and fracture risk

As discussed in **Chapter 2**, SCI can cause rapid-onset osteoporosis, with bone loss of up to 40% in the first 6 months post-injury (Antoniou *et al.*, 2022). This loss of bone density is due to several factors, including reduced mechanical loading, neurological and circulatory dysfunction and hormonal changes (Antoniou *et al.*, 2022). During sports participation, there is an increased risk of collisions or falls involving the wheelchair, which can result in a fracture. Such injuries can lead to several complications, including AD, skin breakdown, pressure ulcers, and, in severe cases, lower limb amputation.

Maintaining good skeletal health is therefore important. A referral can be obtained from a general practitioner or specialist for a *Dual-Energy X-ray Absorptiometry (DEXA)* scan, which measures *bone mineral density (BMD)* and evaluates fracture risk. Individuals with SCI should undergo regular DEXA scans to monitor and guide BMD maintenance. To help maintain BMD, individuals are encouraged to:

1. Consult their GP or specialist about appropriate medications that may prevent further bone density loss
2. Engage a physiotherapist and/or exercise physiologist for exercises that aim to maintain

or improve BMD and ensure safe loading practices during exercise and sport, and
3. Consult a dietitian for dietary support on how to eat to improve bone outcomes.

15.6.2.3. Skin injuries

Skin breakdown is a potential risk factor for individuals with SCI during sports participation. Due to a lack of sensation and impaired motor function, individuals with SCI are more prone to skin breakdown and the development of pressure sores. Individuals with SCI may not be able to feel if something is pressing into their skin, if they are in contact with something hot or if they have experienced a hard impact, limiting their ability to respond and prevent injury.

Key recommendations: Preventing and managing skin injuries

The ultimate management technique for managing skin breakdown is prevention. Preventative and early detection strategies include:

- **Daily skin checks:** Perform a full-body inspection in the morning and at night to identify early signs of skin damage. Additional checks should follow poor transfers, falls, the trial of new equipment, episodes of incontinence, the wearing of new clothing and prolonged activity. Signs include redness or darkening of the skin, blisters, bruises, cracked or scraped skin, hardness, swelling or warmth
- **Regular pressure relief:** Change positions regularly to redistribute pressure and allow blood to circulate to different areas of the body
- **Well-fitting equipment:** Occupational therapists who specialise in equipment and seating can ensure proper fit of wheelchairs, cushions and other equipment. Well-fitting equipment can reduce the risk of pressure sores and injury, and
- **Exercise:** Physical activity can increase circulation through a muscle pump effect, enhancing skin health. Exercise also provides an opportunity to load the body in a variety of ways and minimise time spent in one position, reducing the risk of pressure injuries.

If any potential skin breakdown or pressure areas are identified:

- Stay off that area and remove all pressure
- Keep the area clean and dry
- Maintain good hydration, and
- If the area does not improve within a few days, consult a GP or specialist (Queensland SCI Service, 2024).

15.7. Practical considerations for health professionals, carers and support workers

Health professionals, carers and support workers can play a critical role in enabling access to sport for people living with SCI by:

- Initiating conversations about sport and physical activity as part of rehabilitation goal-setting
- Referring individuals to sport organisations and programs that provide opportunities for people living with SCI
- Supporting participation by identifying and addressing needs, such as equipment, transportation or other potential barriers, such as managing pain and injuries
- Promoting physical activity to increase strength, endurance and general fitness, which underpins sporting performance and reduces injury risk
- Offering support and education in areas that enhance sport performance, such as nutrition, hydration, sleep, recovery strategies and classification, and
- Collaborating with sport and community organisations to promote safe and inclusive sport opportunities.

Recognising sport as a continuum from rehabilitation to community or club sport, perhaps elite competition for some, can empower people living with SCI to pursue fulfilling pathways that align with their goals and interests, contributing to their overall health, well-being and quality of life.

Video: Health and sports professionals can foster sports participation

Professor Sean Tweedy also provided suggestions on how health and sports professionals can assist individuals with SCI to reap the rewards of participation in sport.

One or more interactive elements has been excluded from this version of the text. You can view them online here: https://bond.studium.pub/life-well-lived-with-spinal-cord-injuries/?p=217#video-217-5

Key Take-aways

- There are increasing opportunities for individuals living with SCI in Australia, from community and club sports to international sports
- Exercise and participation in sports have numerous physiological and psychological benefits
- If individuals wish to compete in certain sports, such as Paralympic sports, they will probably need to undergo classification
- While there are potential physical and physiological risks involved in sport participation, preventive management strategies can mitigate them, and
- Healthcare and sport professionals and carers can all play important roles in helping individuals living with SCI access and benefit from participating in sport.

The next chapter, **Chapter 16**, the research chapter, is highly relevant, as it explores various research methods, all aimed at restoring function, which, in many cases, will improve movement and mobility for those engaged in sport. It also addresses nutritional research related to SCI.

Reminder: Relevant chapters

- **Chapter 2:** Sport involves pushing the body, which may have implications for individuals living with SCI, as it could result in pressure injuries as well as autonomic dysreflexia, all of which are discussed in Chapter 2
- **Chapter 3:** Those involved in sport are meeting one of the pillars of good health and well-being: Physical activity. The other four pillars of health and well-being will also support those engaging in sport: *Good nutrition, quality sleep, exposure to sunlight and socialising*
- **Chapter 4:** Tracking health and well-being is important for managing a body that is already anatomically and physiologically different
- **Chapter 5:** Engaging in sport is also about socialising. There may be sports scholarships available at a university
- **Chapter 6:** Ageing will impact a sporting body, particularly in competitive sport. You may have to switch to a different sport as you age
- **Chapter 7:** Many young people participate in para-sport, so understanding their physical and emotional developmental needs is important
- **Chapter 9:** Intersectionality, such as identifying as LGBTQIA+ or neurodiverse, is an important element of sport

- **Chapter 12:** If you play sport, you are likely to be flying locally and perhaps internationally. Chapter 12 offers numerous resources and LLEs
- **Chapter 16:**There may be opportunities to engage in research related to sport as well as clinical trials
- **Chapter 17:** The Impact of a changing climate is important for those engaged in sport, particularly if they are unable to regulate their body temperature. There could be mobility issues during calls to evacuate in the event of a bushfire or flood. This may also happen while abroad for a sporting event. Having an appropriate emergency plan is crucial, and
- **Chapter 18:** Health professions education explores how members of multiprofessional teams are trained and educated to assist with the health and well-being of individuals with SCI. Exercise physiologists (training), OTs (equipment), physiotherapists (remediation, pain), dietitians (tailored and balanced diet) and GPs (regular check-ups) are likely to be the key health professionals involved.

Podcast: Professor Sean Tweedy's complete interview (audio only)

For those interested in listening to the complete interview (audio) with **Professor Sean Tweedy,** the 33-minute audio is below.

Sean Tweedy LinkedIn profile

One or more interactive elements has been excluded from this version of the text. You can view them online here: https://bond.studium.pub/life-well-lived-with-spinal-cord-injuries/?p=217#audio-217-1

References

Antoniou, G., Benetos, I.S., Vlamis, J., & Pneumaticos, S.G. (2022). Bone mineral density post a spinal cord injury: A review of the current literature guidelines. *Cureus, 14*(3). https://doi.org/10.7759/cureus.23434

Arnold, R., Wagstaff, C. R. D., Steadman, L., & Pratt, Y. (2017). The organisational stressors encountered by athletes with a disability. *Journal of Sports Sciences, 35*(12), 1187-1196. https://doi.org/10.1080/02640414.2016.1214285

Australian Sports Commission. (2017). *AusPlay survey results July 2016 – June 2017*. Retrieved 27th May 2021 from https://www.ausport.gov.au/clearinghouse/research/ausplay/2015-2023

Beacom, A., French, P., & Nesti, M. (2016). *Inclusive sports development: Principles and practice.* Routledge.

Blauwet, C., & Willick, S. E. (2012). The Paralympic Movement: using sports to promote health, disability rights, and social integration for athletes with disabilities. *Physical Medicine and Rehabilitation, 4(*11), 851-856. https://onlinelibrary.wiley.com/doi/10.1016/j.pmrj.2012.08.015

Brittain, I. (2012). The Paralympic Games: From a rehabilitation exercise to elite sport (and back again?). *International Journal of Therapy and Rehabilitation, 19*(9), 526-530. https://doi.org/10.12968/ijtr.2012.19.9.526

Burkett, B. (2012). Paralympic sports medicine – current evidence in winter sport: Considerations in the development of equipment standards for Paralympic athletes. *Clinical Journal of Sport Medicine, 22*(1), 46-50. https://doi.org/10.1097/JSM.0b013e31824200a4

Chieffo, C., Chini, G., Varrecchia, T., Gennarelli, I., Silvetti, A., Molinaro, V., Poni, I., Mariotti, A., Tiberti, S., Tamburro, A., Calabrese, I., Felici, S., Bartoli, M., Gigli, L., Minella, R., Lucia, B., Toscano, A., & Ranavolo, A. (2024). The impact of sports training on the spinal cord injury individual's balance. *Sensors, 24*(23), 7808. https://doi.org/10.3390/s24237808

Darcy, S., & Dowse, L. (2013). In search of a level playing field—The constraints and benefits of sport participation for people with intellectual disability. *Disability & Society, 28*(3), 393-407. https://doi.org/10.1080/09687599.2012.714258

Dehghansai, N., Lemez, S., Wattie, N., & Baker, J. (2017). Training and development of Canadian wheelchair basketball players. *European Journal of Sport Science, 17*(5), 511-518. https://doi.org/10.1080/17461391.2016.1276636

Dehghansai, N., Pinder, R. A., & Baker, J. (2021). "Looking for a golden needle in the haystack": Perspectives on talent identification and development in Paralympic sport. *Frontiers in Sports and Active Living, 3*(75). https://doi.org/10.3389/fspor.2021.635977

DePauw, K. P. & Gavron, S. J. (2005). *Disability Sports* (2nd edition). Human Kinetics. https://www.scribd.com/document/488004820/Karen-P-DePauw-Susan-J-Gavron-Disability-sport-Human-Kinetics-2005

Fenton, J.M., King, J.A., Hoekstra, S.P., Valentino, S.E., Phillips, S.M., & Goosey-Tolfrey, V.L. (2022). Protocols aiming to increase muscle mass in persons with motor complete spinal cord injury: a systematic review. *Disability and Rehabilitation, 45*(9), 1433-1443. https://doi.org/10.1080/09638288.2022.2063420

Gioia, M.C., Cerasa, A., Di Lucente, L., Brunelli, S., Castellano, V., & Traballesi, M. (2006). Psychological impact of sports activity in spinal cord injury patients. *Scandinavian Journal of Medicine & Sports Science, 16*, 412-416. https://doi.org/10.1111/j.1600-0838.2005.00518.x

Gold, J. R., & Gold, M. M. (2007). Access for all: The rise of the Paralympic Games. *Journal of the Royal Society for the Promotion of Health, 127*(3), 133-141. https://journals.sagepub.com/doi/10.1177/1466424007077348

Henke, A.M., Billington, Z.J., & Gater, D.R. (2022). Autonomic dysfunction and management after spinal cord injury: A narrative review. *Journal of Personalized Medicine, 12*(7), 1110. https://doi.org/10.3390/jpm12071110

International Paralympic Committee. *About the IPC.* https://www.paralympic.org/the-ipc

International Paralympic Committee. *What is classification?* https://www.paralympic.org/classification

Kavanagh E. (2012). Affirmation through disability: one athlete's personal journey to the London Paralympic Games. *Perspectives in Public Health, 132*(2), 68-74. https://doi.org/10.1177/1757913911435757

Kornhaber, R., Mclean, L., Betihavas, V., & Cleary, M. (2018). Resilience and the rehabilitation of adult spinal cord injury survivors: A qualitative systematic review. *Journal of Advanced Nursing*, 74(1), 23-33. https://doi.org/10.1111/jan.13396

Madigan, C.D., King, J.A., Taylor, C., Hoekstra, S. P., Graham, H. E., Kirk, N., Fenton, J. M., & Goosey-Tolfrey, V. L. (2024). A systematic review and qualitative synthesis of weight management interventions for people with spinal cord injury. *Obesity Reviews, 25*(9). https://doi.org/10.1111/obr.13785

Marsden, M. (2025). Paralympic experience and discursive disability embodiment. *M/C Journal*, *28*(5). https://doi.org/10.5204/mcj.3211

Molik, B., Laskin, J. J., Golbeck, A. L., Kosmol, A., Rekowski, W., Morgulec-Adamowicz, N., Rutkowska, I., Marszalek, J., Gajewski, J., & Gomez, M.-A. (2017). The International Wheelchair Basketball Federation's classification system: The participants' perspectives. *Kinesiology, 49*(1), 117-126. https://ojs.srce.hr/index.php/kinesiology/article/view/5324

Muraki, S., Tsunawake, N., Hiramatsu, S., et al. (2000). The effect of frequency and mode of sports activity on the psychological status in tetraplegics and paraplegics. *Spinal Cord, 38*, 309-314. https://doi.org/10.1038/sj.sc.3101002

NSW Health. (2025). *Treatment of autonomic dysreflexia for adults and adolescents with spinal cord injuries.* https://aci.health.nsw.gov.au/networks/spinal-cord-injury/resources/autonomic-dysreflexia

Paralympics Australia. (n.d.). *What happens during classification?* Paralympics Australia. https://www.paralympic.org.au/classification/

Pullen, E., & Silk, M. (2020). Gender, technology and the abled national Paralympic body politic. *Cultural Studies (London, England)*, *34*(3), 466-488. https://doi.org/10.1080/09502386.2019.1621917

Pullen, E., Mora, L., & Silk, M. (2023). Paralympic cripvertising: On the gendered self-representations of Paralympic athletes on social media. *New Media & Society*, *27*(1), 263-280. https://doi.org/10.1177/14614448231173882

Purdue, D. E. J., & Howe, P. D. (2012). See the sport, not the disability: Exploring the Paralympic paradox. *Qualitative Research in Sport, Exercise and Health, 4*(2), 189-205. https://doi.org/10.1080/2159676X.2012.685102

Queensland Spinal Cord Injuries Service. (2024). *Prevention of Skin Breakdown – Skin Checks*. https://qscis.health.qld.gov.au/resources/skin/key-principles-of-pressure-injury-prevention/

Rayes, R., Ball, C., Lee, K., & White, C. (2022). Adaptive sports in spinal cord injury: a systematic review. *Current Physical Medicine and Rehabilitation Reports, 10*(3), 145-153. https://doi.org/10.1007/s40141-022-00358-3

Rosin, N.R., Tabibi, R.S., Trimbath, J.D., & Henzel, M.K. (2020). A primary care provider's guide to prevention and management of pressure injury and skin breakdown in people with spinal cord injury. *Topics in Spinal Cord Injury Rehabilitation, 26*(3), 177-185. https://doi.org/10.46292/sci2603-177

Sanchez-Jimenez, J. L., Aparicio, I., Romero-Avila, J. L., Bellot-Arcis, C., Ortiz de Anda, R. M. C., & Priego-Quesada, J. I. (2022). Skin temperature measurement in individuals with spinal cord injury during and after exercise: Systematic review. *Journal of Thermal Biology, 105*, 103246. https://doi.org/10.1016/j.jtherbio.2021.103146

Tweedy, S. M., & Vanlandewijck, Y. C. (2011). International Paralympic Committee position stand – background and scientific principles of classification in Paralympic sport. *British Journal of Sports Medicine*, *45*(4), 259-269. https://doi.org/10.1136/bjsm.2009.065060

Vieira Santos, L., Torres Pereira, E., Reguera-Garcia, M.M., Patrocinio de Oliveira, C.E., & Costa Moreira, O. (2022). Resistance training and muscle strength in people with spinal cord injury: A systematic review and meta-analysis. *Journal of Bodywork and Movement Therapies, 29*, 154-160. https://doi.org/10.1016/j.jbmt.2021.09.031

Vivodtzev, I., & Taylor, J.A. (2021). Cardiac, autonomic, and cardiometabolic Impact of exercise training in spinal cord injury: A qualitative review. *Journal of Cardiopulmonary Rehabilitation and Prevention, 41*(1), 6-12. https://doi.org/10.1097/HCR.0000000000000564

Weiller-Abels, K., Everbach, T., & Colombo-Dougovito, A. M. (2021). She's a lady; he's an athlete; they have overcome: Portrayals of gender and disability in the 2018 Paralympic Winter Games. *Journal of Sports Media*, *16*(1), 123-148. https://doi.org/10.1353/jsm.2021.0005

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Chapter 16. Spinal Cord Injury Research and Innovation

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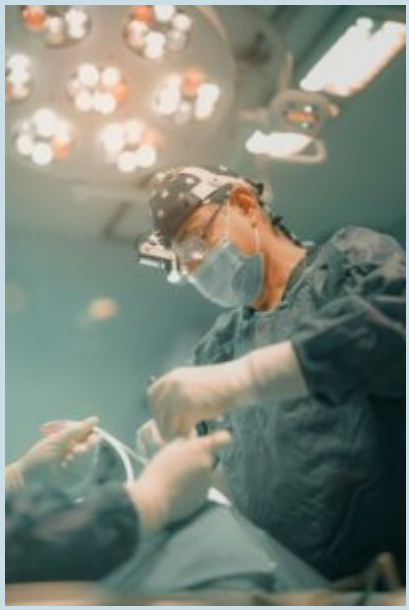
"Everything is possible" **Perry Cross**, Member of the Order of Australia (AM)

A SCI is often profoundly debilitating, with no definitive cure, affecting more than 20,800 Australians and costing the healthcare system billions of dollars each year. Current clinical management focuses on limiting further damage, managing symptoms and reducing complications. At the same time, several therapeutic approaches are being investigated to restore function and repair neural damage. Researchers are also exploring ways to enhance existing therapies to improve clinical outcomes. Throughout these efforts, hope remains an essential element. It is reflected in the steady progress of scientific discovery, in the commitment of researchers and clinicians, and in the resilience of people living with SCI who continue to look to the possibility of improved function and quality of life.

Podcasts: Listen to these SCIA podcasts on research

- SCIA's Have the Nerve podcast, Something to think about: Why invest in medical research is SCI (Episode 43): Listen to one organisation's story about why funding SCI research is important.
- SCIA's Have the Nerve podcast, What is it like to be a researcher in SCI? (Episode 44): Recorded in August 2024, several researchers discuss their research projects and trials.

This Chapter provides an overview of the current status of SCI research, particularly in Australia.



Key Topics in this Chapter

- An overview of the different types of therapies being developed to repair SCI, including how clinical trials work and how participants are recruited
- Current cell therapy research, with a focus on one specific approach:***Olfactory ensheathing cell (OEC)*** transplantation
- Optimising OEC transplantation for SCI repair: An Australian research approach (technical and non-technical explanations)
- Other emerging and complementary areas of SCI research
- Nutrition research relevant to SCI, and
- Insights from people with ***lived and living experiences (LLEs)*** of SCI.

Although SCI primarily affects the *central nervous system (CNS)*, it has biological, social, psychological and financial implications. As such, any therapy aimed at repairing the SCI and recovering function must also consider psychosocial and nutritional recovery, long-term rehabilitation and reintegration of the individual into the community.

16.1. SCI repair: Therapies and clinical trials

Therapies for SCI can be categorised into four approaches:

1. **Pharmaceutical and molecular approaches:** These aim to reduce inflammation and secondary degeneration immediately after injury. *Anti-inflammatory drugs* and agents that neutralise inhibitory molecules are commonly used.
2. **Cell transplantation:** This strategy involves replacing lost glial cells or promoting regeneration using stem or *glial cells*. Amongst these, *olfactory ensheathing cells (OECs)* have

emerged as promising candidates due to their regenerative properties and accessibility via minimally invasive nasal biopsies. Below, we provide details of current research and clinical trials involving OECs (**Sections 16.3 and 16.4**)

3. **Biological therapies:** These include growth factor supplementation and *immunomodulation* to stimulate endogenous repair mechanisms. OECs naturally secrete *neurotrophic factors* and modulate inflammation, making them ideal for such interventions.
4. **Physico-mechanical approaches:** Robotics, electrical stimulation, magnetic stimulation, *transcranial magnetic stimulation, TMS*, ultrasound stimulation and *brain-computer interface (BCI) technology* are used to simulate neural circuitry, specifically motor function, and support rehabilitation. **Section 16.5** describes recent *spinal cord stimulation (SCS)* research.

Figure 16.1 below provides an overview of different experimental and clinical approaches in SCI research, either by proactively repairing the damage or by mitigating complications that worsen it.

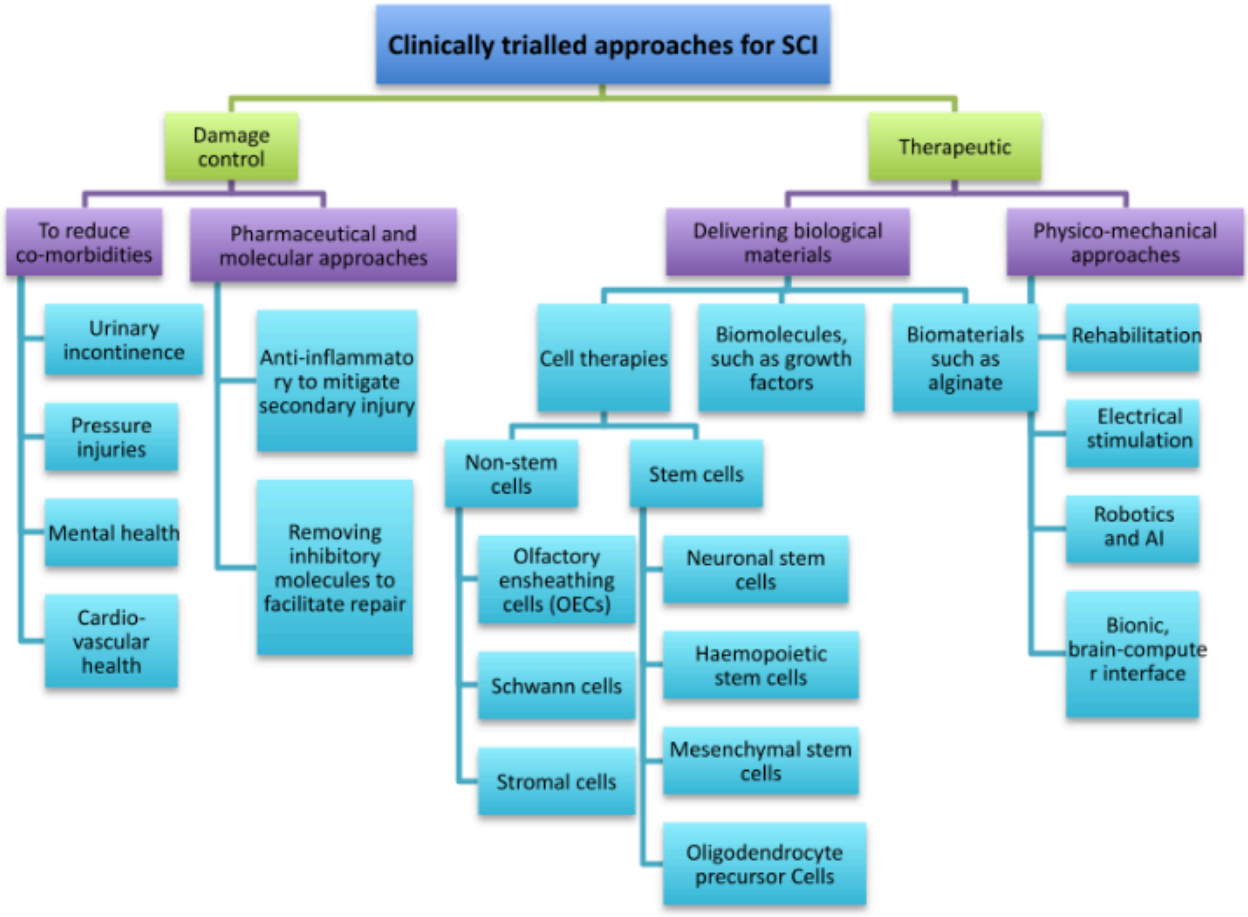


Figure 16.1. Overview of various clinical and experimental management approaches for SCI treatment (Reshamwala *et al.*, 2022). Reproduced under a CC BY 4.0 license.

16.2. Cell therapy research

The next section provides information on current research, such as nerve bridge transfer using cell therapy. **Figure 16.2** summarises the different cell transplantation-based therapeutic options for SCI repair and regeneration.

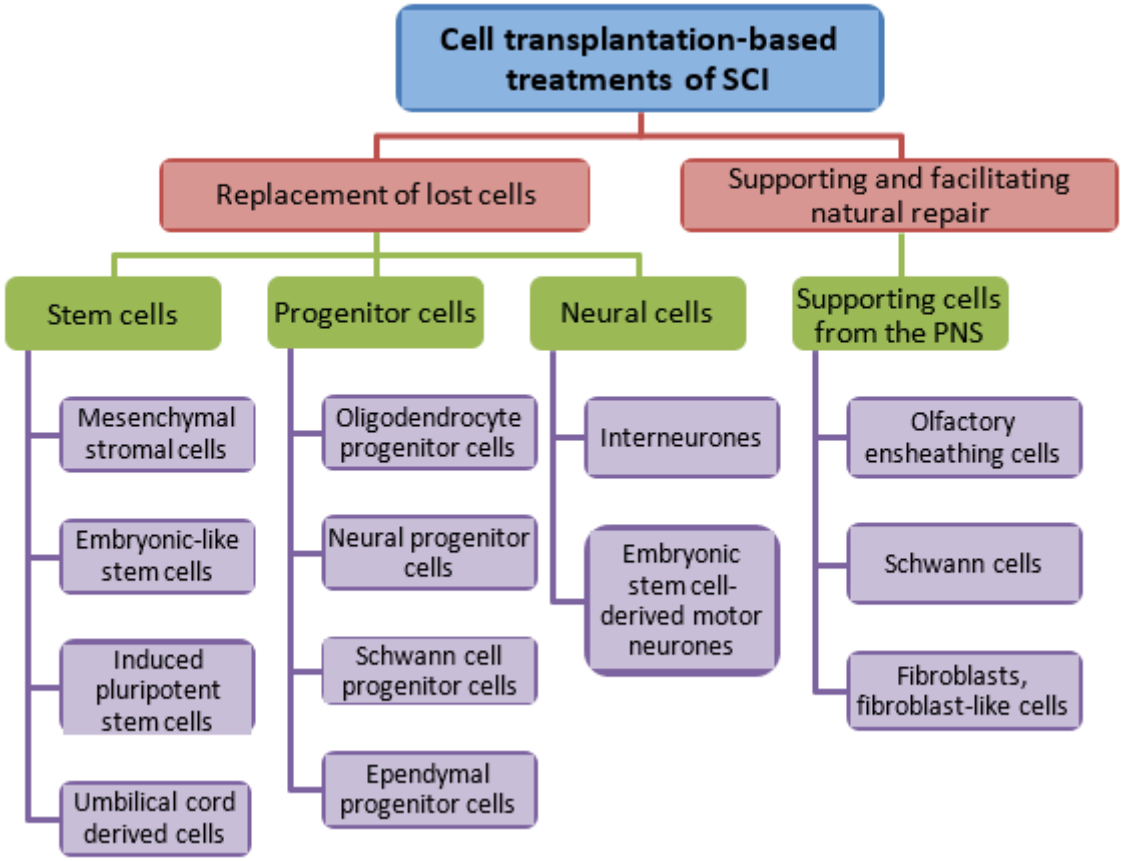


Figure 16.2. Overview of experimental cell therapies for SCI repair. Created by Ronak Reshamwala using Microsoft PowerPoint, adapted from Gilmour *et al.* (2020).

Video: Perry Cross discusses nerve bridge transfer research

Listen to **Perry Cross** discuss research, including the nerve bridge transfer being undertaken at the Perry Cross Spinal Research Foundation.

16.2.1. Cell therapy using olfactory ensheathing cells (OECs)

The OECs are among the most promising cell therapy candidates for repairing SCI. In this section, we will explore these cells, their biological functions in the body, and their specialised properties that make them a desirable candidate for SCI repair from a clinical standpoint. The OECs have been known in the academic community since the 1980s and have been the focus of research into SCI repair strategies. Unfortunately, aside from showing intermittent promising outcomes, the OECs have not yet reached clinical therapy. To overcome this, the research team at the Clem Jones Centre for Neurobiology and Stem Cell Research has recently launched a clinical trial in 2025, using a unique innovative approach (nerve bridge technology) and unprecedented community engagement and co-design. For more information, including videos, visit the SCI Nerve Bridge Transplantation Trial, a world-first clinical trial conducted by Griffith University in Queensland.

OECs are not stem cells. They are fully differentiated glial cells. Normally, the OECs support the neurons of the olfactory nerve. OECs are emerging as a highly promising option for SCI therapy due to their unique biological properties and safety profile. Unlike other stem cell types, OECs rarely form tumours, making them a safer and ethically uncomplicated choice for clinical applications (Gilmour *et al*., 2020; Oieni *et al*., 2022; Reshamwala *et al*., 2023).

OECs are mature, differentiated glial cells that naturally guide olfactory axons through tunnel-like structures formed with fibroblasts. Their ability to integrate into the spinal cord is facilitated by the similarity between the spinal cord's environment and their native habitat, allowing them to support and guide damaged axons at injury sites. They also interact with astrocytes and fibroblasts, contributing to the modulation of scar formation and the stabilisation of axons.

Beyond structural support, OECs actively modulate inflammation by secreting ***cytokines,*** such as ***tumour necrosis factor-α (TNF-α)***,***CXCL1, CXCL2*** and ***IL-1RA***, similar to immune cells in the CNS. They also release ***neurotrophic factors*** and extracellular matrix proteins, such as laminin and fibronectin, enhancing tissue repair and regeneration.

OECs possess innate migratory and phagocytic abilities, enabling them to reach injury sites and clear debris, which promotes axonal regrowth. Their preference for cellular contact allows them to form bridges across damaged areas, facilitating neural repair.

Advancements in genetic engineering and cell reprogramming have further enhanced the therapeutic potential of OEC. Techniques such as overexpressing beneficial molecular factors and manipulating cell fate have improved cell yield and function, opening avenues for targeted and effective treatments.

Historically, however, researchers worldwide have reported some consistent challenges with this approach. OECs are a heterogeneous population and are difficult to purify due to the lack of specific markers. They can be sourced from the olfactory bulb or mucosa, with the latter being more clinically viable due to its minimally invasive collection method. Differences in behaviour between these subtypes and contamination with other cell types complicate con-

sistency in therapeutic outcomes. Two approaches are popular: One aims for pure OEC populations, while the other embraces a multicellular environment, suggesting that OECs may function optimally alongside other cells. Further research is needed to determine the optimal cell combinations and improve the reproducibility of clinical outcomes. Nevertheless, several clinical trials have explored the promise that OECs offer for repairing SCI structurally and functionally.

16.2.2. Designing a clinical trial: Considerations from previous clinical trials

Clinical trials using OECs have demonstrated safety and feasibility but variable efficacy. Since 2005, around 11 trials have tested OEC transplantation in countries such as Australia, Portugal, India, China and the USA. These trials used different cell sources (olfactory mucosa *vs.* bulb), formats (cultured cells *vs.* tissue grafts) and delivery methods (injections *vs.* direct grafting). While most trials reported no severe adverse events, inconsistencies in cell purity, dosage and rehabilitation protocols have hindered progress beyond Phase II-A of clinical trials. Despite these challenges, OECs remain a strong candidate for SCI therapy due to their unique biological properties, low tumorigenic risk and the ability to interact with scar tissue. Future trials must address these limitations to improve therapeutic outcomes (Reshamwala *et al.*, 2022).

Designing a successful clinical trial for OEC transplantation in SCI requires addressing past limitations and incorporating strategic planning across several domains:

- **Cell source and preparation:** The preferred source for OECs is the olfactory mucosa due to its accessibility and minimal risk. Harvesting from the olfactory bulb is more invasive and may impair olfactory function. Mucosal OECs also express proteins crucial for nerve repair, making them an ideal candidate for transplantation. To ensure consistency, cell isolation and expansion must follow *Good Manufacturing Practice (GMP)*. This includes testing at multiple stages, starting material, intermediate cultures, and final product. Cell characterisation should include morphology, growth behaviour and surface marker analysis by immunofluorescence or flow cytometry. A panel of markers, rather than single indicators, should be used to identify OECs and exclude contaminants such as fibroblasts or astrocytes. Functional assays to assess biological activity are essential, but must be designed to use minimal cell quantities to avoid compromising therapeutic doses. These assays should be simple, reproducible and cost-effective for clinical settings.
- **Three-dimensional constructs:** Traditional cell suspension injections often result in poor survival and integration due to a lack of cell-cell contact. A promising alternative is the use of 3D constructs, such as spheroids or scaffold-embedded cells. These structures enhance cell viability, migration and interaction with host tissue. This approach improves transplantation outcomes and enables *in vitro* (literally means 'in glass') modelling of cell behaviour.
- **Cell dose and delivery:** Past trials varied widely in cell dose (500,000-21 million cells) and

injection volume (5 µL-2 mL). A standardised dosing strategy is needed, with flexibility to adjust based on injury size and location. 3D constructs offer an advantage here, allowing surgeons to customise the volume and cell density to fill the lesion cavity effectively. Delivery methods should minimise additional injury. While direct grafting avoids needle trauma, it risks introducing uncharacterised tissue. A hybrid approach using purified 3D constructs placed into the lesion site with minimal scar manipulation may offer the best balance of safety and efficacy.

- **Scar management:** The glial scar formed after SCI is both protective and inhibitory. Molecules like *chondroitin sulphate proteoglycans (CSPGs)* block axonal growth. OECs can penetrate and interact with scar tissue, reducing the need for aggressive debridement. A targeted approach to loosen adhesions and create space for cell placement is recommended.
- **Patient recruitment:** Initial trials should focus on chronic, complete injuries where neurological function has stabilised. This reduces risk and simplifies enrolment. Once safety is confirmed, trials can expand to include acute and incomplete injuries, which may benefit more from regenerative therapies. Inclusion criteria should consider age, injury level and time since injury. Chronic injuries (>12 months) are ideal for Phase I trials, while adaptive designs can incorporate feedback to refine dosing and timing in later phases.
- **Outcome measures:** Safety of the participants remains the primary focus, monitored through adverse events and neurological deterioration. Secondary outcomes should include functional assessments, such as *ASIA grading*, *SCIM*, *MEP*, *SSEP* and imaging (*MRI* , *DTI*). These tests and diagnostic tools must be sensitive enough to detect small yet meaningful improvements that can significantly impact quality of life. Overuse of assessments can burden patients and inflate costs. A balanced, strategic selection of tools is essential for accurate and efficient evaluation.
- **Rehabilitation integration:** Rehabilitation is critical for maximising recovery. Trials should include standardised intensive programs tailored to individual needs. Prehabilitation (pre-operative rehabilitation) primes patients for post-operative recovery and improves adherence to post-operative care. Funding and accessibility are major barriers. Trials must secure resources to support long-term, geographically distributed rehabilitation services, including home-based options.

Below, we offer two versions of the current Australian OEC research. **Section 16.3** provides an in-depth technical exploration, while**Section 16.4** offers an abridged, less technical description of the research.

Media stories: Current Australian SCI research

- News Report, 14 Aug 2025, 9 News Australia: Watch this news report about the research. It explains that the prognosis for SCI has traditionally been severe, with paralysis often lasting for life. A world-first clinical trial has now begun on the Gold Coast that aims to treat chronic SCI and help the body rewire itself from the inside out.
- Groundbreaking Gold Coast trial offers hope for paralysis cure, Bella Schwarzenecker (26 Mar 2025, 9 News Australia): This story reports on an innovative treatment that uses nerve cells from the nose to help repair damaged spinal cord tissue. The approach has the potential to restore mobility and independence for people living with paralysis.

16.3. Optimising OEC transplantation to repair SCI: An Australian approach (technical version)

Following the work of Emeritus Professor Alan Mackay-Sim (2017 Australian of the Year), our team at Griffith University's Clem Jones Centre for Neurobiology and Stem Cell Research has been working to optimise the preparation and therapeutic use of OECs to improve outcomes after transplantation for SCI repair. Our research focuses on three main areas:

- Discovery biology to better understand the roles of OECs
- Developing improved methods to identify OECs within mixed cell populations, and
- Creating 3D cell structures suitable for transplantation, which support better cell survival after the procedure

Each of these areas is discussed below.

16.3.1. Understanding why OECs are useful for neural repair

Although OECs are known to promote neural regeneration, the cellular and molecular mechanisms underlying OEC-mediated regeneration were largely unknown until recently. Over the past decade, we have worked to deepen our understanding of the biological roles of OECs. For example, we have shown that OECs exhibit highly motile lamellipodia, which are crucial for contact-mediated migration and cell-cell interactions, and that greater cell-cell contact between OECs leads to increased cell migration *in vitro*. Migration of OECs is also an important regulator of axon extension, with *in vitro* studies demonstrating that increased OEC migration drives higher axon extension. We have also demonstrated that *in vivo* (meaning live, in the body) OEC mass migration is important within the olfactory system. Transplanted OECs improve ***axon*** growth into the traumatic injury site, indicating that adding more glial cells can enhance regeneration.

Thus, we have robustly established the multiple mechanisms through which OECs naturally induce, promote and augment nerve repairs:

- *Phagocytosis* of debris to clean up the injury site
- Creating a permissive surface by integrating with astrocytes and migrating across the lesion to create a cellular bridge
- Promote axonal outgrowth by secreting growth factors and stimulating damaged axons, and
- Protecting the newly growing axons by ensheathing them and providing physical structural support.

16.3.2. Better, more robust ways to identify OECs

As mentioned above, isolating and unambiguously identifying OECs is difficult due to the lack of specific markers. Our team has successfully developed suitable marker panels for the purification of mouse and human OECs. Being able to identify the OECs in a clinically applicable way is a big step towards safely and successfully translating the OEC therapy and is therefore subject to Intellectual Property protection.

Apart from the potential to contaminate cells in the OEC cell preparations, the risk of uncontrolled cell growth leading to tumour formation needs to be carefully considered. One characteristic of OECs in this regard is that there are very few reports of OECs forming tumours in their natural environment within the human olfactory system (Murtaza *et al.*, 2019). Indeed, among the few reports of potential OEC tumours, the lack of robust identification markers casts doubt on whether the tumours arose from OECs or from other glial cells, such as Schwann cells. We hypothesise that one reason OECs may be less prone to forming tumours is the relatively harsh environment in which the OECs naturally live. They constantly tend to dead and dying olfactory sensory axons to remove cellular debris. They are under threat of bacterial attack, as pathogens can easily penetrate the olfactory nerve. In contrast, other glial cells are less exposed to pathogens and so are less proficient at responding to a wider variety of injuries, infections, and pathogens. Additionally, unlike the OECs, *gliomas* involving*astrocytes* or *oligodendrocytes* are well-documented, making these other cell types relatively riskier for transplantation.

16.3.3. Creating stable 3D nerve bridges for better transplantation outcomes

As with most other cell transplantation therapies, the current standard approach for OEC transplantation into the injured spinal cord, in both preclinical models and human clinical trials, is to inject the cells as a suspension. With this transplantation method, each cell must integrate into the host tissue, migrate to the appropriate region, and form stable cell-cell connections.

OECs are, however, highly dependent on cell-cell contacts for migration, with increased migration at higher density, and OEC migration positively regulates axon guidance. Therefore, injecting a suspension of OECs into the injured spinal cord is unlikely to result in OECs maintaining sufficient cell-cell contact, which may reduce their ability to migrate and interact with axons. Our team has identified poor cell survival and integration post-transplantation as one of the most troublesome factors contributing to poor or inconsistent treatment outcomes across all cell therapies, including OECs. Rather than injecting a cell suspension, an alternative approach is to transplant 3D OEC constructs in which cells have already formed stable cell-cell connections. While biological scaffolds are currently being trialled to support OECs *in vitro* or *in vivo*, the introduction of additional components may lead to unexpected outcomes or complicate the interpretation of results.

In our Griffith University laboratory, we have primarily focused on generating 3D OEC constructs in which cells form stable 3D structures using only cells, without the need for additives, artificial substrates or scaffolds. To address this problem, we have developed a novel nerve bridge technology that enables us to rapidly synthesise 3D structures entirely of cells within hours. These nerve bridges are highly customisable. They can be made in any size, shape or form required for transplantation. Importantly, through our thorough *in vitro* and *in vivo* testing, we have demonstrated that nerve bridges significantly enhance cell survival post-transplantation and yield more consistent, improved functional outcomes. Notably, we have received the 2019 National Health and Medical Research Council (NHMRC) Marshall and Warren Innovation Award and the Research Australia Discovery Award 2020-2021 for the nerve bridge technology. We are launching a clinical trial to assess the safety and feasibility of their clinical application and confirm their efficacy.

16.3.4. Optimising SCI recovery by combining cell therapy with consistent, intensive activity-based rehabilitation

In addition to the innovative approach described above, our Centre has also identified the need for consistent yet personalised intensive rehabilitation to maximise treatment outcomes. In Australia, comprehensive, long-term SCI rehabilitation is not a consistent standard of care post-discharge from the spinal injury unit, which creates a critical gap in support. Initial inpatient periods offer varying degrees of access to SCI rehabilitation, but this access is often limited after hospital discharge and depends on individual insurance or disability scheme provisions. Compare this with other developed nations where extensive, intensive rehabilitation services are more readily available. The perceived lack of sufficient local, Australian-based studies impedes policy change, compounded by the relatively high cost of specialised services such as neurorehabilitation. There is, however, compelling evidence from around the world that demonstrates that regular, intensive, organised, multimodal exercise significantly improves neurological recovery and functional outcomes, particularly compared with self-regulated programs.

Intensive activity-based therapies, including partial body-weight-supported locomotor training and functional electrical stimulation, are proven to promote neurological improvement by actively engaging paralysed extremities. Griffith University recently completed two clinical trials to investigate, not only the feasibility and acceptability of incorporating intensive long-term rehabilitation into forthcoming cell therapy trials, but also to demonstrate that long-term intensive rehabilitation can be safely and effectively delivered, yielding positive medical, functional, social and psychological outcomes in an Australian context. Even for those with functionally complete injuries, some degree of recovery is possible due to intact cellular connections, underscoring that emerging therapies like drug treatments, cell therapies, and robotic devices will invariably require long-term rehabilitation to maximise their transformative potential. These feasibility trials feed directly into the requirements for a national strategy for activity-based therapy, which is urgently needed to maximise the benefits of any transformative drug, cell and robotic treatments for SCI and which aligns directly with national disability strategies to enable people with SCI to regain health and independence. The results of the two feasibility studies are currently being analysed and will be published soon.

16.3.5. Griffith University Spinal Injury Project clinical trial

The clinical trial, designed and led by Professor James St John, Dr Ronak Reshamwala, Dr Mariyam Murtaza and Dr Andrew Rayfield of the Clem Jones Centre for Neurobiology and Stem Cell Research, commenced in the third quarter of 2025. The trial benefits from a thorough clinical oversight under Dr Brent McMonagle as the coordinating Principal Investigator (PI), Dr Wayne Ng as the Site Principal Investigator (PI) at the Gold Coast University Hospital and Dr Arman Sabet and Dr Michael Johson as the sub-PIs to ensure the smooth conduction of the trial and best patient experience throughout the trial. This trial combines the groundbreaking OEC nerve bridge technology with intensive physical rehabilitation to repair SCI and restore function. This trial is funded by the State and Federal Governments, with support from the community and philanthropists.

There will be 30 participants, 20 of whom will receive the nerve bridges with intensive rehabilitation. Ten participants will be randomly assigned to the rehabilitation-only control group. All participants will undergo three months of prehabilitation, a five-week break in ‘rehab’ for the surgical intervention and recovery and eight months of post-operative regenerative rehabilitation.

16.4. Advancing spinal cord repair with OECs: An Australian approach (non-technical version)

Building on the pioneering work of Professor Alan Mackay-Sim, our team at Griffith University’s Clem Jones Centre for Neurobiology and Stem Cell Research is focused on improving therapies

for SCI using olfactory ensheathing cells (OECs). These unique cells, found in the olfactory system, naturally support nerve regeneration. Our research addresses three key areas: Understanding OEC biology, improving identification methods and creating advanced cell structures for transplantation.

1. **Why OECs matter for neural repair:** OECs play a critical role in repairing damaged nerves. They clean up debris at injury sites, form bridges across lesions, and release growth factors that stimulate axon regrowth. They also physically protect new axons by wrapping around them. Our studies have shown that OECs migrate effectively and guide axon extension, both in laboratory settings and in living systems. This migration is essential for successful regeneration, making OECs a promising tool for SCI repair.
2. **Identifying OECs safely and accurately:** One challenge in OEC therapy is distinguishing them from other cell types, as they lack unique markers. Our team has developed reliable marker panels for both human and mouse OECs, a major step toward safe clinical use. Importantly, OECs appear less likely to form tumours compared with other glial cells, possibly because they naturally operate in a harsh environment exposed to pathogens and injury. This makes them relatively safer for transplantation.
3. **Improving transplantation with 3D nerve bridges:** Current methods inject OECs as single-cell suspensions, which often leads to poor survival and integration. To overcome this, we developed a novel "nerve bridge" technology, which uses a customisable 3D structure comprising OECs. These bridges maintain strong cell-to-cell connections, improving survival and function after transplantation. Our innovation has earned national awards and is now moving toward a clinical trial to test safety and effectiveness. Through these advances, we aim to make OEC-based therapies more reliable and effective, offering hope for improved recovery after SCI.

16.4.1. Combining cell therapy with intensive rehabilitation for SCI recovery

Griffith University is addressing a critical gap in SCI care in Australia, which is a lack of consistent, long-term rehabilitation after hospital discharge. Evidence from around the world shows that structured, intensive exercise programs significantly improve recovery compared with self-directed efforts. Our Centre has completed two feasibility trials proving that long-term, activity-based rehabilitation using techniques such as locomotor training and electrical stimulation can be safely delivered in Australia with positive outcomes. This approach is now integrated into our groundbreaking clinical trial, which combines OEC nerve bridge technology with intensive rehabilitation to restore function. Results will inform a national strategy to maximise the impact of future SCI therapies.

Next, we will explore a few more supportive approaches, such as *spinal cord stimulation (SCS)*, corrective surgical interventions and nutrition.

16.5. Spinal cord stimulation (SCS) in individuals living with SCI

Spinal cord simulation (SCS) has been used for over five decades to help manage chronic pain. It is now being explored as a potential therapy for the rehabilitation of individuals with SCI. This therapy seeks to manage pain and assist in restoring motor, sensory and autonomic functions in patients living with chronic SCI (Chalif *et al.*, 2024). Many studies indicate that SCS therapy may offer benefits beyond conventional rehabilitation practices.

16.5.1 What is involved in SCS?

SCS therapy involves delivering electrical impulses to the spinal cord via leads implanted in the *epidural space* of the spinal cord (epidural SCS) or via surface adhesive electrodes placed over the skin (transcutaneous SCS). Epidural SCS is the most used form of SCS for individuals with SCI (Lin *et al.*, 2022).

The implantable epidural SCS system consists of leads with an array of electrodes positioned in the dorsal epidural space and connected to a rechargeable or non-rechargeable implanted pulse generator (IPG), typically placed under the skin near the flank or buttock. There is a wide range of stimulation waveforms, including perceptible (tonic) and non-perceptible (burst, high-frequency) stimulation (Sdrulla *et al.*, 2018). **Figure 16.3** depicts where the SCS system is typically embedded in a person with SCI. The person can use a remote control or an iPhone (with *iOS 13.4* or later installed with the right software) to turn the device on and off. They can also choose from preset stimulation programs that help manage their symptoms.

Figure 16.3. A spinal cord stimulator. Figure adapted from Ramakrishna *et al.* (2025), reproduced under a CC BY-NC license.

16.5.2. Who can benefit from SCS?

Candidates for SCS-assisted rehabilitation are typically people with chronic, stable SCI, primarily patients with incomplete SCI (*AIS B-D*) with some preserved sensorimotor pathways. Incomplete SCIs tend to respond better due to remaining neural connections, though some cases of complete SCI have shown improvements with epidural SCS and rehabilitation (Angeli *et al.*, 2018). SCS is most effective for patients whose recovery has plateaued but still have functional spinal circuitry capable of responding to stimulation and physical therapy (Solinsky *et al.*, 2020).

People considering SCS will first need to undergo thorough patient screening, including medical and psychological evaluations. Screening helps clinicians identify people who are most likely to benefit from SCS therapy.

16.5.3. SCS for movement control

Even in cases of complete SCI, studies suggest that some supraspinal nerve connections remain intact below the injury site (Sherwood *et al.*, 1992). The nerves below a SCI remain functional but often become hyperexcitable due to the loss of inhibitory signals from the brain. Without input from the brain, however, they cannot generate purposeful movement. Electrical stimulation can provide or amplify the necessary excitatory drive to engage these spinal networks and enable coordinated motor output. By stimulating the affected area, neural activity can be influenced, potentially enhancing movement control. One key component involved is the lumbo-sacral central pattern generator, which is crucial in coordinating rhythmic movements, such as walking. This system responds to electrical stimulation, facilitating locomotion. SCS also helps compensate for lost signals from the brain. After SCI, the normal balance of nerve signals is disrupted, but SCS provides an alternative route to activate motor neurons. High-frequency stimulation may further help by reducing spasticity and excessive reflex responses. With movement control, SCS works by transforming weak signals into stronger motor responses and reactivating dormant spinal networks, thereby improving voluntary movement when combined with rehabilitation (Chalif *et al.*, 2024; Dorrian *et al.*, 2023).

To encourage movement, stimulation is typically administered to the lumbo-sacral region of the spinal cord. Depending on the specific objectives, however, cervical SCS can also be utilised to achieve the desirable outcomes (Malone *et al.*, 2021). Iwahara *et al.* (1992) found that stimulation at the C4-C8 and L1-L6 levels could trigger stepping movements in decerebrate cats. Subsequently, SCS therapy was successfully applied to patients with SCIs, inducing rhythmic locomotor activity. This study provided evidence supporting the existence of a lumbo-sacral central pattern generator in humans (Dimitrijevic *et al.*, 1998). Moreover, the application of SCS therapy in combination with intensive physical rehabilitation enabled individuals with AIS-B SCIs to achieve full-weight-bearing locomotion (Harkema *et al.*, 2011). This research played a key role in the widespread implementation of SCS following SCI.

SCS combined with intensive physical therapy has shown promising results in many clinical trials (Angeli *et al.*, 2018; Aslan *et al.*, 2018; Herrity *et al.*, 2018; Lu *et al.*, 2016; Wagner *et al.*, 2018). SCS can lead to significant improvements for responsive patients, helping reduce muscle spasticity, restore voluntary movements, mobility, postural control and upper-limb functions, such as grip strength and hand mobility (Angeli *et al.*, 2018; Gill *et al.*, 2018; Lu *et al.*, 2016; Wagner *et al.*, 2018).

Wagner *et al.* (2018) achieved major motor function gains with SCS. Within a week of stimulation, individuals with paralysed muscles showed more coordinated and functional activation during walking compared to baseline, and locomotor function continued to improve with SCS-

assisted rehabilitation. Following rehabilitation, participants showed significant progress in walking ability, with two individuals standing from a seated position and walking using crutches without active SCS (Wagner *et al.*, 2018). Expanding on this work, the team developed an electrode array specifically designed to enhance motor function recovery, enabling standing, walking, cycling, swimming and trunk control in three chronically paralysed individuals. After undergoing rigorous activity-focused neurorehabilitation, these capabilities successfully translated into real-world applications (Rowald *et al.*, 2022).

16.5.4. Additional benefits of SCS for people living with SCI

Research has identified these potential benefits of SCS:

- Reduced pain
- Increased motor control
- Improved pulmonary function
- Increased bladder capacity, and
- Improved quality of life.

Additional benefits have been identified for some people with SCS, including improved pulmonary function, such as restoration of cough reflex (Kowalski *et al.*, 2016), autonomic functions, such as better bladder and bowel control and stabilised blood pressure (Aslan *et al.*, 2018; *Herrity et al.*, 2018). Further, a study by Herrity *et al*. (2021) revealed notable enhancement in bladder capacity, compliance and detrusor pressure following activity-based recovery training combined with SCS, despite the stimulation not being specifically tailored for bladder function. Many individuals with incomplete SCIs experience substantial pain relief and an enhanced quality of life.

In some studies, SCS has also helped restore voluntary movements in AIS-A (complete) SCI patients (Angeli *et al.*, 2014; Darrow *et al.*, 2019). Though less studied, cervical SCS shows promise, enhancing hand strength and control in two patients with cervical spinal injuries (Lu *et al.*, 2016)

16.5.5. Limitations of SCS

Despite the improvements listed above, SCS therapy has some limitations. Complications such as device migration or infections are common but can be managed conservatively or with revision procedures. Stimulation parameters vary by patient, and optimising stimulation patterns to meet each patient's specific needs takes time, potentially delaying rehabilitation (Calvert *et al.*, 2019). Typically, stimulation is applied continuously, but this approach can disrupt proprioceptive signals crucial for locomotor recovery (Formento *et al.*, 2018). Additionally, SCI studies often use electrodes designed for chronic pain rather than motor recovery (Calvert *et al.*, 2019).

Rowald *et al.* (2022) addressed this by developing a specialised ***electrode array*** to enhance functional recovery. Clinical trials of SCS in SCI patients typically involve intensive rehabilitation, exceeding standard post-SCI physical therapy (Calvert *et al.*, 2019). For instance, Rowald *et al.* (2022) provided 80-300 hours of rehabilitation over five months, compared with the SCI-Rehab study's 55.3-hour inpatient average (Taylor-Schroeder *et al.*, 2011). This difference must be taken into account when evaluating SCS outcomes.

Other limitations of SCS include its availability. As a specialised skill, relatively few clinicians in Australia are experienced in the insertion and maintenance of SCS, and they are located in major cities. People who live outside these cities face major logistical barriers to accessing treatment and management services, with the most remote people experiencing the most access issues. Limited access and transportation hinder rehabilitation (Gorgey, 2014).

Once a person has an implanted SCS device, they then face the task of adjusting to its presence in their body, learning how to use technology, adapting to living with the stimulator and coming to terms with what SCS can and cannot do for them, as not all individuals will experience all of the potential benefits of SCS. Sometimes the benefits are not as expected, such as partial pain reduction (Ramakrishna *et al.*, 2025). Although research has shown that SCS can improve rehabilitation outcomes in patients with SCI, not every patient shows sensorimotor improvements, highlighting the large variability in treatment outcomes (Lin *et al.*, 2022). Additionally, the existing literature on SCS for SCI is limited to case reports or case series, including a few prospective case series, with no case-control, cohort or randomised control trials.

16.5.6. Future research directions of SCS

In terms of future directions for research on SCS for SCI, we note that existing studies often have small sample sizes and protocols that are not easily comparable. We call for larger sample sizes to provide greater confidence in the patterns emerging in this field. We recommend that researchers consider existing protocols in this field when crafting their own protocols, with a view to enhancing data comparison and synthesis across studies.

Recommendations for future research include identifying optimal patient selection criteria, determining optimal stimulation settings for people with SCI based on their individual goals (e.g. the best stimulation settings for someone aiming to improve motor control) and assessing the long-term benefits of SCS for people living with SCI.

16.5.7. How can I find out about clinical trials for SCS?

There are many ways to find SCS clinical trials.

1. Clinical trial registries

- ANZCTR (Australian New Zealand Clinical Trials Registry), and
- ClinicalTrials.gov: The largest U.S. registry of clinical trials.

Key recommendation: Searching for clinical trials

When searching for clinical trials, try using combinations of terms such as "SCI" and "spinal cord stimulation", or "SCS" and "neuromodulation". Using paired keywords like these can help you find more relevant studies.

2. SCI-specific clinical trial finder sites (international)

- SCITrialsFinder.net: A useful, curated tool specifically for SCI trials, where you can sign up for notifications when new trials open that match your criteria, such as SCS, and
- Asia Spinal Injury Association (ASIA): This online platform helps people with SCI easily find clinical trials that match their specific situation. It is designed for people living with SCI, their families, clinicians, researchers, carers and funders.

3. Research institution and centre websites

Many academic medical centres or rehabilitation hospitals run their own trials. For example, the Neuroscience Research Australia (NeuRA), the University of Melbourne and Austin Health's TESCoN Trial and the University of New South Wales Neurorecovery Research Hub.

4. Reach out and get on a registry

- Ask your GP or SCI specialist if they are aware of any SCS clinical trials. They may have contacts in research groups, and
- Sign up for various registries: There are SCI research registries, such as SpinalCure Australia's Clinical Trial Page. on which researchers draw to recruit participants.

Current or recent SCS for SCI clinical trials in Australia include studies focused on rehabilitation and functional restoration. Examples of current clinical trials include:

- SCI Neuroplasticity Study: Non-invasive brain stimulation methods to measure and induce neuroplasticity in individuals with SCI.
- The RESTORE Trial: Will investigate a novel virtual reality haptic (touch) walking treatment to restore or improve sensation in people with a thoracic SCI: AIS Grade A (complete) or B (incomplete).
- OpenXstim tSCS Safety Trial: Examining the safety and feasibility of an open-source tran-

scutaneous SCS device (OpenXstim) in people with SCI and other neurological conditions.

In the US, several important clinical trials are investigating the potential of SCS to restore motor and autonomic functions in people with chronic SCI:

- UCLA Spinal Cord Neuromodulation Trial (NCT02313194): Uses epidural stimulation combined with pharmacological therapy, such as drugs like buspirone, to enhance forelimb function in people with cervical SCI and tetraplegia (quadriplegia) (closed)
- Epidural Stimulation Trial in Chronic SCI (NCT05690074): Enrolled participants with chronic SCI (C7-T10) to test 80 outpatient sessions of epidural stimulation, measuring effects on leg function, trunk stability, bowel/bladder control, blood pressure, pain and quality of life
- Spasticity *vs.* Motor Function Study (NCT05422716): Compares epidural SCS to standard intrathecal baclofen pumps in treating severe spasticity in SCI. Participants are randomised to either an implanted stimulator or a baclofen pump, and
- Brain Activity and Invasive SCS (NCT06725836): Investigating how implanted epidural stimulation affects brain activity (using EEG) in SCI to understand physiological effects beyond motor outcomes.

16.5.8. What to expect when participating in SCS and SCI research

Getting involved in a clinical trial can feel daunting, especially when surgery or new technology is involved. Knowing the typical steps during the initial screening phase and what visits look like can make the process feel clearer and more manageable.

Initial screening (often 1-3 hours over 1-2 days)

- A short phone call or online questionnaire to check basic eligibility
- Review of your injury level and completeness (*AISA grade*), time since injury and overall medical history. Implanted devices and recent surgeries are checked because they can affect safety and eligibility
- You may be asked to attend an in-person assessment for strength, spasticity and a standard neurological examination, and
- Some studies also review medications, screen for pressure injuries or infection and confirm whether you can safely participate in standing or stepping tasks.

Study visits and time commitment

- **Transcutaneous SCS (non-invasive):** Visits are typically outpatient and may involve parameter "mapping" sessions and short treatment blocks over days to weeks. Skin electrodes are placed on the back, and stimulation is adjusted while clinicians monitor your

responses. Most studies report good tolerability with mainly minor skin irritation
- **Epidural or implanted SCS:** Involves surgery to place a stimulator and leads, followed by programming sessions and structured rehabilitation with scheduled follow-ups (for example, at 1, 3, 6, 9 and 12 months). Expect a higher time commitment than non-invasive studies, and
- Some programs **combine stimulation with intensive rehabilitation** (for example, daily or several times per week) to optimise outcomes after implantation.

What might you do during visits?

- Functional tests, such as the 10-metre walk, 6-minute walk, standing/stepping and independence measures and neurological scales, such as ISNCSCI/*ISNCSCI AISA grade* and SCIM, are common
- Programming sessions to personalise stimulation settings and track responses over time, and
- In some trials, neurophysiological (*EMG*, *MEP*, *SSEP*) or imaging methods are used to understand mechanisms and safety.

Safety and consent

Before anything starts, you will review and sign an informed consent form that explains the potential benefits, risks and your right to withdraw at any time. Trials generally monitor for device-related issues (for implanted systems) and for skin irritation or discomfort (for non-invasive systems). Serious adverse events in implanted eSCS are uncommon but can include infection or lead migration, so centres screen carefully.

16.6. Other areas of research

Below is a summary of other areas of highly promising research being actively pursued in Australia and globally:

- **Tendon and nerve transfers:** Groundbreaking nerve transfer surgery in Australia has enabled paralysed patients to regain hand function, offering new hope and independence to those living with quadriplegia. This innovative technique reroutes functioning nerves to reanimate paralysed muscles, with promising results from clinical trials. For more information, see below.

Media: Successful nerve surgery in Australia

Paralyzed Patients Regain the Use of Their Hands Thanks to Breakthrough Nerve Surgery in Australia (4 August 2019): The article describes a breakthrough nerve-transfer surgery performed in Australia that has helped paralysed (tetraplegic) patients regain use of their hands and arms.

Below is a video relating to this surgery.

Video: Successful nerve transfer in Australia

Reanimating hand movement after SCI (Pursuit, University of Melbourne, 5 July 2019), by **Professor Mary Galea** AM, University of Melbourne and **Dr Natasha van Zyl,** Austin Health: This short video features individuals who have undergone nerve transfer surgery. It highlights findings from a study by the University of Melbourne and Austin Health showing that nerve transfer surgery for people living with tetraplegia (quadriplegia) after TSCI can significantly improve independence.

- **Neuroprotection:** Preventing cell death and protecting surviving nerve cells from further damage improves functional outcome. This includes using medicines to reduce nerve cell death, lowering the body's core temperature and ***hypoxia***:
  - Glyburide (DiaBeta): Currently in clinical trials, this oral medication is being tested for its ability to reduce secondary injury by limiting inflammation and oedema in patients with acute SCI
  - Minocycline: An antibiotic with anti-inflammatory properties that has demonstrated neuroprotective effects in preclinical SCI models
  - Exosome-based therapies: Derived from stem cells, these nano-vesicles deliver anti-apoptotic and anti-inflammatory molecules to injured spinal tissue.
  - Pre-hospital cooling with cold saline (Batchelor *et al.*, 2023): A pilot study in Australia demonstrated that administering ice-cold saline in the field, followed by hospital-based cooling, is feasible and safe
  - Systemic ***hypothermia*** (Ransom et al., 2022): Cooling the body to 33-34 °C has shown promise in preclinical studies and small clinical trials for improving neurological recovery

    - Local hypothermia (Ransom *et al.*, 2022): Targeted cooling of the spinal cord area using surface or catheter-based methods can reduce inflammation and cell death, and
    - Acute intermittent ***hypoxia*** (AIH): Recurrent episodes of breathing low oxygen, which is called acute intermittent hypoxia (AIH), are a potential therapy to promote walking recovery after incomplete SCI via endogenous mechanisms of neuroplasticity (Tan *et al.*, 2020).
- **Neuroplasticity and neuromodulation:** Retraining CNS circuits to restore body functions and form new nerve connections and pathways may help with voluntary muscle movement and coordination. These techniques happen after injury or cell death. They include rehabilitation, electrical or magnetic stimulation, robot-assisted training and ***brain-computer interface technology (BIC).*** Magnetic stimulation includes ***repeated transcranial magnetic stimulation*** (rTMS) and paired cortical magnetic stimulation (PCMS). Both TMS and PCMS are non-invasive neuromodulation techniques being explored for the treatment of SCI. They work to improve motor function, reduce spasticity, and alleviate neuropathic pain. A key difference is that the TMS uses repeated magnetic pulses to modulate brain or spinal cord activity, whereas PCMS uses precisely timed magnetic pulses to induce plasticity at the cellular level in the cortex, especially when paired with voluntary muscle contraction. Research suggests these techniques can promote neural pathway restoration and functional recovery after SCI.

Video: Epidural stimulation after SCI

Epidural Stimulation After SCI: Restoration of Motor and Autonomic Function (10 March 2020) by **Dr Andrei Krassioukov** and **Geoff Jessup**: This video explains epidural stimulation (neuromodulation), also known as spinal cord stimulation (SCS). The procedure involves delivering electrical stimulation to the epidural region of the spine. Although still experimental, it offers the possibility of restoring some motor and autonomic function for people with SCI. It has been performed in a small number of individuals, and some have experienced improvements such as regained movement in previously immobile areas and enhanced bowel, bladder, sexual and blood-pressure regulation.

- **Brain-computer interfaces (BCI):** Pioneering work in this area has enabled a paralysed man to fly a virtual drone using only his thoughts, marking a major leap in neural control of fine motor functions. This breakthrough demonstrates the potential of BCIs to decode complex finger movements, paving the way for more versatile assistive technologies. This video and others can be watched below.

Media stories: BCIs

- Paralysed man flies virtual drone using brain implant, and
- BCI: First human recording with new, high-capacity device (Michigan Medicine) explains what this involves for patients with epilepsy.

A research team at Griffith University is also making significant strides towards clinical application of thought control-assisted rehabilitation and assistive technology at BioSpine. Learn more about thought control research that **Dr Dinesh Palipana** and his team are working on below, as well as other recent research:

Media stories: Other research areas

- The doctor and engineer helping people with quadriplegia one day walk again: This article profiles **Dr Dinesh Palipana**, a doctor with quadriplegia, and **Dr Claudio Pizzolato**, an engineer. Together they lead the BioSpine research program, which combines brain-computer interfaces, robotics, electrical stimulation and advanced computational modelling to develop new rehabilitation technologies for people with SCI. Their work aims to restore movement and help people with quadriplegia walk again. If you are on LinkedIn, Dinesh was featured in this LinkedIn post in late March 2026.
- Multi-million dollar funding boost for BioSpine: BioSpine recently received $3.8 million in funding from the Motor Accident Insurance Commission (MAIC). This investment supports the next phase of BioSpine's development, including testing new technologies in volunteers and preparing the program for clinical use. The BioSpine project aims to restore motor and sensory function after SCI using integrated technologies, such as electrical stimulation, thought-controlled interfaces and rehabilitation robotics.
- SpinalCure Australia: SpinalCure Australia is a leading Australian non-profit supporting SCI research, advocacy and clinical trials. Recent updates from the organisation highlight progress in neurostimulation research, the expansion of Project Spark and clinical trials focused on recovering movement, hand function and walking ability. Their work aims to bring emerging SCI treatments, such as non-invasive neurostimulation, into real-world clinical settings across Australia.
- Virtual reality mediated brain-computer interface training improves sensorimotor neuromodulation in unimpaired and post-SCI individuals (2026): This early online research article reports that immersive ***virtual reality (VR)*** combined with ***brain-computer interface (BCI)*** training can help both unimpaired people and those with chronic SCI learn to better control their sensorimotor brain activity during motor-imagery tasks. Participants showed improved EEG modulation and BCI accuracy over multiple

sessions, demonstrating the potential of VR-BCI systems to support future rehabilitation approaches.

- Lab grown human spinal cord heals after injury in major breakthrough (February 2026): Researchers built a realistic human mini spinal cord in the lab and used it to simulate traumatic injury. The model reproduced key damage seen in SCI injuries, including inflammation and scar formation. After treatment with fast-moving "dancing molecules," nerve fibres began regrowing and scar tissue shrank. The results suggest the therapy could eventually help repair spinal cord damage.

Globally, technology companies such as Neuralink and Synchron are leading the development of implantable, chip-based BCI devices to help overcome motor deficits in the brain and SCIs. Some other companies working in the same field of BCI include Paradromics (a clinical trial commencing soon), Precision Neuroscience, Neurable, Kernel and MindMaze Therapeutics.

- In addition to BCIs, robotics-assisted technologies are being researched and clinically applied to support early mobilisation and rehabilitation following SCI and other disabilities. A great example of this is the Atalante X robotic exoskeleton, a cutting-edge mobility device designed to help people with disabilities walk, dance, and regain independence. Watch the video below for more information.

Video: Exoskeleton helps people with disabilities walk

The exoskeleton that helps people with disabilities walk again (RAZOR Science Show, 5 May 2023): This video introduces the Atalante X, a robotic exoskeleton that can mimic human movement and even walk independently. Although it appears futuristic, its true value lies in supporting people with disabilities. For centuries, individuals with lower-limb impairments have relied on crutches and wheelchairs, which can limit mobility and contribute to long-term physical and mental health challenges. The Atalante X offers a new approach to assisted mobility by enabling upright movement and expanding opportunities for daily activity.

- In Australia, Royal Rehab (Sydney) uses several robotic exoskeletons for rehabilitation to help patients with neurological conditions stand and walk. These robotic systems provide adjustable assistance to help users regain strength, coordination, and functional mobility. They are often combined with interactive games or virtual reality to improve engagement and motivation, and
- The Gold Coast University Hospital is also starting to use robots like ROBERT for upper and lower limb rehabilitation, but it is primarily limited to stroke and similar neurological conditions at this time. While several more centres in Australia offer robotics-assisted exoskeletal devices for rehabilitation and mobility enhancement, their specific application

in SCI remains limited to date. Stroke or brain injuries are being more widely recognised indications at this time. Some common limiting factors are the relative scarcity of SCI-specific research and the availability of bespoke technologies for SCI. The promise of these technologies offers hope for their wider implementation and accessibility for SCI in the near future.

Clinical resources: Advances in SCI research

- **Why Research Matters 2024 – New spinal cord research from around the world:** This online book presents a global snapshot of new SCI injury research. It compiles the top 12 from the Spinal Research Institute's 2024 SCI Research Writing Prize. The authors represent six countries and the collection highlights diverse research directions, clinical challenges and innovations across different health systems and cultural contexts.
- **Advances and New Therapies in Traumatic SCI (2025):** This open-access review summarises recent progress in the acute management of traumatic SCI, including neuroprotection, surgical decompression, emerging pharmacological options, cell therapies and advances in neuromodulation and rehabilitation technologies such as robotics and exoskeletons.
- **Navigating the Complexities of SCI: An Overview of Pathology, Treatment Strategies and Clinical Trials (2025):** This review provides a concise and accessible synthesis of the multifactorial pathology of SCI, current pharmacological and non-pharmacological treatment strategies, and emerging interventions under investigation in preclinical and clinical studies. It is a useful starting point for clinicians wanting an evidence-based overview of contemporary treatment pathways.

16.7. Nutrition research in SCI

Nutrition remains a critical yet underdeveloped research domain within SCI. Although clinical nutrition and condition-specific concerns, such as pressure injuries, are addressed elsewhere in this book, the purpose of this section is to synthesise what research has established, highlight gaps and methodological challenges and identify directions for future investigation. Research in this domain reveals substantial metabolic alterations after SCI, wide variability in dietary intake patterns (and their measurement approaches) and significant limitations in the evidence base informing practice.

A notable focus in recent research is the use of hospital food services as an early touchpoint for nutrition intervention for individuals who have sustained SCI (Iyer *et al.*, 2020; Morgan *et al.*, 2025). Given the extended hospital stays commonly seen in SCI rehabilitation (Burns *et al.*, 2017), the food service environment represents a unique opportunity to embed supportive nutrition practices early, normalising healthy routines, improving food literacy and providing practical exposure to meals aligned with long-term health needs. Integrating nutrition into

the recovery journey from the outset would offer a pragmatic, scalable pathway to influence dietary behaviour beyond discharge.

The broader challenge remains that nutrition guidance for SCI is outdated, with most clinical practice guidelines (CPGs) drawing from general population data and the last SCI nutrition guidelines published by the Academy of Nutrition and Dietetics in 2009 (cited in Zengul *et al.*, 2025) being more than a decade old and outdated, although they have recently been removed from the source website. As a result, variation in practice persists. Addressing this requires more robust SCI-specific evidence and, critically, the development of a core nutrition dataset to standardise outcomes and measurement tools across research and practice.

16.7.1. Altered metabolism and energy expenditure

A consistent theme across SCI nutrition literature is that total energy expenditure is substantially lower than in able-bodied populations. ***Resting metabolic rate (RMR)*** may be reduced by 14-27%, largely due to decreased metabolically active lean mass and altered autonomic function (Buchholz & Pencharz, 2004; Cox *et al.*, 1985). Despite this, most predictive energy equations used in clinical and research settings systematically overestimate energy requirements (Buchholz & Pencharz, 2004; Shea *et al.*, 2018). This overestimation complicates the interpretation of energy-balance studies, undermines dietary intervention trials, and reinforces the need for SCI-specific predictive models. Emerging tools, including indirect calorimetry, which is considered the 'gold standard' (Nevin *et al.*, 2016), wearable metabolic monitors and advanced body composition methods, may enable more personalised approaches to energy assessment, but large-scale validation studies remain limited (Farkas *et al.*, 2021; Nevin *et al.*, 2016).

16.7.2. Body composition shifts after SCI

Research consistently shows that individuals with SCI experience substantial changes in body composition, including decreased skeletal muscle, increased visceral adiposity, and altered fat distribution (Gorgey *et al.*, 2014). Importantly, these shifts may occur even when total body mass appears stable, complicating both research assessment and clinical interpretation. Most body composition tools, such as***body mass index (BMI)***, ***skinfold measurement*** and ***bioelectrical impedance***, lack SCI-specific validation (van der Scheer *et al.*, 2021). This discrepancy introduces measurement bias and limits comparability across studies. There is a clear research need for SCI-specific reference values and longitudinal designs that examine how dietary patterns influence body composition trajectories across the lifespan.

16.7.3. Dietary intake patterns in community-dwelling persons living with SCI

Across observational studies, individuals with SCI commonly demonstrate suboptimal intake of macronutrients such as protein, and micronutrients such as vitamin D, calcium and essential fatty acids, alongside a high consumption of saturated fat and sodium (Farkas *et al.*, 2021; Iyer *et al.*, 2020). These patterns may reflect metabolic changes, limited access to appropriate foods, socioeconomic constraints and gaps in SCI-specific nutrition education. Despite this, little research has explored how to design dietary patterns that effectively support long-term health or prevent common secondary conditions. Large-scale nutritional surveillance studies in SCI populations remain notably absent.

16.7.4. Neurogenic bowel and diet

Diet plays a central role in managing neurogenic bowel dysfunction, yet high-quality SCI-specific evidence remains limited. A comprehensive systematic review (Yeung *et al.*, 2021) examined the available dietary recommendations for SCI neurogenic bowel management. The review revealed substantial inconsistencies:

- Nutrition recommendations across existing CPGs vary widely
- Most statements are based on low-level evidence or expert consensus, and
- Few studies directly examine the bowel-specific impact of diet in SCI populations.

These findings are supported by other literature (Bernardi *et al.*, 2020; Magnuson *et al.*, 2023). These findings emphasise the need for research that measures diet-related bowel outcomes using validated tools, including patient-reported outcomes that incorporate both physiological and psychosocial dimensions of neurogenic bowel management. Given the impact of bowel management (Sober-Williams *et al.*, 2024) on quality of life in persons with SCI, research in the area should be prioritised to mitigate concerns

16.7.5. Diet and pressure injuries in SCI

Pressure injuries are highly prevalent and clinically significant in adults with SCI and nutrition is essential for prevention and recovery (Xu *et al.*, 2025). A recent systematic review of clinical

practice guidelines led by an interdisciplinary team of dietitians and a nurse academic from NSW, Victoria and Queensland evaluated 17 international clinical practice guidelines published since 2010 that included nutrition recommendations for pressure injuries in adults with SCI (Wang *et al.*, 2026). The quality and rigour of nutrition recommendations in existing CPGs vary widely, with few meeting high standards for recommendation quality. Most clinical practice guidelines emphasise nutrition interventions, while providing limited guidance on nutrition assessment and monitoring, key components of the Nutrition Care Process (Swan *et al.*, 2017). This review has highlighted a critical need for high-quality, SCI-specific guidelines that deliver consistent, evidence-based, actionable nutrition guidance to improve pressure injury prevention and management.

Some recent studies underscore the need for further primary evidence to inform CPG development and clinical practice:

- Nevin *et al*. (2023) demonstrated that hypermetabolism does not occur in individuals with SCI who present with pressure injuries. This challenges the assumption underpinning current energy provision practices, and
- Nevin *et al.* (2025) further reported that excessive energy and protein intake may actually impede wound healing in some SCI individuals. This finding suggests that optimal ranges for nutrient provision may differ from general population pressure injury protocols.

16.7.6. Variability in nutrition outcomes used in spinal nutrition research

A major barrier to progress in SCI nutrition science is a lack of standardisation in outcomes and assessment methods. A large international scoping review (174 studies) led by Iyer (2026, in press) and developed in collaboration with expert researchers from the United States of America (LaVela and Farkas), illustrates this challenge. Key findings include:

- Most studies relied on biomedical outcomes, such as body composition or serum nutrient levels
- Only 8% examined nutrition behaviours, despite their relevance to long-term adherence, and
- Many studies used non-validated or low-precision measurement tools, such as self-report systems, which are known to exhibit underreporting bias. This heterogeneity severely limits its comparability across studies and strongly supports the creation of a core nutrition dataset for SCI. Proactively, however, the dedicated team from the Nutrition Special Interest Group of the International Spinal Cord Society (ISCoS) is currently leading the development of the core nutrition dataset (Iyer *et al.*, 2025).

16.7.7. Diet, physical activity and cardio-metabolic health

Given the elevated prevalence of cardio-metabolic disease in SCI (Cragg *et al.*, 2013; Kao *et al.*, 2025), there is growing interest in the interaction between diet and physical activity. A systematic review by Iyer *et al.* (2021) found that combined interventions may potentially reduce cardiovascular risk factors, although evidence remains sparse and heterogeneous. Most studies were small, short-term and used non-standardised dietary assessments. Nevertheless, this research highlights the promise of integrated lifestyle interventions and the need for well-powered, multi-centre trials as supported by another systematic review (Stojic *et al.*, 2023).

16.7.8. Emerging themes: Microbiome, personalised nutrition and lived experience

Below are examples of emerging themes in nutrition research associated with SCI.

16.7.8.1. Diet, gut microbiome and metabolism

Recent work points toward a systems-level understanding of nutrition in SCI. A comprehensive review by Li *et al.* (2025) documented altered gut bacterial diversity following SCI, with potential links to bowel function, chronic inflammation and metabolic dysregulation. While evidence remains preliminary (Valido *et al.*, 2024), personalised diet-microbiome approaches may hold promise for future therapeutics and health optimisation, as well as expanding the evidence base with a holistic view of gut microbiome and its many manifestations in SCI, as highlighted by Jogia & Ruitenberg (2020).

16.7.8.2. Genomics

Advances in genomics and other biomarkers (Gao *et al.*, 2024; Graves *et al.*, 2023; Park & Solinsky, 2024; Zamboni *et al.*, 2026) will help advance research on SCI, aiding the implementation of personalised nutritional approaches to improve overall health and well-being, or change trajectories for better outcomes after SCI.

16.7.8.3. Lived experience as a research driver

An important emerging trend is the integration of lived experience into research design (Ross *et al.*, 2025; Kifley *et al.*, 2024). Individuals with SCI have identified challenges, such as food access,

fatigue, knowledge-driven choices, financial constraints and limited cooking capacity (LaVela *et al.*, 2023; LaVela *et al.*, 2025). Incorporating these perspectives ensures that research questions remain relevant and interventions are feasible in everyday life.

16.8.9. Toward a SCI-specific nutrition evidence base

Across the diverse body of research, several unifying themes emerge:

- Nutrition guidance for SCI is outdated, inconsistent and urgently requires rigorous primary or empirical evidence to inform practice
- Lived experience and practice-informed insights must guide future research to ensure relevance and feasibility
- Hospital food services are a powerful but underused platform for early dietary intervention
- Variability in outcomes and measurement tools limits comparability across studies, reinforcing the need for a core nutrition dataset
- Emerging fields of microbiome science, personalised nutrition and integrated diet and physical activity interventions show promise but require rigorous SCI-specific trials to validate and strengthen evidence, and
- Interdisciplinary, national and global collaborations are essential for advancing the evidence base and updating clinical guidelines.

A recent systematic review and meta-analysis by Stojic *et al.* (2025) mapping research trends and evaluating the quality of evidence found that the use of systematic review and meta-analysis methodology in SCI research has grown substantially over recent decades, with major themes including recovery, management of secondary complications and quality of life. Many, however, had methodological limitations, such as poorly described search strategies and inadequate handling of publication bias, highlighting the need for more methodologically sound evidence synthesis to inform care. Another recent systematic review (Stojic *et al.*, 2025) revealed inconsistent differentiation or use of the terms gender and sex in SCI research. The authors proposed an inclusive research framework to guide future SCI research.

16.8. The ‘lived and living experience’ (LLE)

As the researchers in the previous sections have repeatedly and thoroughly established, any therapy for SCI must have an integral component of co-designing and consumer involvement. Without the voice of those with***LLE***, research and technology are at risk of not addressing the truly unmet needs.

Perry Cross (AM) is one of the most prominent figures and a ferocious community advocate for SCI. He founded the Perry Cross Spinal Research Foundation to spread awareness and raise funds for SCI research. Here is what Perry says:

"Research into SCI is not just about a cure, but about bringing hope. If clinicians provide hope and resources straight away, the patient takes on the ownership of their health and looks after their health better. This leads to a better diet, exercise and fewer injuries such as bed sores. The result is fewer hospital re-admissions in the future."

Key recommendation: SCI trials in Australia

Check this website – Cure-related SCI trials in Australia – for details of Australian-based clinical trials which aim to restore function or feeling to people living with SCI. Also included are clinical trials exploring treatments for neuropathic pain. You may wish to be part of the trial.

Key Take-aways

- **Multidimensional impact of SCI:** SCI affects over 20,800 Australians and has systemic, psychosocial and financial. Effective therapies must address not only neural repair but also rehabilitation, community reintegration and quality of life
- **Therapeutic approaches for SCI repair:** SCI therapies can be classified into pharmaceutical, cell-based, biological and physico-mechanical approaches, including anti-inflammatory drugs, stem cell transplants, growth factors and technologies such as robotics and brain-computer interfaces (BCIs)
- **Olfactory ensheathing cells (OECs):** OECs are promising non-stem glial cells used in SCI repair due to their regenerative properties, low tumorigenic risk and ability to modulate inflammation and support axonal growth
- **Innovative nerve bridge technology:** Griffith University team has developed scaffold-free 3D OEC constructs ('nerve bridges') to enhance cell survival and integration post-transplantation. This is currently being tested in a world-first clinical trial
- **Spinal cord stimulation (SCS):** SCS is being repurposed from pain management to the restoration of motor and autonomic function. Epidural stimulation combined with intensive rehabilitation has enabled walking and voluntary movement in some patients

- **Neuroprotection and other technologies:** Therapies involving Glyburide, Minocycline and hypothermia aim to prevent secondary damage by reducing inflammation and cell death. These are in various stages of clinical testing. Brain-computer interfaces, robotic exoskeletons and AI-assisted rehabilitation are being explored to restore function and independence. Australian centres such as Royal Rehab and Gold Coast University Hospital are leading efforts
- **Nutrition in SCI recovery:** Nutrition research highlights gaps in guidelines and practices. Studies call for SCI-specific datasets and for early intervention through hospital food services to improve outcomes, such as bowel function and pressure injury prevention, and
- **Lived experience and co-design:** Consumer involvement is central to SCI research. Advocates such as **Perry Cross** emphasise the importance of hope, early support and holistic care in improving long-term outcomes.

The next chapter, **Chapter 17,** addresses the impact of a changing climate on people living with SCI. A changing climate brings heat and other adverse weather events that can have physiological, physical and psychological impacts on individuals.

Reminder: Relevant chapters

- **Chapter 2:** As Chapter 2 deals with the Anatomy and Physiology of SCI, you might have to go back to remind yourself when reading Chapter 16, and
- **Chapter 5:** Getting back into the community is important. Finding meaning may be about participating in clinical trials.

References

Angeli, C. A., Boakye, M., Morton, R. A., Vogt, J., Benton, K., Chen, Y., Ferreira, C. K., & Harkema, S. J. (2018). Recovery of over-ground walking after chronic motor complete spinal cord injury. *The New England Journal of Medicine*, *379*(13), 1244-1250. https://doi.org/10.1056/NEJMoa1803588

Angeli, C. A., Edgerton, V. R., Gerasimenko, Y. P., & Harkema, S. J. (2014). Altering spinal cord excitability enables voluntary movements after chronic complete paralysis in humans. *Brain*, *137*(5), 1394-1409. https://doi.org/10.1093/brain/awu038

Aslan, S. C., Legg Ditterline, B. E., Park, M. C., Angeli, C. A., Rejc, E., Chen, Y., Ovechkin, A. V., Krassioukov, A., & Harkema, S. J. (2018). Epidural spinal cord stimulation of lumbosacral networks

modulates arterial blood pressure in individuals with spinal cord injury-induced cardiovascular deficits. *Frontiers in Physiology*, *9*, 1-11. https://doi.org/10.3389/fphys.2018.00565

Batchelor, P., Stephen Bernard, S., Gantner, D., Udy, A., Board, J., Fitzgerald, M., Skeers, P., Battistuzzo, C., Stephenson, M., Smith, K., & Nunn, A. (2023). Immediate cooling and early decompression for the treatment of cervical spinal cord injury: A safety and feasibility study. *Therapeutic Hypothermia and Temperature Management, 13*(2), 77-85. https://liebertpub.com/doi/pdf/10.1089/ther.2022.0046

Bernardi, M., Fedullo, A. L., Bernardi, E., Munzi, D., Peluso, I., Myers, J., Lista, F. R., & Sciarra, T. (2020). Diet in neurogenic bowel management: A viewpoint on spinal cord injury. *World Journal of Gastroenterology, 26*(20), 2479-2497. https://doi.org/10.3748/wjg.v26.i20.2479

Burns, A. S., Santos, A., Cheng, C. L., Chan, E., Fallah, N., Atkins, D., Dvorak, M. F., Ho, C., Ahn, H., Paquet, J., Kwon, B. K., & Noonan, V. K. (2017). Understanding length of stay after spinal cord injury: Insights and limitations from the Access to Care and Timing Project. *Journal of Neurotrauma, 34*(20), 2910-2916. https://doi.org/10.1089/neu.2016.4935

Buchholz, A. C., & Pencharz, P. B. (2004). Energy expenditure in chronic spinal cord injury. *Current Opinion in Clinical Nutrition and Metabolic Care, 7*(6), 635-639. https://doi.org/10.1097/00075197-200411000-00008

Calvert, J. S., Grahn, P. J., Zhao, K. D., & Lee, K. H. (2019). Emergence of epidural electrical stimulation to facilitate sensorimotor network functionality after spinal cord injury. *Neuromodulation: Technology at the Neural Interface*, *22*(3), 244-252. https://doi.org/10.1111/ner.12938

Chalif, J. I., Chavarro, V. S., Mensah, E., Johnston, B., Fields, D. P., Chalif, E. J., Chiang, M., Sutton, O., Yong, R., Trumbower, R., & Lu, Y. (2024). Epidural spinal cord stimulation for spinal cord injury in humans: A systematic review. *Journal of Clinical Medicine*, *13*(4), 1090. https://doi.org/10.3390/jcm13041090

Cox, S. A., Weiss, S. M., Posuniak, E. A., Worthington, P., Prioleau, M., & Heffley, G. (1985). Energy expenditure after spinal cord injury: an evaluation of stable rehabilitating patients. *The Journal of Trauma, 25*(5), 419-423. https://pubmed.ncbi.nlm.nih.gov/3999162/

Cragg, J. J., Noonan, V. K., Krassioukov, A., & Borisoff, J. (2013). Cardiovascular disease and spinal cord injury: results from a national population health survey. *Neurology, 81*(8), 723–728. https://doi.org/10.1212/WNL.0b013e3182a1aa68

Darrow, D., Balser, D., Netoff, T. I., Krassioukov, A., Phillips, A., Parr, A., & Samadani, U. (2019). Epidural spinal cord stimulation facilitates immediate restoration of dormant motor and autonomic supraspinal pathways after chronic neurologically complete spinal cord injury. *Journal of Neurotrauma*, *36*(15), 2325-2336. https://doi.org/10.1089/neu.2018.6006

Dimitrijevic, M. R., Gerasimenko, Y., & Pinter, M. M. (1998). Evidence for a spinal central pattern generator in humans. *Annals of the New York Academy of Sciences*, *860*(1), 360-376. https://doi.org/10.1111/j.1749-6632.1998.tb09062.x

Dorrian, R. M., Berryman, C. F., Lauto, A., & Leonard, A. V. (2023). Electrical stimulation for the treatment of spinal cord injuries: A review of the cellular and molecular mechanisms that drive functional improvements. *Frontiers in Cellular Neuroscience*, *17*. https://doi.org/10.3389/fncel.2023.1095259

Farkas, G. J., Pitot, M. A., Berg, A. S., & Gater, D. R. (2019). Nutritional status in chronic spinal cord injury: a systematic review and meta-analysis. *Spinal Cord, 57*(1), 3-17. https://doi.org/10.1038/s41393-018-0218-4

Farkas, G. J., Sneij, A., & Gater, D. R. jr. (2021). Energy expenditure following spinal cord injury: A delicate balance. *Topics in Spinal Cord Injury Rehabilitation, 27*(1), 92-99. doi: 10.46292/sci20-00030

Formento, E., Minassian, K., Wagner, F., Mignardot, J. B., Le Goff-Mignardot, C. G., Rowald, A., Bloch, J., Micera, S., Capogrosso, M., & Courtine, G. (2018). Electrical spinal cord stimulation must preserve proprioception to enable locomotion in humans with spinal cord injury. *Nature Neuroscience*, *21*(12), 1728-1741. https://doi.org/10.1038/s41593-018-0262-6

Gao, X., Su, Y., Shan, S., Qian, W., & Zhang, Z. (2024). Identification of immune-related hub genes in spinal cord injury. *European Journal of Medical Research, 29*(1), 483. https://doi.org/10.1186/s40001-024-02075-0

Gill, M. L., Grahn, P. J., Calvert, J. S., Linde, M. B., Lavrov, I. A., Strommen, J. A., Beck, L. A., Sayenko, D. G., Van Straaten, M. G., Drubach, D. I., Veith, D. D., Thoreson, A. R., Lopez, C., Gerasimenko, Y. P., Edgerton, V. R., Lee, K. H., & Zhao, K. D. (2018). Neuromodulation of lumbosacral spinal networks enables independent stepping after complete paraplegia. *Nature Medicine*, *24*(11), 1677-1682. https://www.nature.com/articles/s41591-018-0248-7

Gilmour, A. D., Reshamwala, R., Wright, A.A., Ekberg, J. A. K., & St John, J. A. (2020). Optimizing olfactory ensheathing cell transplantation for spinal cord injury repair. *Journal of Neurotrauma, 37*(5), 817-829. https://doi.org/10.1089/neu.2019.6939

Gorgey, A. S. (2014). Exercise awareness and barriers after spinal cord injury. *World Journal of Orthopedics*, *5*(3), 158. https://doi.org/10.5312/wjo.v5.i3.158

Gorgey, A. S., Dolbow, D. R., Dolbow, J. D., Khalil, R. K., Castillo, C., & Gater, D. R. (2014). Effects of spinal cord injury on body composition and metabolic profile – part I. *The Journal of Spinal Cord Medicine*, *37*(6), 693-702. https://doi.org/10.1179/2045772314Y.0000000245

Graves, L. Y., Schwartz, K. R., Shiff, J., Chan, E. R., Galea, M., Henzel, M. K., Olney, C., & Bogie, K. M. (2023). Genomic biomarkers can provide a deeper understanding of recurrent pressure injuries. *Advances in Skin & Wound Care, 36*(10), 534-539. https://doi.org/10.1097/ASW.0000000000000041

Harkema, S., Gerasimenko, Y., Hodes, J., Burdick, J., Angeli, C., Chen, Y., Ferreira, C., Willhite, A., Rejc, E., Grossman, R. G., & Edgerton, V. R. (2011). Effect of epidural stimulation of the lumbosacral spinal cord on voluntary movement, standing, and assisted stepping after motor

complete paraplegia: a case study. *Lancet*, *377*(9781), 1938-1947. https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(11)60547-3/abstract

Herrity, A. N., Aslan, S. C., Ugiliweneza, B., Mohamed, A. Z., Hubscher, C. H., & Harkema, S. J. (2021). Improvements in bladder function following activity-based recovery training with epidural Stimulation After Chronic Spinal Cord Injury. *Frontiers in Systems Neuroscience*, *14*, 614691. https://www.frontiersin.org/journals/systems-neuroscience/articles/10.3389/fnsys.2020.614691/full

Herrity, A. N., Williams, C. S., Angeli, C. A., Harkema, S. J., & Hubscher, C. H. (2018). Lumbosacral spinal cord epidural stimulation improves voiding function after human spinal cord injury. *Scientific Reports*, *8*(1), 1-11. https://doi.org/10.1038/s41598-018-26602-2

Iwahara, T., Atsuta, Y., Garcia-Rill, E., & Skinner, R. D. (1992). Spinal cord stimulation-induced locomotion in the adult cat. *Brain Research Bulletin*, *28*(1), 99-105. https://doi.org/10.1016/0361-9230(92)90235_P

Iyer, P., Beck, E. J., & Walton, K. L. (2020). Exploring nutrition knowledge and dietary intake of adults with spinal cord injury in specialist rehabilitation. *Spinal Cord*, *58*(8), 930-938. https://doi.org/10.1038/s41393-020-0430-x

Iyer, P., Beck, E. J., & Walton, K. L. (2021). A systematic review of the effect of dietary interventions on cardiovascular disease risk in adults with spinal cord injury. *Journal of Spinal Cord Medicine*, *44*(2), 184-203. https://doi.org/10.1080/10790268.2019.1592926

Iyer, P., Farkas, G. J., LaVela, S. L., Hirani, S. P., & Wong, S. (2025). Protocol for developing the nutrition dataset for the International Spinal Cord Society: an international eDelphi approach. *Spinal Cord, 63*(8), 432–436. https://doi.org/10.1038/s41393-025-01102-z

Jogia, T., & Ruitenberg, M. J. (2020). Traumatic spinal cord injury and the gut microbiota: Current insights and future challenges. *Frontiers in Immunology, 11*, 704. https://doi.org/10.3389/fimmu.2020.00704

Kao, S. K., Yu, Y. T., & Tsai, M. H. (2025). Risk of adverse cardiovascular events following spinal cord injury in patients with osteoporosis: Real-world evidence. *American Journal of Preventive Cardiology,* 21, 100938. https://doi.org/10.1016/j.ajpc.2025.100938

Kifley, A., Geraghty, T. J., Arora, M., Bourke, J., Craig, A., Cameron, I. D., … Middleton, J. W. (2024). Complex lived experiences and hidden disability after spinal cord injury: a latent profile analysis of the Australian arm of the International Spinal Cord Injury (Aus-InSCI) Community Survey. *Disability and Rehabilitation, 46*(20), 4675-4686. https://doi.org/10.1080/09638288.2023.2283101

Kowalski, K. E., Romaniuk, J. R., Brose, S. W., Richmond, M. A., Kowalski, T., & DiMarco, A. F. (2016). High frequency spinal cord stimulation – New method to restore cough. *Respiratory Physiology & Neurobiology*, *232*(5), 54-56. https://doi.org/10.1016/j.resp.2016.07.001

LaVela, S. L., Wu, J., Nevedal, A. L., Frayne, S. M., Harris, A. H. S., Arnow, K. D., Davis, K., Farkas, G. J., Reyes, L., & Eisenberg, D. (2025). Nutrition and eating beliefs and behaviors among individuals with spinal cord injuries and disorders: Healthy or misconceived?. *Rehabilitation Psychology, 70*(1), 1-14. https://doi.org/10.1037/rep0000544

LaVela, S. L., Wu, J., Nevedal, A. L., Harris, A. H. S., Frayne, S. M., Arnow, K. D., Barreto, N. B., Davis, K., & Eisenberg, D. (2023). The impact of the COVID-19 pandemic on individuals living with spinal cord injury: A qualitative study. *Rehabilitation Psychology, 68*(1), 12-24. https://doi.org/10.1037/rep0000469

Li, Z., Wang, X., Du, H., Liu, W., Zhang, C., Talifu, Z., Xu, X., Pan, Y., Zhang, J., Ke, H., Yang, D., Gao, F., Yu, Y., Jing, Y., & Li, J. (2025). Unraveling spinal cord injury nutrition: Effects of diet on the host and microbiome. *Advances in Nutrition*, *16*(7), 100448. https://doi.org/https://doi.org/10.1016/j.advnut.2025.100448

Lin, A., Shaaya, E., Calvert, J. S., Parker, S. R., Borton, D. A., & Fridley, J. S. (2022). A review of functional restoration from spinal cord stimulation in patients with spinal cord injury. *Neurospine*, *19*(3), 703-734. https://doi.org/10.14245/ns.2244652.326

Lu, D. C., Edgerton, V. R., Modaber, M., AuYong, N., Morikawa, E., Zdunowski, S., Sarino, M. E., Sarrafzadeh, M., Nuwer, M. R., Roy, R. R., & Gerasimenko, Y. (2016). Engaging cervical spinal Cord networks to reenable volitional control of hand function in tetraplegic patients. *Neurorehabilitation and Neural Repair*, *30*(10), 951-962. https://doi.org/10.1177/1545968316644344

Magnuson, F. S., Christensen, P., Krassioukov, A., Rodriguez, G., Emmanuel, A., Kirshblum, S., & Krogh, K. (2023). Neurogenic bowel dysfunction in patients with spinal cord injury and multiple sclerosis—An updated and simplified treatment algorithm. *Journal of Clinical Medicine, 12*(22), 6971. https://doi.org/10.3390/jcm12226971

Malone, I. G., Nosacka, R. L., Nash, M. A., Otto, K. J., & Dale, E. A. (2021). Electrical epidural stimulation of the cervical spinal cord: implications for spinal respiratory neuroplasticity after spinal cord injury. *Journal of Neurophysiology*, *126*(2), 607-626. https://journals.physiology.org/doi/full/10.1152/jn.00625.2020

Montoto-Marqués, A., Benito-Penalva, J., Ferreiro-Velasco, M. E., Wright, M. A., Salvador-De la Barrera, S., Kumru, H., Gaitán-Pérez, N., Hernández-Navarro, A., Rodríguez-Sotillo, A., Martins Braga, F., Palencia-Vidal, A., & Vidal-Samsó, J. (2025). Advances and new therapies in traumatic spinal cord injury. *Journal of Clinical Medicine, 14*(7), 2203. https://doi.org/10.3390/jcm14072203

Morgan, I. B., Wang, Y., Fisher, M., Collins, P. F., & Iyer, P. (2025). Foodservice models and nutrition practices in spinal facilities: Insights and opportunities for improvement from a pilot multinational survey. *Journal of Human Nutrition and Dietetics, 38*(5), e70115. https://doi.org/10.1111/jhn.70115

Murtaza, M., Chacko, A., Delbaz, A., Reshamwala, R., Rayfield, A., McMonagle, B., St John, J. A, & Ekberg, J. A. K. (2019). Why are olfactory ensheathing cell tumors so rare? *Cancer Cell International, 19*(1), 260. https://link.springer.com/article/10.1186/s12935-019-0989-5

Nevin, A. N., Dwyer, K., Atresh, S. S., Vivanti, A., Hickman, I. J., & Banks, M. (2025). Nutritional intakes of people with spinal cord injury who have pressure injuries in hospital: A secondary analysis of a randomized controlled trial. *Topics in Spinal Cord Injury Rehabilitation*, *31*(1), 17-29. https://doi.org/10.46292/sci24-00003

Nevin, A. N., Urquhart, S., Atresh, S. S., Geraghty, T. J., Walter, E., Ryan, E. G., Vivanti, A., Ward, L. C., & Hickman, I. J. (2023). A longitudinal analysis of resting energy expenditure and body composition in people with spinal cord injury undergoing surgical repair of pressure injuries: a pilot study. *European Journal of Clinical Nutrition*, *77*(3), 386-392. https://doi.org/10.1038/s41430-022-01248-6

Nevin, A. N., Steenson, J., Vivanti, A., & Hickman, I. J. (2016). Investigation of measured and predicted resting energy needs in adults after spinal cord injury: a systematic review. *Spinal Cord*, *54*(4), 248-253. https://doi.org/10.1038/sc.2015.193

Oieni, F., Reshamwala, R., & St John, J. (2022). Olfactory ensheathing cells for spinal cord injury: The cellular superpowers for nerve repair. *Neuroglia, 3*(4):139-143. https://www.mdpi.com/2571-6980/3/4/9?utm_source=researchgate.net&utm_medium=article

Park, A., & Solinsky, R. (2024). Leveraging genetics to optimize rehabilitation outcomes after spinal cord injury: contemporary challenges and future opportunities. *Frontiers in Genetics*, *15*, 1350422. https://doi.org/10.3389/fgene.2024.1350422

Ramakrishna, S., Moore, M., Davies, E., Merry, A. F., Sleigh, J., & Jowsey, T. (2025). Long-term lived experiences of patients with chronic pain or angina pectoris treated with spinal cord stimulation: a qualitative study. *BMJ Open*, *15*(3), e082840. https://doi.org/10.1136/bmjopen-2023-082840

Reshamwala, R., Murtaza, M., Chen, M., Shah, M., Ekberg, J., Palipana, D., Vial, M. L., McMonagle, B., & St John, J. (2022). Designing a clinical trial with olfactory ensheathing cell transplantation-based therapy for spinal cord injury: A position paper. *Biomedicines, 10*(12), 3153. https://www.mdpi.com/2227-9059/10/12/3153

Reshamwala, R., Oieni, F., & Shah, M. (2023). Non-stem cell mediated tissue regeneration and repair. In N. Chakravorty & P. C. Shukla (Eds.), *Regenerative medicine* (pp. 13-36). Springer Nature Singapore.

Ransom, S. C., Brown, N. J., Pennington, Z. A., Lakomkin, N., Mikula, A. L., Bydon, M., & Elder, B. D. (2022). Hypothermia therapy for traumatic apinal cord injury: An updated review. *Journal of Clinical Medicine, 11*(6), 1585. https://doi.org/10.3390/jcm11061585

Ross, J. T., Noonan, V. K., Chernesky, J., Hektner, J., Peter, R., Hawes, S., Forshner, A., Shekhar, S., Ray, T., Raina, A., & Laskin, J. J. (2025). Engagement of people with lived experience in spinal cord injury to address innovation priorities. *Health Expectations, 28*(4), e70369. https://doi.org/10.1111/hex.70369

Rowald, A., Komi, S., Demesmaeker, R., Baaklini, E., Hernandez-Charpak, S. D., Paoles, E., Montanaro, H., Cassara, A., Becce, F., Lloyd, B., Newton, T., Ravier, J., Kinany, N., D'Ercole, M., Paley, A., Hankov, N., Varescon, C., McCracken, L., Vat, M., … & Courtine, G. (2022). Activity-dependent spinal cord neuromodulation rapidly restores trunk and leg motor functions after complete paralysis. *Nature Medicine*, *28*(2), 260-271. https://doi.org/10.1038/s41591-021-01663-5

Sdrulla A. D. Guan, Y., & Raja, S. N. (2018). Spinal cord stimulation: Clinical efficacy and potential mechanisms. *Pain Practice, 8*(8), 1048-1067. https://doi.org/10.1111/papr.12692

Shea, J. R., Shay, B. L., Leiter, J., & Cowley, K. C. (2018). Energy Expenditure as a Function of Activity Level After Spinal Cord Injury: The Need for Tetraplegia-Specific Energy Balance Guidelines. *Frontiers in Physiology*, *9*, 1286. https://doi.org/10.3389/fphys.2018.01286

Sherwood, A. M., Dimitrijevic, M. R., & Barry McKay, W. (1992). Evidence of subclinical brain influence in clinically complete spinal cord injury: discomplete SCI. *Journal of the Neurological Sciences*, *110*(1-2), 90-98. https://doi.org/10.1016/0022-510X(92)90014-C

Sober-Williams, E. K., Lee, R. H. Y., Whitehurst, D. G. T., McBride, C. B., Willms, R., & Claydon, V. E. (2024). Bowel burdens: a systematic review and meta-analysis examining the relationships between bowel dysfunction and quality of life after spinal cord injury. *Spinal Cord*, *62*(9), 495-506. https://doi.org/10.1038/s41393-024-01002-8

Solinsky, R., Specker-Sullivan, L., & Wexler, A. (2020). Current barriers and ethical considerations for clinical implementation of epidural stimulation for functional improvement after spinal cord injury. *The Journal of Spinal Cord Medicine*, *43*(5), 653-656. https://doi.org/10.1080/10790268.2019.1666240

Stojic, S., Eriks-Hoogland, I., Gamba, M., Valido, E., Minder, B., Chatelan, A., L.G. Karagounis, L. G., M. Ballesteros, M., C. Díaz, C., M. Brach, M., J. Stoyanov, J., N. Diviani, N., S. Rubinelli, S., C. Perret, C., & Glisic, M. (2023). Mapping of dietary interventions beneficial in the prevention of secondary health conditions in spinal cord injured population: A systematic review. *The Journal of Nutrition, Health and Aging, 27*(7), 524-541. https://doi.org/10.1007/s12603-023-1937-6

Stojic, S., Minder, B., Boehl, G., Rivero, T., Zwahlen, M., Gemperli, A., & Glisic, M. (2025). Systematic review and meta-analysis use in the field of spinal cord injury research: A bibliometric analysis. *The Journal of Spinal Cord Medicine*, *48*(1), 54-64. https://doi.org/10.1080/10790268.2023.2251205

Stojic, S., Affolter, S., Stadler, G., Missmer, S. A., Pannek, J., Stoyanov, J., Eriks-Hoogland, I., Lüscher, J., & Glisic, M. (2025). Mapping sex and gender in the landscape of spinal cord injury research: a bibliometric analysis and research framework. *Spinal cord*, *63*(7), 333-341. https://doi.org/10.1038/s41393-025-01089-7

Swan, W. I., Vivanti, A., Hakel-Smith, N. A., Hotson, B., Orrevall, Y., Trostler, N., Beck Howarter, K., & Papoutsakis, C. (2017). Nutrition care process and model update: Toward realising people-centred care and outcomes management. *Journal of the Academy of Nutrition and Dietetics*, *117*(12), 2003-2014. https://doi.org/10.1016/j.jand.2017.07.015

Tan, A. Q., Barth, S., & Trumbower, R. D. (2020). Acute intermittent hypoxia as a potential adjuvant to improve walking following spinal cord injury: evidence, challenges, and future directions. *Current Physical Medicine and Rehabilitation Reports, 8*(3),188-198. https://doi.org/10.1007/s40141-020-00270-8

Taylor-Schroeder, S., LaBarbera, J., McDowell, S., Zanca, J. M., Natale, A., Mumma, S., Gassaway, J., & Backus, D. (2011). Physical therapy treatment time during inpatient spinal cord injury rehabilitation. *The Journal of Spinal Cord Medicine*, *34*(2), 149-161. https://doi.org/10.1179/107902611X12971826988057

Valido, E., Capossela, S., Glisic, M., Hertig-Godeschalk, A., Bertolo, A., Stucki, G., Flueck, J. L., & Stoyanov, J. (2024). Gut microbiome and inflammation among athletes in wheelchair in a crossover randomized pilot trial of probiotic and prebiotic interventions. *Scientific Reports*, *14*(1), 12838. https://doi.org/10.1038/s41598-024-63163-z

van der Scheer, J. W., Totosy de Zepetnek, J. O., Blauwet, C., Brooke-Wavell, K., Graham-Paulson, T., Leonard, A. N., Webborn, N., & Goosey-Tolfrey, V. L. (2021). Assessment of body composition in spinal cord injury: A scoping review. *PLOS ONE*, *16*(5), e0251142. https://doi.org/10.1371/journal.pone.0251142

Wagner, F. B., Mignardot, J.-B., Le Goff-Mignardot, C. G., Demesmaeker, R., Komi, S., Capogrosso, M., Rowald, A., Seáñez, I., Caban, M., Pirondini, E., Vat, M., McCracken, L. A., Heimgartner, R., Fodor, I., Watrin, A., Seguin, P., Paoles, E., Van Den Keybus, K., Eberle, G., … Courtine, G. (2018). Targeted neurotechnology restores walking in humans with spinal cord injury. *Nature*, *563*(7729), 65-71. https://doi.org/10.1038/s41586-018-0649-2

Wang, Y., Lo, M. C., Fisher, M., Desneves, K., Nevin, A., & Iyer, P. (2026). Nutrition care in adults with spinal cord injuries and disorders with pressure injuries: A systematic review of clinical practice guidelines. *Clinical Nutrition (Edinburgh, Scotland)*, *58*, 106580. https://doi.org/10.1016/j.clnu.2026.106580

Xu, J., Jiao, Y., Wang, N., Xu, X., Yang, L., Han, L., & Lv, L. (2025). Incidence of pressure injuries in patients with spinal cord injury: A systematic review and meta-analysis. *Journal of Tissue Viability*, *34*(2), 100881. https://doi.org/10.1016/j.jtv.2025.100881

Yeung, H. Y., Iyer, P., Pryor, J., & Nicholson, M. (2021). Dietary management of neurogenic bowel in adults with spinal cord injury: an integrative review of literature. *Disability and Rehabilitation*, *43*(9), 1208-1219. https://doi.org/10.1080/09638288.2019.1652702

Zamboni, M., Martínez-Martín, A., Rydholm, G., Häneke, T., Pintado Almeida, L., Seçilmiş, D., Ziegenhain, C., & Llorens-Bobadilla, E. (2026). The regulatory code of injury-responsive enhancers enables precision cell-state targeting in the CNS. *Nature Neuroscience*, *29*(2), 337-349. https://doi.org/10.1038/s41593-025-02131-w

Zengul, A. G., Ferguson, C. C., Rimmer, J. H., Cofield, S. S., Davis, E. N., Hill, J. O., & Thirumalai, M. (2025). Expert-reviewed nutritional guidance for adults with spinal cord injury: A Delphi study. *Nutrients, 17*(9), 1520. https://doi.org/10.3390/nu17091520

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Chapter 17. A Changing Climate: Implications for Individuals Living with Spinal Cord Injury

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"People with disabilities already experience vulnerabilities across multiple levels, and climate change functions as a threat multiplier, amplifying existing barriers and creating new health disparities." (Kim *et al.*, 2026; p. 3).

Our global climate is changing, mainly due to human activities. From burning fossil fuels to changing the landscapes for agriculture and infrastructure, the planet is in crisis. This is impacting the health and well-being of all 'beings', with some being more vulnerable than others. Average global temperatures are increasing, as are other adverse weather events, such as tropical cyclones, floods and wildfires (bushfires). Individuals living with SCI are at-risk physiologically, psychologically and physically in such disaster-prone environments.

Climate change and disability are connected through barriers that make it harder for disabled people to access healthcare, get important information and respond to emergencies and these challenges get worse during climate events. Rising cost-of-living caused by climate change hit disabled people especially hard, since they already bear higher everyday expenses related to their disabilities. Disability rights and climate action go hand-in-hand. Support organisations and advocates are increasingly working to support disabled communities prepare for and respond to climate impacts, recognising that disabled people face unique risks and are often left out of climate planning and response efforts. Importantly, enabling people with disabilities to enter healthcare professions and collaborate in development and disaster risk reduction can provide untapped knowledge on disability discrimination and climate adaptation (Stein & Stein, 2022).

This Chapter will explore the impacts of Australia's shifting climate through a disability lens. The focus will be on the effects of these changes on climate, particularly adverse events such as heatwaves, floods and other extreme weather, on individuals living with SCI.

Also included is a section on ***environmental sustainability*** in healthcare. As global healthcare systems become more environmentally accountable, for example, by reducing single-use items and greenhouse gases, all sectors are looking for strategies to prevent injury and illness. When

resources are required, they aim to use the best available evidence to guide treatment, which may include not treating, limiting interventions, reusing equipment and recycling materials.

Key Topics in this Chapter

- Being at risk physiologically, such as respiratory and cardiac issues and for individuals with higher-level SCI with impaired body temperature regulation
- Being at risk because of limited mobility, for example, during floods
- Preparedness strategies before an event, such as early warning systems and access to urgent information
- During the event, such as evacuation transport and shelters
- After the event, such as housing, food, water and support
- Emergency procedures and response protocols for individuals with SCI during adverse weather events, as well as during other disasters such as earthquakes
- Policy and strategic frameworks, such as the 2023 National Health and Climate Strategy, with the inclusion of 'disability' in the Stakeholder discussions and the 2025 National Climate Risk Assessment and National Adaptation Plan, and
- The need for healthcare to become more environmentally sustainable.

Before proceeding with this Chapter, it is important to distinguish between the following terms: **Disaster** and **Emergency**.

Important information: Disaster or emergency?

The terms 'emergency' and 'disaster' are used differently across State Governments in Australia. At the Australian Government level and in several State jurisdictions, the term *emergency* is often used interchangeably with *disaster*.

The Australian Institute for Disaster Resilience (AIDR) defines a **disaster** as:

> *"A serious disruption of the functioning of a community or a society at any scale due to hazardous events interacting with conditions of exposure, vulnerability and capacity, leading to one or more of the following: human, material, economic and environmental losses and impacts. Note, there are jurisdictional legislative variations."*

This resource will largely use the term 'disaster', which, by its nature, is invariably an 'emergency'. Thus,***Do you have a Disaster Management Plan?*** is a key message in this Chapter.

Interesting information: #NoNaturalDisasters (UNDRR)

The UNDRR (United Nations Office for Disaster Risk Reduction) has a website #NoNaturalDisasters, in which it states that a hazard can only become a disaster once it impacts society or community. A hazard is natural; disasters are not.

Disaster = hazard + exposure + vulnerability: A natural hazard, such as a hurricane, earthquake or flood, only becomes a disaster when it impacts a community that is not adequately protected and whose population is vulnerable as a result of poverty, exclusion or social disadvantage.

17.1. A changing climate through a disability lens

On 12 July 2019, the Human Rights Council of the United Nations (UN) General Assembly adopted Resolution 41/21 Human rights and climate change, which contains the following, amongst other notes:

> *"Recognizing that persons with disabilities are among the most adversely affected in an emergency, sustaining disproportionately higher rates of morbidity and mortality, and at the same time being among those least able to have access to emergency support. In line with this, the Human Rights Council:*
>
> - *Urges States to strengthen and implement policies aimed at increasing the participation of persons with disabilities in climate change responses at the local, national, regional and international levels, and calls upon the United Nations Partnership to Promote the Rights of Persons with Disabilities and other United Nations agencies to support, upon request, national programmes and projects in this regard;*
> - *Decides to incorporate into the programme of work for the forty-fourth session of the Human Rights Council, on the basis of the different elements contained in the present res-*

olution, a panel discussion on the theme "Promoting and protecting the rights of persons with disabilities in the context of climate change", focusing on best practices and lessons learned in the promotion and protection of the rights of persons with disabilities in the context of the adverse impact of climate change, and also decides that the panel discussion will have international sign interpretation and captioning."

Important information: Impact of climate change on the rights of persons with disability

United Nations Human Rights, Office of the High Commissioner: The impact of climate change on the rights of persons with disabilities.

Chapter 11 discusses the United Nations Convention on the Rights of Persons with Disabilities, adopted on 12 December 2006 (Resolution A/RES/61/106). In late March 2024, at the Conference of States Parties to the Convention on the Rights of Persons with Disabilities (17th session) held in New York, the following extract relates to persons with disabilities, highlighting their lack of inclusion in disaster risk management, plus the findings relating to those with disability and their disaster management plans:

"The lack of inclusion of the perspectives and needs of persons with disabilities in disaster risk reduction is reflected in the findings of the 2023 Global Survey Report on Persons with Disabilities and Disasters: 84 per cent of respondents stated that they did not have a personal preparedness plan for a disaster; 17 per cent said that, even with adequate warning systems in place, they would have difficulties evacuating independently, with 6 per cent being unable to evacuate independently at all; and, crucially, a mere 8 per cent reported that local disaster risk reduction plans addressed the specific needs of persons with disabilities. Respondents reported low or lack of awareness of disaster risk reduction plans at the national and subnational levels; inaccessible disaster risk reduction information; and a lack of participation in community-level disaster risk reduction decision-making, with reported barriers to participation including a lack of physical accessibility and reasonable accommodation, as well as negative attitudes and behaviours towards persons with disabilities. Thus, the midterm review of implementation of the Sendai Framework found that disability inclusion in disaster risk reduction remains "under-resourced and under-prioritized", progress is uneven and too slow, and the inclusion of persons with disabilities and/or their representative organizations is limited and lacks support from other stakeholders."

Video: 2023 Global survey: United Nations Office for Disaster Risk Reduction (UNDDR)

You can watch the accompanying video for the **2023 Global Survey Report on Persons with Disabilities and Disasters** and the findings on the United Nations Office for Disaster Risk Reduction (UNDDR) website.

UNDRR has a strategy on disability inclusion aligned with the UN Disability Inclusion Strategy. To ensure policies and plans are effective, persons with disabilities need to be consulted and fully engaged in the development and implementation of national and local strategies. This is supported by a group of Australian researchers (Chapman *et al.,* 2022) whose article, *An undignified disaster reality for Australians with disability,* highlighted that, despite the UN Convention on the Rights of Persons with Disabilities and the Sendai Framework for Disaster Risk Management, the reality of disasters for individuals living with disability is one of indignity, human rights violations and corruption. Later in the Chapter, we discuss the extensive Australian consultation process to develop the 2023 National Health and Climate Strategy, which included stakeholder representation from the disability sector.

With Australia in a perpetual state of environmental and ecological crisis following several years of adverse weather events, its most vulnerable and at-risk populations, which include people living with disability, are at great risk of human rights violations. Integrating the principles of dignity and a whole-person perspective into disaster management and recovery can safeguard human rights and improve outcomes for people with disability (Chapman, 2023).

In 2023, the Petrie-Flom Center (Centre) at Harvard Law School published Understanding Climate and Disability Justice: Mitigating Structural Barriers to the Right to Health. The report begins by noting that people living with disability, who are among the most climate-vulnerable group, are often overlooked before, during and after disasters. It emphasises the importance of structural competency, which involves recognising and addressing systemic factors such as bias, inequity and institutional blind spots that contribute to environmental racism and ableism in climate and disaster policy.

The ***social determinants of health*** offer a useful framework for understanding how broader social and economic conditions shape vulnerability. Factors such as poverty, discrimination, health disparities and governance influence daily living conditions and have a considerable effect on how individuals experience climate-related hazards. Addressing these underlying conditions is essential, rather than focusing solely on the immediate impacts of climate events. In terms of climate and disability justice, Figure 1 on the Petri-Flom Center website, which

depicts the intersection of social determinants of health and vulnerability, identifies the following vulnerabilities for people living with disability:

- **Exposure:** Ableist policies and physical infrastructure increase climate threat exposure
- **Health impacts:** For individuals with heat sensitivity, as a result of an injury, such as SCI or a chronic condition or medication, they face higher mortality and morbidity, and
- **Health outcomes:** People with disability have reduced access to healthcare, social services and disaster preparation tools, in addition to structural marginalisation.

The model in **Figure 1** includes adaptive capacity, which will require social, health, and economic policies to ensure social supports, transportation, education, and emergency-planning resources.

The authors of the Petri-Flom Center Report also provide US data on the intersection between disability, prison and climate change. In the US, prisons are typically not air-conditioned, which for prisoners living with SCI, could be lethal:

> *"Heat exposure within prisons is a key area of focus for advocates, political officials and researchers. For example, a 2022 research studyshows that compared to the U.S. general population, there is a 30-fold increase in heat-related deaths in prisons without air conditioning in Texas. In fact, researchers found on average more than ten deaths a year can be attributed to heat exposure in prisons without air conditioning. Texas Prisons Community Advocates (TPCA)'s 85 To Stay Alive campaignworks to improve temperature control oversight and reduce extreme temperature exposure within correctional institutions."*

17.2. Status of global climate change

There is no doubt that the global climate is changing. The last decade, but particularly the last few years (especially 2023 and 2024) were the hottest on record, as highlighted in a World Economic Forum (WEF) video: More than 150 unprecedented extreme weather events struck in 2024 – the planet's hottest year ever (World Economic Forum).

In late October 2025, in an interview before the COP30 climate summit in Brazil, António Guterres, the UN Secretary General, acknowledged that it is *"inevitable"* that humanity will overshoot the Paris Agreement target of 1.5 °C with *"devastating consequences"* for the world. He urged global leaders not to delay reducing emissions to prevent passing ***tipping points*** in the Amazon, the Arctic and the oceans.

In late March 2026, the World Meteorological Organisation (WMO) released its State of the Global Climate Report 2025, stating that 2015-2015 were the hottest 11 years on record. There is an interactive report that can be viewed in full screen. If you are a LinkedIn user, there is a series of infographics reflecting key issues in the report. *The Conversation* has also published

an article with the implications for Australia: The latest world climate report is grim, but it's not the end of the story (King, 2026).

Additional information, if interested: Explore 30 facts about climate change

How much do you know about climate change and its impacts? (Climate Counts, UNDP): On this interactive site, you draw cards to explore 30 facts about climate change as a global emergency. You can also download the document with the information on the cards.

17.2.1. Impact of Australia's adverse weather events

Video: 70% of Australians lived in a disaster area in 2022

This is described in a video from the ABC: 70% of Australians lived in a disaster area. **Note:** This does not mean that everyone in that disaster zone was affected.

If the bushfires and floods of 2023 onwards were included, the 70% disaster zone might be more like 80 or 90%. At the time of writing most of this Chapter (May-June 2025), the East Coast was still cleaning up after Cyclone Alfred, Central Queensland had just emerged from unprecedented floods in which hundreds of thousands of livestock had been lost and the NSW Mid-South Coast was experiencing extensive floods, with several lives lost.

Although now somewhat outdated (2023), the Australian Institute of Health and Welfare's (AIHW) Let's talk about the weather: injuries related to extreme weather, Extreme heat website provides figures and data relating to the increasing heat and heatwaves, extreme cold, bushfires (smoke inhalation, burns) and rain and storms, floods and cyclones. The Report shows that in the 10 years from 2012-2022, extreme heat was responsible for most weather-related injuries and that bushfire-related injuries increased during El Niño years:

- Extreme weather-related hospitalisations spiked at over 1,000 cases every three years, with the spikes becoming progressively higher
- There were 1,027 injury hospitalisations in 2013-14, 1,033 in 2016-17 and 1,108 in 2019-20. In each of these three years, extreme heat had the biggest impact on hospitalisations and deaths, and
- Extreme heat accounted for 7,104 injury hospitalisations and 293 deaths in the 10 years analysed.

In addition to the adverse weather events described for May and June 2025 above, Australia experienced several other extreme weather and environmental events in 2025, which are continuing well into 2026:

- Queensland weather forecast: Storms bring chaos to south-east Queensland while heatwave lingers (January 2025)
- South Australia's algal bloom (began in March 2025)
- This *Conversation* article (May 2025) explains why Australia was still hot when it was almost winter (*Answer:* A large blocking high-pressure cell).
- SEQ swelters (October 2025)
- Records tumble across Australia (21 October 2025)
- Severe heatwave warning with Birdsville reaching 46 degrees – ABC News (October 2025)
- Expert commentary: Extreme heat records (January 2026)
- Australia's forecast for February-April 2026 (2026)
- Possible El Niña within months, raising potential for a hot, dry year across Australia (2026)
- NSW SES works through the night after flash flooding in Sydney (February, 2026), and
- North Queensland weather event, March 2026 (March, 2026).

Media story: *Why is Australia's weather so unpredictable?*

This January 2026 Conversation article (Bowman, 2026) explains what is driving our unpredictable weather, with fires devastating the southern part of Australia and flooding further North.

Important information: CSIRO's 2025/2026 Climate Whiplash Report

As we were putting the finishing touches on this e-resource, the CSIRO (Commonwealth Scientific and Industrial Research Organisation) released its 2025/2026 report, Breakneck Speed: Summer of Climate Whiplash, explaining Australia's horrific summer of climate-related events. The Introduction begins as follows:

"On 9 January 2026, the fire danger across Victoria was the worst experienced since Black Summer in 2019-20, with Catastrophic and Extreme fire conditions forecast across the region. Record-breaking heat and flash drought fuelled a major bushfire crisis of more than 200 fires. Some so ferocious they produced their own weather systems, ultimately destroying around 1,590 structures, including 451 homes. The Otways in Victoria epitomised the 2025/26 summer of breakneck climate whiplash. Some residents of Wye River on Victoria's Great Ocean Road evacuated under catastrophic fire danger warnings. A week later, the same community watched floodwaters carry cars out to sea after record-breaking rainfall... This is not a one-off. It is climate whiplash... Across Australia this summer, communities were flung from one extreme weather event to another. In north-west Queensland, record daily rainfall for December was followed by Tropical Cyclone Koji making landfall on 11 January, bringing heavy rainfall to already saturated soils and hitting graziers hard. More than 100,000 head of livestock were dead or missing. Meanwhile, for six consecutive days in late January, at least one place in Australia recorded a temperature of 49°C or higher. Port Augusta became the most southerly point on Earth to reach 50°C, and extreme heat in southeastern Australia spread to southern parts of Queensland" (p. 1).

17.2.2. Australia's heat vulnerability

In December 2024, the CSIRO provided a summary report of the heat vulnerability of the Australian population during the loss of electricity supply. The study was prompted by the fact that in the 2023-24 summer, extreme temperatures affected much of the Australian population, particularly in South Australia, Victoria and NSW. The conditions were exacerbated by damaging winds and heavy rainfall, disrupting energy infrastructure and leading to power outages. More than 100,000 households and businesses were affected.

The CSIRO developed a national Heat Vulnerability Index (HVI) to assess how different communities are affected by extreme heat using three components, in line with the model described above (**ESA**):

- **Exposure:** The degree to which a population is subjected to heat stress
- **Sensitivity:** The extent to which a population experiences adverse reactions to heat stress, and
- **Adaptive capacity:** The ability of a population to mitigate the effects of exposure and sensitivity through access to services, infrastructure and preparedness measures.

Within the **Sensitivity** component, CSIRO identifies several population groups that are especially vulnerable during heat events. Some individuals living with SCI can be included as 'vulnerable' because of physiological issues, such as being unable to regulate body temperature and having chronic diseases, while others need assistance with daily living. An intersectional approach further highlights vulnerabilities associated with age, socio-economic disadvantage and rural or remote location.

These three ESA components interact to shape how communities experience extreme heat. Exposure defines who encounters high temperatures, sensitivity influences the degree of harm experienced, and adaptive capacity determines the resources available to prevent, reduce or recover from heat impacts. Together, they illustrate how social, economic and health-related factors compound climate risk for some groups, such as people living with SCI.

A KPMG January 2024 Climate Risk Report concluded the following in terms of Australians' heat vulnerability:

- Over 10 million (38%) Australians live in areas of very high to hazardous heat risk
- Heatwaves cause, on average, over 3,000 deaths per year, with 36,000 deaths due to heat between 2006 and 2017, and
- Rising temperatures will cost Australia AU$19 billion by 2030 in lost agricultural and labour productivity.

Research: Heat and mortality in Australia

- In February 2025, the University of Queensland researchers found that people in cities were at a higher risk of dying from heatwaves than those in regional areas:

  > *"Our results suggest heatwaves with associated periods of higher mortality will occur more often than they did in the past. These higher mortality rates associated with extreme temperature heatwaves are projected to continue and we hope our research will help communities be better prepared for heatwaves."*

- Also in 2025, Amoatey and colleagues investigated the association between heatwave vulnerability, as measured by the heatwave vulnerability index (HVI), and related deaths across Australia. An HVI factor, characterised by individuals with low education, low income, diabetes prevalence and suburbs without health professionals, showed a stronger association with heatwave-related deaths in greater capital cities. An HVI factor characterised by the excess heat factor and the Indigenous population was a better predictor of heatwave-associated deaths across Australia. They concluded that *heatwave management strategies should include HVI maps to help protect communities against heatwave-related death and morbidity*, and
- In their 2025 article, Mapping heatwave-related mortality across 2288 local communities in Australia: a nationwide time-series analysis, Xu and co-researchers analysed 249,546 death records (47.9% female, median age 81) from 2,288 communities in statistically defined smaller geographic areas that generally have a population of 3,000-25,000, which included four islands, between 2016 and 2019. An estimated 1,009 deaths were attributable to heatwaves, equivalent to a national attributable mortality rate of 1.08 deaths per 100,000 residents per year. Queensland and NSW had the highest attributable mortality rates, which were three times those of Western Australia. Communities with higher proportions of elderly residents, gender imbalance, individuals needing assistance and lower income or education experienced higher mortality burdens. A Guardian article provides further details and a graphical representation of these data.

17.3. With heatwaves come wildfires and air pollution

As the average global temperature rises, so too do wildfires, which we call bushfires in Australia. It is worth noting that the global terminology seems to be changing from 'wildfires' to 'landscape fires'. Landscape fires include fires in natural and cultural landscapes, such as forests, shrublands, grasslands, pastures, agricultural lands and peri-urban areas, including both wildfires (uncontrolled or unplanned fires in wildland vegetation) and human-planned fires (prescribed burns and agricultural fires) (Xu *et al.*, 2024). It is unlikely, however, that the term 'bushfire' in Australia will be replaced by 'landscape fire'.

Research: Types of landscape fires

Also in 2024, Johnston and colleagues' global perspective on climate change, landscape fires and human health identified seven distinct types of landscape fires: Remote area fires, wildfire disasters, savanna fires, Indigenous burning, prescribed burning, agricultural burning, and deforestation fires. All can have substantial impacts on human health and well-being directly and indirectly through:

- Exposure to heat flux, such as injuries and destructive impacts
- Emissions, such as smoke-related health impacts, and
- Altered ecosystem functioning in terms of biodiversity, amenity, water quality and climate impacts.

Australia's dry summers and heatwaves bring bushfires, which are burning more land across more of the year, according to a 2021 CSIRO Report – Australia's Black Summer of fire was not normal – and we can prove it. These fires burned more than 24 million hectares, directly causing 33 deaths and almost 450 more from smoke inhalation. Three billion animals were either killed or impacted by the fires.

The OurWorldinData website (last updated April 2024) shows the hotspots in terms of the areas burnt, which in 2024 were the US, Bolivia, Botswana, Portugal and Australia. The fires not only destroy vegetation and, in some instances, property, but the carbon emissions exacerbate climate change and contribute to air pollution. In an October 2025 *Conversation* article, The climate crisis is fuelling extreme fires across the planet, Melbourne University researcher, Hamish Clark, noted that human-caused climate change has increased the area burned by wildfires by a magnitude of 30 in some regions of the world: *"In the past year [2024-2025], a land area larger than India – about 3.7 million square kilometres – was burnt globally. More than 100 million people were affected by these fires, and US$215 billion worth of homes and infrastructure were at risk*."

Landscape fires thus pose an increasing threat to both the environment and public health, intensified by climate change. The flames and heat from these fires can kill those in the immediate vicinity, but it is air pollution that is the biggest health threat. Landscape smoke is more dangerous than other forms of pollution because it contains fine particulate matter, carbon monoxide, ozone and hazardous air pollutants (HAPs). Exposure to wildfire can result in increased respiratory morbidity from respiratory infections, asthma and chronic obstructive pulmonary disease COPD). Fine particulate matter, such as PM2.5 particles, which are < 2.5 µm (micrometres) in diameter, comprises hundreds of different chemical compounds, which, once inhaled, can cause cardiovascular disease, lung disease or premature mortality. If the wildfires burn human structures in urban or farming areas, materials such as plastics, building materials

and vehicles, leading to a range of volatile organic compounds (VOCs), as well as dioxins and furans (from plastic), polycyclic aromatic hydrocarbons (PAHs) and heavy metals, such as lead, arsenic and chromium, are released when cars and paint burn.

Research: Health effects of wildfire (landscape fire) smoke

- Most studies have only considered the short-term effects of exposure to wildfire smoke. In terms of long-term impacts, Grant and Runkle's (2022) scoping review pointed to increased population-level mortality due to wildfire exposure and increased respiratory morbidity. In addition, exposure to PM2.5, ozone and chemicals in wildfire smoke were correlated with an increased risk of cancer of all types. The researchers recommended that future research should assess the impacts of wildfires on the most vulnerable, including in low- and middle-income countries
- Xu and co-researchers (2025) recently mapped landscape fire-sourced (LFS) air pollution-related mortality across 2288 local communities in Australia. Between 2016 and 2019, LFS air pollution was responsible for 22,809 all-cause deaths in Australia, costing AU$138.41 billion. Communities in the Northern Territory had the highest LFS air pollution-related excess mortality rate, at 33.97 per 100, 000 residents per year, followed by communities in NSW and Queensland. Southern Australia had the lowest burden, with 12.25 deaths per 100,000 residents per year. Notably, mortality burdens were greater in communities with higher proportions of Indigenous Australian residents or residents of lower socio-economic status and in communities situated in rural locations. The results, presented as community-level mortality burden maps, could inform the development of targeted public health interventions and climate policies at both local and national levels, and
- Partheepan and colleagues (2025) modelled bushfire severity to predict future trends, including high-risk areas in Australia, using remote sensing and machine learning. The model achieved a high accuracy – 86.13% – demonstrating its effectiveness in predicting fire severity across diverse Australian ecosystems. Areas at high risk of future severe bushfires were identified, potentially informing fire management strategies, enhancing resilience to future fire events in Australia.

Media story: Explaining Australia's 2025 bushfires

Why experts are 'rewriting' Australia's bushfire risk this summer (2025): *"Our bushfire outlook for spring was actually for much wetter than normal [weather] and probably negligible fire risk, except in some parts of drought-affected South Australia and Victoria,"* Greg Mullins, founder of Emergency Leaders for Climate Action and former Commissioner of Fire and Rescue, NSW, told the ABC's Radio National on 3 October 2025.

17.4. Cyclones, hurricanes, typhoons and floods

Is there a difference between a cyclone, a hurricane and a typhoon?

We read that many parts of the world are prone to cyclones, hurricanes or typhoons, which are often accompanied by floods. According to NASA, cyclones, hurricanes and typhoons are the same. Over the Atlantic and East Pacific (near the US), tropical cyclones are commonly called hurricanes. In the Indian Ocean and near Australia, we have tropical cyclones, while in the West Pacific (through much of Asia), cyclones are called typhoons. In this Chapter, we will use 'cyclone' as the e-resource is for an Australian audience.

On the WHO's webpage devoted to *Floods*, floods are identified as the most frequent type of 'natural' disaster. Three types of floods are identified on this website:

- **Flash flooding** after rapid and excessive rain, such as the monsoonal rains in countries such as India and Pakistan
- **River floods** when there is constant rain or when snow melts and the river exceeds its capacity, and
- **Coastal floods** caused by storm surges associated with tropical cyclones, such as the recent Cyclone Alfred that hit the Gold Coast in March 2025 or tsunamis.

Between 2000 and 2009, Wu and collaborators' (2024) special *New England Journal* report on climate change, floods and human health, found that more than 1.65 billion people were affected by floods, with 104,614 lives lost, making flooding the most common global climate hazard. A changing climate is altering precipitation patterns, soil moisture, and the global cryosphere, leading to changes in the frequency, magnitude and duration of floods. Wu and colleagues' (2024) **Figure 2** graphically illustrates the health consequences of floods. The most obvious would be drownings after being swept away while trying to escape the rising water levels, injuries due to floating or submerged items, which can become infected as rising water levels often inundate sewage plants, contaminating the water. For anyone who uses the social media platform, **X**, **Figure 2** can be accessed at Climate change, floods and human health.

In its 2021 report, the Climate Council of Australia provide a graphic on the proportion of total extreme weather damage in Australia (2010-2019) by different types of events, based on data from EM-DAT, the International Disaster Database (Steffen & Bradshaw, 2021):

- Floods (29%)
- Tropical cyclones (23%)
- Droughts (19%)
- Thunderstorms (16%)
- Fires (10%), and

- Other storms (2%).

In addition to the devastating impact on infrastructure, animals and the natural environment, floods often bring water-borne diseases. A series of floods in North Queensland in the first part of 2025 led to several melioidosis outbreaks, which were caused by a 'mud bug'. In a May 2025 NewsGP article, 'Melioidosis outbreak continues to grow', there had been 221 cases and 31 deaths, substantial increases over previous years (Jeffries, 2025). Melioidosis is caused by the bacterium *Burkholderia pseudomallei*, which lives in soil, mud and groundwater and usually causes no harm. With flooding, it can enter the skin through a cut and also be inhaled through droplets. The bacterium produces a biofilm that hinders antibiotic effectiveness, leading to prolonged recovery periods. During the 2025 floods, 95% of melioidosis cases occurred in individuals with diabetes or lung disease.

It goes without saying that adverse weather events such as these have psychological impacts. With the increasing frequency of these events in some regions and countries, some individuals and families may experience the impact and, in some instances, the devastating effects, more than once. This would be the case for some Australians.

Research: Psychological impacts of climate disasters

- Extreme weather events are becoming more frequent and intense under a changing climate. Whilst there is considerable evidence that exposure to a single weather-related disaster is detrimental for mental health, few studies have explored how exposure to multiple disasters impacts mental health. Over the last few years in Australia, this has been the situation for many individuals. Mitchell *et al.* (2024) used 11 waves of data from the Household, Income and Labour Dynamics in Australia (HILDA) Survey, yielding a sample of 16,629 observations from

2003 individuals. Their analysis revealed that exposure to multiple disasters is associated with worsening mental health outcomes. As extreme weather events increase, these findings highlight the need for greater attention to climate change action and to mental health interventions targeting affected populations.

- A study by Aung and colleagues (2025) examined the mental health outcomes (depression and anxiety symptoms) of displacement in a large sample of US adults who reported displacement from home due to natural disasters. Depression and anxiety symptoms were assessed using clinically validated versions of the Patient Health Questionnaire (PHQ-2) and the Generalized Anxiety Disorder (GAD-2) questionnaire. The authors found higher odds of depression and anxiety among survey participants who reported being displaced for over a week compared with other participants. Furthermore, they found a dose-response association between the duration of displacement and these mental health outcomes: The longer the displacement, the more likely depression and anxiety. The authors noted that the findings point to the need for plans to address the mental health care needs of populations displaced by natural disasters.

Applying these findings to SCI, recurrent climate-related disasters can exacerbate existing challenges in health management, mobility and care coordination. Disruptions to routines, medication schedules, assistive technologies, personal care and thermoregulation increase the likelihood of depressive and anxiety symptoms, particularly when displacement occurs. Health professionals should thus incorporate brief disaster-exposure screening into post-event consultations, review and update heat and evacuation plans and ensure continuity measures are in place, including medication supply, equipment charging and maintenance and contingency arrangements for carers. Where indicated, clinicians should provide or refer to evidence-based psychological support.

In parallel**,** SCI advocacy organisations should engage as members of disaster and climate-health committees to advance policy and service changes that explicitly account for disability-related needs across preparedness, response and recovery from disasters.

Important resources: Australian Government and other mental health support

- The Australian Government's National Mental Health Commission has a framework to support Australians' mental health through disasters, and
- ReachOut Australia provides an online chat service to a peer worker if you need support to cope with stress from bushfires, floods and other natural disasters. ReachOut also offers other advice for young people, such as Five ways to manage your well-being during the bushfires, which includes gratitude for those fighting the fires, being generous in terms of time, money and spirit.

17.5. Australia's climate risk assessment: What does the future hold?

In September 2025, the Australian Government released its National Climate Risk Assessment after two rounds of extensive consultation. Also in September 2025, the Government published its National Adaptation Plan. Below is information on the Risk Assessment and the Adaptation Plan.

Video: Australia's national climate risk

The National Health and Climate Strategy accompanying video explains why we need to plan and adapt to rising temperatures and other adverse weather events. The actions are highlighted in the September 2025 National Adaptation Plan, which we explore below.

The 2025 National Adaptation Plan identifies the 10 priority hazards facing Australia, for which planning and adaptation are required, while continuing to reduce emissions (mitigation) (**Figure 17.1**).

Figure 17.1. The 10 priority hazards identified in the 2025 National Adaptation Plan. *Source:* National Adaptation Plan, Department of Climate Change, Energy, the Environment and Water, Canberra, 2025, CC BY 4.0

The Australian Climate Service website has a video explaining these 10 priority hazards for Australia. In the drop-down menu, Understanding hazards (Australian Climate Service) provides additional information on the hazards likely to impact Australia. Below are the links to the 10 hazards, with different types of floods amalgamated into one hazard and two types of storms combined in Floods and Storms:

1. Heatwaves and temperature extremes
2. Floods, including riverine and flash flooding and coastal and estuarine flooding
3. Bushfires, grassfires and air pollution
4. Storms, including extratropical storms and convective storms, including hail
5. Tropical cyclones

6. Drought and changes in aridity
7. Coastal erosion and shoreline change, and
8. Ocean warming and acidification.

The Hazards section has an interactive tool to explore how the 10 priority hazards are likely to change across three temperature increases above the current 1.2 °C rise, which in reality may already be 1.5 °C.

In terms of risks, eight categories with 63 significant climate risks for Australia have been identified in the 2025 National Climate Risk Assessment (p. 15 for a diagram identifying the 63 risks). These are risks to (# risks, in terms of):

1. Aboriginal and Torres Strait Islander Peoples (7, including self-determination, Country, cultural knowledges, practices, values and sites)
2. Communities (10, including water, what the natural environment provides, physical and mental health [...])
3. **Health and social support** (9, including individuals and communities at risk, health and extreme weather, mental health, service delivery [...])
4. Infrastructure and the built environment (10, including supply chains, building liveability, critical and essential services infrastructure)
5. Defence and national security (8, including migration and displacement, social cohesion, disaster response and recovery)
6. The natural environment (8, including natural resources, species loss, natural places and associated values)
7. The economy, trade and finance (5, including the Australian economy, Government finances and capacity), and
8. Primary industry and food (6, including ecosystem services, infrastructure, health and well-being).

Figure 17.2 below shows the Health and social support risk category, which is the most relevant for this Chapter.

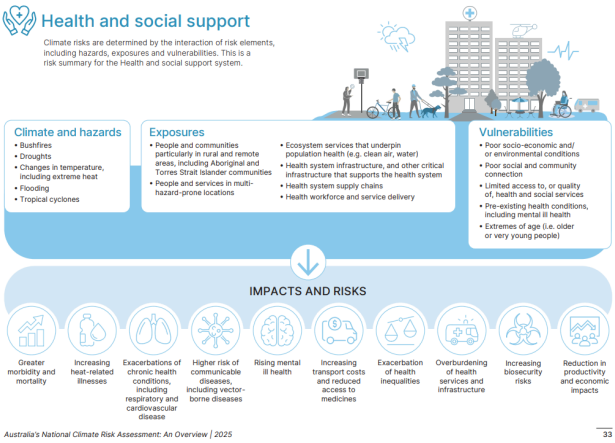


Figure 17.2. Details in terms of the risks to *human health and social support. Source:* Australia's National Climate Risk Assessment (2025), Australian Climate Service, CC BY 4.0, p. 33.

Media stories: Australia's climate risk

- The Guardian's Australia's horrifying climate future in four charts – and how we can avoid the worst explains in four charts how hot it is going to get in Australia.
- First climate risk assessment finds 1.5 m Australians at risk from sea level rise by 2050 – ABC News has extracted data from the 2025 National Climate Risk Assessment. The release of this report was soon followed by Australia's legislated 2050 emissions reduction target (62-70% below the 2005 level).

Interesting resources: How hot will your suburb get?

To explore how hot Australia is predicted to get if it is 'business as usual', i.e. no reduction in greenhouse gas emissions.

Have a go with these three tools:

- The Australian Conservation Foundation's MyClimate 2050 tool allows you to insert your postcode. You will see the average historical (1960-1990) temperature for your postcode, followed by the predicted heating by 2050
- How hot will your neighbourhood be by 2050 (Climate Council), with a Direct link to the tool, and
- The Australian Climate Service Heat Health Risks page introduces the Health Risk Index. You can add your physical address to one of the maps.

17.6. Australia's response to a changing climate: National Health and Climate Strategy and National Adaptation Plan in relation to disability

In the extensive consultation process for the 2023 National Health and Climate Strategy, representative organisations included patients and the disability sector. The Stakeholder Report mentions 'disability' in two places in the **Tackling Health Inequities** section:

- **Vulnerable populations and health equity:** The Strategy and principles should clearly define and describe which populations are most at risk from climate change, acknowledge that each group is impacted differently, and acknowledge the significant intersection between many of these groups and other demographic factors.
- **Support and incentives for lower carbon:** People in the disability sector often rely on their cars for transport, as public transport sometimes is not accessible or appropriate for them. As many cannot afford sustainable transport options such as electric vehicles, this barrier needs to be removed, and people supported to invest in low-carbon travel options. A less emissions-intensive transport system also needs to be more accessible and affordable.

In terms of**Prevention and Preparedness**, *Surge workforce capacity* was considered crucial for preparing for extreme climate events. Stakeholders were of the opinion that, to ensure continuity of care, a surge workforce is essential to adapt and respond effectively to shifting demands, patient volumes, and workforce supply disruptions during extreme events. 'Disability' was included in the following:

- Hospital emergency departments, First Nations communities and *recipients of disability care in the community*. Agencies should work closely with Primary Health Networks, Aboriginal Community Controlled Health Organisations and Local Hospital Networks to support these areas, and
- *State and territory governments should be responsible for funding and developing hospital surge workforces*, while the Department and the Commonwealth Government should focus on primary, aged and *disability care.*

Still under**Prevention and Preparedness**, for *Scenario exercises and community training,* it was agreed that performing response exercises, community disaster training and community awareness on disaster preparedness are critical actions in better preparing for climate change extremes. Many stakeholders suggested that agencies should collaborate to facilitate regional, multi-district workshops, including future local climate scenario planning exercises. This should involve primary care, emergency services, hospitals, First Nations leaders*, the disability sector* and aged care facilities, among others.

In translating stakeholder perspective into actionable items in the 2023 National Health and Climate Strategy, the following was extracted from the Strategy:

- **People with chronic illness**, including physical and mental health conditions such as asthma, heart disease, chronic kidney disease or anxiety and depression, are at particular risk during bushfires, heatwaves or floods. People at risk of developing chronic conditions may also be negatively affected by these climate events, as they may delay or completely avoid health screening assessments during these times. *People with disability* – for example, those with restricted mobility – and their carers are more likely to be affected by flooding and to have less capacity to successfully adapt or relocate to safe long-term housing.

- **Working with local councils and state and territory governments to improve public transport options to health and aged care facilities.** Walking or cycling to health and aged care facilities may not be possible or practical, particularly due to disability and/or long distances to services. Furthermore, almost 700,000 households in Australia do not have a motor vehicle, so driving to health and aged care facilities may not be an option. Improving public transport options to health services will improve access and reduce inequities. It can also reduce health system emissions from staff and patient travel as public transport becomes cheaper and more convenient.
- **Active travel is not always a viable optionfor everyone.** Uneven and narrow pavements and other limitations to accessible infrastructure can disproportionately prevent *people with a disability*, children and the elderly from walking or travelling with mobility aids. Furthermore, people with care responsibilities can experience difficulty undertaking journeys by active modes or even by public transport. These challenges require ongoing creative policy-thinking.

A progress report was provided (updated 4 June 2025), which did not mention the term 'disability'.

In terms of the 2025 National Adaptation Plan, extensive action is underway in Australia in response to predicted future climate risks: $3.6 billion has been committed to adaptation and resilience measures since 2022, and around $9 billion to 2030 has been committed to policies and programmes that support broader efforts. Key adaptations already underway include:

- The Disaster Ready Fund, the Government's flagship initiative for disaster resilience and risk reduction, provides up to $1 billion over five years from July 2023 to 2028. This fund is part of the Government's National Emergency Management Agency (NEMA), which develops, leads and coordinates Australia's connected and collaborative approach to emergency management. NEMA works to reduce disaster risk and build resilience, such as the Northern Rivers Resilience Initiative and the National Emergency Management Stockpile
- Continuing the Regional Investment Corporation (RIC) by providing an additional $1 billion in loan funding and broadening the RIC's loan scope to include assistance for improving climate resilience, boosting sector productivity, and supporting agriculture to be part of Australia's net-zero transition
- Investing $250 million in the Saving Australia's Bushland Program over the next 5 years to boost conservation, contributing to the 30 x 30 target, meaning that 30% of land needs to be conserved by 2030 and 30% of marine areas by 2030
- Investing in blue and green infrastructure and integrated catchment management to support urban cooling, climate resilience and flood mitigation in urban areas through the $200 million Urban Rivers and Catchments Program
- A $15.9 million Torres Strait and Northern Peninsula Area Climate Resilience Centre that will provide a coordinated response to the on-ground impacts of climate change in these areas
- $11.4 million over 4 years to support First Nations groups to participate in consent and agreement-making processes for Australian Carbon Credit Unit (ACCU) Scheme projects

on Native Title lands, and

- Implementing Australia's first National Health and Climate Strategy and development of a National Adaptation Plan, led by the Department of Health, Disability and Ageing.

Clinical resource: A clinician's perspective

You might be interested in reading Professor Nick Talley's October 2025 perspective on the Australian Government's responsibility to address the country's contribution to climate change.

The article is pertinent, considering that in late September 2025, the International Court of Justice (ICJ) issued a groundbreaking ruling for climate action, which stated that countries are legally obliged to prevent harms caused by climate change. As we know, the emissions from burning fossil fuels are the biggest contributor to climate change. During the court's deliberations, Australia sided with other fossil fuel exporters and major emitters such as Saudi Arabia, the US and China. The ICJ disagreed. It found that countries have additional obligations to protect the climate and take action to prevent climate harm within and outside their national boundaries. These obligations arise in human rights law, the law of the sea and general principles of international law.

In Australia, Independent Senator, David Pockcock, has been petitioning Canberra for the 2022 Climate Change Bill/Act to be amended to include a Duty of Care.

"We should be thinking about young people when we make decisions. It's our duty as politicians and policy makers to make sure the climate young people and future generations inherit is one they can live and thrive in. I want to be part of a parliament, and more importantly a country, that takes this responsibility seriously." **David Pocock**, Independent Senator for the ACT.

"Like so many of my friends, I'm increasingly scared about my future. The past few years have seen temperatures that have broken records and climate-fuelled natural disasters unfolding across the world. And all evidence shows us this will only get worse unless we act. We are at a crossroads in history, the government can either act in accordance with its duty to young people to deliver us a safe and liveable future or set us on a path to climate catastrophe." **Anjali Sharma**, lead litigant in *Sharma v Minister for the Environment*

The petition on the Duty of Care website states:

> *"We support the Climate Change Amendment (Duty of Care and Intergenerational Equity) Bill 2023 which imposes a statutory duty on decision makers:*
>
> 1. *To consider the likely impact of decisions that could harm the climate on the health and*

well-being of current and future children as the paramount consideration; and,

2. *Not to make a decision that could harm the climate if the decision poses a material risk of harm to the health and well-being of current and future children in Australia."*

17.7. Individuals living with SCI are at risk in a changing climate

When applying a 'disability' lens to a changing climate, there is consensus that individuals living with SCI are likely to be *physically, physiologically and psychologically* at risk in terms of the climate-related hazards, particularly rising temperatures, smoke from wildfires, cyclones and flooding.

Newman and colleagues' (2025) scoping review on climate change and health through the lens of *physical medicine and rehabilitation (PM&R)*, which reflects North America, found that most physiatrists (rehabilitative physicians) are concerned about climate change threatening the health and well-being of patients requiring PM&R services. While there has been increasing research over the past 15 years, gaps remain in the nexus between PM&R and climate change, with several regions around the world poorly represented in the literature. The authors recommend that physiatrists work with persons with disabilities to ascertain their specific concerns, perspectives and solutions regarding climate change. This collaboration will help to advance mitigation and adaptation strategies related to PM&R to ensure that knowledge and preparation are progressing towards better outcomes in the climate crisis.

Below, we expand on the acknowledged physical (mobility), physiological and psychological 'vulnerabilities' of a changing climate for people living with SCI.

17.7.1. Restricted mobility, accessibility and power outages

If one lives with SCI and uses a wheelchair, while it may still be possible, *albeit* physiologically risky, to be out and about on a hot day or during a heatwave, mobility will be restricted in a flood or following a cyclone when trees are brought down and debris scattered. During such events, power outages are common and would certainly be an issue for individuals who require ventilation and for those who live in high-rise apartments if there is no backup power. It may then not be possible to attend healthcare appointments, go shopping for groceries or support workers to visit. Sometimes during heatwaves, the power grid may not cope with the demand from air conditioning, which could have dire consequences in terms of temperature regulation. As will be discussed later, preparation for such events could be the difference between life and death. Standard emergency evacuation procedures often fail to account for the time, equipment and support needed to safely evacuate someone with SCI, particularly those who use power wheelchairs or require multiple assistants.

Power wheelchairs and other assistive technologies require electricity for charging. During climate-related power outages or evacuation scenarios, loss of mobility can be life-threatening and severely limit the capacity to seek safety or access resources.

17.7.2. Physiological vulnerability

For Alexander and colleagues (2019), given the range of potential impacts of a changing climate on compromised organ systems, individuals living with SCI easily top the list of those at risk. It is therefore imperative that those living with SCI are involved in discussions of climate change and disability to voice their concerns and advocate for their health and well-being.

17.7.2.1. Hot weather and extreme heat

In **Chapter 2**, SCI injury level and completeness were discussed in terms of the impacts on various organ systems. Ebi and colleagues' (2021) article, 'Hot weather and heat extremes: Health risks', provides a list of physiological factors associated with increased risk of death during hot weather and extreme heat, such as anyone with cardiovascular, respiratory, especially chronic obstructive pulmonary disease, and genito-urinary disease, such as chronic kidney disease (CKD), diabetes and hypertension.

In addition, Ebi and colleagues identified a range of circumstances that place individuals at greater risk, some of which would apply to individuals living with SCI:

- **Altered sensation of thirst leading to potential dehydration:** While SCI may not directly cause a loss of thirst sensation, some individuals have reported a diminished or altered sense of thirst, possibly due to the disruption of sensory signals. Thirst might be impacted by autonomic dysfunctions, such as bladder and bowel control, leading to urinary retention or incontinence, which may limit fluid intake. A third factor that could lead to dehydration is dysphagia (difficulty swallowing), making it difficult to consume fluids, and
- **Poor regulation of body temperature due to a high-level injury:** This would make a person vulnerable in hot (*hyperthermia*) and cold (*hypothermia*) ambient temperatures.

Important resource: Knowing the risks and taking action

The Craig Hospital's website (with a downloadable PDF) provides good information about how to check for dehydration in hot weather, which includes dark urine, frequent constipation and dry skin, adding: *"Finally, know that your thirst sensation runs quite a bit slower than your body's need for water. By the time you realize that you're feeling thirsty, your body will already be suffering from drought. Most experts suggest that you drink before you get thirsty. If you're exercising – even if you're just pushing a long distance – drink water before, during and after."*

Two 'vulnerable' groups are:

- Children younger than a few years have a lower heat loss capacity relative to adults, while a relatively high surface area allows them to absorb heat more quickly when the air temperature is higher than the skin temperature. Infants are also unable to behaviourally thermoregulate, such as remove themselves from hot cars, and
- Older than 65 years, due to a diminishing sense of heat and cold and thirst sensations, as well as a diminished sweating ability. Many older people are on several medications (***polypharmacy***), so they could be affected in hot weather.

Important information: Medications and hot weather

Several prescription medications could add to the risk. These include drugs that could alter the thermoregulatory centre, such as anti-cholinergics, anti-depressants, anti-epileptics, anti-hypertensives, muscle relaxants and opioids, possibly by altering sweat gland activity. Additionally, some medications alter cutaneous vasculature stimulation peripherally, such as anti-cholinergics, anti-histamines, anti-psychotics, anti-vertigo medications, bladder anti-spasmodics, gastric anti-secretories and muscle relaxants, which again affect heat dissipation and sweat production. It is worth noting that there is almost no human research undertaken on the effects of regularly prescribed doses of many drugs in heatwave conditions.

Five drugs that can make it harder to cope in the heat, and a longer but not complete list was provided in this January 2026 *Conversation* article: The common medications that can become 'quite dangerous' on hot days.

Research: Physiological impacts of heat

- Alexander *et al.*'s (2019) cross-sectional survey of US health professionals (HPs) working in SCI care identified individuals living with SCI as one of the most climate-sensitive disability groups, in particular those who could not maintain a constant core temperature independent of ambient temperature. Thus, health concerns during extreme heat reported by these health professionals (%) included:
    - Difficulty regulating temperature (47.2%)
    - Fatigue (41.6%)
    - Breathing difficulties (40.0%)
    - Dehydration (37.6%)
- Although not dealing specifically with climate change, Vasquez and colleagues' (2024) cross-sectional survey of individuals with SCI self-reporting the effects of warmer seasonal temperatures provides a useful lens to examine the impact of higher ambient temperature, an increasing likelihood in current climate modelling, on individuals with different levels of SCI. Individuals with higher-level injuries (quadriplegia) reported significantly more difficulty cooling down compared with those living with paraplegia and non-SCI participants. This impacted their daily living activities, such as limiting their outdoor social activities and attending health appointments. Individuals living with SCI, particularly those with higher-level injuries (such as quadriplegia), experienced more frequent symptoms of heat-induced dizziness and light-headedness, suggesting that as the level of impairment increases, so does vulnerability to heat-related complications, and
- Sisodiya and colleagues (2024) provide an evidence-based summary of how the incidence, prevalence and severity of many nervous system conditions, such as stroke, neurological infections and some mental health disorders, can be affected by climate change. The data show broad and complex adverse effects, especially of temperature extremes and wide diurnal temperature fluctuations to which people are unaccustomed. The authors suggest local forecasting may offer some protection. They also ***concluded*** that only a few studies project the future effects of climate change on brain health, advocating for urgent research relating to those at risk.

Below are additional physiological factors that may heighten vulnerability to adverse weather events:

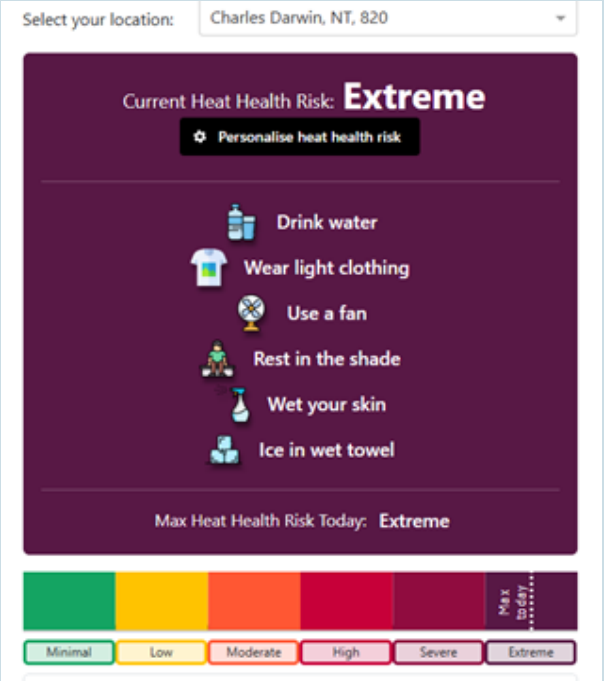
- **Compromised cardiovascular function:** Circulatory challenges may arise in both hot and cold conditions, including reduced vasodilation needed for heat loss in high temperatures and impaired vasoconstriction required to conserve heat in cold environments
- **Diabetes:** Extreme weather can create multiple complications for people with diabetes, such as reduced access to primary care, hospitals and medication, increased psychological stress, and lifestyle disruptions that influence glycaemic control and day-to-day diabetes management (Ratter-Rieck *et al.*, 2023)
- **Sleep apnoea:** This condition has been associated with hotter overnight temperatures linked to a changing climate (Lechat *et al.*, 2025; Thompson, 2025)

- **Reduced immune function:** Lowered immunity (Imberti *et al.*, 2025) increases susceptibility to infections, for example, melioidosis during floods, vector-borne diseases and mould-related illnesses during periods of high humidity. Thunderstorm asthma, a storm-triggered hypersensitivity reaction during pollen season, is another example
- **Moisture-related skin vulnerability:** Rising humidity, including during power outages, can contribute to skin breakdown and increase the risk of both heat- and cold-related illnesses (Alexander *et al.*, 2019), and
- **Heat-related medication instability:** Heat waves may compromise the effectiveness of medications used to manage spasticity, pain or bladder function and without refrigeration during power outages, some medications may degrade or become unusable.

Key recommendation: HeatWatch app

The University of Sydney has developed HeatWatch, a postcode-based heat app. In the words of one of the developers who permitted us to use the screenshots below,*"HeatWatch does not just integrate temperature, but also humidity and other aspects of the climate that determine how hot is too hot. We figure this out using a physiological model."* Once the postcode image appears (**Figure 17.3a**), you can use the dropdown Detailed Cooling Recommendations section to see how to cool yourself, keep your house cool and plan your day. A short video explains the app.

The app can be personalised. The developer also indicated that*"it is probably worth flagging that in the 'personalised' part of the tool, you can create profiles including age, chronic disease and medications, etc. We do not currently have spinal cord injury as a category, but the risk levels will likely be higher for a given set of environmental conditions for some with SCI."*



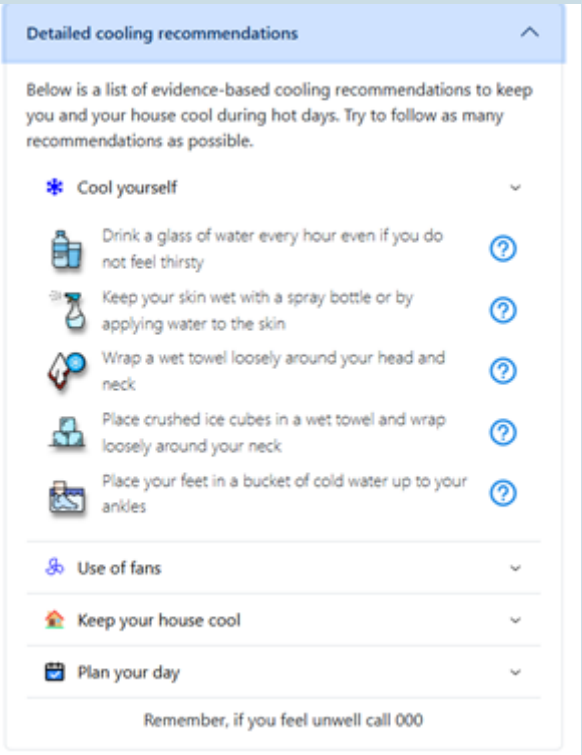
While writing this section of the resource on 29 October 2025, a coolish day on the Gold Coast with no heat warnings, I changed the postcode to Darwin. The heat warning and recommendations are on the left and right, respectively.

Figures 17.3a (left) & b (right). Extreme heat warning for Darwin on 29 October 2025 (left) and advice about how to cool yourself and your home (right). If the app is personalised, there would be specific recommendations. *Source:* University of Sydney Heatwatch, Heat and Health Research Centre, permission to use screenshots granted by Ollie Jay and Federico Tartarini.

The HeatWatch tool has been adapted for a Sports Heat Tool (30 sports). You can read about the Sports Heat tool here.

Disclaimer: As with any health app or recommendation, communicating with your GP is always advised.

Carers and support workers, as well as health professionals, can also use the app, as it provides hourly temperatures colour-coded from **green (minimal risk)** to **maroon (extreme risk)**. It also provides advice for the day on hydration and clothing to wear, among other things, depending on the risk. Since many individuals living with SCI are more at risk in terms of heat, it may be advisable to consider the advice for the next heat warning level.



Clinical resource: Chapter 21 Health impacts of climate change

Relevant to the Australian context is Chapter 21, Health impacts of climate change (Matthews & Larkins, 2024) in a joint National Aboriginal Controlled Health Organisation-Royal Australian College of General Practice (NACHO-RACGP) publication, National Guide to Preventive Healthcare for Aboriginal and Torres Strait Islander people. Although the Chapter is aimed at promoting the health and well-being outcomes of First Nations people, often regarded as 'vulnerable' in terms of access to health resources, etc., the tables in the **Recommendations** section relate to types of preventative activities that would contribute to health and well-being improvement in a changing climate. Tables highlight preventative activities, such as immunisation (children and high risk individuals), screening (for vulnerabilities to heatwaves and other extreme events), behaviour (those with chronic respiratory, cardiac, CVS, diabetes and particularly the elderly) and medications, as some may be less stable with extreme temperature fluctuations without refrigeration, while other may be associated with higher degrees of heat-related morbidity.

Key information from Chapter 21 includes:

- In the current climate emergency, Aboriginal and Torres Strait Islander communities are disproportionately exposed to environmental degradation, rising seas and extreme weather, unjustly compounding existing health and well-being inequities
- GPs and other primary healthcare professionals have a key role in preventing adverse health outcomes in their patients from climate change and extreme weather events and in advocating for patient access to appropriate resources to reduce health risks. Consideration of the patient's context is needed to develop preventive health strategies for climate change. This may include their location and potential climate hazards; demographics and disease profile; access to financial and social resources, including adequate housing and access to cooling, power and refrigeration
- Best-practice clinical care that holistically promotes physical, social and emotional well-being (SEWB) and includes activities that facilitate connection to and caring for Country will support the health of patients, communities and the planet for future generations
- Practice recommendations centre on identifying patients at risk of climate change effects, educating patients on physical and mental health impacts from climate change events, designing risk-reduction strategies appropriate to patient context, helping patients and their families to prepare disaster plans and strong advocacy where necessary to improve environmental, social and cultural determinants of health, and
- GPs and other primary healthcare professionals can also model behaviours that reduce carbon emissions and urge their profession and the broader health and political systems to adopt environmentally sustainable policies and practices.

17.7.2.2 Cold weather

As temperature regulation is affected for many individuals following a high-level SCI injury, these individuals are vulnerable to both non-optimal heat and cold temperatures. The general climate change literature, however, describes the impact of heat on the body, with little written

about cold temperatures. In a March 2025 *Lancet Planetary Health* commentary, Alahmad and colleagues asked this question, Are there more cold deaths than heat deaths?, in response to a global analysis reporting that of the 9.4% attributable temperature-related deaths, on average 8.5% (4.6 million deaths) were cold-related, with only 0.9% (489 000 deaths) heat-related. After explaining the mathematical intricacies of how these figures are calculated, leading to this general conclusion, it is important to consider the influence of temperature on the risk of death on a given day relative to the optimal temperature. When the researchers used study data from Barcelona (2000-2018) and compared the risk on the coldest day (1.4 °C) with the hottest day (32.1 °C), which, at the time was rare, they found more cold days and, consequently, more cold-related deaths. The authors, however, concluded that with climate change, the number of hot days will increase, as will the frequency of extreme heat events, resulting in more deaths. Compared with the 2018-2020 summers, Spain's summer of 2022 had three times as many extreme hot days, leading to nearly five times as many heat-attributable deaths.

"The heat doesn't bother me as much as the cold. I tried to think how I would go through winters without a heater. I still have it, a little heater next to my bed." **Dinesh Palipana**

We do not really think about cold temperatures in Australia, but winters are cold in Victoria, Tasmania, NSW and South Australia. Australia's National Health and Climate Strategy has used the Victorian Healthy Homes Program as a case study (Case Study 18 below) about energy efficiency in Victorian homes, which also removes the indoor air pollution hazard of gas and woodfires.

Important information: Case study 18: Victorian Health Homes Program

"Cold winters in Victoria, combined with thermally inefficient housing, can pose serious health risks to some populations. Cold indoor temperatures are associated with negative health impacts for elderly people, children and people with disability or chronic illnesses. High indoor humidity can also exacerbate asthma and allergies.

The Victorian Health Homes Program was a randomised controlled trial that measured the impact of home upgrades to improve energy efficiency and thermal comfort on temperature, energy use, health and wellbeing. Run by Sustainability Victoria, the program delivered home upgrades to 1000 vulnerable households in the state. It found a small upgrade (average cost $2809) increased indoor temperatures and improved mental health outcomes during the winter period, including reduced breathlessness and improved mental health and quality of life for participants. Other benefits include lower energy bills and reduced emissions, due to significantly lower gas use.

Improved health outcomes translated into savings to the health system of $887 per person over the three-month winter period. Cost-benefit analysis also demonstrated the upgrade would be cost-saving within

three years, yielding new savings of $4,783 per household over ten years due to energy savings and health gains.

Climate change is increasing housing insecurity in Australia. Floods in Queensland and NSW in 2022 affected an estimated 20,000 homes, with 3,800 homes deemed unlivable in NSW. The 2019-20 bushfires in south-eastern Australia triggered around 65,000 displacements and destroyed more than 3,100 homes. Climate-related disasters can strain transitional and short-term housing services and providers as well as the broader housing sector. Many people experience mental trauma from the experience of emergency evacuation and losing their homes. Homelessness can have significant impacts on a person's mental and physical health, their ability to access healthcare, and their security and safety. In addition, people already experiencing homelessness prior to a climate-related disaster will often have less access to public safety information and services, increasing danger during events and creating barriers to recovery."

Source: Australian Government, National Health and Climate Strategy, CC 4.0.

17.7.2.3. Wildfire (landscape) smoke

Wildfire (now often called landscape) smoke can have severe impacts on everyone's health, but especially for those with an existing respiratory or cardiovascular condition, which is common in individuals with SCI. Smoke inhalation can:

- **Increase aspiration risk:** SCI can impair effective coughing, increasing the risk of inhaling smoke and other irritants into the lungs
- **Exacerbate any existing respiratory problems:** Likely to lead to increased coughing, shortness of breath and wheezing. Those with asthma will be particularly at risk, and
- **Increase risk of respiratory infections:** Wildfire smoke can irritate the respiratory tract and weaken the immune system, making individuals more susceptible to respiratory infections, such as pneumonia and bronchitis. The diaphragm and muscles involved in breathing, leading to reduced lung capacity and increased difficulty breathing.

Important resource: Bushfires and your health

Healthdirect's Bushfires and your health is a useful resource that addresses the impacts of bushfire smoke on health. These key facts are provided:

- Bushfires are common throughout Australia and can happen at any time of the year
- There is a higher risk of bushfires in areas close to the bush or grassland

- If you live in at-risk areas, be prepared for a bushfire, make a survival plan and create an emergency kit for your health needs
- Bushfire smoke can have serious health effects, and
- Health conditions such as asthma, heart issues and diabetes can be worse during a bushfire.

Key recommendations: Be proactive and protect yourself from bushfires

In response to the January 2026 bushfires, Professor Brian Oliver wrote 'How to protect yourself from bushfire smoke', saying that there is no safe level of exposure. His key recommendations:

- *"If you are concerned about smoke, it's important to talk to your health-care provider, especially if you are pregnant or have a pre-existing health condition. In an emergency, call triple 000. […]*
- *Be proactive to minimise exposure and manage potential respiratory challenges. Recommendations for individuals living with SCI during wildfire smoke:*
    - *Monitor air quality as soon as you hear about a wildfire by checking local air quality reports and forecasts to determine the level of smoke in your area*
    - *Make sure that you have supplies, particularly medications*
    - *If you have to stay indoors, close windows and doors to minimise smoke exposure*
    - *Wear a mask if you need to go outdoors because you need to travel to work, school, university or for a health appointment, wear an N95 or another suitable mask*
    - *Stay hydrated, as this helps loosen mucus and clear the airways*
    - *Use an air purifier with a HEPA filter to remove particulate matter from the air*
    - *Consult a healthcare professional if you are concerned about an aspect of your health, and*
    - *If you experience symptoms like coughing, shortness of breath or dizziness, seek medical attention immediately."*

As was discussed in **Chapter 3**, people living with SCI are reported to have higher levels of psychological distress. Climate change has already been linked to heightened anxiety and suicidal behaviours in the general population, as has been described by Australia's Black Dog Institute and Doctors for the Environment.

Research: Climate change and suicidality

- Burke's (2024) recent Australian research, 'Rise in suicidal behaviours among young people linked to hotter temperatures', has linked hot weather to an increase in suicidal thoughts and behaviours among young Australians, prompting calls for an overhaul of public health approaches to higher temperatures.
- Dey and co-researchers (2024) found ED visits by young people for suicidal thoughts or behaviours increased by 1.3% for every 1 °C rise in daily mean temperature. Risks are not isolated to heatwaves. They included single hot days.
- Boyd *et al.* (2024) undertook a qualitative study involving clinicians and clients at a youth mental health service in regional NSW. Clients and clinicians responded to a version of the same questions:
    - Whether the effects of climate change impact the regional youth with mental health problems,
    - How young people cope with eco-anxiety, and
    - How regional communities can help young people cope with eco-anxiety better.

To conclude: The researchers found that ***eco-anxiety*** can be experienced by regional youth with mental health problems as both an acute response to 'natural' hazards and a more sustained sense of hopelessness about the future. Impacts of acute anxiety and chronic hopelessness, with their associated depression risk, among young people with pre-existing mental health problems warrant further investigation, as this study suggests, may exacerbate their existing conditions. Clinicians and clients in this region would benefit from specific training and resources related to the identification and treatment of eco-anxiety.

If non-disabled people are vulnerable to the psychological impacts of adverse weather events, the impacts will be exacerbated for individuals with SCI, who may already have stress and anxiety relating to the physical and physiological impacts of their injury. Several studies have reported psychological vulnerability in the context of climate-related events for individuals with SCI, including anxiety, *post-traumatic stress disorder (PTSD)* and major depressive disorder (MDD), during hurricanes, largely due to elevated perceptions of threat and reliance on others for evacuation and safety (Shapiro *et al.,* 2020a, 2020b). Andreae *et al.* (2024) found that individuals with pre-existing trauma or disability-related stressors were more susceptible to storm-related psychiatric symptoms. Alexander *et al.* (2019) used the term 'climate jail' to describe the prolonged confinement experienced by individuals with SCI during periods of extreme environmental conditions. This isolation was associated with heightened psychological distress, including symptoms of depression, social withdrawal and a diminished quality of life.

17.7.4. Cyclones, often accompanied by flooding

Many parts of the world are prone to cyclones, which are often accompanied by floods. In an earlier section, we provided Wu and collaborators' (2024) summary of the general impacts of

flooding for communities. For individuals using wheelchairs or with impaired mobility, many of the impacts Wu and colleagues (2024) described are relevant, such as increased mortality from drowning or an inability to access health services, hypothermia, exacerbation of existing chronic medical conditions, including psychological well-being and risk of communicable diseases and wound infections. We should not forget power outages that could compromise medications if they require refrigeration and food. Power outages would mean elevators would not work unless there was backup power. There may also be a disruption to the water supply. Particularly with flooding, support workers may not be able to travel.

With Australia prone to flooding, Bailie and colleagues (2022) explored exposure to risk and experiences of river flooding for 164 people with disability and 91 carers in the Northern Rivers, NSW, Australia, six months after river flooding in 2017. Both groups had increased odds of having their home flooded. On evacuation, respondents reported inaccessible, conflicting and confusing information regarding flood warnings. Essential services such as healthcare and social services were disrupted. After taking socio-demographic factors into account, respondents with a disability and carers had greater odds of probable PTSD compared with other respondents. Their findings show the profound impact and systemic neglect experienced by people with disability and carers during and after the 2017 flood.

Dinesh's story: Cyclone Alfred, March 2025, Gold Coast

Did you attend to anyone with SCI in ED during Cyclone Alfred?

"During [Cyclone] Alfred, they had two people [with SCI] who lived at Mount Tamborine who had to be brought to the hospital because support workers had their own issues and could not always get there.

When the lift didn't work, who had to get you up and down the stairs during Cyclone Alfred?

"It was hard. The fire escape, especially. It was very steep. We had three people help. For most stairs, we can just roll backwards down it. The fire escape was actually very steep, and the stairs are very steep. So, it was more difficult than normal stairs, but we did it. Yes, evacuation is an important point. […] I will be doing some work with Queensland Fire and Emergency Services on disability inclusion. One of the leads there was talking to me about Townsville [2025 floods] or somewhere like that in terms of responding to a disaster where they needed to evacuate people. They partnered with the Army, which tried to airlift a person in a wheelchair, but the wheelchair wouldn't fit in the helicopter. I think these are things to consider during disasters."

Rachael's story: Healthcare experiences during Cyclone Alfred

Below, **Rachael Norman** describes her experiences as a mother and a doctor during Cyclone Alfred, Gold Coast, early March 2025.

"My daughter and I were sheltering at home, in a high-rise ocean-fronting apartment which sustained some water ingress through a wind-damaged balcony glass door, which soaked the living area carpets. We were fearful of the windows and glass doors being blown in by the strong winds when the cyclone was at its worst. My daughter sheltered with temporary beds in the hallway, away from any windows. The basement car park was flooded. Unlike most of the Gold Coast, we still had power and limited Internet. There was widespread damage, including vegetation and debris on the roads, fallen power lines and flooding that made many roads impassable. The last thing I wanted to do was leave home to go outside or drive somewhere.

As a credentialled special-interest GP for Queensland Health providing gynaecology outpatient services, I was contacted by the GP Liaison Officer requesting me to admit and provide medical cover at Varsity Day Hospital for 24 diverted social admission patients, who would be arriving in the coming hour to free up beds at the other hospitals. All the patients were chronically unwell and frail, mostly with COPD, but were overall stable. The majority needed a reliable source of oxygen for their Home Oxygen concentrators, and some had high-level nursing care requirements. Either their homes or their carers' homes had blocked road access, resulting in them being unable to provide the necessary care for these patients.

I was advised to pack an overnight bag in the event that I became 'flooded-in' and to bring my own food and water as the hospital kitchen was not operating. I remember it being very eerie driving the 40 minutes through the roads of the Gold Coast, which are usually congested with multiple lanes of traffic and not seeing another vehicle the whole journey.

An Emergency Physician colleague advised me that during this cyclone, a part of the roof of the Pindara Hospital Emergency Department collapsed and not all generators were able to function as they should have, providing further disruption to the Department."

17.8. Inequity and adverse weather events and disasters

Persons with disabilities comprise 16% of the world's population, with 80% of persons with disabilities living in the Global South. Persons with disabilities are frequently the most affected by 'natural' hazards, climate-induced disasters and global health emergencies, such as the COVID-19 pandemic. Disability is a risk multiplier that cuts across identity characteristics and social determinants, such as gender, age and socio-economic status and amplifies pre-existing social inequalities and power imbalances. Disability is diverse, ranging from physical to cogni-

tive, leading to different exclusion experiences, including in terms of being marginalised and underrepresented in decision-making.

The Sendai Framework for Disaster Risk Reduction 2015-2030 recognises individuals with disabilities as contributing stakeholders, emphasising the need for inclusion in all DRR policies and practices. Similarly, the 2030 Agenda for Sustainable Development commits to leaving no one behind and to ending poverty for all people in all its forms. Achieving the Sustainable Development Goals (SDGs) will be reliant on reducing and preventing disaster risk and ensuring inclusion for all.

Despite the UN Human Rights and the Sendai Framework for inclusion in disaster planning, there is considerable inequity in terms of being involved in disaster planning and in terms of the impacts of disasters. This exclusion is systemic globally.

Research: SCI and disaster planning

- Alexander *et al.* (2019) noted that individuals with mobility issues, such as those living with SCI, are among the most at-risk groups in climate emergencies. Their absence from preparedness plans raises serious human rights concerns. They also noted that, in many instances where climate information is available, it is often delivered in ways that are not accessible to people with mobility impairments, thereby limiting their ability to prepare or respond effectively.
- Stein and Stein (2022) have also highlighted the continued exclusion of people with disabilities from climate mitigation and adaptation planning breaches international human rights obligations, particularly those outlined in the Convention on the Rights of Persons with Disabilities (CRPD). They reported that access to essential services such as early warning systems, transportation, emergency shelters and evacuation support is often restricted, due to inaccessible information, lack of inclusive planning and discriminatory attitudes, placing people with disabilities at greater risk during climate-related events. The authors have advocated for full participation of Disabled Persons' Organizations (DPOs) in international spaces, such as the UN Climate Change Conference of the Parties (COP), calling for disability rights to be built into both national and global climate policies as a matter of urgency. Additionally, they recommended that more individuals with disabilities become health professionals to collaborate in development and disaster risk reduction to address disability discrimination.
- Amatya and Khan (2023) argued that disability must be embedded at every level of climate planning from design through to implementation. Inclusion must go beyond tokenism and should focus on leadership and lived experience informing policy. In addition, Makuyana and Dube's (2024) review found that most climate-disability research originates in the Global North, with limited attention to disability-specific data or distinct subgroups, particularly individuals with mobility impairments and those who are blind, deaf or autistic. Research was skewed towards mental disability and medical sociology. The authors advocate for a rights-based, participatory approach to climate policy, one that places disability at the centre of governance efforts and points out that many climate policies still lack clear definitions of disability and fail to engage disabled communities in co-creating solutions. This ongoing exclusion, they contend, weakens both the legitimacy and the effectiveness of climate responses, particularly for 'marginalised' groups who are already disproportionately affected.

We also need to look at climate change for individuals living with SCI through an intersectional vulnerability or at-risk lens. Data on how climate change specifically affects people with different types of disabilities remains extremely limited. Many nuances in the lived experiences of people with disability are still not well understood, as discussed in **Chapter 9.** Intersectional vulnerability describes how overlapping factors, such as gender, 'race', income and social isolation, compound disadvantage during climate events. Thus, for a person with a disability, Andreae *et al.* (2024) described highly vulnerable individuals with disability in relation to cyclones in the US, such as those living in flood-prone areas, the elderly, pregnant women, Black and Native Americans. They also raised the issue of climate gentrification, meaning that property in low-risk areas becomes more desirable, resulting in higher prices. While there is no research on the effects of this on individuals with disabilities, this gentrification disproportionately affects individuals who are Black, unemployed and/or renters.

Research: Inequity and climate

- Amatya and Khan (2023) highlighted that non-White women living alone or in poverty often face heightened risks during climate events due to barriers in accessing care, timely information and transportation. Additionally, McClure *et al.* (2011) found that among individuals with SCI, women, older people, those from minority backgrounds and individuals living alone reported significantly lower levels of preparedness and reduced ability to evacuate
- For Stein *et al.* (2024), despite more than 1 billion people with disabilities being disproportionately and differentially at risk from the climate crisis, this is notably absent from climate policy, programming and research. To advance climate justice, urgent action is required. Below, they offer a list of Guiding Principles for disability-inclusive climate research and action: Guiding principles for global disability-inclusive climate research and action:
    - Recognise that people living with a disability and their representative organisations are experts on their own lives, with experience as change agents and value disability knowledge
    - Enable organisations of people living with a disability and researchers with disabilities to participate in the development, design and implementation of climate knowledge and solutions
    - Value knowledge diversity in decision-making and social change, including the Traditional Knowledges of Indigenous people with disabilities.
    - Enable representation of a diverse range of disability perspectives, including the frequently marginalised categories of people with intellectual and psychosocial disabilities, displaced people and individuals facing intersectional discrimination based on gender, age, race, caste, class and other categories
    - Ensure that disability perspectives from low-income countries and small island states are represented in global decision-making and policy formation.
    - Adopt a decolonial approach that recognises harms and accordingly decentralise the dissemination of resources and funds
    - Enable people living with a disability to access co-generated knowledge and climate information
    - Ensure climate advocacy, policy, processes and solutions respect, protect and fulfil disability

human rights
    - Make sure that disability communities decide on measures of well-being and success and enable disability-inclusive accountability mechanisms

- Jodoin *et al.* (2025) have provided the first systematic analysis of whether, how and to what extent people with disabilities and their human rights are included in two subsets of climate policies adopted by 195 parties to the Paris Agreement. They found that only 41 parties mention people with disabilities in their ***nationally determined contributions (NDCs)***, whereas only 75 do so in their adaptation policies. Moreover, these references are rarely accompanied by concrete measures to include people with disabilities, their rights or their knowledge in climate decision-making. The authors concluded that: *"Our findings demonstrate that states are generally not abiding by their obligations to respect, protect and fulfil the human rights of persons with disabilities under international and domestic law. This exposes people with disabilities to climate-related harm and reinforces, rather than disrupts, the inequities they face in societies around the world. It also fails to harness the multiple benefits associated with a disability-inclusive approach to climate action."*

Exercising one's democratic right to vote (where this exists) is one way to ensure that action is taken. As we identified in **Chapter 10**, even in a country such as Australia, which is lauded for its voting system, inaccessibility remains an issue. Below, **Dinesh Palipana** reflects on those living with disability needing to be strong advocates for action on climate change:

"In terms of extreme weather events… this just got me thinking. How can people with a SCI be a strong voice? Because I went to vote and when you vote, you need to hold a pen, but someone can help. So even accessing democracy and being a voice, and especially with such an important topic like climate change, how do we, how do I contribute, be a voice?

I'm just thinking about this because a lot of advocates for climate change are passionate, vocal participants in this conversation and they are demonstrative, with placards, going to Canberra and standing on the steps of Canberra. So how did people participate in that? Maybe it is through a hand [meaning that someone writes and documents for the voices or is it through voting for the right people, i.e. exercising your democratic right]?

With regard to voting, I think we were discussing how sometimes, maybe another person can be the hand for someone who cannot raise it. This might be where allyship is important. There has been much discourse about access to democracy for people with disability. There are about 1 in 5 to 1 in 6 people with disability in Australia, but one who is using a wheelchair in the parliament. With regards to climate change, he is a Green. But, without proportional representation, you are right, how do people disability engage appropriately in the climate change conversation?"

For Abadi *et al.* (2025), while frameworks exist to guide support for people with disabilities, evidence on building psychological resilience is limited. Drawing on the work of others, the authors highlight the following:

- Three critical factors shape health vulnerabilities*: Exposure, sensitivity and adaptive capacity*. These are especially relevant for people with disabilities, who often depend on others for communication and emergency response
- Social networks, including family, faith communities and workplaces, enhance resilience, yet global climate policy remains largely exclusionary. Fewer than 40% of countries mention people with disabilities in their climate adaptation plans and most references lack meaningful inclusion (Jodoin *et al.*, 2025)
- Calls for disability justice emphasise recognising the diversity within disability communities and addressing intersecting social determinants like poverty and racial discrimination, and
- Despite well-documented barriers, such as inadequate communication and evacuation planning, few solutions have been rigorously tested or scaled. Research and advocacy evaluation are needed to inform effective, inclusive climate responses.

Reminder: Climate change and the rights of people with disability

The UN Office of the Commissioner of Human Rights: Impact of climate change on the rights of people with a disability, as several countries are winding back climate change agreements and discrimination and inclusion legislation.

17.9. To prepare or not prepare for adverse weather and climate events?

In researching content for a narrative review of the impacts of a changing climate on people living with SCI, we (Shah *et al.*, 2026 in press) found a disconnect between perceived preparedness and actual readiness among individuals with SCI during climate-related emergencies. To this end, McClure *et al.* (2011) found that most full-time wheelchair users with SCI felt they would be able to safely evacuate their place of work (94.3%), with a smaller percentage (69.1-84.8%) of the opinion that they would be able to evacuate their home and city or town during an emergency or natural disaster. The researchers concluded that:

"Although improvements are needed for all wheelchair users, targeted education and further investigation of women, people of minority status, people with new injuries, and those living alone are necessary because these people reported a decreased ability to evacuate and are not as prepared as their peers. Wheelchair users should be educated on the benefits of AT, and further investigation is needed to determine whether there is sufficient access to and appropriate use of AT. Clinicians and emergency response personnel should instruct wheelchair users on actual steps to take such as calling local emergency officials and packing a bag of needed equipment and medicine. It is essential that people are educated on the importance of having a plan in place and that they feel they can safely evacuate" (p. 496).

Hogaboom and colleagues' (2013) small US cross-sectional study found that while some individuals living with SCI who were full-time wheelchair users had plans, they mostly overlooked critical components, such as identifying designated post-evacuation meeting places and transportation options, having essential supplies and having vital documents on their person or communicating with their personal support networks. Preparedness, as measured on a 10-point scale, was generally poor, with a median score of 3/10 for both home and town or city evacuations.

Bass and colleagues' (2024) US-based survey highlighted two important insights: Beliefs about not being vulnerable and beliefs about climate change. In the first instance, some individuals living with SCI did not perceive that they were vulnerable, which may, in part, be because only 30% were convinced that climate change was occurring, which, surprisingly, was more than their caregivers (carers or support workers) (12%). In comparison, 61% of the public believed climate change was happening. In an earlier study, Hogan and colleagues' (2011) interviews with US veterans living with SCI found that prior traumatic experiences shaped attitudes about disaster preparedness. One veteran expressed a sense of resignation, based on their past hurricane experience – *"I've survived [Tropical cyclone] Katrina [...] there's nothing that's ever going to be that bad again."*

Media story: Our attitude towards disasters defines how we prepare

A recent *Conversation* article, The disasters we talk about shape our priorities and determine our preparedness, is an interesting read as the researchers explore attitudes to disasters. The authors identify why certain disasters are overlooked while others are front and centre. We and the media tend to focus

on narratives about rapid-onset events, such as floods, wildfires, earthquakes and cyclones, rather than longer-term issues like climate change. For centuries, 'natural' disasters were often viewed as punishment from the gods, but now, research and scientific knowledge is increasingly attributing disasters to human activities, such as burning fossil fuels. The media, of course, focuses on newsworthy and dramatic events like earthquakes and floods and tends not to report on statistics such as droughts, which account for 15% of natural hazard-induced disasters, which exact a high human toll – 650,000 deaths globally between 1970 and 2019. During the same period, weather-, climate- and water-related hazards accounted for 50% of all disasters but only 45% of disaster-related deaths, mostly in lower-income countries. In the authors' view, *a shift in approach to disasters is required, recognising all forms of disasters and their impacts, which are felt inequitably.*

Interesting information: International Day for Disaster Risk Reduction (13 October each year)

Each 13 October since 1989 has been International Day for Disaster Risk Reduction, the aim of which is to highlight disaster risk reduction as part of everyday thinking globally.

17.10. Preparing for adverse weather and climate events: A global perspective

Another long-standing adage that is relevant at a time of increasing adverse weather events is *"It is better to be safe than sorry".* In the same vein, *"A stitch in time saves nine",* and in relation to adverse weather events, this means preventing injury and minimising the costs.

Stories: Case studies and best practice

The United Nations Disaster Risk Reduction's (UNDRR) PreventionWeb website provides international examples of preparedness, including case studies, challenges and best practices to ensure the full participation of persons with disabilities in disaster risk reduction.

Important resource: Strong warning messages are necessary

The UNDRR recently released an infographic (**Figure 17.3**) that comprises the five elements of an effective warning message. One link on the UNDRR's website is to Murdoch University's When disaster strikes, a new toolkit puts power in the hands of the most vulnerable.

Figure 17.3. UNDRR's five elements of an effective warning system: Source, hazard type, location, guidance and time. *Source:* Flickr, Five elements of an effective warning message, CC BY-NC-ND 4.0

The international literature on preparedness for individuals living with SCI largely focuses on the US and on preparing for hurricanes (cyclones). American health professionals (mostly ***Phys-***

ical Medicine and Rehabilitation (PM&R) physicians or physiatrists) caring for patients with a range of neurological, musculoskeletal, chronic pain and sports-related injuries are concerned about the impacts of climate change on their patients. They have published several articles specifically relating to those living with SCI and their preparation for these adverse weather events. Shapiro and colleagues (2020a) provided the following list to prepare individuals living with SCI for hurricanes (cyclones):

- Ensure that the person can direct their care. In an emergency, they must have the skills to verbally provide detailed instructions to an untrained carer on how to meet their needs
- Encourage the individual to develop a local, personal support network of at least three people who know their needs and are willing to help in an emergency
- Encourage individuals and caregivers (carers and support workers) to develop a comprehensive evacuation plan that includes key elements, such as transportation and a designated meeting place.
- Educate individuals about registering for evacuation assistance through their local government in advance of an adverse weather event
- Complete physician certificates for utility companies to provide priority turn-on service for individuals dependent on electricity for life or function
- Ensure that ventilator-dependent individuals have a generator or battery and bag-mask equipment, and
- Discuss methods of cooling and heating during emergencies for those with impaired temperature regulation.

17.11. Preparing for adverse weather and climate events in Australia

Considering Australia's vulnerability to adverse weather events, it should not be surprising that there is a wealth of resources to prepare for such disasters. Before providing details relating to some of these resources, below is a first report on one of the measures in the 2025 Third Report section Health & Wellbeing Outcome in the National Disability Strategy: Improving emergency service response for people with disability. Eighty-six % of people living with disability were satisfied with the accessibility of disaster preparedness and response information and services in 2024 (AIHW, 2025). This indicator was, however, not reported in the January 2026 Fourth Report.

Podcast: Emergency preparedness and planning for people with disability

SCIA's Have the Never podcast, Emergency Preparedness and Planning for people with disabilities (Episode 26): Listen to **Professor Michelle Villeneuve** talk about disability-inclusive disaster risk preparedness. A good plan starts with each of us.

Important information: ABC and emergency preparedness with disability

Emergency preparedness for people living with disability (ABC Emergency): A three-and-a-half-minute video produced as part of the Resources for NDIS Emergency and Disaster Management (R4NED) initiative. While designed with NDIS participants and providers in mind, it offers broadly useful, highly accessible information. The resource includes easy English explainers and Auslan, making guidance on emergency and disaster preparedness clear and inclusive for diverse audiences.

Below are several resources relevant for individuals living with SCI, their carers and health professionals.

17.11.1. Australian Disaster Resilience Knowledge Hub

The Australian Disaster Resilience Hub is a collaboration between the Australian Government's National Emergency Management Agency and the Australian Institute for Disaster Resilience. The website's landing page provides a range of resources, as well as courses, to help people become more informed about the needs of people with disabilities during disasters. Examples include:

- Disability and Inclusion page with numerous resources, including some of those described below, such as Collaborating 4 Inclusion and Leaving Nobody Behind webinar series
- Introduction to Disability Awareness: A free 90-120-minute eLearning course. It promotes an awareness of disability and the impact that societal attitudes and inherent stigma and

discrimination have on the lives of people with disability. This course is recommended for emergency managers and those planning to reduce disaster risk to improve their knowledge of disability inclusion, and
- Emergency Sector Disability Awareness (University of Sydney): A three-part introductory learning module for the emergency sector on disability inclusion in emergency management. It includes Part 1: Introduction to disability for the emergency sector; Part 2: Introduction to disability advocacy for the emergency sector; Part 3: Introduction to disability representation for the emergency sector.

17.11.2. Collaborating 4 Inclusion Person-centred Emergency Preparedness

Collaborating 4 Inclusion (watch the video) offers a Person-centred Emergency Preparedness (P-CEP) Toolkit, which has been co-designed and tested with people with disability. Disability Inclusive Disaster Risk Reduction (DIDRR) will allow individuals to self-assess their preparedness, capabilities and support needs to develop a personal emergency plan in terms of how they will manage these needs in emergencies and work with their support network before, during and after a disaster. P-CEP is strengths-based in that it focuses on *function rather than impairment*, local community assets and cross-sector collaboration to remove barriers that increase risk for individuals with disability, as well as other groups who may be at-risk during these events, such as the elderly. P-CEP highlights an individual's capabilities and the role of numerous stakeholders to reduce disaster risk, in line with national emergency management and disability strategies.

Video: P-CEP Tool

Be sure to watch the very informative video on the landing page about how you can use the P-CEP Tools to prepare for disasters in relation to eight topics, such as your health (specific needs, medications, etc.), assistive technology (such as what is required and back-up) and everyday personal support (who assists you, etc).

There is a series of videos to explain the process, such as self-assessment. The CDRP created the Person-Centred Emergency Preparedness (P-CEP) toolkit to empower people to make plans. The **P-CEP Workbook** walks you through four key steps, which are summarised in **Figure 17.4** below:

- **Identify** your strengths and support needs in everyday life
- **Know** your level of preparedness and learn about your disaster risk
- **Plan** for how you will manage your support needs in an emergency, and

- **Communicate** the plan with the people in your support network and address gaps through collaboration.

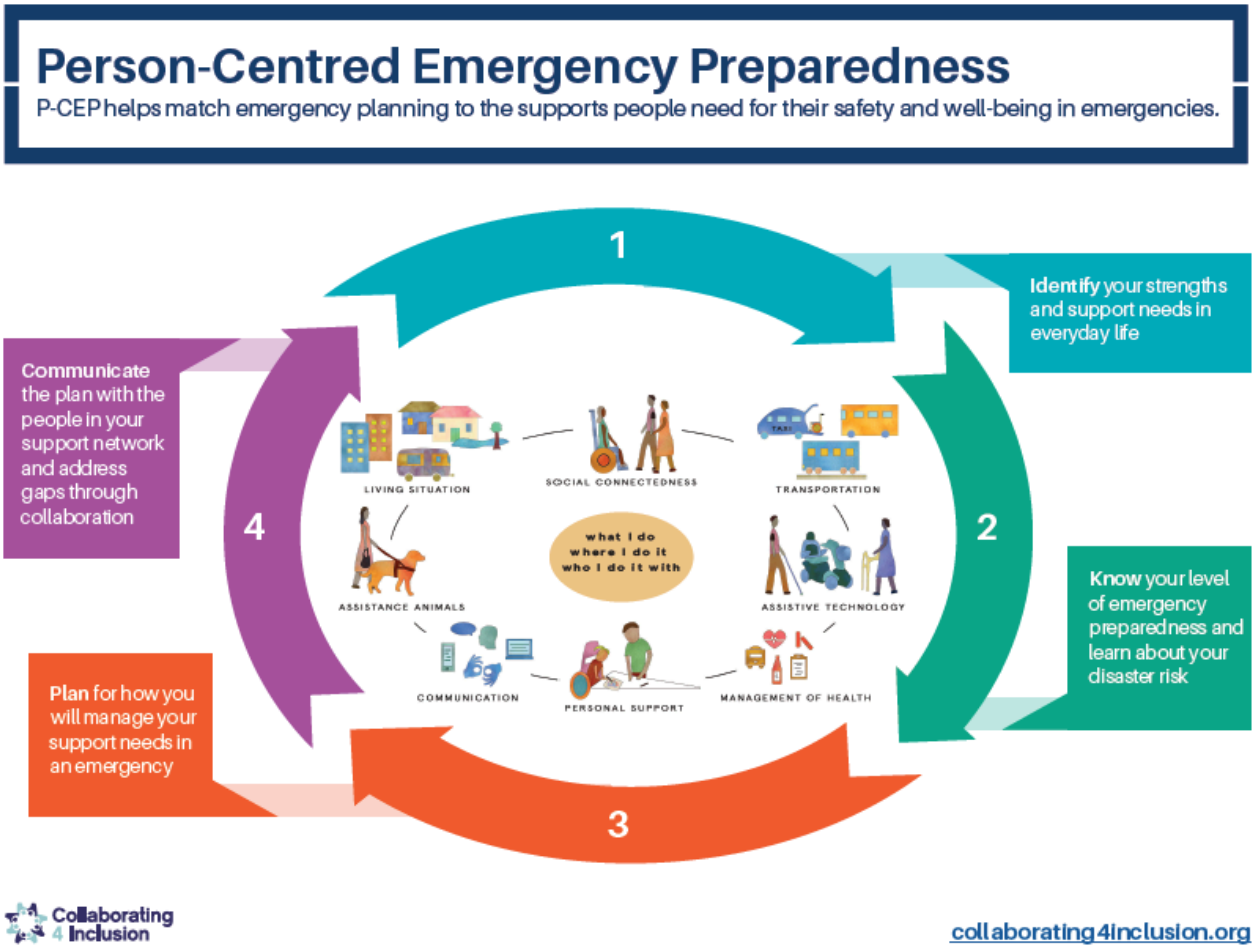


Figure 17.4. Person-centred Emergency Preparedness (P-CEP) overview. *Source:* www.collaborating4inclusion.org , Image of the P-CEP Framework image shared with permission of the lead researcher, Professor Michelle Villeneuve, The University of Sydney.

Key recommendations: *What is required by whom?*

Things to think about when making your plan

- Medications you might need. Do they need to be refrigerated?
- If you require electricity or certain devices, what will you do if the power is cut off in a big storm or fire?
- Can you evacuate on your own if ordered to or would you need help?
- How will you include your carers or support workers in your planning?
- What other resources are available to you?

People living with physical disability or wheelchair users

- Have a lightweight or manual wheelchair as a backup
- Show others how to operate your wheelchair, so they can help if you need it
- Keep an extra battery for power wheelchairs and other devices
- Have a patch kit for flat tyres and a portable pump for wheelchair tyres
- Keep an extra mobility device with you
- Make a plan with the people who could help you evacuate, and
- I'm Okay has emergency planning help for people with disabilities from the Physical Disability Council of NSW.

People with conditions requiring medications

- Ask your doctor for options for emergency medications.
- Keep a document with your prescription medicines, prescriptions and health cards
- If you don't have your prescription, a pharmacy can call your GP for a verbal prescription or provide a three-day emergency supply (excluding controlled substances), but you may need to pay the full cost. Have ice packs ready for medicines that need to be kept cold
- Think about non-prescription medications or food that you might need and plan to store them in an emergency kit, and
- The National Diabetes Services Scheme has a planning tool for people living with diabetes and has tips on storing medication.

Important information: Prescription medications in an emergency

How do I get a prescription or medicines in an emergency?

If you need to leave without your prescriptions or medicines or they are lost, try one of these options:

- Contact your local pharmacist, who may be able to call your doctor for a verbal prescription
- Request an eScript (electronic prescription) from your doctor
- Use a telehealth service, and
- Keep your doctor's information handy for these situations. If your doctor or medical centre does not offer telehealth consultations, you can use the Healthdirect service finder to find a provider.

17.11.3. NDIS Quality and Safeguards Sector Readiness Project

In 2021, the NDIS Commission introduced a Quality and Safeguards Sector Readiness Project Factsheet, primarily in response to experiences that people with disability and their networks shared with the NDIS Commission and the Royal Commission into Abuse, Neglect and Exploitation of People with Disability on the impact of the COVID-19 pandemic to people with disability, their well-being and safety and the impact that service disruptions were having on people's lives. The Royal Commission website acknowledges that people with disability are at much greater risk of neglect during emergencies, such as barriers to services and supports, inaccessible information and communications, social isolation and lack of safeguards and oversight.

Video: NDIS R4NED (Resources 4 NDIS Emergency and Disaster Management)

- Welcome (R4NED Resources): For NDIS providers and participants, this explains what the R4NED website offers, how it works, and the types of information available, with multiple accessible format options
- Plan with your provider (R4NED resources): Guidance to support collaborative planning between NDIS participants and their providers, using R4NED tools and information, and
- Resources for NDIS Emergency and Disaster Management (R4NED): A direct link to the various important resources.

Additional information, if interested: Royal Commission and COVID-19

If you are interested in the responses received by the Royal Commission, they can be accessed here. A group of 33 for-purpose registered disability services organisations, providing services to over 24,000 people with disability in Australia, submitted a 22-page document to the Royal Commission regarding the COVID-19 pandemic. The COVID-19 pandemic is considered a 'disaster' and required disaster management. Similarly, heatwaves, cyclones and floods are disasters for which planning is required, but particularly for those who are physically and psychologically compromised.

The **NDIS Readiness Project** resource includes information and resources on:

- Emergency and Disaster Management in NDIS Supports and Services Overview

- Preparing, preventing, managing and responding to emergencies and disasters, and
- Planning: Including Business Contingency, Emergency and Individual Support Planning.

The **Prevention, Preparedness, Response and Recovery (PPRR) cycle** is a risk management framework used by emergency management agencies and businesses to guide their emergency response. It borrowed the RRRR cycle from the Resilient Community Organisation. The PPRR cycle can help organisations to anticipate possible direct impacts to the people they support, their workers, suppliers and the whole organisation, by identifying and planning for potential risks and identifying the actions workers need to take in the event of an emergency or disaster.

It also provides the Queensland Government's disaster management site as an example in terms of warnings and disaster management resources and in the updates to providers, the NDIS Commission State the Emergency and Disaster Management Practice Standard outlines that: *"the planning required by providers to prepare, prevent, manage and respond to emergency and disaster situations whilst mitigating risks to and ensuring continuity of supports that are critical to the health, safety and wellbeing of NDIS participants."*

17.11.4. Crisis toolkit, comprising the Australian Red Cross RediPlan

This Crisis Toolkit was designed to assist individuals living with a disability or a chronic health condition to prepare for various crises (**Figure 17.5**).

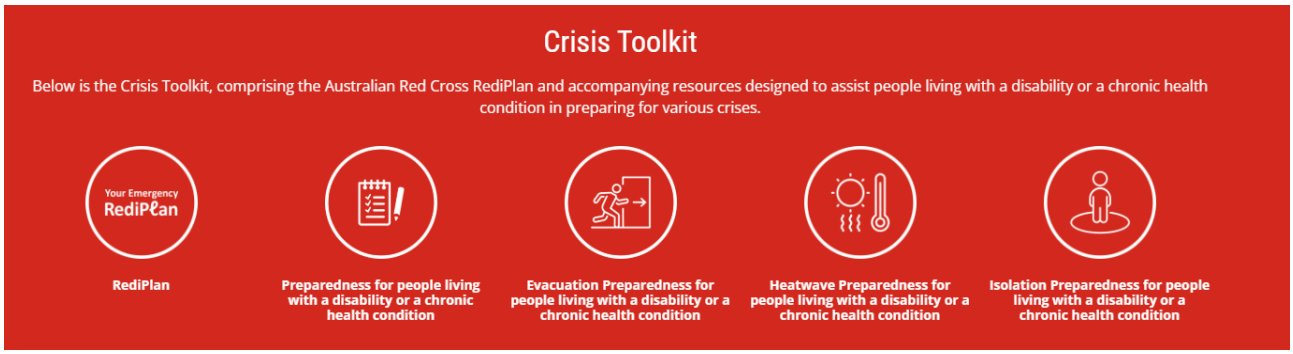


Figure 17.5. The Crisis Toolkit has five active 'buttons' for extra resources. *Source:* MS Australia Crisis Toolkit, used with permission.

The five elements of this Crisis Toolkit are:

- Your Emergency RediPlan
- Preparedness for people living with a disability or a chronic health condition
- Evacuation preparedness

- Heatwave preparedness, and
- Isolation preparedness.

Video: The Crisis Toolkit unpacked

Watch the associated video: Crisis Toolkit unpacked: Empowering preparedness (The Raw Nerve podcast on Spotify, Episode 44).

17.11.5. Additional resources to support people living with disabilities and their carers

Below are additional Australian resources to support people with disability and their carers:

- **National Disability Services (NDS):** A comprehensive website covering national and state-based services with the NDIS Commission requirements and emergency and disaster resources. Emergency information for the States and Territories. There is a section of accessible resources for people with disability. This website is probably your first port o'call, as it looks like a one-stop shop
- **Red Cross:** A resource page with an Easy English accessible PDF version of its RediPlan that can be used by assistive software and devices and caters for people of all abilities, Auslan resources for hearing impaired people, emergency planning tips for people with physical disabilities, chronic diseases and older people and Recovering from disaster resources and Stay Connected #ReadyTogether Toolkit
- **Council for Intellectual Disability:** Easy-to-read guides on many subjects, including heatwaves and bushfires
- **ABC Emergency:** Planning and advice, as well as an incident map, Recover after an emergency. Find emergency services wherever you are. Your mobile phone could help save your life
- **Early Connections Alliance:** Bushfire Social Story is a social learning tool for young people. The site has a range of other resources for children.
- **NSW Rural Fires Service:** Practical support via a program called AIDER (Assist Infirm, Disabled and Elderly Residents)
- **CFA Victoria:** Developed an Easy Read set of resources on bushfires
- **I'm OK:** Emergency planning for people with physical disabilities
- **Disability Services Consulting:** Search for 'emergency' and find a series of general on-demand learning, events and templates. Emergency evacuations in disability service

providers is here.

- **DEAS Australia***:* Dedicated page to bushfire crisis information. They also have a national disability information service that you can contact on 1800 029 904.
- **Physical Disability Council of NSW:** Developed a website dedicated to supporting people with disability to understand natural disasters and put in place an emergency plan
- **Youth Affairs Council Victoria:** A list of bushfire resources for Victorians with a disability, and

Important resources: Carers

Specific **resources for carers** include:

- An e-learning module prepared by the Victorian CFA in collaboration with Carers Victoria
- A Bushfire Ready Carers Kit from Bushfire Ready Neighbourhoods Tasmania, and
- Ember's Preparability (Flagstaff Group): Emergency preparedness for NDIS and care providers. The animated booklet could be given to children to read.

Media story: Prepare your home, plus more Queenslanders with disability are prepared

- While working on Chapter 17 on 1 November 2025, aware of the warning of another day of possible 'supercell' storms in SE Queensland, the following appeared on a news feed: Prepare your home and property for severe weather (ABC Emergency). It is an extensive article providing numerous links for the States and Territories, and
- As storm season begins, report finds more Queenslanders with a disability are prepared for natural disasters (ABC News).

Mr Prince's story: Ready for the next weather event after being evacuated twice

Voice of Queensland Disability Report (Chapman *et al*., 2025), released in September this year, found that more people were prepared for disasters than in previous years. Mr Prince had to be evacuated a second time, spending five days away from his home until the water had receded. Three years later, Mr Prince had his emergency kit ready as Brisbane braced for ex-Tropical Cyclone Alfred in March. It included items such as a first-aid kit, medication, spare batteries for his power wheelchair and food.

"I've now got a box set aside at any given moment that can come out with us if we need to evacuate," he said.

When the ex-Tropical Cyclone [Alfred] crossed the mainland just north of Brisbane, Mr Prince stayed in his home with the assistance of his support worker. *"We had everything prepared,"* he said.

Key recommendation: Grab-and-go bag for individuals living with SCI

A grab-and-go bag is a pre-assembled kit that can be taken quickly during an evacuation or unexpected disruption. It is essential for individuals living with SCI, due to their reliance on medical routines, assistive equipment and personal care supports. The bag should contain medications, catheter and bowel care supplies, pressure-relief cushions or aids, essential skin-care products, and any required respiratory or autonomic management items. It should also include charging cables, power banks, or spare batteries for wheelchairs, communication devices, and other assistive technologies, along with copies of emergency plans, key medical information, and contact details for carers, support workers and clinicians. Including lightweight cooling aids or temperature-regulation supports is also recommended. Preparing such a kit enhances continuity of care, reduces health risks during displacement and supports a more stable transition through the acute stages of a disaster. Clinicians and community organisations should encourage and assist individuals with SCI in maintaining an up-to-date grab-and-go bag as a core component of personal preparedness planning.

Essential medical supplies

- All current medications (minimum 7-14 day supply)
- Catheter supplies (intermittent or indwelling)
- Bowel care supplies
- Skin-care items (barrier creams, dressings and pressure injury prevention items)
- Respiratory support items (if relevant), and
- Autonomic dysreflexia emergency card and supplies.

Assistive technology and equipment

- Charging cables for wheelchairs, communication devices and medical equipment
- Power bank or spare batteries
- Small toolkit for wheelchair adjustments, and
- Backup mobility aids (if feasible).

Temperature regulation and comfort

- Cooling aids (cooling towel, spray bottle, portable fan if available), and
- Light blanket or pressure-relief cushion.

Personal care and hygiene

- Gloves, wipes and hand sanitiser, and
- Soap, toothbrush and essential hygiene items.

Important documents and information

- Printed medical summary (diagnosis, medications, allergies and baseline functions)
- Emergency contacts (carers, clinicians and family)
- Copies of prescriptions, and
- Copy of personal emergency and evacuation plan (look on your local council website).

Communication and safety items

- Mobile phone charger
- List of emergency numbers, and
- Whistle or small alert device.

Other items

- Water bottle and spare water
- Non-perishable snacks,
- Torch and spare batteries, if not rechargeable, and
- Small amount of cash.

Reminder: 27 July 2026, nationwide emergency alert testing

AusAlert (Introduced on 27 July 2026): AusAlert is being introduced in response to the 2020 Royal Commission into National Natural Disaster Arrangements. The Royal Commission found that emergency warning systems, including mobile-based alerts, are critical.

The Australian Government funded the development of a national messaging system in the 2022–23 and 2023–24 Budgets. NEMA is co-delivering the system with the Department of Infrastructure, Transport, Regional Development, Communications and the Arts (DITRDCA).

The system is also being designed with relevant Federal, State and Territory government agencies, including emergency services organisations. This will ensure the coordinated and appropriate use of AusAlert

and recognises the leading role state and territory emergency services organisations play in issuing warnings and responding to emergencies.

After community testing, there will be a national test on Monday, 27 July 2026, between 11h00 and 14h00, depending on the State and Territory in which you live. During this test, all compatible devices across Australia will receive a test alert. This helps ensure the system works as expected before it is used in real emergencies. There is a table on the website with the times when the national test will happen across time zones.

17.11.6. Powered medical devices

The Queensland Government's two-page resource, Powered medical devices and disasters, assists in preparing for managing a powered medical device during a power outage. The document has several checklists for completion, as well as links to other resources. For individuals living with SCI who need to be ventilated, such an event would be regarded as life-threatening in terms of **Figure 17.6** below.

Planning resource for community members

Powered medical devices and disasters

This resource is to help you prepare for managing your powered medical devices during a power outage.

If losing power to your medical device would result in a **medical emergency**, go to a nearby hospital immediately if you lose power. If **it is not a medical emergency** and you just need power to charge your medical device, use all other options first. The hospital should be the last option for this circumstance.

Emergency services are often busy during disasters and power outages and may not always be available to help you, unless it is a life-threatening medical emergency. Make sure you have a backup plan before trying to call them (**unless it is a medical emergency**).

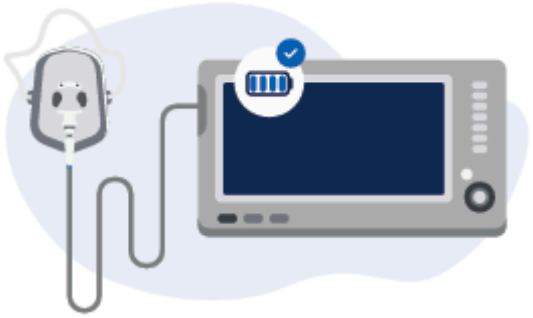
Examples of powered medical devices that might be affected by a power outage

LIFE THREATENING

- Respiratory ventilator for life support
- Home oxygen delivered via an oxygen concentrator
- Nebulisers (example – for asthma)
- Suction devices
- Intermittent peritoneal or kidney dialysis machine
- Infusion, insulin, and feeding pumps
- CPAP/BiPAP machines (depending on the severity of your condition)
- Phototherapy equipment
- Any other equipment that a registered medical practitioner certifies is required for life support, or a medical condition which requires continued supply of electricity and/or gas

NOT IMMEDIATELY LIFE THREATENING

- Powered mobility devices and equipment (wheelchairs, scooters, hospital-grade beds, patient lifting devices)
- Vacuum assisted closure (VAC) dressings
- Some CPAP/APAP machines (depending on the severity of your condition)



Call **13 HEALTH (13 43 25 84)** at any time.
Contact **13 QGOV (13 74 68)** for your nearest Public Health Unit.

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SCI2500875

Figure 17.6. Queensland Health's examples of powered medical devices that might be affected by a power outage. This is p. 1. *Source:* Queensland Health, Powered medical devices and disasters, CC BY 3.0

This Resource states the following:

> *"If losing power to your medical device would result in a medical emergency, go to a nearby hospital immediately if you lose power. If it is not a medical emergency and you just need power to charge your medical device, use all other options first. The hospital should be the last option for this circumstance. Emergency services are often busy during disasters and power outages and may not always be available to help you, unless it is a life-threatening medical emergency. Make sure you have a backup plan before trying to call them (unless it is a medical emergency)."*

17.11.7. Investing in resilient accommodation

An impact of fires, floods and other climate-related events could be the need to evacuate one's home, which may be destroyed or severely damaged. *What will be your sanctuary during hot weather may, in fact, become an inferno during a bushfire?*

In 2014, Kate Cotter established the Bushfire Building Council of Australia to translate research into action to reduce climate and disaster risk for households, communities, governments and industry, focusing on bushfire resilience. The organisation has evolved to address all hazards and energy efficiency, delivering national systems to rapidly increase resilience of the built environment. Now called the Resilient Building Council, it offers a collaborative, systems-based approach to reducing Australia's growing risk and vulnerability to all natural hazards. The mantra is that if we invest in protecting the built environment from the impacts of extreme weather and disasters, we will protect lives, businesses, livelihoods and communities and deliver attractive assets for investors, creating socially and economically sustainable, thriving communities. The Council offers two services:

- FORTIS New Builds: Free architectural drawings and specifications for any site and environment to fast-track the construction of disaster-resilient homes, and
- Resilience Ratings: A world-first, independent standard to measure the disaster resilience of buildings and enable financial benefits. By retrofitting your home, you will be reducing your dwelling's carbon footprint and making your property more climate-resilient, which will also have positive financial implications. A win-win situation for you and the planet.

17.12. Continuity of care during and after disasters

In the section below, two case studies are described relating to healthcare delivery during an earthquake in New Zealand in 2011 and during a wildfire in California in 2015.

Case Study 1: Christchurch Hospital's response to the February 2011 Earthquake

Ardagh *et al.* (2012) have described their hospital's preparation for and response to the Christchurch Hospital's mass casualty incident plan that was triggered during the February 2011 earthquake. A senior doctor and nurse assume the roles of medical and nursing controllers and doctors and nurses are assigned leadership roles for each of the colour-coded areas of the International Disaster colour triage differentiation:

- **Green:** *Minor injuries*. Patients treated in the ED ambulatory area (five treatment spaces) during an incident response.
- **Yellow:** *Moderate injuries*. Patients were treated in the ED work-up area (15 treatment spaces) during the incident response.
- **Red:** *Severe injuries*. Patients treated in the ED resuscitation area (20 treatment spaces) and then monitored during incident response.
- **Black:** *Dead or dying patients.* Patients not considered for active resuscitation but kept in the observation ward (10 beds).

The Hospital's mass casualty plan is as follows: Under the medical and nursing controllers' direction:

- Medical staff are assembled into teams and directed to patients.
- Medical controllers responsible for surgery, anaesthesia and the Intensive Care Unit (ICU) are deployed to the Emergency Department (ED).
- Each clinical department has its own sub-plan.
- A hospital control room is established.
- Patients are tracked with documentation pre-labelled with pre-allocated unique identifier numbers, kept in packs with pre-labelled assessment, radiology and laboratory request forms. A pack is pinned to each patient's clothing on arrival. In February 2011, 500 packs were available for immediate use.
- The plan is rehearsed annually and has been implemented in response to major multivehicle road accidents, chemical leaks, fires and a passenger train crash.

On Sept 4, 2010, the plan was activated in response to an earthquake 40 km west of Christchurch, which saw 97 earthquake-related presentations at Christchurch Hospital, including three serious injuries. On 22 February 2011, the Christchurch earthquake struck. The hospital shook severely. Staff were unable to stand unaided, trolleys were shunted across rooms and items fell from shelves and benches. Ceiling panels fell in many areas. Broken water conduits began flooding parts of the hospital, particularly the blood bank. Alarms sounded continuously. Power was lost immediately. Within seconds, six diesel-fuelled generators activated to provide power to electrical outlets designated as essential services. The severe shaking, however, disturbed the sump sludge in the diesel tanks, resulting in the generator failing several times and

leaving the ED clinical areas, ICU, blood bank, radiology department and other areas without power. The stairwells down which many were evacuated, as well as lift accesses, were also affected.

Within minutes of the earthquake, a young girl was carried into the ED by a stranger who had found her buried in the rubble. Subsequently, large numbers of patients arrived at the hospital, on foot, carried by members of the public, in cars or police vehicles, on doors strapped to the top of cars and in the back of small trucks. Impassable roads and communication difficulties resulted in little pre-hospital triage or treatment for many who presented early. Most injuries were minor and did not require hospital care. More seriously injured casualties presented to Christchurch Hospital within the first few hours, with injuries from falls or being struck by falling rubble. Later, patients who had been trapped and extricated arrived. These patients had varying degrees of crush injury syndrome. Most serious injuries occurred in the central business district. In the first 24 h, mortality was 182, with 175 people dying in the community and seven in hospital. Patients with aftershock-related injuries presented beyond 24 h, including several elderly patients with neck or femur fractures who had stayed in their beds rather than travel to the hospital during the earthquake.

Based on these experiences of the 2011 Christchurch earthquake, key points for earthquake preparedness include:

- Rehearsed response plans, strong teamwork and a clear hierarchy of strong leadership are essential
- Hospitals should have robust backup electrical power and communication systems, with contingency plans for a complete power outage
- Patients will present without pre-hospital care and many will be reluctant to come into a hospital building for fear of collapse
- Registration and tracking of patients will be difficult, but will be aided by the use of unique patient identifiers and dedicated staff to identify and track patient movements
- The prospect of having many willing helpers should be anticipated and accommodating and managing them should be incorporated in the plans.
- Plans should include processes for managing media interest, and
- An integrated approach is required in which primary care providers, non-acute hospitals and acute hospitals are prepared to provide care to large numbers of injured people.

Rachael Norman's story: Burwood Hospital and the 2011 Christchurch earthquake

Below, **Rachael Norman** describes what happened to the Burwood Hospital where she had worked as a PGY3 doctor in the spinal cord unit on the 22 February 2011 Christchurch earthquake.

> *Burwood Hospital suffered significant damage in the 6.2 magnitude Christchurch earthquake, which occurred around midday on 22 February 2011, killing 185 people and injuring about 8,600. The earthquake resulted in 20 spinal injury claims submitted to the ACC. Spinal specialist, Dr Raj Singhal, reported that on 7 March 2011, five new SCI patients were admitted in one day because of the earth-*

quake, which is the usual admission numbers over three months. A female patient and her daughter were transferred to the Auckland Spinal Unit. A $215m upgrade of Burwood Hospital was opened in August 2016."

Research: Meeting the challenge of SCI after a sudden onset disaster

In 2012, Burns and colleagues provided a special report on 'Meeting the challenges of SCI care following sudden onset disaster: lessons learned' after several global earthquakes. They reported that improved disaster response has led to higher survival rates and hence an increasing number of injuries, i.e. a high injury:death ratio. These earthquakes had led to an unprecedented rise in SCIs, including in low-resource countries such as Iran, Pakistan and Haiti. Learning from experiences and proactively addressing how to best meet needs in future disasters, the authors review and propose measures targeted to specific challenges, such as coordination and mobilisation, identification and procurement of required expertise, initial survey and assessment, health care delivery, community reintegration and health maintenance, and sustainability and capacity building.

Important resources and information: Acute management of SCI

- With one of their recommendations being 'Sustainability and capacity building', Ausmed offers short courses relating to caring for individuals in a range of circumstances, with the landing page currently (October 2025) being **Acute Management of TSCI**, updated on 20 September 2024
- Australian Resuscitation Council and the New Zealand Resuscitation Council: Combined Guideline 9.1.6. Management of a suspected SCI, which is for use by bystanders, first aiders and first aid providers and applies to infants, children and adults with a suspected SCI, and
- NSW Health Children's Hospital at Westmead: Emergency Management of a Suspected SCI (CHW).

The goal of pre-hospital management of an acute SCI is to minimise neurological deficit and prevent further injury by:

- Treating the patient as having a high probability of SCI
- Identifying and reversing any immediate threats to life

- Appropriately restricting spinal motion to maintain the integrity of the spinal column and therefore the spinal cord
- Providing cardiovascular and ventilation support when required, and
- Maintaining thermoregulation, as neurogenic shock can impair body temperature regulation.

Case Study 2: Telemedicine during the 2015 California fire

In Provision of care through telemedicine during a natural disaster, Pasipanodyna and Shem (2020) describe how health services were delivered through telemedicine during a devastating California Valley fire in 2015.

The individual described was an adult who sustained SCI. Before discharge from acute inpatient rehabilitation, they were enrolled in a research study that provided outpatient SCI-specific care via telemedicine (teleSCI). The participant attended several teleSCI visits before the start of the Valley Fire. In the midst of and immediate aftermath of a prolonged wildfire, and despite significant personal loss, the participant continued to receive teleSCI services. TeleSCI was thus used successfully to address emergent and extant medical concerns and to facilitate the replacement of medical supplies and equipment destroyed by fire.

17.13. A global early warning system

Early warning systems save lives, but only half of the world's countries have adequate multi-hazard early warning systems. On *World Meteorology Day* on 23 March 2022, UN Secretary-General António Guterres stated the following:

> *"Today, one third of the world's people, mainly in least developed countries and small island developing states, are still not covered by early warning systems [...] This is unacceptable, particularly with climate impacts sure to get even worse. Early warnings and action save lives. To that end, today I announce the United Nations will spearhead new action to ensure every person on Earth is protected by early warning systems within five years."*

In line with this, the Early Warnings for All (EW4All) initiative aims to ensure universal protection from hazardous hydrometeorological, climatological and related environmental events through life-saving early warning systems by the end of 2027 through a *Multi-Hazard Early Warning System (MHEWS)*, which is an integrated system that informs people of hazardous weather or climate events on the way, and informs how governments, communities and individuals can act to minimise the impacts. MHEWS should be people-centred to empower those threatened by hazards to act in sufficient time and in an appropriate manner and must build

on partnerships within and across relevant sectors. The Early Warning for All initiative comprises four pillars to deliver effective and inclusive MHEWS, and is co-led by the World Meteorological Organization (WMO), the United Nations Office for Disaster Risk Reduction (UNDRR), the International Telecommunication Union (ITU) and the International Federation of Red Cross and Red Crescent Societies (IFRC), with other partners.

The pillars of what will be people-centred MHEWS are:

- **Pillar 1:** Disaster risk knowledge
- **Pillar 2:** Detection, observation, monitoring, analysis and forecasting
- **Pillar 3:** Warning dissemination and communication, and
- **Pillar 4:** Preparedness and response capabilities.

The WMO leads the implementation of **Pillar 2:** *Detection, observation, monitoring, analysis, and forecasting*, with support from UN Development Programme (UNDP), UN Educational, Scientific and Cultural Organization (UNESCO) and UN Environment Programme (UNEP).

> *"Pillar 2 is critical for societies to be better equipped to understand, prepare for, and respond to the evolving challenges of our changing climate: Early Warning Systems rely on worldwide sharing of data collected from the Earth's surface and space. This information is freely exchanged between countries and analyzed by highly advanced supercomputing modelling centres. These centres run numerical models which simulate how different parts of the Earth System (weather, hydrology, oceans and cryosphere), interact with each other. From these simulations, predictions are made and then passed down from global to regional and national levels. This allows National Meteorological and Hydrological Services (NMHSs) to provide accurate forecasts to citizens. Without this coordinated effort facilitated by WMO, modern day weather and hydrology forecasts would not be possible."*

Important resource: Early Warning for All Implementation Toolkit (EW4All)

Since writing this part of the Chapter in September-October 2025, the Early Warning For All Implementation Toolkit has become available in four languages. The Toolkit guides national leads and partners in the rollout of the EW4All Initiative. It includes the "Rollout Step-by-Step Guide" and all necessary documents and forms to proceed with the EW4All implementation.

Dinesh's experiences: Alone in a wheelchair in Sri Lanka during an earthquake

"I have been in an earthquake overseas. I was in Sri Lanka when the earthquake and a tsunami warning came. Mum wasn't around and everyone ran away. I was at the top of this building [...] It was hectic, actually. Terrifying. So, I was on the 13th floor or something. You feel everything and you're like, okay, this is shaking. Then there is a tsunami warning, and everyone just took off, and I guess I'm just here."

17.14. Environmental sustainability: Mitigating the footprint of SCIs

All human activities have an environmental footprint because they use resources, generally burn fossil fuels and generate large amounts of waste. The impact of these activities can be summarised as contributing to biodiversity loss, for example, through deforestation, a changing climate, GHG emissions, and many forms of pollution, such as air pollution from burning fossil fuels and chemical pollution of water and soil from pesticides, plastics and other synthetic substances. Healthcare delivery is no different. Hospitals have a large environmental footprint today, especially in high-income countries with high energy demands and where single-use items are now the norm. Preventable chronic illnesses such as diabetes and cardiovascular disease, which are prevalent in high-income countries, result in increasing rates of hospitalisation and, hence, an increasing ecological footprint.

17.14.1. Australian healthcare becoming more environmentally sustainable

In October 2024, the Australian Commission on Safety and Quality in Health Care, in partnership with the interim Australian Centre for Disease Control and Australian medical colleges, released a historic Joint Statement: Working together to achieve sustainable high-quality health care in a changing climate, to signify a shared commitment to address the health impacts of climate change. In an Australian first, all specialist medical colleges and the Australian Indigenous Doctors' Association endorsed the Joint Statement.

Clinical resource: Healthcare Sustainability and Resilience Module

In October 2025, the Commission released the Healthcare Sustainability and Resilience Module after a year-long pilot to address healthcare impacts on the environment and the climate risks affecting health outcomes and access to healthcare. The Module supports health service organisations to set their priorities, targets and strategies for their existing and new services. It supports partnering with consumers (patients) to design, monitor and evaluate services. Action taken to measure and address sustainability and resilience outcomes should form part of the health service organisation's safety and quality performance monitoring.

The Module also aligns with the strategic work on climate change developed by the Australian Government Department of Health, Disability and Ageing, including the 2023 National Health and Climate Strategy. This Strategy makes climate change a national health priority, calling on all health professionals to practice environmentally sustainable healthcare (*Action 7.1. Mobilising the health workforce to lead action on climate and health*). The Strategy comprises 49 Actions, which, in addition to 7.1. above, include actions such as *Action 4.14. Reducing emissions from respiratory inhalers* and Action 5.1. Considering the role of the emissions footprint of health technology products. The Actions also advocate for preventative health and health promotion (such as *Action 6.11. Promoting active travel, such as walking or cycling to work* and *Action 6.6. Taking account of sustainability considerations in Australian Dietary Guidelines*) and actions to address rising temperatures, which include *Action 6.1. Developing a National Heat-Health Action Plan and Action 6.2. Addressing the impacts of climate change on air quality.*

17.14.2. SCI and sustainability

Sustainability is a relatively new topic in the professional literature relating to SCIs. An early adopter of sustainability in rehabilitation was the World Federation of Occupational Therapists (WFOT), which published Sustainability Matters: Guiding Principles for Sustainability in Occupational Therapy Practice, Education and Scholarship (2018). As we have seen in various chapters of this e-resource, OTs play a key role in the rehabilitation of individuals who have sustained SCI, particularly in terms of going home and getting back into the workforce.

In a 2019 editorial, Alexander raised the topic of sustainability and SCI in response to the UN's July 2019 acknowledgement of the issues of people living with disabilities with respect to climate change as a human rights concern. Alexander wrote:

> *"Hence, it is imperative that discussions of climate change and disability include the unique issues of persons with SCIs. Likewise, it is important that we, as professionals, look into the nuances of how our clinical practices can be fine-tuned to ascertain that they are sustainable and that we are doing our*

best to insure people with SCIs maintain their quality of life despite the impacts of climate change."

Alexander (2019) went on to ask several questions about the lifecycle of the products used for SCI, including the now common single-use items such as disposable catheters. *If they must be single-use, could they be biodegradable?*

An aspect of sustainable healthcare that Alexander (2019) raised, which has gained traction since COVID-19, is virtual healthcare. She cited two examples:

- Tsai and colleagues' feasibility and usability of a mobile application for performing home evaluations to ensure wheelchair accessibility. After training with an online module, a family member used the mobile app to outline a floor plan of the home instead of having a clinician visit to measure. Clinicians found the 20 floor plans created by consumers useful 75% of the time. The benefits of this app included that the clinician did not have to travel to a person's home, which could be hundreds of kilometres away, thereby saving time, plus not travelling would decrease costs and lower carbon emissions, and
- Tyagi *et al.*'s (2019) 'Improving quality of life after SCI in India with telehealth' describes how a 44 yo male and a 35 yo female living with SCI, who resided 142 km and 1083 km, respectively, from the tertiary care spine centre, were able to increase their functional status after an initial post-discharge decline through the development of a specific home care program and the use of WhatsApp, video chats and phone calls. They thus received specialised service, but there was a saving in terms of fewer miles travelled, thereby reducing costs and carbon emissions.

Important information: WFOT's position statement on telehealth

In response to the WHO's 2017 Rehabilitation 2030: A Call to Action, the WFOT published a position on OT and telehealth in May 2021. Below is an extract from this document:

> *"Statement of the significance of the position to society: Telehealth connects people with occupational therapists, assistants and students through information and communication technologies and improves access to services for underserved populations when in person encounters are not possible or practical. Telehealth can address education gaps for local providers and contribute to initiatives to address shortages of occupational therapy personnel. Occupational Therapy and Telehealth (2021). The efficacy of telehealth was documented by the World Health Organization in 2011. For example, the World Report on Disability co-produced by the World Health Organization and World Bank affirmed the efficacy of telehealth for the delivery of rehabilitation services (i.e. telerehabilitation) stating its use yields comparable outcomes to rehabilitation services delivered in-person. Telehealth technologies also facilitate remote*

training and support health-care providers and "sharing professional expertise between countries, as well as at critical times such as in the aftermath of a disaster." (p. 119).

Taylor *et al.* (2022) wrote the following in their **Climate Change and Physiatry: A Call to Proportional and Prospective Action** (an American Association of Physiatrists' Position Statement):

> *"There is currently minimal published research on the medical specialty of Physical Medicine and Rehabilitation (PM&R)-specific emissions or waste; however, with its many procedures, long inpatient rehab stays and heavy reliance on disposable equipment (e.g., catheters and wound care supplies), rehabilitation health care likely produces a significant amount of waste, thus increasing CO2 emissions. This underscores the need for optimizing use of telerehabilitation in PM&R to reduce transportation-related emissions, committing to carbon-neutral medical conferences, increasing recycling of commonly used equipment such as wheelchairs and systematically conducting research to identify and reduce key waste generators within the specialty".*

Interesting information: SCIA's Social Impact Statement

SCIA's 2024-2027 Social Impact Statement uses the United Nations 2030 Sustainable Development Goals (SDGs) (social, environmental, and financial) to frame its operations. In terms of addressing the environmental SDGs, two SDGs appear: the SCIA's 2023, which is to review energy suppliers and incorporate environmental impact into the process and to amend contracts with major suppliers to consider efficiency.

17.14.3. SDA Design Standard Review: Environmental Sustainability

On 19 December 2025, the Specialist Disability Accommodation (SDA) Standard Review process closed. The review sought stakeholder, including participants and their families and carers, SDA providers, peak bodies, developers, investors, architects, town planners, SDA assessors, access consultants, building certifiers and surveyors, state and territory statutory bodies and local planning authorities, allied health professionals, technology providers, NDIS Quality and Safeguards Commission and NDIA staff) input in terms of:

- How well the design requirements meet participant needs.
- Ways to improve safety, accessibility and quality.
- New technologies and sustainability.
- How and when the new SDA Design Standard will be rolled out.

The Terms of Reference for the Review included *Innovation, technology and environmental sustainability:*

- Assess opportunities for innovation in design, including the integration of assistive technology and home automation, and design solutions that support independence, the delivery of best practice and cost-effective in-home supports and future-proofing of properties.
- Consider environmental sustainability, including features that are environmentally sustainable and energy-efficient.

These are expanded in an extract from the NDS Policy Submission Template:

> *"4.6. Environmental sustainability*
>
> *The Standard does not include specific sustainability measures beyond those mandated by the NCC and state-based frameworks such as BASIX in NSW. However, SDA dwellings often have higher energy demands due to assistive technology and climate control needs, which can increase costs and environmental impact.*
>
> ***Key issues identified***
>
> - *There are no SDA-specific requirements for energy efficiency or renewable energy integration. This misses the opportunity to leverage these mechanisms to reduce long-term operating costs for providers and utility costs for participants and improve comfort for residents.*
> - *Balancing environmental sustainability with affordability and participant safety remains a challenge.*
>
> ***Recommendations***
>
> ***4.6.1. Include SDA-specific sustainability measures***
>
> - *Require minimum energy performance standards above NCC baseline for SDA dwellings.*
> - *Encourage integration of renewable energy sources for example solar panels and battery storage for backup power.*
> - *Encourage the use of recycled and low-carbon materials.*
>
> ***4.6.2. Balance sustainability with affordability***
>
> *Provide cost-benefit analysis guidance for providers to select sustainable features that deliver long-term savings without excessive upfront costs.*

*4.6.3. Promote water efficiency and the use of durable materials**Include best practice recommendations for water-saving fixtures and low maintenance materials to reduce lifecycle costs."*

The next section addresses food sustainability, with the food sector being resource-intensive and currently wasteful. Individually, by making mindful choices, which involve plenty of fresh fruit and vegetables (lots of fibre, as discussed in **Chapter 3**), reducing red meat and avoiding ***ultra-processed foods (UPFs)***, our health improves, as does the health of the planet.

17.15. Food sustainability in the 21st century: Plate and Planet

In the face of escalating climate change, biodiversity loss and pollution, the connection between what is on our plate and the future of our planet has never been more crucial. Sustainable food systems are essential not only for human health but also for the health of Earth's ecosystems. Food production is a leading driver of:

- Greenhouse gas emissions, especially from livestock, especially cows
- Deforestation and land degradation for crops and pasture
- Water and soil, pollution due to agricultural run-off containing pesticides and nitrogen from fertilisers, leading to algal blooms in freshwater systems,
- Loss of biodiversity from monoculture farming, habitat destruction and pesticide use, and
- Water loss as a result of over-irrigation and planting the crops in the wrong areas.

What we choose to eat directly affects these processes. Shifting toward sustainable diets rich in plants and sourced through environmentally responsible practices can significantly reduce these impacts. To align human diets with ***planetary boundaries***, action is needed at several levels:

- **Individuals:** Choose more plant-based meals, reduce food waste and support local and seasonal produce
- **Governments and policy:** Develop food policies that incentivise sustainable agriculture, protect ecosystems and support equitable access to nutritious foods, and
- **Industry and innovation:** Invest in sustainable food technologies, such as plant-based proteins and regenerative agriculture and develop transparent supply chains.

In 2019, the EAT–*Lancet* Commission on Food, Planet, Health (Willett *et al.*, 2019) published a groundbreaking report outlining a global reference diet designed to promote both human health and environmental sustainability. As the EAT-*Lancet* Commission asserts, transforming our food system is essential for achieving the 2030 UN SDGs and meeting the 2015 Paris Agreement climate targets. A sustainable plate is not only good for personal health, but also a neces-

sary step for securing the future of our planet. The report emphasised a 'planetary health diet', characterised by:

- Increased consumption of plant-based foods, such as vegetables, fruits, legumes, whole grains and nuts
- Reduction in animal-based foods, particularly red meat and processed meat, and
- Limited added sugars and refined grains.

According to the Commission, adopting such a diet worldwide could prevent over 11 million premature deaths annually and reduce the environmental degradation caused by current food systems.

Important information: EAT-*Lancet* Commission update

In October 2025, the EAT-*Lancet* Commission on healthy, sustainable and just food systems provided an update on the 2019 version of the diet. They released Version 2 of the 11-minute video, which explains this flexitarian diet (less meat and dairy, more plant-based).

Video: 2025 EAT-Lancet video and podcast

- You can watch Johan Rockström's five-minute video about the EAT–*Lancet* Commission Report 2025, Scientific Assessment of the Global Food System. Fifteen million premature deaths could be prevented if the world adopted a healthier plant-based diet.
- The EAT-*Lancet* Commission on healthy, sustainable and just food systems video is a 40-minute podcast in which Commission members discuss the global need for equitable, sustainable, and health-promoting food systems and explain how our everyday food choices impact the wider world.

Harvard's TH Chan School of Public Health's Plate and Planet article highlights the importance of dietary choices that promote both human health and environmental sustainability, advocating for a shift towards plant-based foods and mindful consumption of animal products. Please check the link above for more information and an illustration of a sustainable, healthy meal plate and a seven-day sample meal plan. As was discussed in **Chapter 3**, generic meal plans

and plating ideas need to be customised to suit an individual's unique nutrition requirements. An accredited practising dietitian can assist with this.

17.16. Preventing SCIs

Preventing SCIs in the first place is an important conversation in the context of sustainability. SCIs are costly financially, not just to the State but also to the individual. These SCIs are also costly psychologically, as they take a toll on the well-being of many.

Important resources: Preventing SCIs

- The Paraplegic Benefit Fund (PBF) offers Injury prevention programs (workplace, road, youth and aqua). Watch the PBF Injury Prevention Workplace Trailer.
- There are also stories such as Tegan's story (regarding 'Road'), What are you diving into? (regarding 'Aqua') and a Peer support program.
- Scroll down Forward's website on this page (SCI prevention) to the *Don't be a statistic* infographic, which highlights some of the road accident *TSCI* statistics. Importantly, scrolling down further, is advice relating to what to do if there is a suspect SCI following an accident or fall.

Bellon and colleagues (2013) note that SCI not only results in paralysis but also has lasting impacts on both physical and mental health. An estimated 236,000 to 327,000 people in the United States live with the consequences of SCI, creating a substantial economic burden for individuals, their support networks, and society. These far-reaching impacts highlight the need for health care professionals to prioritise primary prevention. While efforts often concentrate on treatment and cure, evidence-based prevention should play a more prominent role. Primary prevention offers significant cost benefits, and initiatives that promote safer behaviours and reduce risk deserve greater emphasis. Such approaches can be applied across major causes of injury, including motor vehicle crashes, sports-related trauma and firearm misuse, with the overarching goal of eliminating preventable injuries and their life-altering effects.

17.17. Final thoughts: Learning from the COVID-19 pandemic and SCI

In 2020, in Pandemics, climate change, and disability related to SCI, Alexander wrote about two major issues of our time: disasters related to the climate crisis and the COVID-19 pandemic. As we already know, the climate crisis will increase the frequency of fires and extreme weather conditions such as droughts, excessive heat, storms and floods, amongst other societal concerns. This final section of the chapter considers how the COVID-19 pandemic, which quickly enveloped our world and created an unprecedented need for global unity and collaboration, can serve as a bellwether for preparing for adverse weather and climate events and, perhaps, the next pandemic.

Video: Dinesh and COVID-19

Dinesh Palipana discusses disability and the COVID-19 pandemic (ABC News, 19 August 2020), highlighting findings from the Disability Royal Commission that no COVID-19 plan existed for the disability sector until mid-April, more than a month after the WHO declared a pandemic and noting that the Commission had only just resumed hearings following earlier disruptions.

COVID-19 challenged every country, with over 7 million deaths across the world and while the pandemic may not be considered a sudden-onset disaster, it was an emergency. The International Disability Alliance (IDA) advocated for persons with disability needing to be prioritised in accessing the COVID-19 vaccine. Just like adverse weather events, COVID-19 interrupted health and rehabilitation services and we can certainly learn from how that was handled (not well). Alexander (2020) is of the opinion that it would be prudent to consider the COVID-19 pandemic as a drill for how we need to respond to the climate crisis, with the recent worldwide immediate transition to telemedicine, online education and communication. The reduction in travel and the reduced air pollution during the COVID-19 pandemic showed us what we can achieve with a reduction in fossil fuel burning.

Using an online survey of the WHO's QOL-Brief Version (BREF) and disability (DIS) modules, Altahla *et al.* (2024) compared the ***quality of life (QOL)***, depression and anxiety of SCI patients before and during COVID-19 in Wuhan City, China (Nov 2020-Apr 2021) with pre-COVID records of non-SCI patients (Nov-Dec 2019) who had completed the survey. They found that SCI patients had lower QOL scores during the pandemic than before. Participants showed higher adherence to self-isolation and quarantine measures for high-risk encounters (64.94%), but lower compliance with home disinfection and proper rest practices (23.38%). Based on the find-

ings, the authors advocate for telehealth-based rehabilitation to mitigate the impact of pandemic-related isolation.

In June 2025, WHO Member States agreed to a global process to draft and negotiate a convention, agreement or other international instrument under the WHO Constitution to strengthen pandemic preparation and response. The Pandemic Agreement was adopted on 20 May 2025 at the Seventy-eighth World Health Assembly through resolution WHA78.1, which also established an Intergovernmental Working Group to conclude the work on the Pandemic Agreement, so that it may be opened for signature and ratification by WHO Member States. The WHO website provides a series of questions and answers about this Agreement.

Interesting information: Disease Outbreak News

For emergencies, the WHO provides regular updates through its Disease Outbreak News (DONs), the organisation's official platform for publishing authoritative public reports on confirmed or potential acute public health events that meet criteria for international concern, offering reliable and independent information under the International Health Regulations.

In terms of future pandemics, in their September 2025 commentary and call to action on climate change and pandemics, Treskova and colleagues highlight how climate change is expected to increase cross-species viral transmission as animals migrate to more favourable habitats. This will elevate the risk of viruses and other microorganisms mutating and potentially infecting humans. Some potential pathogens that could become the next pandemic include Ebola, Nipah, Hendra and the rabies virus. The authors have called for increased research on the impact of climate change on biological and ecological systems to identify potential transmission risks.

Key Take-aways

- The global climate is changing, including Australia's climate
- Australia can expect an increase in the frequency and intensity of heatwaves, storms, floods and rising sea levels
- Some individuals, such as those with a high-level SCI, are physiologically at-risk in terms of an inability to regulate body temperature, while compromised organ systems, such as the respiratory, cardiovas-

cular and renal systems, pose a risk during such events
- There are also physical vulnerabilities, particularly mobility issues during power outages and with debris and flooding during storms and cyclones
- This adds extra anxiety and stress, heightening psychological distress
- Disaster management planning is essential for people living with SCI and their support teams. The 2025 National Climate Adaptation Plan addresses this
- Many tools exist to prepare disaster management plans for emergencies, which include providing a list of essential items, such as a torch, spare batteries, food and extra medication. For ventilated individuals, back-up power is important
- An emerging area in SCIs is environmental sustainability, in line with global and national efforts to reduce the environmental footprint of healthcare and meet the 2030 UN Sustainable Development Goals (SDGs). The 2023 National Climate and Health Strategy's 49 Actions are largely directed to making healthcare delivery more environmentally sustainable, and
- The COVID-19 pandemic led to lockdowns, which resulted in considerable psychological distress. Individuals living with SCI appear to have imposed stricter self-isolation, resulting in negative psychological effects.

"By assessing climate risks, understanding their implications, and taking informed actions, we strengthen our ability to adapt and thrive in a changing world."

Australian Climate Service: Australia's first National Climate Risk Assessment website

The final chapter (**Chapter 18**) discusses the education of a range of health professionals involved with SCI, from OTs to GPs. The Chapter explores curriculum content related to SCI and disability in general, as well as learning to work in multidisciplinary teams. For medicine, there is also a section on disability inclusion and applicants.

Reminder: Relevant chapters

- **Chapter 1:** When coming 'home', wherever that might be, it is worth exploring whether your home or accommodation is climate-resilient, in terms of how hot the suburb may get and whether it will be affected by flooding or rising sea levels.*Does the accommodation or home allow the maintenance of a physiologically acceptable temperature? What is the backup plan for elevators and batteries if ventilation fails? How easy is it to evacuate the building?*
- **Chapter 2:** As many of the physiological changes associated with SCI potentially place someone with SCI at risk, Chapter 2 is a good reference chapter. Higher ambient temperatures mean the pathogens thrive. It is important to be extra vigilant with hygiene during warmer weather
- **Chapter 3:** The five pillars of good health and well-being may be interrupted during an adverse weather event. Part of an emergency plan would be to have sufficient food, water and support
- **Chapter 4:** Documenting health and well-being is important during adverse weather events, such as heatwaves

- **Chapter 5:** Working and studying venues need to ensure that safe physiological temperatures can be maintained and must have evacuation plans in case of an emergency
- **Chapter 6:** A SCI adds another layer to degenerative changes associated with ageing. Older individuals are more susceptible to heat due to declining perception of temperature and thirst, and the impact of heat on the body due to polypharmacy. Decreased muscle mass and bone density, unless carefully monitored, may lead to declining strength and hence mobility and an increased likelihood of falls
- **Chapter 7:** Children and adolescents, too, are vulnerable and so understanding what is happening to their bodies is important
- **Chapter 8:** RRR Australia is likely to be impacted by a changing climate in terms of increasing ambient temperatures, droughts, flooding and, if coastal, rising sea levels
- **Chapter 9:** Of the different areas of intersectionality discussed in Chapter 9, in terms of a changing climate and emergency warnings relating to adverse weather events that indicate evacuation, not understanding English might be a risk factor. Those who are homeless or incarcerated would be particularly vulnerable to adverse weather events
- **Chapter 10:** Having access to early warnings in case of an emergency is a basic human right, which, based on some of the considerations discussed in Chapter 9, might compromise the safety of certain groups of people
- **Chapter 12:** While we may have an emergency plan for adverse weather events at home, this may not be the case when we travel nationally and internationally. Some regions are prone to weather events, often at certain times of the year. These considerations need to be incorporated into travel plans, and
- **Chapter 15:** With many people with SCI involved in parasport, the dangers of physical activity both outdoors, such as dehydration and heat stress or heat stroke, and indoors, which may have higher humidity, need to be considered. Check the Sports Heat Tool.

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References

Alahmad, B., Tobias, A., Maddelot, P., & Gasparrini. (2025). Are there more cold deaths than heat deaths? *Lancet Planetary Health, 9(*3), E170-E171. https://www.thelancet.com/journals/lanplh/article/PIIS2542-5196(25)00054-3/fulltext

Alexander, M. (2019). Sustainability and spinal cord injury: attending to climate change and disability. *Spinal Cord Series Cases, 5*, 88. https://doi.org/10.1038/s41394-019-0232-6.

Alexander, M. (2020). Pandemics, climate change, and disability related to SCI. *Spinal Cord Series Cases, 6,* 36. https://doi.org/10.1038/s41394-020-0285-6

Alexander, M., Alexander, J., Arora, M., Slocum, C., & Middleton, J. (2019). A bellwether for climate change and disability: educational needs of rehabilitation professionals regarding disaster management and spinal cord injuries. *Spinal Cord Series Cases, 5*(1), 90. https://doi.org/10.1038/s41394-019-0239-z

Altahla, R., Alshorman, J., Ali, I., & Tao, X. (2024). A cross-sectional survey on the effects of the COVID-19 pandemic on psychological well-being and quality of life in people with spinal cord injury. *Journal of Orthopaedic Surgery and Research, 19,* 564. https://doi.org/10.1186/s13018-024-04955-x.

Amoatey, P., Trancoso, R., Xu, Z., Darssan, D., Osborne, N. J., & Phung, D. (2025). Evaluating the association between heatwave vulnerability index and related deaths in Australia. *Environmental Impact Assessment Review, 112,* 107812. https://doi.org/10.1016/j.eiar.2025.107812.

Amatya, B., & Khan, F. (2023). Climate change and disability: a physical medicine and rehabilitation (PM&R) perspective. *Journal of the International Society of Physical and Rehabilitation Medicine, 6*(1), 5. https://rmsanz.net/wp-content/uploads/2023/11/Amatya_2023_Climate_change_and_disability_JISPRM.pdf

Andreae, M., Shultz, J.M., Shepherd, J.M., Espinel, Z. & Shapiro, L. T. (2024). Weathering the storms of climate change: Preparing persons with disabilities and the psychiatrists who provide their care for extreme hurricanes. *Physical Medicine & Rehabilitation,* 1-11. https://onlinelibrary.wiley.com/doi/full/10.1002/pmrj.13159?msockid=2c16d98a012360f13802cc1b0026611e

Ardagh, M., Richardson, S. K., Robinson, V. R., Than, M., Gee, P., Henderson, S., Khodaverdi, L., McKie, J., Robertson, G., Schroeder, P.P. & Deely, M. M. (2012). The initial health-system response to the earthquake in Christchurch, New Zealand, in February, 2011. *Lancet, 279*(9831), P2109-20115. https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(12)60313-4/fulltext

Aung, T. W., O'Donnell, K., De Luca, S. & Gunzler, D. (2025). Depression and anxiety symptoms in adults displaced by natural disasters. *JAMA Network Open, 8*(8), e2528546. https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2837935

Australian Climate Service. (2025). *Australia's first National Climate Risk Assessment*. Australian Government. National Climate Risk Assessment | Australian Climate Service Website

Australian Government. (2023). *National Health and Climate Strategy.* Department of Health, Disability, and Ageing. https://www.health.gov.au/news/launch-of-australias-first-national-health-and-climate-strategy

Australian Government. (2025). *National Adaptation Plan*. Department of Climate Change, Energy, the Environment and Water. https://www.dcceew.gov.au/climate-change/publications/national-adaptation-plan

Australian Institute of Health and Welfare. (2023). *Let's talk about the weather: injuries related to extreme weather*. https://www.aihw.gov.au/reports/injury/extreme-weather-injuries/contents/extreme-heat

Australian Institute of Health and Wellbeing (AIHW). (2025). *Australia's Disability Strategy 2021-2031 Outcomes Framework Third Annual Report.* Health and Wellbeing. https://www.aihw.gov.au/australias-disability-strategy/outcomes/health-and-wellbeing

Bailie, J., Matthews, V., Bailie, R., Villeneuve, M., Longman, J. (2022). Exposure to risk and experiences of river flooding for people with disability and carers in rural Australia: A cross-sectional survey', *British Medical Journal Open*, *12*(8), e056210. https://bmjopen.bmj.com/content/12/8/e056210.

Bass, D. H., Ghamasaee, P., Bigford, G. E., Wakefield, M., Duthely, L. M., & Samano, D. (2024). Assessing regional weather's impact on spinal cord injury survivors, caregivers, and general public in Miami, Florida. *International Journal of Environmental Research in Public Health, 21*(4), 382. https://www.mdpi.com/1660-4601/21/4/382

Bellon, K., Kolakowsky-Hayner, S. A., Chen, D., McDowell, S., Bitterman, B., & Klaas, S. J. (2013). Evidence-based practice in primary prevention of spinal cord injury. *Top Spinal Cord Injury and Rehabilitation*, *19*(1), 25-30. https://pubmed.ncbi.nlm.nih.gov/23678282/.

Bowman, D. (2026). Rain one minute, heatwave the next. How climate 'whiplash' drives unpredictable fire weather. *The Conversation*, January 12. https://theconversation.com/rain-one-minute-heatwave-the-next-how-climate-whiplash-drives-unpredictable-fire-weather-273104

Boyd, C. P., Jamieson, J., Gibson, K., Duffy, M., & Williamson, M. (2024). Eco-anxiety among regional Australian youth with mental health problems: A qualitative study. Early Intervention in Psychiatry, 18(12), 1022-1031. https://doi.org/10.1111/eip.13549

Burke, K. (2024). *Rise in suicidal behaviours among young people linked to hotter temperatures*. UNSW Newsroom. https://www.unsw.edu.au/newsroom/news/2024/10/rise-in-suicidal-behaviours-among-young-people-linked-to-hotter-temperatures

Bratanova, A., Chebn, H., Pham, H., Tursunalieva, S. Dunstall, S., Schleiger, E., & Dunne, R. (2024). *Why do we need to understand the health vulnerability of Australians? Summary report* (December 2024). CSIRO, Energy Networks. https://research.csiro.au/heat-and-los/

Burns, A. S., O'Connell, C., Rathore, F. A. (2012). Meeting the challenges of spinal cord injury care following sudden onset disaster: lessons learned. *Journal of Rehabilitation Medicine*, *44*(5):414-420. https://medicaljournalssweden.se/jrm/article/view/16055.

Chapman, K. (2023, October 30). *Dignity means seeing the whole person: Why this matters for people with disability.* Inclusive Futures, Griffith University. https://inclusivefutures.griffith.edu.au/dignity-means-seeing-the-whole-person-why-this-matters-for-people-with-disability

Chapman, K., Kendall, E., Ambrose, E., & Barker, R. (2025). *The Voice of Queenslanders with Disability.* Griffith University. https://apo.org.au/sites/default/files/resource-files/2025-08/apo-nid332013.pdf

Chapman, K., Norwood, M., Shirota, C., Palipana, D., & Kendall, E. (2022). An undignified disaster reality for Australians with disability. *Australian Health Review*, *46*(6), 710-712. https://doi.org/10.1071/AH22212

Clark, H. (2025). The climate crisis is fuelling extreme fires across the planet. *The Conversation*, October 16. https://theconversation.com/the-climate-crisis-is-fuelling-extreme-fires-across-the-planet-267626

Climate Council of Australia. (2026). *Breakneck Speed: Summer of Climate Backlash*. Climate Council of Australia Limited. https://www.climatecouncil.org.au/wp-content/uploads/2026/03/Climate-Council-End-of-Summer-2026-Report.pdf

Cook, G., Dowdy, A., Knauer, J., Meyr, M., Canadell, P., & Briggs, P. (2021). *Australia's Black Summer of fires was not normal – and we can prove it*. CSIRO, 29 November. https://www.csiro.au/en/news/all/articles/2021/november/bushfires-linked-climate-change

Dey, C., Wu, J., Uesi, J., Sara, G., Dudley, M., Knight, K., Scott, J. G., Jay, O., Bowden, M. & Perkes, A. E. (2024). Youth suicidality risk relative to ambient temperature and heatwaves across climate zones: A time series analysis of emergency department presentations in New South Wales, Australia. *Australian & New Zealand Journal of Psychiatry, 59*(1), 8-28. https://doi.org/10.1177/00048674241290449

Ebi, K. L., Capon, A., Berry, P., Broderick, C., de Dear, R., Havenith, G., Honda, Y., Kovats, S., Ma, W., Malik, A., Morris, N. B., Nybo, L., Seneviratne, S. I., Vanos, J., & Jay, O. (2021). Hot weather and heat extremes: health risks. *Lancet, 398*(10301), P698-6978. https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(21)01208-3/fulltext

Golembeski, C. Irfan, A., Méndez, M., Dominick, A., Dopson, R., & Skarha, J. (2023). *Understanding Climate and Disability Justice: Mitigating Structural Barriers to the Right to Health.* The Petrie-Fom Center, Harvard Law School. https://petrieflom.law.harvard.edu/2023/08/08/understanding-climate-and-disability-justice-mitigating-structural-barriers-to-the-right-to-health/

Grant, E., & Runkle, J. D. (2022). Long-term health effects of wildfire exposure: A scoping review. *Journal of Climate Change and Health*, *6,* 100110. https://www.sciencedirect.com/science/article/pii/S2667278221001073?via%3Dihub.

Hogaboom, N. S., Oyster, M. L., Riggins, M. S., & Boninger, M. L. (2013). Evacuation preparedness in full-time wheelchair users with spinal cord injury. *The Journal of Spinal Cord Medicine, 36*(4), 290-295. https://doi.org/10.1179/2045772312Y.0000000050

Hogan, T.P., Holmes, S.A., Rapacki, L.M., Evans, C.T., Lindblom, L., Hoenig, H., Goldstein, B., Hahm, B., & Weaver, F. M. (2011). Disaster preparedness and response practices among

providers from the Veterans Health Administration and veterans with spinal cord injuries and/or disorders. *Journal of Spinal Cord Medicine, 34*(4), 35361. https://doi.org/10.1179/2045772311Y.0000000011

Imberti, L., Tiecco, G., Logiudice, J., Castelli, F., & Quiros-Roldan, E. (2025). Effects of climate change on the immune system: A narrative review. *Health Sciences Reports, 8*(4), e70627. https://doi.org/10.1002/hsr2.70627.

Jeffries, T. (2025). Melioidosis outbreak continues to grow. *NewsGP.* https://www1.racgp.org.au/newsgp/clinical/melioidosis-outbreak-continues-to-grow

Jodoin, S., Bowie-Edwards, A., Lofts, K., Mangar, S., Adjel, B., & Lesnikowski, A. (2025). A systematic analysis of disability inclusion in domestic climate policies. *npj Clim. Action, 4*, 24. https://doi.org/10.1038/s44168-025-00228-3.

Johnson, F. H., Williamson, G., Borschers-Arriagada, N., Henderson, S. B., & Bowman, D. M. J. S. (2024). Climate change, landscape fires, and human health: A global perspective. Annual *Review of Public Health, 45,* 295-314. https://www.annualreviews.org/content/journals/10.1146/annurev-publhealth-060222-034131.

Kim, S., Kim, Y., Park, J., Kim, R., Lee, W., Bell, M. L., & Lee, J-T. (2026). Leave no one behind: a call to include people with disabilities in climate change and health research. *Lancet Planetary Health*, 101440. https://www.thelancet.com/journals/lanplh/article/PIIS2542-5196(26)00013-6/fulltext

King, A. (2026). The latest world climate report is grim, but it's not the end of the story. *The Conversation*, 23 March. https://theconversation.com/the-latest-world-climate-report-is-grim-but-its-not-the-end-of-the-story-278886

KPMG. (2024). *Climate risk report 2024*. https://assets.kpmg.com/content/dam/kpmgsites/au/pdf/2024/kpmg-climate-risk-report-2024.pdf

Lechat, B., Manners, J., Pinilla, L. et al. (2025). Global warming may increase the burden of obstructive sleep apnea. *Nature Communications, 16*, 5100. https://doi.org/10.1038/s41467-025-60218-1.

Makuyana, T. & Dube, K. (2024). Mapping disability and climate change knowledge base in Scopus using bibliometric analysis. *African Journal of Disability, 13*, 1339. https://ajod.org/index.php/ajod/article/view/1339

Matthews, V. & Larkin, S. (2024). Health impacts of climate change. In *National Guide to Preventive Healthcare for Aboriginal and Torres Strait Islander people*. National Aboriginal Controlled Health Organisation-Royal Australian College of General Practice. https://www.racgp.org.au/clinical-resources/clinical-guidelines/key-racgp-guidelines/national-guide

McClure, L. A., Boninger, M. L., Oyster, M. L, Roach, M. J, Nagy, J., & Nemunaitis, G. (2011). Emergency evacuation readiness of full-time wheelchair users with spinal cord injury. *Archives*

of Physical Medicine and Rehabilitation, 92(3), 491-498. https://www.archives-pmr.org/article/S0003-9993(10)00843-9/abstract

Mitchell, A. M., Maheen, H., & Bowen, K. (2024). Mental health impacts from repeated climate disasters: an Australian longitudinal analysis. *Lancet Regional Health – Western Pacific, 47*, 101087. https://www.thelancet.com/journals/lanwpc/article/PIIS2666-6065(24)00081-6/fulltext

Newman, M., Kokame, K. A., Ceochico, C. F. D., Fogarty, A. E., Burton, J., Tenforde, A. S. & Alexander, M. (2025). Climate change and health through the lens of physical medicine and rehabilitation: A scoping review. *The Journal of Climate Change and Health, 22*, 100362. https://www.sciencedirect.com/science/article/pii/S2667278224000658

O'Connell, C. M., Eriks-Hoogland, I., & Middleton, J. W. (2020). Now, more than ever, our community is needed: spinal cord injury care during a global pandemic. *Spinal Cord Series Cases*, *6*. https://doi.org/10.1038/s41394-020-0270-0.

Oliver, B. (2026). How to protect yourself from bushfire smoke. *The Conversation*, January 9. https://theconversation.com/how-to-protect-yourself-from-bushfire-smoke-272065

Ozdogan, F. (2025). The disasters we talk about shape our priorities and determine our preparedness. *The Conversation*, October 13. https://theconversation.com/the-disasters-we-talk-about-shape-our-priorities-and-determine-our-preparedness-266200

Partheepan, S., Sanati, F., & Hassan, J. (2025). Modelling bushfire severity and predicting future trends in Australia using remote sensing and machine learning. *Environmental Modelling & Software, 88*, 106377. https://doi.org/10.1016/j.envsoft.2025.106377

Pasipanodya, E. C., & Shem, K. (2020). Provision of care through telemedicine during a natural disaster: a case study. *Spinal Cord Series and Cases*, *6*, 60. https://doi.org/10.1038/s41394-020-0309-2.

Ratter-Rieck, J. M., Roden, M. & Herder, C. (2023). Diabetes and climate change: current evidence and implications for people with diabetes, clinicians and policy stakeholders*. Diabetologia. 66,* 1003-1015. https://doi.org/10.1007/s00125-023-05901-y.

Rockström, J., Thilsted, S. H., Willett, W. C., Gordon, L. J., Herrero, M., Hicks, C. C., Mason-D'Croz, D., Rao, N., Springmann, M., Wright, E. C., Agustina, R., Bajaj, S., Bunge, A. C., Carducci, B., Conti, C., Covic, N., Fanzo, J., Forouhi, N. G., Gibson, M. F. Gu, X., …. DeClerck, F. (2025). The EAT–*Lancet* Commission on healthy, sustainable, and just food systems. *Lancet, 406*(10512), P1625-1700. https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(25)01201-2/fulltext

Shah, I, McLean, M., & Rhaman, K. (2026). A changing climate, including adverse weather events, impacts on individuals with spinal cord injury: a narrative review. *The Journal of Climate Change and Health, xx*, 100678. in press.

Shapiro, L. T., Gater, D. R., Espinel Z, Kossin JP, Galea S, Shultz, J. M. (2020a). Preparing individuals with spinal cord injury for extreme storms in the era of climate change. *eClinicalMedicine, 18,* 100224. https://www.thelancet.com/journals/eclinm/article/PIIS2589-5370(19)30237-8/fulltext

Shapiro, L. T, Gater, D. R., & Shultz, J. M. (2020b). It is time to put hurricane preparedness on the radar for individuals living with spinal cord injury. *Spinal Cord Series Cases, 6*, 34. https://www.nature.com/articles/s41394-020-0282-9

Sisodiya, S. M., Gulcebi, M. I., Fortunato, F., Mills, J. D., Haynes, E., Bramon, E., Chadwick, P., Ciccarelli, O., David, A. S., De Meyer, K., Fox, N. C., Wetton, J. D., Koltzenburg, M., Kullmann, D. M., Kurian, M. A., Manji, H., Maslin, M. A., Matharu, M., Montgomery, H., Romanello, M., Werring, D. J. Zhang, L., Friston, K. J. & Hanna, M. G. (2024). Climate change and disorders of the nervous system. *Lancet Neurology, 23*(6), 636-648. https://www.thelancet.com/journals/laneur/article/PIIS1474-4422(24)00087-5/fulltext

Steffen, W. & Bradshaw, S. (2021). *Hitting home: The compounding costs of climate inaction*. Climate Council of Australia. https://www.climatecouncil.org.au/wp-content/uploads/2021/01/hitting-home-report-V7-210122.pdf

Stein, P. J. S. & Stein, M. A. (2022). Climate change and the right to health of people with disabilities. *Lancet Global Health, 10*(1), e24-e25. https://www.thelancet.com/journals/langlo/article/PIIS2214-109X(21)00542-8/fulltext?ref=disabilitydebrief.org.

Stein, P. J. S. Stein, Ashley Stein, M. A., Groce, N., Kett, M., Akyeampong, E. K., Alford, W. P., Chakraborty, J., Daniels-Mayes, S., Eriksen, S. H., Fracht, A., Gallegos, L., Grech, S., Gurung, P., Hans, A., Harpur, P., Jodoin, S., Lord, J. E., Macanawai, S. S., McClain-Nhlapo, C. V., Mezmur, B. D., Moore, R. J., Muñoz, Y., Patel, V., Pham, P. N., Quinn, G., Sadlier, S. A., Shachar, C., Smith, M. S., & Van Susteren, L. (2024). Advancing disability-inclusive climate research and action, climate justice, and climate-resilient development. *Lancet Planetary Health, 8*(4), e242-e255. https://doi.org/10.1016/S2542-5196(24)00024-X

Talley, N. J. (2025). Fighting for our health in the wake of the National Climate Risk Assessment. *Insight, 39*. https://insightplus.mja.com.au/2025/39/fighting-for-our-health-in-the-wake-of-the-national-climate-risk-assessment/.

Taylor, A. L., Perret, D., Morice, K., Zafonte, Ross., Skelton, F., Rivers, E., Alexander, M., (2022). Climate change and physiatry: A call to proportional and prospective action. *American Journal of Physical Medicine & Rehabilitation 101*(10), 988-993. https://journals.lww.com/ajpmr/fulltext/2022/10000/climate_change_and_physiatry__a_call_to.13.aspx

Thompson, B. (2025). Sleep apnea cases to rise 45% and one global factor is to blame. *New Atlas.* https://newatlas.com/sleep/sleep-apnea-climate/

Treskova, M. Semenza, J. C., Arnés-Sanz, C., Al-Ahdal, T., Markotter, W., Sikkema, R. S., & Rocklöv, J. (2025). Climate change and pandemics: a call for action. *Lancet Planetary Health*, *9*(9), 101302. https://www.thelancet.com/journals/lanplh/article/PIIS2542-5196(25)00180-9/fulltext

Tsai, C. Y., Miller, A. S., Huang, V. *et al.* (2019). The feasibility and usability of a mobile application for performing home evaluations. *Spinal Cord Series Cases, 5*, 76. https://doi.org/10.1038/s41394-019-0219-3.

Tyagi, N., Amar Goel, S. & Alexander, M. (2019). Improving quality of life after spinal cord injury in India with telehealth. *Spinal Cord Series Cases, 5*, 70. https://doi.org/10.1038/s41394-019-0212-x

Vasquez, L. O., Lee, I., Bart, J., Barton, C. R., Chui, J., Tascione, O., Kumar, N. S., Cirnigliaro, C. M., Lombard, A. T., Kirschblom, S. C., Bauman, W. A., & Handrakis, J. P. (2024). Self-reported effects of warm seasonal temperatures in persons with spinal cord injury. *Journal of Spinal Cord Medicine, 47*(3), 395-403. https://doi.org/10.1080/10790268.2023.2194962

Willett, W., Rockström, J., Loken, B., Springmann, M., Lang, T., Vermeulen, S., Garnett, T., Tilman, D., DeClerck, F., Wood, A., Jonell, M., Clark, M., Gordon, L. J., Fanzo, J., Hawkes, C., Zurayk, R., Rivera, J. A., De Vries, W., Sibanda, L. M., Afshin, A., ... Murray, C. J. L. (2019). Food in the Anthropocene: the EAT-*Lancet* Commission on healthy diets from sustainable food systems. *Lancet, 393*(10170), 447-492. https://doi.org/10.1016/S0140-6736(18)31788-4

World Meteorological Organisation. *State of the Global Climate 2025.* https://wmo.int/publication-series/state-of-global-climate/state-of-global-climate-2025

Wu, Y., Wen, B., Gasevic, D., Patz, J. A., Haines, A., Ebi, K. L. Murray, V., Li, S., & Guo, Y. (2024). Climate change, floods, and human health. *New England Journal of Medicine, 391*(20), 1949-1958. https://www.nejm.org/doi/abs/10.1056/NEJMsr2402457

Xu, Z., Xu, R., Yang, Z., Huang, W., Muray, S., Guo, Y., & Li, S. (2025). Mapping heatwave-related mortality across 2288 local communities in Australia: a nationwide time-series analysis. *Environment International, 203,* 109747. https://doi.org/10.1016/j.envint.2025.109747.

Xu, R., Ye, T., Huang, W., Yue, X., Morawska, L., Michael J Abramson, M. J., Chen, G., Yu, P., Liu, Y., Yang, Z., Zhang, Y., Wu, Y., Yu, W., Wen, B., Zhang, Y., Hales, S., Lavigne, E., Saldiva, P. H. N., Coelho, M. S. Z. S., Matus, P., Roye, D., Klompmaker, J., Mistry, M., Breitner, S., Zeka, A., Raz, R., Tong, S., Johnston, F. H., Schwartz, J., Gasparrini, A., Guo, Y., & Li, S., (2024). Global, regional, and national mortality burden attributable to air pollution from landscape fires: a health impact assessment study. *Lancet, 404*(10470), P2447-2459. https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(24)02251-7/fulltext

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Chapter 18. Health Professions Education: Curriculum and Inclusion

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> *"The lack of disability awareness amongst health providers isn't due to reluctance or lack of empathy. It's a knowledge and skills gap. Our university courses and workplaces tend to be focused on discipline-specific education training, which leaves a shortfall in disability awareness. This realisation, coupled with my lived experience as a dietitian with a disability compelled me to jump at the change to help develop the Access for All disability awareness training."*
>
> **Amanda Frier**, a dietitian (PhD) on social determinants of health, who acquired a disability as a health provider, allowed her to experience healthcare as a provider and as a user.

Through a series of diagrams in **Chapters 1, 3, 5 and 6** of this e-resource, ***Towards a life well-lived with spinal cord injury: A resource for those affected, their carers and health professionals***, we have described various health professionals who, as part of different multidisciplinary teams, accompany individuals with SCI on their very personal journeys from coming home (**Chapter 1**) after rehabilitation, staying healthy and well (**Chapter 3**), getting back to work, study and socialising (**Chapter 5**) to ageing well with SCI (**Chapter 6**).

It seems fitting then that this final chapter explores how the various health professions in Australia prepare their graduates for working clinically with individuals living with SCI. While each profession is governed by professional Accreditation or Competency Standards, regulated by the Australian Health Practitioner Regulatory Agency (AHPRA), they all need to work as members of various multidisciplinary teams. Included in their competencies should thus be the ability to work and communicate with other health professionals and team members.

While each health profession will have inherent requirements to ensure that its graduates are competent to deliver safe care, universities also have a legal and ethical responsibility to ensure that education is inclusive of learner diversity.

Key Topics in this Chapter

- Human rights and disability in Australia in relation to education and work
- Inherent requirements in Australian education (curriculum, admissions and student support)
- Health Professions Standards:
    - Physiotherapy Practice Thresholds for Australia and New Zealand
    - Competency Standards for Occupational Therapy
    - Exercise Physiologist Professional Standards for Accreditation
    - National Competency Standards for Dietitians
    - Registered Nurse (RN) and Nurse Practitioner (NP) Standards for Practice, plus specialist courses for bladder and bowel management, wound healing, etc.
    - Podiatry Professional Capabilities
    - Speech Pathology Professional Standards
    - Standards for Australian undergraduate, prevocational and graduate medical education, including ***continuing professional development (CPD)*** for medical graduates, and
- Inclusive medical education and training: Applicants and those already studying (primary medical programs, prevocational training, General Practice specialist training).

18.1. Human rights and disability in Australia in relation to education

The 2006 UN Convention on the Rights of Persons with Disabilities has two articles relating to education and employment:

- **Article 24:** The right to education, without discrimination, on the basis of equal opportunity, at all levels and lifelong learning.
- **Article 27:** To work, on an equal basis with others, including the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible.

The Australian Human Rights Commission's Disability Rights program aims to protect and promote the human rights and freedoms of people with disabilities. This includes safeguarding

against discrimination and ensuring rights to equality, participation, inclusion, autonomy and accessibility in various aspects of life. Central to this program is the Disability Discrimination Act 1992 (currently under review), which makes discrimination based on disability unlawful in areas, such as employment and education and access to public services. In terms of this Act:

- **Direct discrimination** involves treating someone less favourably than another person because of disability.
- **Indirect discrimination** involves a rule, policy or practice that appears to be neutral (same for everyone), but has the effect of placing people with disability at a disadvantage by failing to make reasonable adjustments, harassing or victimising individuals.

The Commission provides guidance to help individuals and organisations understand and comply with the Act. The Commission offers a range of resources, including:

- **Guides and advisory notes:** Provides advice on the application of the Disability Discrimination Act in various contexts
- **Training programs:** Designed to raise awareness and promote inclusive practices in workplaces and communities, and
- **Complaint mechanisms:** Enable individuals to report instances of discrimination and seek redress.

The Commission also engages in advocacy to influence public policy and promote systemic change. Notably, the final report of the 2023 Disability Royal Commission in 2023 recommended the enactment of a new Disability Rights Act to better align with the UN Convention on the Rights of Persons with Disabilities. This includes reforms in areas, such as housing, education and employment and emphasised the importance of consulting with people with disabilities in policy planning.

18.2. Inherent requirements of Australian universities, and hence health professions programs

In **Section 5.5.2** in **Chapter 5,** we described the onus of Australian universities to define and implement inherent requirement statements to ensure that students meet essential course requirements while also accommodating students with disabilities. Each health professions program should therefore include not only requirements relating to the competencies of its graduates to meet Australian health needs, inclusive of diversity, but also in terms of inclusion of applicants to different health professional programs.

In the Australian higher education context, accredited programs also outline inherent requirements, which describe the core abilities needed to meet professional competency standards and participate safely in learning and clinical placement environments. These commonly include domains such as communication, cognitive, behavioural, sensory and physical capac-

ities. Importantly,*inherent requirement statements generally acknowledge that reasonable adjustments may be implemented to enable students with disability to demonstrate competencies in line with professional standards or patient safety.* These requirements are, however, typically developed and published at the individual university level rather than through a single national framework. As such, detailed information about accessibility provisions, interpretation of inherent requirements and the implementation of reasonable adjustments must be reviewed through each university's program documentation and disability support resources. Consequently, the extent to which individual programs align with the Disability Discrimination Act and broader accessibility principles cannot be comprehensively verified within the scope of this e-resource summary.

Additionally, each Australian university advertises its Inherent requirements for students generally and then for specific programs. Since this e-resource is a Bond publication, it seems appropriate to provide the Bond University inherent requirements as an example. The site also provides Program-specific requirements for Medicine, Occupational Therapy, Physiotherapy and Psychology.

18.2.1. Making health professions' education accessible to students with disabilities, including SCI

Across Australian universities, health professions programs routinely publish 'inherent or essential requirements' documents. These describe the core skills, abilities, attributes and performance standards deemed necessary to safely complete the program and eventually practice as a health professional. University health programs combine face-to-face learning, laboratory practice and clinical placements. Students with an SCI may face physical, cognitive or environmental barriers in these settings, but *accessibility is achievable through inclusive design and reasonable adjustments*. This is important as it ensures compliance with disability legislation, such as the Disability Discrimination Act 1992, promotes equity and supports professional development without compromising competency standards. Physical and digital accessibility need to be ensured. Clinical placements must be adapted while maintaining competency achievement. Universal Design for Learning (UDL) principles by CAST will ensure that all students, including those with SCI, have multiple ways to access information, demonstrate skills and engage in collaborative learning. Faculty training in inclusive practice, coordinated support from disability services and accessible simulation environments will further enhance participation.

18.2.2. Graduate competencies of Australian health professionals

Most tertiary courses and programs have inherent requirement statements reflecting graduate competencies. Commonly used inherent requirement statements across the health professional programs might include statements about what graduates need to be able to do, such as:

- Work constructively in a diverse and changing academic and clinical environment as a member of a multidisciplinary team.
- Have knowledge, understanding of and be compliant with legislative and regulatory requirements, as prerequisites to clinical placements to reduce the risk of harm to self and others.
- Complete tasks that involve fine motor skills, including being able to grasp, press, push, turn, squeeze and manipulate various objects.

18.3. Health Professions Competency and Accreditation Standards

For much of this Chapter, we provide accreditation standards for several Australian health professions training programs whose graduates have been described as part of the multidisciplinary teams in **Part A** (**Chapters 1**, **3**, **5** and **6**). These health professions include Physiotherapy, Occupational Therapy, Exercise Physiology, Dietetics, Nursing, Podiatry, Speech Pathology and Medicine.

We have used different coloured text to highlight which Standards apply to two key areas relating to this e-resource: Competencies involving **SCI (or disability in general)** and **working in a multidisciplinary team.**

18.3.1. Physiotherapy Practice Thresholds for Australia and Aotearoa New Zealand

Physiotherapy is a dynamic health profession dedicated to enhancing health and functional ability across the lifespan. As registered practitioners, they apply scientific knowledge and clinical reasoning to autonomously assess, diagnose and manage human movement and function without requiring third-party referral. Physiotherapists adopt a holistic, people-centred approach that addresses physical, psychological, emotional and social well-being.

To ensure safe, effective and ethical practice, the Physiotherapy Boards of Australia and Aotearoa New Zealand have established the Physiotherapy Practice Thresholds for Australia and Aotearoa New Zealand (Physiotherapy Board, 2024). These Thresholds define the minimum competencies required for initial registration and continuing practice, organised into seven integrated roles: *Physiotherapy Practitioner, Professional and Ethical Practitioner, Communicator, Reflective Practitioner and Self-Directed Learner, Collaborative Practitioner, Educator, and Manager and Leader*, based on the Canadian Medical Education Directives (CanMEDS) physician competency framework. While presented as distinct roles, they operate synergistically, with the Physiotherapy ***Practitioner*** role at the core of practice. This framework emphasises cultural safety, client-centred care, evidence-based decision-making and **interprofessional collaboration**, ensuring physiotherapists deliver high-quality care across all settings, including **complex rehabilitation contexts such as SCI**.

Physiotherapists work across diverse contexts, assuming roles that extend beyond traditional clinical practice. These Thresholds guide physiotherapists to adopt evidence-informed strategies that optimise function, participation and quality of life for clients. Integration of these thresholds into SCI care promotes holistic, client-centred rehabilitation that addresses physical, psychological and social dimensions of recovery. Outlined below are examples that align with each competency role for physiotherapists in terms of **SCI rehabilitation**.

Role 1: Physiotherapy Practitioner

Physiotherapists optimise function and participation using evidence-informed strategies, integrating cultural safety and client-centred approaches, by:

- Performing standardised neurological assessment and early risk screening to determine the American Spinal Injury Association (ASIA) Impairment scale (AIS)**grade and Zones of Partial Preservation, screen for respiratory function and skin integrity in acute SCI rehabilitation**
- **Engaging in shared planning for locomotor recovery that co-designs programs** with the patient, their**family and the multidisciplinary team, discuss benefits and risks and set measurable goals aimed to** improve activities of daily living (ADLs), muscle strength and walking indices
- Actively participating and **supporting individuals with SCI during community transitions through adapting or advancing wheelchair skills, upper limb preservation and community participation.** They can also be a link to peer support and services and **coordinate with OT for seating optimisation**
- Facilitating tele-rehabilitation for regional, rural or remote clients (**Chapter 8**) and **advocating for appropriate assistive technologies** to support cardio-metabolic health and participation.

Role 2: Professional and Ethical Practitioner

Physiotherapists comply with legal, professional, ethical and cultural standards to ensure safety, consent, privacy and recognise professional boundaries, through:

- Implementation of**autonomic dysreflexia (AD) safety in therapy contexts by recognising risk, monitoring BP, identifying and removing triggers and adherence to the AD guidelines**. Followed by accurate and timely documentation of the episode and actions taken, all while communicating in a culturally safe way with the client, carers and **the multidisciplinary team**
- Ethical integration of emerging modalities, such as transcutaneous spinal cord stimulation, involves considering evidence, risks, alternatives, and cultural preferences, as well as practice within scope and **consult with the multidisciplinary team**.

Role 3: Communicator

Physiotherapists deliver clear, sensitive communication to foster trust and shared decision-making, such as:

- Explaining a new intervention in an understandable, respectful way, for example, explaining how standing can **support bone health, circulation and posture**, and
- Uses active listening to understand the person's priorities, repeating back key points to ensure accuracy, such as "It sounds like being able to grip utensils independently is really important to you" and validates feelings without dismissing them.

Role 4: Reflective Practitioner and Self-Directed Learner

Physiotherapists critically reflect on practice, identify learning needs, apply research and manage risk and engage in quality improvement by:

- Reflecting on their own assessment habits, recognise gaps in knowledge and complete targeted CPD, then implement developed skills to support quality-improvement initiatives to **ensure consistency across their own service and the multidisiplinary team**, and
- **Engage in research to support evidence-informed strategies** and undertake ongoing training to optimise health function for patients, such as systematic reviews that explore the use of*FES* for **muscle health and aerobic fitness**.

Role 5: Collaborative Practitioner

Physiotherapists practice interprofessional collaboration that ensures comprehensive SCI care, such as:

- **Co-managing seating and upper-limb preservation (quadriplegia) with an occupational therapist (OT) and prosthetics or orthotics** to optimise wheelchair seating, pressure distribution and shoulder protection and educate the family in safe transfers and equipment use
- **Coordinate with medicine, nursing and respiratory therapy** on ventilator-weaning plans and the prevention of atelectasis or pneumonia; integrate physiotherapy, airway clearance and early mobilisation consistent with guidelines, and
- **Community mobility and participation by collaboration with OT and peer support-**

ers to deliver **Wheelchair Skills Training Program sessions, including advanced skills for community navigation using evidence to support gains in skills and mobility domains.**

Role 6: Educator

Through tailored learning strategies and adult learning principles, physiotherapists empower clients, carers and colleagues. Examples include:

- Teaching SCI clients to independently manage pressure care and training support workers on safe, evidence-based transfers to prevent secondary injuries and enhance daily participation.
- Client and caregiver education with a physiotherapist conducting customised education sessions with an individual with a new T10 paraplegia and their family regarding AD, pressure injury prevention strategies and bladder and bowel management routines, and
- A physiotherapist **leads a training workshop for community-based support workers** on safe manual handling techniques for a patient, ensuring compliance with evidence-based practice and minimising injury risk.

Role 7: Manager and Leader

Physiotherapists manage time, workload, resources, and lead others within ethical and legal frameworks to enable high-quality, risk-aware practice. Examples include:

- Prioritising high-risk cases and resources: A senior physiotherapist in a spinal rehabilitation unit manages daily resources by allocating, for example, two staff members for the safe transfer of a newly injured, high-level quadriplegic patient, thereby ensuring risk-aware practice, and
- **Leading clinical education and mentorship:** The physiotherapist leads in-service training for staff on updated, evidence-based guidelines for respiratory management of individuals with SCI, improving team competency and ensuring consistent, high-quality care.

These role-based competencies translate into **tangible behaviours, including standardised assessment, prevention and management of complication**s. In 2022, the Australian and New Zealand SCI Physiotherapy Guidelines were developed to provide physiotherapists with a comprehensive, evidence-based resource to support best-practice care. **Figure 18.1** further demonstrates how a Physiotherapist implements the Physiotherapy Practice in SCI care across the various stages and settings to maximise patient health and well-being.

An interactive H5P element has been excluded from this version of the text. You can view it online here:
https://bond.studium.pub/life-well-lived-with-spinal-cord-injuries/?p=247#h5p-11

Figure 18.1. Understanding the role of the Physiotherapist in SCI care and the integrated application of the Physiotherapy Practice Thresholds. Created by Jaclyn Szkwara using Canva and HP5, licensed under a CC BY-NC (Attribution NonCommercial).

Applying the Physiotherapy Practice Thresholds to SCI rehabilitation offers a coherent and actionable framework for delivering evidence-informed, client-centred and culturally safe care. Through robust education strategies, **collaborative practice**, leadership in quality improvement and routine engagement in reflection and continuing professional development, physiotherapists ensure **care remains responsive to evolving evidence and client priorities, ultimately maximising independence and participation across the lifespan.**

18.3.2. Occupational Therapy Australia (OTA) Competency Standards

Occupational therapy, and hence occupational therapists (OTs), support people in engaging in everyday activities that bring purpose and fulfilment to their lives. These activities can include caring for oneself or others, working, volunteering, or engaging in hobbies, interests, and social connections that enhance health and well-being. Occupational Therapy practice in Australia is regulated by the Occupational Therapy Board of Australia**,** which falls under Ahpra. The 2019 Occupational Therapy Competency Standards (OTBA, 2018) guide safe and ethical practice by registered OT practitioners working in all practice settings and populations, including people living with an SCI.

The Competency Standards focus on four domains of OT practice: *Professionalism, Knowledge and Learning, OT Process and Practice and communication* (OTBA, 2018). Each area is supported by a set of practice behaviours which address specific core competencies. An OT working with individuals with SCI can apply the Australian Occupational Therapy Competency Standards (2018) across all four domains of practice. Below are applied examples that align each Standard with evidence-informed rehabilitation and client-centred care for SCI clients.

Standard 1: Professionalism

OTs practice ethically, safely and accountably by:

- Applying ethical decision-making when balancing client autonomy with safety, for example, by respecting a client's wish to trial independent transfers while ensuring risk management strategies are in place
- **Maintaining professional boundaries when providing long-term support to clients experiencing significant lifestyle changes due to SCI**
- Upholding**occupational justice by advocating for accessible public spaces, adaptive equipment funding or inclusion in employment programs**, and
- Adhering to work health and safety standards when assisting with transfers to avoid injury to both client and therapist.

Standard 2: Knowledge and Learning

OTs maintain and apply evidence-informed knowledge by:

- **Applying current theory and evidence from spinal cord rehabilitation research, such as functional electrical stimulation or assistive technology innovations**
- **Using frameworks like the Model of Human Occupation to analyse how environmental, personal, and occupational factors affect participation after SCI**
- Engaging in *continuing professional development (CPD)* through workshops on **pressure injury prevention, wheelchair prescription, or sexuality and intimacy post-injury**, and
- **Developing a learning plan when transitioning into SCI rehabilitation to ensure competent, safe and culturally responsive care.**

Standard 3: Occupational Therapy Process and Practice

OTs deliver client-centred, evidence-based occupational enablement by:

- **Conducting comprehensive assessments of occupational performance,** for example, self-care, mobility, work and leisure, using tools such as the Functional Independence Measure.
- Collaborating with clients to **set meaningful goals, such as returning to parenting, employment, or sports and co-develop graded rehabilitation plans**
- Recommending and training in the **use of assistive technology**, for example, powered wheelchairs, adaptive utensils and environmental control systems
- **Modifying environments (home, workplace, vehicle) to enhance independence and participation**, and
- Evaluating outcomes and adapting interventions based on progress and feedback, **using interprofessional teamwork with physiotherapists, psychologists and rehabilitation engineers.**

Standard 4: Communication

OTs practice open, respectful and culturally safe communication by:

- Using clear, compassionate communication to address **sensitive issues such as changes in identity, intimacy or self-concept following SCI**
- **Educating family members on safe transfer techniques, skin care and the psychological impact of injury**
- Tailoring communication for culturally and linguistically diverse clients or Aboriginal and Torres Strait Islander clients by incorporating interpreters or community consultation, and
- Maintaining accurate and contemporaneous documentation on functional outcomes, equipment trials and **multidisciplinary communication**.

OTs thus play a central role in multidisciplinary teams, **helping individuals with SCI regain independence, function and participate in meaningful life roles.** Occupational therapy addresses physical, psychosocial and environmental barriers to **enable optimal engagement in daily occupations across the continuum of recovery from acute care** (Wall *et al.*, 2023) **to community reintegration** (Eriks-Hoogland *et al.*, 2024; Mitchell *et al.*, 2025).

18.3.3. Exercise Physiologist Professional Standards for Accreditation

Accredited exercise physiologists (AEPs) are university-qualified allied health professionals who prescribe, deliver and adapt exercise-based interventions to optimise health status, function, recovery and independence for individuals across the lifespan. AEPs work with individuals across the full health spectrum, from those at risk of developing health conditions to people living with chronic, complex conditions and disabilities. **For people living with SCI, AEPs play a critical role in addressing the complex physiological, functional and psychosocial challenges that affect participation in daily life, work and community activities.** Exercise physiology practice in Australia is regulated by Exercise & Sports Science Australia (ESSA), a self-regulating professional body. The AEP Professional Standards form part of ESSA's self-regulatory framework and inform public expectations of the profession, while assuring safe practice.

The Accredited Exercise Physiologist Professional Standards for Accreditation (ESSA, 2025) set the minimum standards for entry to and ongoing professional practice. These standards, approved in 2025 for implementation in accredited university programs from 2027, represent a significant evolution from the 2021 standards, with strengthened emphasis on cultural safety, inclusive practice, person-centred care and the integration of sustainable healthcare principles (**Chapter 17**) AEPs are also Accredited Exercise Scientists, with the AEP Professional Standards build on the foundational Accredited Exercise Scientist Professional Standards (ESSA, 2024), which provide a strong scientific foundation in exercise science principles for health, fitness and well-being. The 2025 Standards are structured around four equally important domains: *Professional Practice, Foundational Knowledge, Screening, Assessment, Client Management, Exercise Prescription and Delivery of Interventions*. Each domain includes specific elements designed to ensure AEPs can deliver safe, effective and evidence-based care to individuals with complex health conditions, including SCI.

Standard 1: Professional Practice

AEPs practice ethically, collaboratively, and inclusively across clinical and non-clinical settings. When working with individuals living with an SCI, this includes:

- Practising within the AEP Scope of Practice and individual scope of practice, adhering to the ESSA Code of Professional Conduct and Ethical Practice and relevant legislation, including privacy, informed consent and professional boundaries when managing sensitive information

- **Applying person-centred and trauma-informed approaches when supporting clients who have experienced significant physical and psychological trauma related to their injury**
- **Collaborating within multidisciplinary teams, for example, with physiotherapists for mobility equipment, OTs for adaptive devices or psychologists for adjustment support**, and
- Practising in a culturally safe manner when working with Aboriginal and Torres Strait Islander peoples who may experience additional barriers to healthcare access.

Standard 2: Foundational Knowledge

AEPs critically evaluate and apply evidence from clinical exercise physiology to develop effective interventions. For SCI populations, this requires:

- **Integrating knowledge of neurological injury, including understanding lesion level and completeness, when assessing exercise capacity and safety considerations**
- **Evaluating how SCI impacts physiological responses to exercise, including cardiovascular adaptations, respiratory function in higher-level injuries and altered metabolic regulation**, and
- **Examining medication effects on exercise responses, including adjusting exercise prescriptions for clients taking anti-spasmodic and/or pain medication or bowel management drugs.**

Standard 3: Screening, Assessment and Client Management

AEPs conduct comprehensive screening and assessment to inform safe exercise prescription. This is particularly critical for SCI where specific considerations include:

- **Applying appropriate risk screening to identify potential complications during exercise, including autonomic responses, skin integrity and respiratory function**
- **Formulating safe assessments using validated outcome measures such as wheelchair-based fitness tests and adapted exercise protocols**
- **Recognising and responding to changes in client status by monitoring for signs, such as autonomic dysreflexia, orthostatic hypotension or thermoregulatory challenges during exercise,** and
- **Integrating appropriate equipment, assistive technology and environmental modifications to enable safe participation.**

Standard 4: Exercise Prescription and Delivery of Interventions

AEPs design and deliver tailored, evidence-based exercise interventions in collaboration with clients. For individuals living with an SCI, this includes:

- **Designing evidence-based interventions addressing SCI-specific goals, such as improving cardiovascular fitness, maintaining upper body strength for transfers**

and mobility, and preventing secondary complications
- **Delivering and adapting interventions for clients with complex presentations, including those with incomplete injuries, high-level tetraplegia or multiple co-morbidities**
- **Formulating risk management strategies, including environmental modifications for temperature regulation, positioning strategies for pressure injury prevention and protocols for managing autonomic responses**, and
- **Collaborating with clients and the multidisciplinary team to evaluate and adapt exercise prescription and behavioural change strategies** that increase engagement, motivation, and adherence while empowering self-management during and following discharge or transition of care.

AEPs work as integral members of multi-disciplinary SCI rehabilitation teams, contributing **specialised expertise in exercise-based interventions throughout the health continuum**. Their role addresses physical, biopsychosocial and environmental factors to support engagement in physical activity and meaningful participation in daily life for people living with an SCI.

18.3.4. National Competency Standards for Dietitians

Below, we describe the National Competency Standards for Dietitians in terms of their application to SCI and to MDT. Dietitians, allied health professionals and people with lived experience all recognise that **nutrition care for SCI must be evidence-based, person-centred and adaptable to individual abilities and preferences.** The 2021 National Competency Standards for Dietitians in Australia (NCS) provide a framework for professional practice, outlining the knowledge, skills, values and behaviours required to deliver safe, effective and culturally responsive care. The NCS are divided into four domains, and each domain provides guidance for dietetic practice that can be applied to:

- **Domain 1: Professional practice ensures ethical, legal, safe and culturally responsive care, recognising the rights of people with disability** and supporting reflective and accountable practice
- **Domain 2: Expert practice** provides the evidence-based foundation for **assessment, diagnosis and nutrition intervention**
- **Domain 3: Research practice** supports continuous quality improvement, critical evaluation of new interventions and translation of research into practice. This will **allow dietitians to refine SCI-specific care pathways based on emerging evidence**, and
- **Domain 4: Collaborative practice emphasises interprofessional teamwork and effective communication**.

People living with SCI bring unique expertise to nutrition care, from understanding bowel routines and nutrition needs to navigating accessible meal preparation and community access

(Ehrlich-Jones *et al.*, 2025; LaVela *et al.*, 2016; LaVela *et al.*, 2024). Their experiences will inform the design of both clinical care and educational programs, ensuring that curricula and professional practice reflect real-world challenges and solutions. Inclusive programs benefit all learners by modelling person-centred care, adaptive problem-solving and **interprofessional collaboration.** Accessibility and inclusion in health education will also ensure that students living with an SCI can fully participate in learning, practice and research, while ultimately improving care for the people they serve.

18.3.5. Nursing education and training relevant to SCI

Based on the Standards, nurses working with individuals living with SCI require several levels of training, first as a Registered Nurse (RN), then post-graduate training and education as a Nurse Practitioner (NP), and finally completing accredited courses covering one or more specialist areas, such as wound healing and bladder and bowel care.

18.3.5.1. Registered Nurse Standards for Practice

A **Registered Nurse (RN)** has completed the prescribed education preparation, demonstrates competence to practise and is registered under the Health Practitioner Regulation National Law as a registered nurse in Australia and accountable to the Nursing and Midwifery Board of Australia (NMBA). The Standards are broad, making it difficult to find disability-specific competencies. There are seven Registered Nurse Standards for Practice:

Standard 1: Thinks critically and analyses nursing practice

RNs use a variety of thinking strategies and the best available evidence to make decisions and **provide safe, high-quality nursing practice** within person-centred and evidence-based frameworks.

Standard 2: Engages in therapeutic and professional relationships

RN practice is based on purposefully engaging in **effective therapeutic and professional relationships**. This includes **collegial generosity in the context of mutual trust and respect in professional relationships.** RNs are responsible for autonomous **practice within dynamic systems and in relationships with other health professionals.** Relevant are:

- **Standard 2.6. Uses delegation, supervision, coordination, consultation and referrals in professional relations to achieve improved health outcomes**
- **Standard 2.7.** Actively fosters a culture of safety and learning that includes **engaging with health professionals and others, to share knowledge and practice** that supports person-centred care, and
- **Standard 2.8. Participates in and/or leads collaborative practice.**

Standard 3: Maintains the capability for practice

Standard 4: Comprehensively conducts assessments (could be applied to SCI)

- **Standard 4.2.** Uses a range of assessment techniques to systematically collect relevant and accurate information and data to inform practice.

Standard 5: Develops a plan for nursing practice

Standard 6: Provides safe, appropriate and responsive quality nursing (could be applied to SCI)

- **Standard 6.1.** Provides comprehensive, safe, quality practice to achieve agreed goals and outcomes that are responsive to the nursing needs of people.
- **Standard 6.5.** Practices in accordance with relevant policies, guidelines, standards, regulations and legislation.

Standard 7: Evaluates outcomes of nursing practice

18.3.5.2. Nurse Practitioner (NP) Standards for Practice

A **Nursing Practitioner (NP)** is an RN endorsed as an NP by the NMBA, with 5,000 hours clinically-based advanced practice in the past six years. The NP practises at an advanced clinical level, meets and complies with the Nurse Practitioner Standards for practice, practices independently, and has direct clinical contact. **NPs practice collaboratively in multi-disciplinary environments.** The NP practices within their scope under the legislatively protected title 'nurse practitioner' under the National Law. There are four (4) Standards, each with several sub-standards:

- **Standard 1: Assess using diagnostic capability (could apply to SCI)**
- **Standard 2: Plans care and engages others**
- **Standard 3: Prescribes and implements therapeutic interventions (could apply to SCI)**
- **Standard 4:** Supports health systems.

In terms of prescribing authority, an NP's prescribing practice must be underpinned by their education and clinical competence, enabling them to prescribe appropriate medications and continence products in accordance with relevant State and Territory legislation.

18.3.5.3. Advanced nursing training for SCI care

In Australia, **a Nurse Practitioner (NP) managing, for example, bladder and bowel care for SCI must first meet the general requirements for NP endorsement** by the NWBA and **also possess specialised expertise in neurogenic bladder and bowel management. Figure 18.1** shows examples of some SCI-specific training courses.

Code	Title
NAT11323001	Use equipment and safe manual handling techniques to transfer an individual with spinal cord injury
NAT11323002	Support an individual with a neurogenic bladder
NAT11323003	Support an individual with a neurogenic bowel
NAT11323004	Support an individual with a spinal cord injury to manage skin care conditions
NAT11323005	Support an individual with a spinal cord injury to manage respiratory conditions
NAT11323006	Identify, assess and respond to Autonomic Dysreflexia for an individual with a spinal cord injury

Figure 18.1. Examples of specialist training courses for managing different aspects of caring for individuals living with SCI. *Source:* Training.gov.au, Supporting an individual with spinal cord injury, CC BY 4.0

Other examples of accredited courses for adult and paediatric patients include:

- Continence Health Australia, or the Continence Nurses Society Australia (CoNSA) offers accredited courses in continence care
- Queensland University of Technology (QUT): NSB608: Wound Care in Practice; Murdoch University: Graduate Certificate in Advanced Wound Care
- Australian College of Nursing: Wound management courses, and
- Training.gov.au: Accredited course, 11323NAT: Supporting an individual with a spinal cord injury.

18.3.6. Podiatry Professional Capabilities

The Professional Capabilities for Podiatrists define the knowledge, skills and professional attributes required to practise safely and competently as a podiatrist in Australia. These Capabilities are organised into five domains*: Podiatrist, Professional and Ethical Practitioner; Communicator and Collaborator, Lifelong learner and Quality and Risk Manager*. Professional capability refers to the ability to take appropriate and effective action to solve problems across familiar, unfamiliar, complex and changing practice settings. These capabilities represent the minimum

standard required for both initial and ongoing registration. When working with individuals with an SCI, podiatrists apply these capabilities across all five domains, adapting their knowledge, skills and behaviours to address the unique needs, risks and goals of each individual in their care (**Table 18.1).**

Table 18.1. The relevant modified descriptions of the Professional Capabilities for Podiatrists, with how they can be applied to treating individuals living with an SCI.

Domain	Description (modified)	Example applied to SCI
Domain 1: Podiatrist	This domain describes the **knowledge, skills and attributes required for podiatrists to practise independently and deliver safe, high-quality, culturally responsive and person-centred care, including podiatric assessment, diagnosis, management planning, evaluation of outcomes and the safe and effective use of medicines in practice.**	**Conducts specialised foot and lower limb assessments for the individual with SCI, develops a personalised care plan to maintain skin integrity, circulation and mobility and monitors progress to support independence and long-term foot health.**
Domain 2: Professional and ethical practitioner	Addresses the podiatrist's ethical, legal and professional responsibilities to patients and society within the Australian health, aged care and disability systems, including accountability, personal conduct, patient confidentiality and patient advocacy.	Upholds the individual's autonomy and confidentiality, advocates for access to various types of care, and supports them in achieving their goals.
Domain 3: Communicator and collaborator	Outlines the podiatrist's responsibility to communicate clearly, empathetically, and effectively with patients, families, carers, and **members of the healthcare team** to support safe, high-quality, person-centred, shared care.	Collaborates with the individual, their carers and **the multidisciplinary team to support personalised care, promote independence and ensure consistent, high-quality management.**
Domain 4: Lifelong learner	Focuses on the podiatrist's responsibility to practise evidence-based care, engage in critical reflection, and identify, plan and complete ongoing professional learning to support continuous improvement.	Engages in ongoing professional development, reflects on clinical practice and **applies evidence-based interventions to improve outcomes for the individual living with SCI**.
Domain 5: Quality and risk manager	Covers the podiatrist's responsibility to protect patients, others and the environment from harm through effective risk management, quality assurance and improvement and the provision of safe, high-quality professional care.	**Implements proactive strategies to maintain safety and optimise foot and lower limb health, promoting wellbeing and preventing complications for the individual living with SCI.**

In Australia, accreditation of podiatry programs is overseen by the Podiatry Accreditation Committee. The Committee assess education providers and programs of study against the accreditation standards that require curricula to be explicitly mapped to the above Professional Capabilities. Programs that meet these standards are accredited and monitored to ensure ongoing compliance, and graduates of accredited programs are eligible for general registration to practise as a podiatrist. Podiatry is a registered health profession in Australia, regulated by Ahpra.

18.3.7. Speech Pathology Professional Standards

The Speech Pathology Professional Standards outline the knowledge, skills and professional qualities that all practising speech pathologists are expected to demonstrate and apply throughout their careers, in ways that align with their specific roles and practice settings. They also define the level of capability that graduating speech pathology students must show and be ready to apply upon completion of their entry-level degree. Formatted in a hierarchy, Speech Pathologists in Australia must meet the minimum standard for each of the three Domains (*Professional Conduct; Reflective Practice and Life-long Learning; Speech Pathology Practice*), including several Standards and Elements under each domain (**Table 18.2**).

Speech pathologists working in SCI care apply the same professional knowledge, skills and standards that underpin the broader speech pathology profession, adapting them to the unique needs, contexts and trajectories of individuals living with SCI. They practise as autonomous clinicians, drawing on the transferable domains of the Professional Standards to guide assessment, intervention, advocacy, and interprofessional collaboration across the acute, rehabilitation and long-term phases of care. By integrating the domain standards into SCI practice, Speech Pathologists ensure their work remains person-centred, culturally responsive, ethically grounded and aligned with best-practice principles across the lifespan.

Table 18.2. Modified descriptions of the Professional Standards for Speech Pathologists, with exemplars of how they are applied in caring for individuals with SCI.

Domain	Description (modified)	Examples applied to SCI
Domain 1: Professional conduct	Practice delivered is ethical, safe and lawful, grounded in evidence and strong quality systems that deliver culturally safe,**responsive services that honour the uniqueness of each person and community** through collaboration and advocacy to support the best possible outcomes.	**Conducts a culturally responsive swallowing and communication assessment** through **collaboration with the person, their family and multidisciplinary team to interpret findings**, and then design an evidence-based, ethically grounded intervention plan that honours the person's goals, preferences and cultural identity while advocating for the supports needed to achieve the best possible outcomes.
Domain 2: Reflective practice and Life-long learning	Outlines the speech pathologist's responsibility to continually expand their knowledge, refine their approaches and contribute to the learning of others by engaging in professional development, supervision and mentoring to maintain currency and strengthen the skills required for their roles.	Engage in ongoing professional development, supervision and mentoring to stay current with emerging evidence in dysphagia and communication management after SCI, then, **apply this updated knowledge to refine their assessment and intervention approaches while also sharing insights with colleagues to strengthen collective practice.**
Domain 3: Speech Pathology Practice	**Works collaboratively with individuals, communities and other professionals to build shared understanding,** assess communication and swallowing needs, interpret and report findings and plan evidence-informed interventions that support meaningful participation and optimal outcomes.	**Collaborate with the individual, their family, carers and community-based professionals to build a shared understanding** of their communication and swallowing needs. Together, plan evidence-informed interventions, such as mealtime management strategies, communication supports or partner training that enable meaningful participation at home, at work and in the community.

In Australia, speech pathology operates as a self-regulating profession, with Speech Pathology Australia recognised as a member of the National Alliance of Self-Regulating Health Professions. Speech pathologists practise as independent, autonomous professionals, committed to supporting and advocating for optimal communication and swallowing outcomes for people across all stages of life. Speech Pathology is not regulated by Ahpra. Speech Pathology Australia has a set accreditation process and standards implemented to monitor accredited programs.

18.3.8. Standards for Australian undergraduate, prevocational and graduate medical education

The medical education journey is a long one, with many levels of education and training, and is governed by different councils, associations, and colleges. Below, we have chosen to explore the training of GPs, considering that a GP is the health professional most relevant to this e-resource, which focuses on community integration for those living with SCI. As was discussed in **Chapters 1, 3,5** and**6**, the GP is not only responsible for coordinating the ongoing health and well-being of people living with an SCI, but also their carers and family.

Thus, to become an Australian-trained GP who is accepted into a medical program looks something like this:

1. A primary medical degree in an Australian Medical Council (AMC) accredited program, which is either undergraduate (5-6 years) or graduate-entry (4 years)
2. Following graduation, the first two years post-graduation (PG) are supervised practice called the prevocational years (PGY1, PGY2), the Outcomes of which are defined by the AMC
3. Post-graduate specialist training as a GP, overseen by the Royal Australian College of General Practice (RACGP), and
4. To ensure that doctors remain up to date, they are expected to undertake annual CPD, the Standards for which are set by the Medical Board of Australia and delivered through CPD Homes.

NOTE: The training required for all other Australian specialists that a person living with SCI might encounter, such as surgeons, physicians and psychiatrists, can be found on this AMC website.

Additional information, if interested: GP training pathway

This short video explains the most common journey of becoming a GP.

Below, we describe the different stages of medical education, highlighting where inclusion and disability are included in the AMC Standards.

18.3.8.1. AMC Standards for Assessment and Accreditation of Primary Medical Programs Outcomes

In the 2023 AMC Standards for Assessment and Accreditation of Primary Medical Programs, which apply to all medical programs from 1 January 2024, disability is listed as a community group likely to experience health inequity (**Table 18.3**).

Table 18.3. Community groups that experience health inequities, as identified by the AMC (AMC, 2023).

Community groups that experience health inequities	Community groups are more likely to experience unfair differences in health that result from the differing distribution of resources and opportunities within society. In both Australia and Aotearoa New Zealand, there are community groups that the Australian Medical Council (AMC) recognises as experiencing barriers to healthcare access and poorer health outcomes. **These may include people:** • **with disabilities** • from the LGBTQIA community • from low socioeconomic backgrounds • from migrant and/or refugee backgrounds and those whose first language is not English, and/or • in rural communities. Education providers are expected to partner with stakeholders and local communities to identify community groups experiencing health inequities in their context. The health sector has specific obligations to Aboriginal and/or Torres Strait Islander people in Australia and Māori in Aotearoa New Zealand based on their commitment to cultural safety. In Aotearoa New Zealand, this extends to obligations under Te Tiriti o Waitangi. Therefore, Aboriginal and/or Torres Strait Islander and Māori people, communities and organisations are referred to separately from community groups who experience health inequities in this definition and in the standards.

Outcomes expected of Australian medical program graduates relating to such community groups include:

- **Standard 1.1.2.** The medical education provider contributes to meeting healthcare needs, including the place-based needs of the communities it serves, and **advancing health equity through its teaching and research activities**
- **Graduate Outcome 3.5.** Describe the **structural barriers to accessing healthcare services and apply strategies to increase the inclusivity of these services for community groups who experience health inequities** and Aboriginal and/or Torres Strait Islander and Māori communities by partnering with those groups
- **Graduate Outcome 3.6. Apply health advocacy skills by partnering with patients and their families and carers, and/or communities to define and highlight healthcare issues, particularly health inequities and sustainability**
- **Graduate Outcome 3.8.** Describe how incorporating **health technologies in clinical practice can both improve patient experiences and outcomes and present risks**, particularly for community groups who experience health inequities and for Aboriginal and/or Torres Strait Islander and Māori communities
- **Graduate Outcome 3.9.** Describe a systems approach to **improving the quality, safety, sustainability and inclusivity of health care**, and
- **Graduate Outcome 3.10.** Describe the principles of sustainable and equitable allocation of finite resources to meet the needs of individuals and communities now and in the future, and **the roles and relationships between health agencies, disability agencies and services in resource allocation**.

Doctors who have not completed their primary medical training in Australia or New Zealand (International Medical Graduates) are not required to meet these graduate outcomes, which only apply to Australasian medical schools. Depending on their level of entry to the Australian

healthcare system, however, they are required to meet relevant prevocational or practising CPD requirements described later. The MBA requires supervised practice of International Medical Graduates.

Thus, while 'disability' appears in several AMC Standards and Outcomes, it is generally written as a blanket statement to cover all forms of disability, from physical to cognitive impairment. The term 'spinal cord injury' does not appear in the document.

Australian primary medical education is not alone in not receiving much attention for disability. Seymour *et al.* (2023) found that US medical school teaching material on disability was scant and stereotyped or conveyed negative attitudes towards people with disabilities. Of the 53 patient scenarios used for case-based learning in the medical program, only four overtly mentioned 'disability', with all presenting stereotypical views of disability. Additionally, two scenarios included content that the researchers considered to perpetuate negative attitudes of 'disability'. This left student assumptions about disability unchallenged and risked conveying a hidden curriculum, meaning that students were ill-prepared to care for people with disabilities or indeed to teach the next generation of students about disability care.

In 2024, Sinha (a medical student) *et al.* published 12 tips on disability inclusion in medical education. Their 12 tips are:

- **Tip 1: Embed persons with disabilities in all phases of the curriculum,** from planning, development, delivery and assessment
- **Tip 2:** Follow Kern's sic-step method for curriculum development, which begins with a general needs assessment as Step 1
- **Tip 3: Utilise diverse clinicians with experience working with people living with disability**, including physiotherapists, OTs, speech therapists and psychiatrists, amongst others
- **Tip 4: Include interprofessional education (IPE) elements,** as those caring for **people living with disability generally require communication and planning as a healthcare team**
- **Tip 5:Incorporate a broad spectrum of disability types into the curriculum,** including mobility, cognition, vision and hearing
- **Tip 6:** Include a variety of pedagogies, emphasising experiential learning as the hands-on approach
- **Tip 7: Ensure access to appropriate equipment and facilitie**s, such as assistive and adaptive devices, to help promote independence
- **Tip 8: Introduce students to the Americans with Disabilities Act (ADA), enacted in 1990, which prohibits discrimination against individuals with disabilities and ensures that they have the same rights and opportunities as those without disabilities. Please note, this should also include the UN Rights of Persons with Disabilities, amongst the declarations. In Australia, the Act would be the DAA**
- **Tip 9: Simulate first-hand experiences by placing learners "in the shoes" of people with disability, noting that simulating the experience is not the same as living with the disability. Instead, people living with disability will be invited to help create and**

lead experiential learning activities, such as assessing the accessibility of buildings, sidewalks, and parking, and

- **Tip 10:** Create opportunities for open dialogue between learners and people living with disability by, for example, leading educational activities.

Prof Sivan's story: Student rehabilitation medicine research

In "We must make clinical academia more appealing" – the rehabilitation doctor encouraging a new generation, **Manoj Sivan**, professor of physical and rehabilitation medicine, tells Kathy Oxtoby about his passion for getting medical students and trainees involved in research. *"I believe in adding life to years, not just years to life,"* says Manoj Sivan, professor in physical and rehabilitation medicine, University of Leeds and honorary National Health Service (UK) consultant at the Leeds Teaching Hospitals NHS Trust. *"It's what we do in my specialty."*

18.3.8.2. AMC Prevocational Outcomes (Post-graduate Year 1 = PGY1, PGY2)

As already mentioned, the first two years following graduation as a doctor comprise the prevocational period. During this time, newly graduated doctors have special requirements for supervision and experience in a wide range of specialties in the hospital and community. After completing the second prevocational year, doctors typically choose a specialty and become 'vocational'. The term 'intern' refers to doctors in their first year after graduation. This term is still in wide usage, including by the AMC, although at a governance level, the one-year internship program was replaced by the two-year prevocational program in 2024.

The first iteration of the most recent AMC Prevocational Outcome Statements (2024) is still current. Disappointingly, **specific mention of disability** is reduced to a footnote on p. 17:

> *"4. Whole-of-person care includes consideration of all dimensions that can affect a person's overall health. These dimensions include but are not limited to an individual's geographical location, culture, sexual orientation, gender identity and any disabilities."*

The footnote relates to this Outcome:

Standard 3.2. Apply whole-of-person care principles to clinical practice, including consideration of a **patient's physical,** emotional, social, economic, cultural and spiritual needs and their geographical location, acknowledging that these factors **can influence a patient's description**

of symptoms, presentation of illness, healthcare behaviours and access to health services or resources.

Below, **Dr Rachael Norman** reflects on her steep learning curve regarding SCI, as her undergraduate medical degree did not prepare her to work with patients with SCI.

Rachael's story: A PG2-3 Junior House Officer, Canterbury, New Zealand (2007–2008)

Based on her experiences as a PG2-3 junior house officer in Canterbury, New Zealand, in her second year of work post-graduation from medical school, **Rachael** reflects on some of the knowledge and skills that could be included in the medical curriculum, which would have helped her with providing hospital ward cover in the SCI Unit at Burwood Hospital in Christchurch.

> *"I was not, however, prepared in my [undergraduate, primary] medical training for the complexities and specific conditions and emergencies that I would need to manage for SCI patients, some of which I did not know existed! It was a steep learning curve as a junior doctor, particularly in those times before having access to the Internet and smartphones for easy and rapid reference.*
>
> *I can recall learning from a combination of sources back in the pre-Internet days when there was no library on-site to access literature. I spent downtime reading textbooks and asking questions of the SU nurses and patients. In my time spent working there, which was mostly providing weekend and night ward cover, many of the patients admitted had been inpatients for several months, and many were a 'wealth of knowledge' for me, particularly those who had been there for more than six months post-injury or who were admitted for elective surgery to treat secondary conditions arising after their SCI.*
>
> *I can recall writing myself a checklist of conditions to assess for when a patient with an SCI deteriorated suddenly, such as autonomic dysreflexia, and learning what the 'new normal' parameters were for clinical findings, such as blood test results and vital sign recordings, such as blood pressure readings post-SCI due to the numerous physiological changes and autonomic dysfunctions, which occur as a result.*
>
> *After spending some time trying to access those memories from 18 years ago, I came up with the following list of secondary conditions for which I felt underprepared:*
>
> - *AD triggered by pain or nociception, infection, a full bladder, bowel impaction, skin irritation and wounds.*
> - *Vagal hypersensitivity resulting in bradyarrhythmia that may require a pacemaker.*
> - *Orthostatic hypotension and its management in a patient with an SCI.*
> - *Temperature dysregulation.*
> - *Neurogenic bradycardia and hypotension and understanding what the 'normal ranges' are for patients with an SCI.*
> - *Neurogenic bowel and bladder-related issues, such as incontinence.*
> - *Long-term indwelling catheter management, including replacement of suprapubic catheters, self-catheterisation and infections, impaired bowel function management, including manual evacua-*

tion and prolonged time to evacuate (with subsequent risk of pressure area formation).

- *Impaired ventilation and respiratory mechanics, including cough and swallow reflex function, impaired hypercapnia responses, and secondary respiratory tract infections*
- *Tracheostomy management and care.*
- *Spasticity and contractures, sometimes requiring reconstructive surgeries with tendon-lengthening procedures.*
- *Neuropathic pain management: **Borderzone or At-level pain; Below-level or distant pain**.*
- *Osteoporosis and bone fractures.*
- *Skin pressure injuries and the speed at which pressure injuries can develop and progress into wounds requiring surgery: Skin grafts and flaps and negative pressure wound management. The importance of regular daily early detecting skin checks by checking blanching and non-blanching skin erythema, skin oedema, tissue consistency, indurated skin and skin temperature. Repositioning and mobilisation regime to avoid skin pressure injury and prolonged bed rest.*
- *Transferring and falls from a wheelchair, bed or chair.*
- *DVT risk (85% in the first three months if untreated with anti-coagulants).*
- *Mental health complexities and the impact of an SCI on the family and wider family and friends.*
- *Feeding orally and enterally with naso-gastric (NG), naso-jejunal (NJ) and percutaneous endoscopic gastronomy (PEG) secondary to the neuro-metabolic changes in the acute phase of injury and excessive nitrogen excretion, and the additional specific dietary requirements patients require during the acute and chronic phases post-SCI."*

18.3.8.3. GP training: RACGP

As we identified in **Chapter 3**, GPs are the health professionals who oversee ongoing support and maintenance of health and well-being for individuals living with an SCI. Also included in their caring is checking the carers' well-being. They also need to refer patients to other HPs as needed.

What does the RACGP curriculum and syllabus for Australian General Practice *include in terms of disability?* In addition to the core content, there is a unit dedicated to disability care. The website includes a **Words of Wisdom** section in relation to managing patients with disability:

- **Managing patients with disability can seem complex and challenging, and sometimes it is. But if you use effective communication skills that avoid stigma and discrimination and spend time building rapport, you will see the rewards over time. The skills you develop will make you a better GP and improve your management of all patients with complex chronic conditions**
- **Always consider recalls, health checks, and vaccines during any consultation with a patient with disability. Try to spend a couple of minutes making sure your practice software has captured this information. This will make your workflow more efficient**
- **Take some time to review your local referral pathways and identify allied health**

professionals and specialists you can ask for advice regarding challenging cases

- **If any investigations and/or procedures require sedation due to limited cognition, it is essential that you mention this in your referral/clinical handover to your acute care colleagues to prevent this important information from being lost in transition, and**
- **To learn this contextual unit, take a holistic approach by considering each stage of life as you review the guiding topics and content areas. Also consider the broader biopsychosocial context and environmental factors. By doing this, you will avoid thinking about disability from a purely biological model of disease.**

The RACGP unit dedicated to disability care contains the following information:

Caring for patients with disability: At every stage of caring for a patient with a disability, understand and define the medico-legal implications of appropriate consent to treatment and to undertake preventive activities, specifically:

- **Vaccination of high-risk populations**
- **Healthy lifestyle interventions, including diet, exercise and smoking cessation**
- **Reducing and/or preventing cardiometabolic risk factors**
- **Screening for carer stress**
- **Developing management plans, including managing sick days, for chronic conditions, such as asthma and type 2 diabetes**
- **Ensuring screening is always up to date, including cervical cytology, faecal occult blood test (FOBT), breast screening and screening for diabetes.**

In **Chapter 6** of this disability unit, the competencies expected of GPs following completion of a unit of training on disability included *Caring for patients with disability in residential care*, such as appropriate communication with the individual and their carers and family members, managing polypharmacy and understanding how to prevent falls.

18.3.8.4. Standards for Continuing Professional Development (CPD)

'CPD homes' for practising doctors can be a specialist professional college, such as the RACGP, but can also be independent CPD providers accredited by the AMC. The AMC has a CPD Homes website, which explains the AMC's role in accrediting CPD Homes, including a list of AMC-accredited CPD Homes.

Membership of a College and CPD requirements were decoupled in 2024. A doctor could, for example, hold a Fellowship with the RACGP (FRACGP) but undertake CPD with a different College or an independent provider. There are more than 21 CPD homes available to doctors in 2026, with more being added each year. The curriculum and content of ongoing education about SCI for any individual doctor can therefore be absent or, if present, be highly variable,

and is not defined by the doctor's specialty or College affiliation. To a large degree, further learning about SCI now falls to a doctor's personal interest and motivation.

Clinical resource (CPD): Disability awareness for health providers

In March 2024, the AMA released Access for All: Disability Awareness for Health Providers, which advertised a free Access for All CPD online course for health professionals (2.5-3h). Also available is a downloadable Access for All Cases for Inclusion, with lived experience stories from people with disability and health providers.

In instances of substantial departure from standards of professionalism, the Medical Board of Australia (MBA) sets out a Code of Conduct, which can frame complaints or feedback to Ahpra, resulting in directions to the doctor to undertake further education. Noting that a Code of Conduct applies to all health professionals. For medical doctors, the two most relevant clauses are:

- **Clause 3.4.3.** Upholding your duty to your patient and not discriminating against your patient on grounds such as race, religion, sex, gender identity, sexual orientation, disability or other grounds, as described in antidiscrimination legislation, and
- **Clause 4.8.** Cultural safety involves understanding what individual patients and/or their families believe is culturally safe. Culturally safe and respectful practice requires genuine efforts to adapt your practice as needed, to respect diversity and avoid bias, discrimination and racism. It also involves challenging assumptions that may be based on, for example, gender, disability, race, ethnicity, religion, sexuality, age or political beliefs. Culturally safe practice, like all good medical practice, does not require doctors to provide care that is medically unsafe or inappropriate.

18.3.8.5. Standards for working in multidisciplinary teams across the medical education journey

In the 2023 AMC Accreditation Standards, **working in multidisciplinary teams** is termed 'interprofessional' education or learning (**Table 18.4**).

Table 18.4. Definitions relating to collaboration in the AMC Standards for Assessment and Accreditation of Primary Medical Programs (AMC, 2023).

Interprofessional education or learning collaborative practice	The AMC uses the World Health Organization definition of interprofessional education as the basis for these definitions. **Interprofessional** is between two or more professionals from two or more different professions. **Interprofessional education or interprofessional learning** occurs when two or more students or professionals from two or more different professions "learn about, from and with each other to enable effective collaboration and improve health outcomes. **"Professional"** is an all-encompassing term that includes individuals with the knowledge and/or skills to contribute to the physical, mental and social well-being of a community. **"Collaborative practice"** occurs when multiple health workers from different professional backgrounds provide comprehensive services by working with patients, their families, carers and communities to deliver the highest quality of care across settings." (Framework for action on interprofessional education & collaborative practice (2010))

Graduate Outcomes specific to **multidisciplinary teamwork** include:

- **Graduate Outcome 1.16. Work within the interprofessional team to identify and justify management options based on evidence, resource and service availability, and the patient's needs and preferences**
- **Graduate Outcome 2.2. Apply the principles of professional leadership, followership and teamwork in health care by providing care within interprofessional healthcare teams**
- **Graduate Outcome 2.6. Engage with the interprofessional team to optimise patient outcomes, particularly to manage complexity and uncertainty**, and
- **Graduate Outcome 2.12. Demonstrate the ability to learn and work collaboratively as a member of an interprofessional team.**

The Prevocational Outcome specific to **interprofessional teamwork** is:

- **Outcome 2.5. Respect the roles and expertise of healthcare professionals and learn and work collaboratively as a member of an inter-professional team.**

The MBA Code of Conduct does not use the terms' multidisciplinary' or 'interprofessional', but Section 6 Working with healthcare professions, p. 16, describes **working with other healthcare professionals that emphasises communication, collaboration and the central coordinating role of the general practitioner**. This section further explains the **importance of effective communication and coordination between healthcare professionals to ensure safe, high-quality and continuous patient care. It also outlines doctors' responsibilities in coordinating care and in appropriately delegating, referring and handing over patients while retaining overall accountability** (p. 6, MBA, 2020).

18.4. Inclusive medical education and training

Earlier, we described inclusion and diversity in Australian medical education. We begin with a media story about two individuals with disabilities and their medical studies. **Dinesh Palipana** sustained his injury as a student and had to pick up his medical studies a few years later. **Michael Thomas,** on the other hand, was injured while still at school and so went through the medical school application process with a physical disability. The next story is that of**Jonathan Tang**, who studied medicine despite being quadriplegic.

Drs Dinesh and Michael's stories: Studying medicine with neurological injuries

After a horrific car crash, doctor Dinesh Palipana saw the emergency ward from the patients' side describes **Dinesh Palipana's** journey from his accident to now working in ED.

Once **Dr Dinesh Palipana** returned to work, he said one of the biggest challenges he faced was the attitudes of other medical professionals.

> *"There were some who thought that it would be impossible for me to work, with some of the bureaucratic structures proving to be the most challenging," he said. "I must say that the medical board has been the enabling influence throughout my training. They have taken a safe but inclusive approach, which has enabled my career to continue."*
>
> Dr Palipana's message for other hospitals was a quote taken from Sir Herbert William Massie CBE, a British disability rights campaigner.
>
> *"By welcoming more disabled medical students, and by retaining more disabled doctors in employment, the profession will improve its outward-facing service and better reflect modern society,"* Sir Massie said.
>
> The second story in this 2022 media article describes how Curtin University accepted **Michael Thomas** as a medical student with right-sided paralysis following a car accident while at school.
>
> *"[...] both staff at the medical school and at Curtin Disability and Accessibility Services have been extremely supportive," he said. "The coordinators at the medical school have gone above and beyond, always asking if there were aspects of the course that I needed help with, and would start off by asking what I think the solution was."*

Dr Jonathan Tang's story: As a medical intern after SCI

CODA 2022: Inclusive healthcare. At about 30 minutes of this one-hour presentation, **Jonathan Tang** (C5 SCI) talks about the discrimination he faced on his surgery rotation as an intern in a wheelchair. Each speaker had to choose a word to discuss. His word was **'Workforce'**, in which he argued that healthcare needs more health professionals with disability, as the ***LLE*** added value to holistic, inclusive, patient-centred healthcare.

18.4.1. AMC Equity groups for medical student admission and inclusive primary medical education

The AMC defines the requirements of Australian medical schools for specific medical student equity groups (**Table 18.5**).

Table 18.5. Community groups identified in the AMC Standards as equity groups requiring better representation in primary medical education (AMC, 2023).

Community equity groups	Community groups that, due to differing distribution of resources and opportunities within society, are more likely to be under-represented as students in medical programs and/or to experience barriers to achieving their full academic potential. In both Australia and Aotearoa New Zealand, there are equity groups that the AMC recognises as being under-represented in medicine and/or experiencing barriers to achieving their full academic potential. **These may include people:** • **with disabilities** • who are first in their family to attend university • from the LGBTQIA community • from low socioeconomic backgrounds • from migrant and/or refugee backgrounds and those whose first language is not English • with rural backgrounds. Education providers are expected to partner with stakeholders and local communities to identify equity groups in their context. The health sector has specific obligations to Aboriginal and/or Torres Strait Islander people in Australia and Māori in Aotearoa New Zealand based on their commitment to cultural safety. In Aotearoa New Zealand, this extends to obligations under Te Tiriti o Waitangi. Therefore, Aboriginal and/or Torres Strait Islander and Māori people, communities and organisations are referred to separately from applicants and students belonging to equity groups in this definition and in the standards.

In line with this, Australian medical schools need to meet the following Standards regarding inclusion of these equity groups:

- **Standard 3.1.1.** Students are assessed throughout the medical program through a documented system of assessment that is:
  - consistent with the principles of **fairness,** flexibility, **equity,** validity and reliability
  - supported by research and evaluation information evidence
- **Standard 3.3.1.** The medical education provider regularly reviews its system of assessment, including assessment policies and practices such as blueprinting and standard setting, to evaluate the**fairness,** flexibility, **equity,** validity, reliability and fitness for purpose of the system. To do this, the provider employs a range of review methods using both quantitative and qualitative data
- **Standard 4.1.2.** The medical education provider has **defined the nature of the student cohort**, including targets and strategies for recruiting Aboriginal and/or Torres Strait Islander and Māori students, students with rural backgrounds and **students from equity groups** to support increased participation of these students in medical programs
- **Standard 4.1.3.** The medical education provider complements targets and strategies for recruiting Aboriginal and/or Torres Strait Islander and Māori students, students with rural backgrounds and **students from equity groups with infrastructure and supports for student retention and graduation**
- **Standard 4.1.4.** The medical education provider supports**inclusion of students with disabilities**
- **Standard 4.1.5.** The selection policy and admission processes are**transparent and fair, and prevent racism, discrimination and bias,** other than explicit affirmative action, and support the achievement of student selection targets, and
- **Standard 6.2.4.** The medical education provider **evaluates outcomes of the medical program for cohorts of students from equity groups.** For the evaluation of Aboriginal and/or Torres Strait Islander and Māori cohorts, this is informed and reviewed by Aboriginal and/or Torres Strait Islander and Māori education experts.

There is, however, no research to gauge how well Australian medical schools meet the required standards, although there is little reason to expect we differ from findings in comparable medical education settings. Stergiopoulos *et al*. (2018) in Canada found that medical students with disabilities experienced a direct contradiction between being a 'good student' and a 'good patient' and highlighted how ableist notions of wellness underlie assessment of academic performance at medical school.

Despite work undertaken to improve inclusivity in admissions to Australian medical programs, the Australian Medical Students Association (AMSA) believes the *status quo* is inadequate. In 2025, AMSA published a Policy Document on Disability Entry Pathways (2025), stating that:

> *"Current medical school admissions processes are inequitable and present unjust barriers for students with disabilities. These include a lack of consistent criteria, limited reasonable adjustments, and implicit bias in admissions. AMSA believes that there is a deplorable lack*

of support, equity and access for students of disability in Medicine. Hence, this policy thus calls for the implementation of a Disability Entry Pathway (DEP) into Medicine to ensure medical school entry processes are equitable, inclusive, and responsive for students with disabilities. AMSA calls upon the Federal Governments, State Governments, and medical universities to advance with urgency the implementation of the DEP. This policy specifically supports prospective and current medical students with disabilities and urges the lowering of structural barriers that disadvantage them. The policy applies nationally, across all Australian medical universities. Its most significant impact will be seen in tertiary admissions, student services and national higher education policy. It also has broad implications for the diversity and equity of Australia's future healthcare workforce. The recent increase in Disability Support Fund (DSF) allocations presents a timely opportunity to advance inclusion in medical education. Establishing a DEP, supported by Commonwealth Supported Places and guided by equitable admissions policies, would be essential to supporting upcoming cohorts. The DEP encompasses accessible admissions information, open discussions regarding eligibility and a supportive selection process" (p. 1).

18.4.2. A chronological perspective of equity and inclusion and medical students in Australia

Below, we discuss chronologically some of the events that have led to the current AMC Inclusion Statements on inclusion and equity in medical program admissions and support once in the program. Again, we use **Dinesh's** situation as the example.

Dinesh's story: Returning to medical school after SCI

In 2021, Fitzmaurice *et al.* (which included **Dinesh**) published '*Why we should and how we can increase medical school admissions for persons with disabilities*'. Below is their introduction:

> *"In 2015, Dinesh Palipana was readmitted to the third year of the Griffith University School of Medicine (GUSOM) medical program, 5 years after sustaining traumatic quadriplegia. Academics and university disability services worked together with hospital clinicians to plan his clinical rotations and problem solve any potential challenges. The clinical skills and assessment team designed and implemented reasonable adjustments for his annual objective structured clinical examinations, which did not undermine the technical standards of the stations. An external medical educator was responsible for the quality assurance of the examinations. Palipana met with the Australian Health Practitioner Regulation Agency (Ahpra) before his readmission, and recalls the ongoing communication with Ahpra*

> *was consistently professional, respectful and logical throughout medical school and since graduation. In 2016, Palipana graduated from GUSOM and has since gone on to work in one of Australia's busiest emergency departments. Ahpra has fully registered Palipana, with the appropriate condition that he practises within his physical limitations. Indemnity insurers have insured his practice. He was awarded the Medal of the Order of Australia for services to medicine in 2018 and has recently become the 2021 Queensland Australian of the Year"* (p. 249).

The article was a perspective on the 2017 Medical Deans of Australia and New Zealand (MDANZ) 'Inherent requirements for studying medicine in Australia and New Zealand', which would have excluded **Dinesh**, because of his physical impairment, as he did not meet the mandated physical requirements:

> *"If the practical consequence of the MDANZ inherent requirements document contradicts its aim, it is important to consider whether framing the document through the lens of the deficit medical model is causing this discrepancy. In which case, is there a more appropriate model for considering who can enter medical school?"* (Fitzmaurice *et al.*, 2021, p. 249).

Later in 2021, MDANZ published its more inclusive guide, Inclusive Medical Education: Guidance on medical program applicants and students with disability, which incorporated many of Fitzmorris and colleagues' (2012) suggestions. Key principles and elements of the 2021 Guidance Policy include:

- **Adopt an inclusive, strength-based approach**
- **Adopt a model of disability that does not see disability as the problem, but rather the learning environment not being inclusive**
- **Use ICF models to consider each person's abilities within the person-task-environment framework on a context-specific basis**, and
- **Encourage early and open dialogue through inclusive practices and culture.**

The Guide (Annexure 1) also provides reflective questions for applicants and students for **seven areas of capability (Figure 18.2):**

- **Communication**
- **Professionalism**
- **Cognition**
- **Teamwork**
- *Physical skills*
- **Sustainable performance, and**
- **Culture.**

Figure 18.2. The seven key areas included in the study of medicine indicating what is expected of students throughout the program. *Source:* Medical Deans of Australia and New Zealand (MDANZ). Inclusive Medical Education: Guidance on medical program applicants and students with a disability (p. 3)

Applying the ICF model to medical students with a disability

In the **Introduction** for this resource, the ICF model of disability was introduced as a social model in which functionality was included in definitions. The 2021 MDANZ Guide indicates that we should use ICF models to consider individual applicants or students.

Thus, if the ICF model were applied to **Dinesh** when he was a student:

- **He sustained a C6/7 SCI (*health condition*), which means he has no sensation or ability to move below this level (*bodily function and structures*).**
- **He was determined, resilient, and committed to innovating and working collaboratively to succeed (*personal factors*)**
- **He had a dedicated support team (an environmental factor)**
- **Griffith University School of Medicine provided a supportive environment in which success was possible, including providing a self-opening door and a raised computer desk for study (*environmental factors*), and**
- **As assessment is the common path to graduation, the assessment team considered appropriate reasonable adjustments at the time of admission and throughout the program (*environmental factors*).**

In conclusion, collectively, these factors allowed **Dinesh** to fully participate in all activities of the medical program, including attending theatres during surgical rotations (activities) and to graduate as a doctor.

Research: Disability inclusion in medical education in Australia

- Australian research from Mogensen and Hu (2019) suggested a high (>70% across all categories) level of support for people with disabilities as medical students and doctors. Respondents in this study based this on:

    1. Fair selection, support and monitoring are expected of medical schools
    2. Life experiences of disability promote real empathy in doctors
    3. Career considerations for those with disability
    4. Medical role models to address disabling social barriers, and
    5. Responsibility (of students and doctors) to monitor their own health and ability to perform.

- An international survey of disability inclusion in medical schools by Singh and Meeks (2023) noted MDANZ's contribution to inclusive medical education, alongside contributions from the US and UK. They noted, however, that the narrative has to date been framed as one of deficit (ableism as a comparator and the norm to which to aspire) rather than disability as a strength. In advocating for a quality improvement lens, they wrote:

    "[...] The philosophy of disability inclusion must be adjusted from one where disabled trainees are viewed as problematic and having to 'overcome' disability to one where institutions anticipate and welcome disabled trainees as a normative part of a diverse community" (p. 102).

The Australian Medical Students' Association (AMSA) made a submission to the 2023 Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, in which the Association made numerous recommendations for each of the following:

- **Entry pathways for students with disabilities into medicine** acknowledged that, while the 2021 Guidance principles were far more inclusive than the 2017 inherent requirements, students with disabilities still faced challenges in terms of entry examinations, complex entry requirements, and bias and discrimination in university policies and/or staff. One of the six recommendations was a specific Disability Entry Pathway.
- **Retention of students with disabilities in medical school,** which acknowledges the advances made in admitting students with disability and catering for students who acquired a disability while studying, there is anecdotal evidence that students with disability leave medicine because there is a lack of specific support, staff not understanding or adhering to approved accommodations, learning environments not conducive to disabilities, and, lack of flexibility in the medical degree. One of the four recommendations was that all staff undergo training on accessibility and reasonable adjustments to cater for students with a disability.
- **Medical education regarding patients with disabilities** acknowledges the **need for more doctors with disabilities** and for up-to-date, evidence-based education at all levels of medical training. One of six recommendations was to educate medical students on

how to involve people with disabilities, and where appropriate, their carers or other health professionals, in developing care plans. Another was to learn about the NDIS.

In August 2023, under the general information section in the 2023 AMC Standards, one of the equity groups states the following:

> *"In both Australia and Aotearoa New Zealand, there are equity groups that the AMC recognises as being under-represented in medicine and/or experiencing barriers to achieving their full academic potential. These may include people with disabilities. The health sector has specific obligations to Aboriginal and/or Torres Strait Islander people in Australia and Māori in Aotearoa New Zealand based on their commitment to cultural safety. In Aotearoa New Zealand, this extends to obligations under Te Tiriti o Waitangi. Therefore, Aboriginal and/or Torres Strait Islander and Māori people, communities and organisations are referred to separately from applicants and students belonging to equity groups in this definition and in the standards"* (p. 3).

Standard 4 relates to **Students**. Under this Standard, the education provider must:

- **Standard 4.1.4: Support inclusion of students with disability**
- **Standard 4.2.3: Identify students who require reasonable adjustments and provide these in a timely manner**
- **Standard 4.2.4: Implement safe and confidential processes for voluntary medical student self-disclosure to facilitate support and reasonable adjustments within the medical program and during the transition to internship**, and
- **Standard 4.2.5: Implement flexible study policies that address students' individualised needs to support student success.**

The next few boxes provide information on progress made in inclusive medical education for applicants and students with disabilities.

Media: News from the AMA

AMA issues blueprint to support medical students and doctors with disability: Published on 8 September 2023, the Australian Medical Association (AMA) urges key organisations in the health sector to play a

greater leadership role by developing and embedding pathways that support a career in medicine for people with disability.

Important information: Inclusive Medical Education Self-assessment Tool

On the Medical Deans of Australia and New Zealand (MDANZ) webpage, Inclusive Medical Education, a Self-assessment Tool was recently added to assist applicants to medical programs, as well as medical students already in the system. Below are their key areas to promote an inclusive culture and support students with a disability (**Figure 18.3**).

Figure 18.3. Key areas to promote an inclusive culture and support students with a disability. *Source:* Medical Deans of Australia and New Zealand (MDANZ), Disability Inclusion: Self-Assessment Tool (p. 1)

Video: Disability inclusion, medical education symposium

In December 2025, the MDANZ Disability Inclusion Working Group held the symposium, 'Disability Inclusion in Medical Education: A Symposium for Change'. It is almost 3h, but it is worth watching if this is an area of interest.

Research: Barriers before entry to medical school

In December 2025, Gray and colleagues published 'Barriers before entry: Opportunities for improving pre-admission guidance for disabled medical school applicants in Australian and New Zealand', a study in which they explored the extent to which ANZ medical programs had implemented the 2021 MDANZ Inclusive Medical Education Guidelines and whether their websites communicate to prospective applicants in a way that explicitly recognises disability as a valued dimension of diversity and in terms of accessibility of relevant information and transparency of pre-admission discussions.

What did the study find?

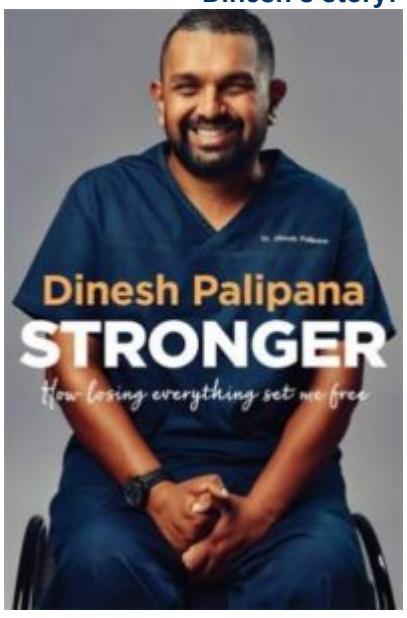
- Examples of inclusive practices, but many programs could improve the clarity and framing of the information provided.
- Many programs framed disability as a deficit or avoided explicit reference to disability
- Clear information regarding procedures for confidentially discussing an applicant's circumstances and for accessing accommodations before admission was often absent, potentially leaving applicants uncertain about the impact of disability disclosure
- Only 50% referenced the MDANZ Guidelines, and
- Those using Inherent Requirements often employed organic framing, which did not acknowledge the role of accommodations.

To conclude, it is important to review pre-admissions communication through a **disability-inclusive lens**. The authors provided a series of reflective questions to support medical programs' efforts to adopt more inclusive, transparent admissions criteria for people with disabilities.

To advance this agenda, the authors provided the following questions to prompt medical educators to reflect on pre-admission guidance in public materials regarding disability inclusion:

- Is information on the program's requirements clearly accessible, non-exclusionary, and described in a manner appropriate for applicants unfamiliar with higher education or discipline-specific terminology?
- Is information regarding possible adjustments and support structures clearly accessible prior to application?
- Are disabled applicants encouraged and provided with clear pathways (including contact details) to access further information and initiate discussions regarding program requirements and possible adjustments?
- Is it clear to potential applicants whether these discussions are confidential, constructive, collaborative, and clearly separated from selection processes?
- Is it clear to applicants whether disclosure is a requirement of application or enrolment, or when, to whom, and why they may choose to disclose?
- What training and resources do staff need to effectively carry out collaborative discussions with prospective disabled applicants?

Dinesh's story: Views on medicine and inclusion



- As an advocate for medical education and medical practice to be more inclusive of disability, **Dinesh** has written, Opening doors: Why medicine must welcome doctors with disability, as an AMA Equity Inclusion and Diversity Committee member (14 January 2026):

"A strengths-based approach is vital. We must highlight the unique skills and perspectives doctors with disability bring, designing education and workplaces that are adaptable and welcoming. Policies must be backed by practical support, disability champions in leadership, clear guidance for managers, and safe avenues for disclosure."

- There is also a recent (December 2025) ABC Podcast featuring **Dinesh**: Changing Australia: Dinesh Palipana and reshaping medicine for the future – ABC listen.

18.4.3. When medical students may not declare their disability

Sometimes, students may not wish to disclose their disability for one reason or another. One such example is medicine, which has inherent requirements for what a graduate needs to be able to do. In an unpublished (but open for review online) article, a study in the UK has investigated the barriers to inclusive medical education (Gray, 2025). Guidance in the UK recommends that medical schools support students with disabilities using reasonable adjustments in clinical teaching. Despite this guidance, the British Medical Association found that only 55% of medical students and doctors surveyed received the reasonable adjustments they requested. An anonymous electronic survey of medical students gathered information on barriers to receiving reasonable adjustments. All (100%) of the students identified concerns about disclosing their disability and adjusting to clinical staff. Only 33% of students had received reasonable adjustments in the clinical teaching environment, for several reasons: a lack of staff understanding of adjustments and students' unwillingness to disclose a disability due to fear of discrimination. Both barriers contribute to there not being reasonable adjustments in place in the clinical learning environment, which can result in negative consequences for student well-being and the perpetuation of stigma of disabilities. The recommendations are for staff education in the health service to bridge the gap between medical students and clinical educators, shift responsibility for initiating discussions about disability and adjustments from students to clinical educators, and set a welcoming, inclusive tone. Empowering students with disabilities is vital to supporting the future generation of doctors.

Additionally, a study of 674 responses from year-two medical students with disabilities in the US (Stergiopoulos & Jain, 2026) found that "exclusion is not only an experience but a feeling." Three main emotions were noted. Positive effects, such as happiness and gratitude, related to receiving accommodations for disabilities they considered their own responsibility, as well as those that did not require formal accommodations. Frustration was a response to repeated denial of accommodations or institutional silencing, giving rise to the concept of the 'disabled killjoy':

> *"In this position, discomfort is not in shadow, but named out loud. Everyone, including the non-disabled, is made to feel uncomfortable. Disabled killjoys agitated, expressed dis-*

> *satisfaction, and asserted their rights. In contrast to the gratitude of happy students, who appeared in awe of any institutional support they received, disabled killjoys did not hesitate to call out where institutions fell short"* (p.15).

The third main emotion was *resignation*, a response to avoiding being the 'killjoy' and an assumption that the system would not change. This response correlated with non-disclosure. The authors note that this finding challenges the assumption that medical students do not disclose due to stigma. Instead, it arises from a 'rugged individualist' understanding of self-regulation as a sign of the "good doctor", which is internalised by the student and codified into policy and practice through institutional narratives that frame accommodations as undesirable or impossible. The downstream personal, workforce, and cultural harms of perpetuating this aspect of the 'good doctor' concept will pose a key challenge to the inclusion of medical students with disabilities and to the diversity of the future medical workforce.

As contributors to this Chapter, we would like to highlight that the role of disability inclusion for faculty is largely missing from the AMC Standards document. The focus is on the inclusion of students and patients with disability. Below, we report on a 2026 Australian study that canvassed health professional educators' perspectives.

Research: Australian health professions' educators' preparedness for inclusive education

Gallego *et al.* (2026) used two scales to measure preparedness and concerns regarding teaching students with disability. One hundred and forty-eight Australian health professional educators (HPEs) completed the survey (72% females, 64% employed part-time, average teaching: 12.6 years). They indicated that while they had some confidence, knowledge and resources for teaching students with disability, they had received limited training. They were most concerned about students not being accepted by healthcare or clinical educators and the difficulty of providing appropriate support.

The authors concluded that:

> *"These findings suggest that reshaping the culture and practices of HPE with regards to disability inclusion may be required to provide HPEs with the skills they need to support students, to dispel misconceptions and to provide students with disability learning environments where they can safely and equitably thrive"* (p. 1).

18.4.4. Inclusion in prevocational, specialty training and specialist practice

The AMC National Standards for Prevocational (PGY1 and PGY2) Training Programs and Terms recommend the **provision of flexible training for disability, but fall short of mandating it**, for example:

> *"Policies about flexible training should be readily available to supervisors and prevocational doctors. Providers should guide and support supervisors and prevocational doctors on implementing and reviewing flexible training arrangements, which may cover a range of circumstances such as prevocational doctors with parental responsibilities, or with a medical condition or disability*" (p. 16).

Other relevant provisions are generically phrased without specific reference to disability. For example:

> *"4.1 Appointment to program and allocation to terms*
>
> *4.1.1 The processes for appointment of prevocational doctors to programs:*
>
> - *are based on the published criteria and the principles of the program concerned*
> - *are transparent, rigorous and fair*
> - *are free from racism, discrimination and bias*
> - *have clear processes for handling disputes.*
>
> *4.1.2 The processes for allocation of prevocational doctors to terms:*
>
> - *are based on the published criteria and the principles of the program concerned*
> - *are transparent, rigorous and fair*
> - *are free from racism, discrimination and bias [...]*
>
> *4.2.4 The prevocational training provider has and implements strategies, systems, and safe reporting mechanisms to effectively identify, address and prevent bullying, harassment and discrimination (including racism). This includes policies and procedures that are publicised to prevocational doctors, their supervisors and other team members"* (p. 27).

Direct statements of disability inclusion from specialty training Colleges are rare. The best developed are those of the RACGP, which takes a strengths-based approach:

> *"Doctors with a disability are valued members of our profession, bringing not only clinical expertise but many additional strengths shaped by lived experience to their work. These strengths may include increased adaptability, empathy, resilience, and a deep understanding of the patient experience."*

The RACGP Disability Support webpage has resources, including Support Services, such as workplace accommodations and accompanying webpage links to a range of helpful resources.

The Royal Australasian College of Medical Administrators (RACMA) has a more neutral inclusion Position Statement, largely focusing on what leaders can do to facilitate medical workforce inclusion, rather than inclusion of people with disabilities *as leaders*. One strong point of the RACMA Statement, however, is the wording around the need for intersectionality to avoid tokenism and the risk of administrative harm from policies that often treat intersectional inequities in isolation:

> *"Intersectionality is fundamental to this approach, system levers must integrate gender equity, LGBTIQA rights, First Nations truths, culturally and linguistically diverse (CALD) representation, disability inclusion, ethnic acknowledgement, neurodiversity presence, racial equity and the empowerment of all diverse groups. By addressing these elements holistically systemic health inequities can be tackled in an interconnected way leading to meaningful change"*(p.1).

There is no research in Australia regarding the progress or achievement of existing standards or outcomes in the health professions. It is likely, however, that doctors with disabilities in Australia face similar challenges to those in the UK, where frequent discrimination and difficulty getting accommodations have been noted. Of particular concern is the finding that experience of bullying and harassment increases with seniority. In a survey of 705 doctors with disabilities by the British Medical Association (BMA), 42% of specialists report bullying or harassment in their current workplace based on their disability, compared with 33% of junior doctors and 24% of medical students (BMA, 2020). This limits the advancement of doctors with disabilities into senior positions where they can most effectively drive change in systems, policies, and practices.

Key Take-aways

- Disability rights inclusion in health professions' curricula is a mandatory (legal) and ethical (moral) responsibility. The inclusion of disability rights challenges ableism, promoting social responsibility, and supports the empowerment of people living with disabilities both within and beyond the university environment
- Since many health professionals are involved in the care, ongoing rehabilitation and social integration of individuals living with an SCI injury, health professional training programs should include competencies relating to disability in their Standards, including working in a multidisciplinary team
- While graduates of Occupational Therapy, Physiotherapy and Exercise Physiology training programs are involved in the rehabilitation of individuals with SCI as part of their core roles, in Medicine, the

broad scope of training (generalist) means that these competencies are developed later, during post-graduate training, such as General Practice. The same holds true for Nursing, with Standards being broad. Specialist SCI courses are completed following graduation.

- Working as part of multidisciplinary teams, sometimes referred as interprofessional teams, was identified across all health professions standards and graduate outcomes
- Including students with all forms of disability in health professions programs is important, as health professionals with disabilities bring a patient's perspective to care. This has not always been the case, but diversity is increasingly recognised as an asset for better serving the Australian healthcare system, and
- Missing from the disability education documents we examined are educators' competencies regarding students with disabilities, as well as the diversity and inclusivity that extend to educators. Having said this, Gallego *et al.* (2026) recently found that health professions educators believed that they required additional skills to better serve students with disability.

The final part of this resource is called **Concluding Comments.**

Reminder: Relevant chapters

- **Chapter 1:** Returning home after SCI highlights how housing, supports and daily living resources can be arranged to promote safety, independence and participation
- **Chapter 2:** This Chapter provides foundational information on how SCI affects the body, which is essential background knowledge for understanding symptoms, complications and the roles of different health professionals
- **Chapter 3:** Reinforces the importance of maintaining overall health and well-being through the five pillars, which remain central to staying active, engaged and able to pursue study, work and community life
- **Chapter 4:** Documenting health and well-being using digital health tools supports self-management and communication with clinicians and ongoing participation in education and employment
- **Chapter 5:** Focuses on reconnecting with the community, finding purpose and exploring pathways to work or study, which are key goals for many people after SCI
- **Chapter 6:** This Chapter outlines what to expect as one ages with SCI and offers strategies to maintain health, independence and quality of life across the lifespan
- **Chapter 7:** The point made in Chapter 7 is that children are not just little adults. Health professional students thus need to develop the appropriate communication, physical examination and diagnostic skills
- **Chapter 8:** Living in regional, rural or remote areas affects access to services, making navigation, planning and telehealth particularly important, which should be taken into consideration during training
- **Chapter 9:** The focus of Chapter 9 is the importance of intersectionality, recognising that people with SCI may also identify as neurodiverse, LGBTQIA+, and be a migrant or asylum-seeker from a CALD community or may be incarcerated. Each context adds layers of complexity to having a disability,

such as SCI

- **Chapter 10:** The discrimination, dignity and safety issues discussed remind health professional students that people living with SCI may face bullying, exclusion or violence in healthcare, education, work and public places
- **Chapter 11:** Knowing the legal rights of people living with SCI, which includes consent, privacy and complaint pathways, should be part of all health professional training programs as these are essential considerations in healthcare, education and workplace settings, and
- **Chapter 17:** At a time of a changing climate, all health professional students need to know the physical, physiological and psychological impacts on people living with SCI, particularly with high-level injuries. Heat safety and emergency planning are essential for all environmental hazards.

References

Australian Human Rights Commission. (n.d). *About Disability Rights.* https://humanrights.gov.au/know-your-rights/rights-of-individuals/disability-rights/disability-rights/disability-rights-and-the-disability-discrimination-act/about-disability-rights

Bialocerkowski, A., Johnson, A., Allan, T., & Phillips, K. (2013). Development of physiotherapy inherent requirement statements – an Australian experience. *BMC Medical Education*, *13*, 1-13. https://bmcmededuc.biomedcentral.com/articles/10.1186/1472-6920-13-54

Brett, M., Harvey, A., Funston, A., Spicer, R., & Wood, A. (2016). *The role of inherent requirement statements in Australian universities.* https://www.ncsehe.edu.au/app/uploads/2016/05/The-Role-of-Inherent-Requirement-Statements-in-Australian-Universities.pdf.

British Medical Association. (2020). *Disability in the medical profession: Survey findings 2020*. British Medical Association. https://www.bma.org.uk/media/2923/bma-disability-in-the-medical-profession.pdf.

Christiansen, C. H., Baum, C. M., & Bass, J. D. (Eds.). (2015). *Occupational therapy: Performance, participation, and well-being* (4th ed.). SLACK Incorporated. https://doi.org/10.4324/9781003522997.

Corcoran, T., Whitburn, B., & Knight, E. (2022). Inherent requirements in higher education: locating You in Us. *Perspectives: Policy and Practice in Higher Education*, *26*(2), 69-75. https://doi.org/10.1080/13603108.2021.1986166

Eriks-Hoogland, I., Müller, L., Baumberger, M., Huber, B., Michel, F., Belfrage, C., Elmerghini, H., Veseli-Abazi, M., Böthig, R., Fiebag, K., Thietje, R., & Jordan, X. (2024). Evidence-based clinical practice guideline for follow-up care in persons with spinal cord injury. *Frontiers in Rehabilitation Sciences*, *5*. https://doi.org/10.3389/fresc.2024.1371556.

Fitzmorris, L., Donald, K., de Wet, C. & Palipana, D. (2021). Why we should and how we can increase medical school admissions for persons with disabilities. *Medical Journal of Australia, 215*(10), 453-453. https://doi.org/10.5694/mja2.51238.

Gallego, G., Forlin, C., Mogensen, L., Gray, L., Ng, C., Bulkeley, K., Moore, A., & Palipaan, D. (2026). Health professions' educators' preparedness for inclusive education: The HEPIE study. *The Clinical Teacher, 23*(2), e70364. https://doi.org/10.1111/tct.70364

Gray, H-L. (2025). What are the barriers to inclusive medical education? Real world experience of medical students with disabilities. [version 1; peer review: awaiting peer review]. *MedEdPublish, 15*, 273. https://doi.org/10.12688/mep.21377.1.

Gray, L., Mogensen, L., Gallego, G., Jain, N. R., Tai, J., Bishop, J., Brett, M., & McNeill, B. A. (2025). Barriers before entry: Opportunities for improving pre-admission guidance for disabled medical school applicants in Australia and New Zealand. *Teaching and Learning in Medicine.* https://doi.org/10.1080/10401334.2025.2601205

Keith, R. A., Granger, C. V., Hamilton, B. B., & Sherwin, F. S. (1987). The functional independence measure: A new tool for rehabilitation. *Advances in Clinical Rehabilitation, 1*, 6-18. https://pubmed.ncbi.nlm.nih.gov/3503663/

Kielhofner, G. (2008). Model of human occupation: Theory and application (4th ed.). Lippincott Williams & Wilkins.

Mitchell, J., O'Loghlen, J., Bray, E., McLennan, V., McLeod, B., Brough, R., Hogan, C., Geraghty, T., & Ownsworth, T. (2025). Assistive technology at work: a metasynthesis of the perspectives of people with spinal cord injury/damage. *Disability and Rehabilitation: Assistive Technology*, *20*(6), 1596-1615. https://doi.org/10.1080/17483107.2025.2475151.

Mogensen, L., & Hu, W. (2019). "A doctor who really knows…": a survey of community perspectives on medical students and practitioners with disability. *BMC Medical Education, 19*(1), 288. https://doi.org/10.1186/s12909-019-1715-7.

Occupational Therapy Board of Australia. (2018). *Australian Occupational Therapy Competency Standards 2018*. Australian Health Practitioner Regulation Agency. https://www.occupationaltherapyboard.gov.au/Codes-Guidelines/Competencies.aspx

Oxtoby, K. (2025). "We must make clinical academia more appealing" – the rehabilitation doctor encouraging a new generation. *British Medical Journal, 391,* r2289. https://doi.org/10.1136/bmj.r2289

Physiotherapy Boards of Australia and Aotearoa New Zealand. (2024). *Physiotherapy practice thresholds in Australia & Aotearoa New Zealand.* Physiotherapy Practice Thresholds for Australia and Aotearoa New Zealand

Seymour, R., Scher, C., Frasso, R., Truong, S., Ziring, D., & Ankam, N. (2023). Exposing the disability-related hidden curriculum in case-based learning: a qualitative study. *Disability and Health Journal*, *16*(4), 101483. https://doi.org/10.1016/j.dhjo.2023.101483

Singh, S., & Meeks, L. M. (2023). Disability inclusion in medical education: towards a quality improvement approach. *Medical Education*, *57*(1), 102-107. https://doi.org/10.1111/medu.14878

Sinha, T., Harada. C. N., Brooks, W. S. & Parish, A. (2024). 12 Tips for including disability awareness within undergraduate medical education curricula [version 3; peer review: 3 approved, 1 approved with reservations, 1 not approved*]. MedEdPublish, 14*, 32. https://doi.org/10.12688/mep.20329.3.

Stergiopoulos, E., Fernando, O., & Martimianakis, M. A. (2018). "Being on both sides": Canadian medical students' experiences with disability, the hidden curriculum, and professional identity construction. *Academic Medicine*, *93*(10), 1550-1559. https://doi.org/10.1097/acm.0000000000002300

Stergiopoulos, E., & Jain, N. R. (2026). Affects of ableism in medical education: happiness, resignation, and the disabled killjoy. *Advances in Health Sciences Education.* https://doi.org/10.1007/s10459-025-10499-4

The Royal Commission (2023). *Final Report: Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability.* https://disability.royalcommission.gov.au/publications/final-report

Wall, G., Isbel, S., Gustafsson, L., & Pearce, C. (2023). Occupation-based interventions to improve occupational performance and participation in the hospital setting: a systematic review. *Disability and Rehabilitation*, *46*(13), 2747-2768. https://doi.org/10.1080/09638288.2023.2236021.

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CONCLUDING COMMENTS: TOWARDS A LIFE WELL-LIVED WITH SCI

Contributors: Michelle McLean, Elmarie Stander and Thomas Titus

After a year of brainstorming, followed by deep discussions and engagement with many individuals with*lived and living experiences (LLEs)* of SCI, including those in their support networks, we can finally write these concluding comments for this resource. The early discussions initiated by **Dr Dinesh Palipana** and **Dr Thomas Titus**, both working at the Gold Coast University Hospital (Queensland), and some Bond University academics, centred on creating 'something' that would be evidence-based for health professionals to ensure quality healthcare for people with SCI, who were now living in the community. To be able to put into practice the adage drilled into many of our heads as medical students, *'a stitch in time saves nine'* requires health professionals to recognise signs and symptoms early to prevent serious, even life-threatening consequences. For many people living with SCI, such a life-threatening situation would be autonomic dysreflexia (AD), triggered perhaps by a UTI or influenza, resulting in a physiological cascade that might have a poor outcome. The *'stitch in time that might save nine'* in this instance may be recommending an annual influenza vaccination or ensuring that current hand hygiene guidelines are followed during daily bladder and bowel care.

While deliberating on what this 'something' might be, an online search for evidence-based and practical resources on SCI guidance for health, well-being and health support services in Australia found a disparate digital maze of information. In early 2025, we then agreed that this 'something' needed to be a resource that not only consolidated the wealth of available evidence and recent research, but was also inclusive of the many community (such as individuals living with SCI, carers and support workers) and healthcare (such as occupational therapists, physiotherapists, GPs) 'voices' with *lived and living experiences (LLEs)* of SCI.

And so, *Towards a Life Well-lived with Spinal Cord Injuries: A Resource for Affected Individuals, their Carers and Health Professionals,* was born. Over the next year, we listened deeply, engaging with individuals who were 'living' with SCI, either directly (the individual with the injury) or indirectly (their 'significant others', some of whom were carers, as well as support workers and health professionals). With a SCI research precinct on the Gold Coast (Griffith University and the Gold Coast University Hospital), involving two disability and SCI advocates (**Dinesh Palipana, OAM)** and **Perry Cross, AM)**, we drew on their experience across many areas for the resource, including pre-NDIS. Dinesh's extensive network of advocacy contacts and both of their research involvements meant we could invite key individuals working in disability and human rights, as well as researchers, to contribute to the resource. Some also reviewed and added depth and value to chapters.

While some people shared their experiences and expertise via email, in other instances, we documented (the *hands*) their lived experiences through in-person conversations over coffee. Others, such as **Dean and Jacqui Durman** had access to all 18 chapters in Google Drive to add their 'stories' where they felt that their LLEs would add authentic context.

This resource recognises the varied backgrounds and life stages of people affected by SCI. While many experience major disruptions in their lives and those of their significant others, they continue to achieve personal and professional goals. Our collaborative approach, guided by the *voice, hand and heart framework* (**Figure 2, Introduction**), ensured their embodied lived experiences were respectfully shared with empathy and translated into practical guidance. This resource thus brings together evidence, practical advice and prevention-focused information contributed by individuals living with SCI, their 'significant others', carers, support workers, health professionals and researchers. It also highlights the value of national data collection and supports the ongoing advocacy for an SCI Clinical Registry to improve long-term care and future decision-making.

In the **Foreword**, **Dinesh Palipana** wrote:

"In the twenty-first century, people with SCI can live a near-normal lifespan, depending on where in the world they live and many other considerations. Still, what is that life like?"

Having settled on the title, ***Towards a Life Well-lived with Spinal Cord Injury,*** we set about documenting what a life well-lived might look like by exploring the many contributing factors. A well-lived life means having a good Quality of Life (QoL), which the WHO defines as:

> *"An individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns."*

QoL is measured using the cross-cultural WHOQOL-BREF questionnaire, a 26-item self-report measure for adults (18+). The inventory has been designed to measure the impact of disease and impairment on daily activities and behaviour, perceived health, disability and functional capacity. The four QoL domains, which are addressed in many chapters of this e-resource, include:

1. **Physical health:** Energy levels, pain, sleep quality, mobility, ability to perform daily activities, dependence on medical treatments and work capacity.
2. **Psychological health:** Positive feelings, thinking and concentration abilities, self-esteem, body image, negative emotions and sense of meaning in life.
3. **Social relationships:** Satisfaction with personal relationships, social support from friends and family and sexual life.
4. **Environment:** Physical safety, home conditions, financial resources, access to health ser-

vices and information, leisure opportunities, quality of the physical environment and transport availability.

To account for the many elements that influence a good QoL and, hence, a life well lived, we proposed an eco-biopsychosocial model (**Figure 5** in the **Introduction** and below) using a strength-based lens.

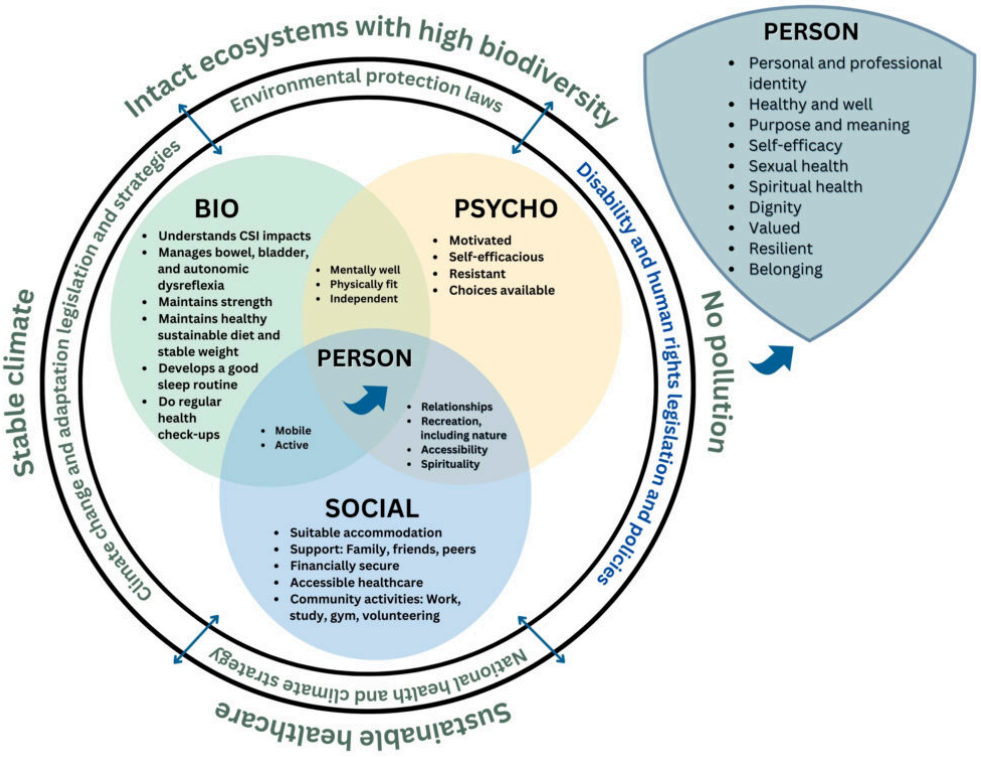

Figure 5. An eco-biopsychosocial model reflecting what is needed to live a life well-lived with SCI in Australia. Designed by Michelle McLean and created by Elmarie Stander using Canva, licensed under a CC BY-NC (Attribution NonCommercial).

All six chapters in **Part A** of the resource address key areas of the *biological (bio)* domain, such as managing one's bowel, bladder and, if relevant, AD, plus having a healthy diet, quality sleep, regular health check-ups and assistive technology that allows independence. The first six chapters also capture the *social* elements, such as having access to suitable accommodation, social and financial support and good healthcare. At the *micro* (individual person) level, the *biological* and *social* elements influence and are influenced by an individual's *psychological well-being (psycho).* Meeting these needs depends largely on strong legislation, policies and strategies collaboratively developed to prevent discrimination and provide opportunities for personal and professional development (*meso* level). Aspects of this *meso* level, such as climate change mitigation and adaptation and vehicle emissions reduction legislation and strategies, impact the overarching determinants of health, *ecological (eco) determinants of health.* A healthy planet, free of pollution, with physiologically conducive temperatures and healthy and biodiverse ecosystems, is essential for good health and well-being. The model depicts individuals with SCI as collaborators and partners in developing the legislation, strategies and policies that ensure a healthy planet and ongoing financial and social support.

Part B, the **Special Topics** chapters, then took a deep dive into many aspects of the eco-biopsychosocial model across different contexts, such as being a child or adolescent with SCI (**Chapter 7**), what it means to live rurally, regionally and remotely with a disability, including a spinal injury, such as SCI. This would be the case in the farming and First Nations communities (**Chapter 8**). In other contexts, individuals with disabilities may be incarcerated or may be culturally and linguistically diverse (CALD) migrants (**Chapter 9**). In Chapter 9, intersectionality extended to neurodiversity and being part of the LGBTQIA+ community. Being 'different' can lead to discrimination, abuse and violence (**Chapter 10**), in which case knowing one's legal rights is important (**Chapter 11**). Also, knowing one's legal rights applies to anaesthesia and surgical procedures, where consent is paramount (**Chapter 13**). Once settled in the community, for many, sport becomes an important part of identity (**Chapter 15**). As Australians love to travel, SCI can make some forms of travel difficult, but not impossible, as **Chapter 12** highlighted. The sensitive topics of intimacy and relationships, fertility and parenthood were explored in **Chapter 10**. Just as sexual health is an important part of a life well-lived, so too is spiritual health (**Chapter 14**).

Chapter 17 then explored planetary considerations, the *macro* issues, particularly a changing climate and Australia's vulnerability in terms of the increasing frequency of adverse weather events, such as heatwaves and bushfires, which lead to air pollution and flooding. As individuals living with SCI are affected directly by many of these weather events, we highlighted the importance of having a disaster management plan.

A key message that emerged from this resource is the need for the health workforce to reflect the society it serves. The 2022 Australian statistics indicate that 21.4% of Australians, which equates to about 1 in 5 or 5.5 million people, live with some form of disability (up from 17.7% in 2018). Just over 75% having a physical disability. Despite this, people with disability (including SCI) are underrepresented in the health professions. **Chapter 18** explored disability inclusion in medical education in detail. The Australian Medical Students' Association (AMSA) says Australia needs more medical students, healthcare workers and doctors with disability, highlighting the following, based on 2018 statistics:

"Disability in medicine is under-represented. As of 2018, 1 in 6 Australians have a disability – constituting 4.4 million individuals. In 2021, 4,153 students commenced a medical degree. The prevalence of disability in Australian medical students remains low, at less than 2%, when compared to similar programs worldwide."

A workforce that mirrors the population demographics is essential for delivering care that is informed, equitable and grounded in lived reality. When health professionals include people who live with SCI (or any other 'disability'), they bring insights that cannot be learned from textbooks. These are insights into daily routines, systemic barriers, the impact of assumptions and the practical realities of managing health and well-being in the community. Their presence strengthens empathy, challenges bias and enriches clinical practice, education and research.

This need for more health professionals with disability was strongly reinforced by the 2023 Royal Commission Final Report (*Volume 6: Enabling autonomy and access*), which highlighted how ableism and inequity continue to shape health experiences for people living with disability. The Report identified several critical challenges for them in healthcare:

- **Ableism and the medical model of disability:** Ableist attitudes towards disability are deeply connected to cultural beliefs and practices that see disability as a deficit or departure from a 'norm' or as a health or medical problem that requires treatment or cure. Health professionals can consciously or unconsciously make negative and false assumptions about the quality of life of people with disability, which can influence decisions, including views on reproductive choices or treatment options. 'Diagnostic overshadowing', in which a person's symptoms or behaviours are inappropriately attributed to their impairment instead of being properly investigated, can lead to delayed or incorrect diagnoses. Diagnostic overshadowing may be due to insufficient education or training relating to disability, particularly cognitive disability.
- **Unintended loss of specialised knowledge:** While the move away from the medical model of disability is important, a consequence has been an assumption that the general or mainstream health system would accommodate people with disability living in the community. Another consequence has been the loss of specialist skills to support the individual health requirements of some people living with disability. Expert opinion was that separating the disability and health sectors had resulted in the de-skilling of the medical workforce.

Thus, increasing representation in the health workforce is not only about equity. It is also a necessary step toward safer care, stronger clinical decision-making and greater trust between health professionals and people living with disability.

Perry Cross and **Christopher Reeve** have articulated the importance of hope. For Perry, hope inspires people to be more productive and willing to contribute to society. Some of this hope relates to research collaboration with individuals living with SCI. The primary objective of the different research and innovation streams described in **Chapter 16** is to improve an individual's *functioning*. The most exciting current Australian research trials are the world-first nerve bridge transplantation and rehabilitation involving a partnership between the Perry Cross Spinal Research Foundation and Griffith University, described in detail in **Chapter 16**.

But knowledge never stands still. While we have endeavoured to include the most up-to-date information in this resource, we are aware of progress relating to SCI prevention, management and research. As a digital resource, it is a living document that be updated regularly to reflect the best available evidence. While *'the journey of a thousand miles starts with a single step'*, we believe that developing this resource, which has involved about **62 collaborators** from all walks of life, we have taken the first step of this journey. Importantly, the resource is open access and has a non-commercial copyright (CC BY NC), so it (and its content) can be freely shared. We thank everyone of the individuals who so willingly contributed by sharing their sto-

ries, their time and their hopes and aspirations, all of which will positively influence the lives of many.

As the Editor-in-Chief, I think I have earned the right to have the last word. Personally, collating the contributions of 60+ individuals and exploring the impacts and management of SCI, as well as the research and innovation underway that brings a flicker of hope to many people and their 'significant others', has been a journey from knowing a little about SCI to learning what life is like for individuals who live every day and night with a body that may not respond or which might experience constant pain. I have also been inspired by the dedication of carers, support workers and families who support their loved ones.

Nothing about having a SCI is simple. There are so many considerations, from preparing to go to bed at night and getting ready for work, let alone the protocols that need to be completed before a 60-minute flight from the Gold Coast to Sydney, while not knowing if your wheelchair will arrive in pieces or even arrive on the other side.

Despite this, many people with SCI are motivated and resilient, and in my opinion, are more 'able' than many 'able-bodied' people. Through a deficit-based ableist lens, being 'able' relates to physical ability. Through a more social lens, being 'able' takes on a wider meaning. Days are busy and might include several activities, such as going to work, studying, engaging in physical activity, either at a gym or at a sports precinct, seeing a health professional, socialising with family and friends, checking for research updates or advocating for a cause. While writing the **Concluding Comments** section, **Dinesh** sent me this LinkedIn post from Sydney, where he and his support crew team were practising for a disability fund-raising event, Long Run To Inclusion 2026.

I have also learnt that no two individuals have the same injury, as the level varies and, if the injury is incomplete, the incompleteness also varies, which means differences in the functioning of different parts of the body. A one-size-fits-all management approach certainly does not work.

Finally, on the right is a photograph of two individuals. One person is using a wheelchair, while the other appears to have no physical impairment. This was one of the photographs as possible front covers for ***Towards a Life Well-lived with Spinal Cord Injury***. The cover with this photograph was my favourite. The contributing editors, however, voted that the editorial team chose the current cover (a young man in a wheelchair). The photograph on the right struck a chord for me on several levels, many of which were touched on in various chapters. In the first instance, it highlights the importance of *accessibility*. Accessibility allows people of all abilities to share the same public spaces. Secondly, it depicts an accessible bridge in a natural environment. Connecting with Nature was highly recommended in **Chapter 5** as being good (and necessary)

for well-being. Drawing on our **Chapter 3** *five pillars of good health and well-being* model, thanks to **Emma Simpson** (support worker and now occupational therapist), access to the same outdoor space means these individuals can be *physically active* while *engaging socially* and '*getting some sun exposure*' at the same time. The potential beneficial outcomes could be extended if their day of exercising and socialising in Nature included a picnic with *wholesome food*, which would probably result in a night of *quality sleep*. This would meet the remaining two pillars of good health and well-being. It also reminds me of O'Connor and colleagues' (2024) article about a high-quality 'dose of nature' in a national park saves the Australian health budget $98. The evidence about the importance of spending time in nature cannot be ignored, as these recent articles describe:

- What happens to your brain in nature? The neuroscience explained.
- An analysis of data from 75 countries confirms that nature connectedness predicts well-being.

We had also decided to start each chapter of the resource with an inspiring quote, mostly from the SCI community. We end the **Concluding Comments** section with this quote, which we think reflects the motivation and resilience of so many individuals who have sustained SCI:

"A hero is an ordinary individual who finds the strength to persevere and endure in spite of overwhelming obstacles."

Christopher Reeve, actor and SCI advocate, from his 1998 autobiography *Still Me*.

Professor Michelle McLean, Bond University, Gold Coast, Queensland

Editor-in-Chief, ***Towards a Life Well-lived with Spinal Cord Injury***

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- Figure 5. An eco-biopsychosocial model reflecting what is needed to live a life well-lived with SCI in Australia. © Michelle McLean & Elmarie Stander is licensed under a CC BY-NC (Attribution NonCommercial) license
- A person in a wheelchair alongside someone on a bicycle (Adobe Stock Photo) © Adobe

Glossary

Acceptance and commitment therapy (ACT)

Acceptance and commitment therapy (ACT) is a type of therapy that teaches you to accept your thoughts and feelings rather than try to control them.

Acetylcholine

Acetylcholine (ACh) is a neurotransmitter that regulates muscle contraction, heart rate, digestion and glandular secretion in the peripheral nervous system (PNS), while facilitating memory, arousal and attention in the brain. It enables neuromuscular junction function, acting as a chemical messenger between neurones and muscles, which is essential for movement.

Activity-based therapy (ABT)

Activity-based therapy (ABT) uses repetitive, task-specific movements below the level of injury to stimulate the brain and spinal cord. By doing so, ABT encourages the development of new neural pathways, giving people living with SCI the best possible chance to restore or improve function. ABT focuses on neuroplasticity, which is the nervous system's ability to reorganise itself and form new connections after injury.

Adaptive immunity

Adaptive immunity is more specific than innate immunity. It is slower acting and involves specialised immune cells and antibodies (produced by activated B-cells called plasma cells that destroy foreign invaders). This system has cells that 'remember' (memory cells) an antigen (foreign body) and then react quickly the second time or subsequent time it is encountered.

Adipokine

An adipokine is a signalling protein secreted by fat (adipose) tissue that act like a hormone, communicating with other organs to regulate metabolism, inflammation, immunity, appetite and blood pressure, essentially turning fat into an active endocrine organ.

Adrenal gland

Adrenal glands, or suprarenal glands, are small, triangle-shaped endocrine glands located on top of each kidney. They are crucial for survival, producing hormones that regulate metabolism, the immune system, blood pressure and stress responses, such as cortisol,

aldosterone and adrenaline. Adrenal glands are vital for maintaining homeostasis (steady state physiology).

Advanced Care Directive

An Advanced Care Directive is a record, usually a written document, of a person's wishes respecting their future treatment and care made in anticipation of a possible future loss of decision-making capacity. An example of an advanced care directive might be a documented refusal to receive certain interventions or treatments in the event they experience a loss of decision-making ability, such as due to illness progression or an event such as a stroke or a major heart attack, which renders them unconscious or otherwise unable to communicate for an extended period.

Algorithm

An algorithm is any step-by-step process that is completed the same way every time. A good example is tying your shoelaces. There is a limited number of steps that effectively result in a traditional shoelace knot, known as the “bunny rabbit” or “loop, swoop and pull” knot. Clinicians use algorithms in diagnosis and disease management.

Alpha-motor neurones

Alpha-motor neurones are large, multipolar lower motor neurones found in the ventral horn of the spinal cord and brainstem that directly innervate extrafusal muscle fibres (cells). Extrafusal muscle fibres are the abundant cylindrical cells that form the bulk of skeletal muscle, which is responsible for generating force and controlling movement.

Alzheimer’s disease and related dementia (ADRD)

Alzheimer's is the most common form of dementia in older adults. There are several other types:

Alzheimer's Disease (AD): Gradually affects memory and thinking skills, eventually impacting daily activities. Changes in the brain, including protein build-up (amyloid plaques and *tau* tangles), can begin years before symptoms appear.
Lewy body dementia: Affects movement and thinking, often causing visual hallucinations and sleep problems.

Fronto-temporal dementia: Primarily impacts behaviour, personality and language skills, typically starting at a younger age than other dementia types.

Vascular dementia: Results from conditions that block or reduce blood flow to the brain, affecting thinking skills (National Alzheimer’s Coordinating Center).

Anaemic

Anaemia is when the body has a deficiency of red blood cells or low haemoglobin so that insufficient oxygen is carried to the tissues.

Analgesics

Analgesics are painkillers that relieve pain without causing loss of consciousness, ranging from over-the-counter options like paracetamol and NSAIDs, such as ibuprofen and aspirin, to prescription-only opioids. They are used for mild-to-moderate pain, inflammation and fever. Opioids treat severe, chronic pain. Risks include liver damage, addiction and gastrointestinal issues, with common side-effects being nausea, dizziness or constipation.

Anatomy

Anatomy is the study of the structures of the body, including bones, muscles and organs.

Ano-rectal coordination

Ano-rectal coordination is the synchronised action of rectal muscles, anal sphincters and pelvic floor muscles required for normal defaecation, where increased rectal pressure is matched with relaxation of the anal sphincter. Dysfunction leads to constipation or faecal incontinence.

Antegrade colonic irrigation

Antegrade colonic irrigation is a surgical technique used to manage chronic constipation and faecal incontinence by washing out the colon from top to bottom.

Anterior cord syndrome

Anterior cord syndrome (ACS) is a rare neurological condition caused by damage to the front two-thirds of the spinal cord, often due to anterior spinal artery occlusion or trauma. It presents with sudden-onset, bilateral motor paralysis, loss of pain and temperature sensation below the injury. Proprioception and vibration are preserved.

Anti-cholinergic

Anti-cholinergic medications block the action of the neurotransmitter acetylcholine in the nervous system, preventing it from binding to its receptors. By inhibiting acetylcholine, these drugs can block the effects of the parasympathetic nervous system, which regulates involuntary functions such as heart rate, digestion and breathing and gastrointestinal motility.

Anti-diuretic hormone (ADH)

Anti-diuretic hormone (ADH) is a hormone produced in the hypothalamus and released by the pituitary gland that acts as the body's primary fluid regulator, the kidneys. The kidneys increase water reabsorption, reducing urine volume and conserving bodily fluids. It also constricts blood vessels to raise blood pressure.

Anti-inflammatory drugs

Anti-inflammatory drugs are usually non-steroidal and are known as NSAIDS (non-steroidal anti-inflammatory drugs. They are used to relieve pain and reduce inflammation (redness and swelling), the latter of which often causes pain.

Antibodies

An antibody (an immunoglobulin) is a protein made by plasma cells (a type of white blood cell) in response to an antigen (a substance that causes the body to make a specific immune response). Each antibody can bind to only one specific antigen (foreign particle). The purpose of this binding is to help destroy the antigen.

Antigen

An antigen is any 'substance' that causes the body to raise an immune response against that substance. Antigens include toxins, chemicals, bacteria, viruses or other substances that come from outside the body. Body tissues and cells, including cancer cells, also have antigens on them that can cause an immune response.

Apnoea

Apnoea is when breathing stops. Sleep apnoea means you stop breathing while you are sleeping. Loud snoring can indicate a potentially serious problem, but not everyone who has sleep apnoea snores. Given the current literature limitations, sleep disordered breathing as currently defined is high in patients with SCI, approaching 60% in motor complete persons with quadriplegia. Central apnoea is more common with quadriplegia than paraplegia. For more information here.

Talk to your healthcare professional if you have symptoms of sleep apnoea, which is often noticed by someone sleeping next to you, or any sleep problem that leaves you very tired, sleepy and irritable. Two of the main types of sleep apnoea are:

Obstructive sleep apnoea (OSA): This more common form of sleep apnoea occurs when throat narrowing blocks the flow of air into the lungs, and
Central sleep apnoea (CSA): This type of sleep apnoea occurs when the brain does not send proper signals to the muscles that manage breathing.

Apoptosis

Apoptosis is a natural, pre-programmed way in which the body causes the death of cells that are old, damaged or no longer needed.

Areflexic injuries

Areflexia means the absence of deep tendon reflexes. Areflexia is one symptom of nerve problems. You may also get other muscle problems along with the loss of involuntary

reflexes. If you have muscle weakness or losing muscle mass, your doctor may test your reflexes and discover areflexia.

ASIA grading

The American Spinal Injury Association (ASIA) grading or ASIA Impairment Scale (AIS) is a system for classifying the severity of SCI. Under this system, a grade of A implies the most severe or a clinically complete SCI; grades B, C and D indicate gradually decreasing severity in incomplete SCI and a grade of E indicates normal neurological function without any deficits.

Astrocyte

Astrocytes are star-shaped neuroglial cells in the central nervous system (CNS). They act as 'housekeepers', maintaining brain homeostasis by providing structural support, regulating the permeability of the blood-brain barrier, pruning synapses and managing energy metabolism

Astrogliosis

Astroglyosis is the process of scar tissue formation in the nervous system following injury or disease, driven by glial cells (astrocytes). Glial cells support neurones (nreve cells).

Asymptomatic bacteriuria

If a bacteriuria is asymptomatic, bacteria are found in properly collected urine, but the person has no signs or symptoms of a urinary tract infection (UTI).

Atrophy

Means to waste away, especially as a result of the degeneration of cells. In SCI, with nerve damage, muscles of the affected limbs will not be used and so will waste.

Autonomic dysreflexia (AD)

Autonomic dysreflexia (AD) is a potentially life-threatening condition seen in individuals with SCI, typically at or above the T6 level, characterised by an uncontrolled sympathetic nervous system response to stimuli below the level of injury. It results in sudden severe hypertension and may be accompanied by headache, flushing, sweating, bradycardia and anxiety. Common triggers include bladder or bowel distension, skin irritation or pain.

Autonomic nervous system (ANS)

The autonomic nervous system (ANS) is a part of the peripheral nervous system (PNS), so is outside the central nervous system (CNS, which comprises the brain and spinal cord). The ANS regulates involuntary physiological processes, including heart rate, blood pressure, respiration, digestion and sexual arousal. It maintains internal homeostasis, operating primarily through the sympathetic ("fight or flight") system for stress response and

the parasympathetic ("rest and digest") system for conserving energy. The ANS is always active, even when one is asleep.

Autonomic neuroplasticity

Autonomic neuroplasticity is the ability of the autonomic nervous system (ANS) to structurally and functionally reorganise itself, allowing it to adapt, repair and change in response to stimuli, such as exercise, stress or injury.

Autonomic reflexes

Autonomic reflexes are involuntary motor responses mediated by the autonomic nervous system (ANS) that regulate visceral functions, such as heart rate, blood pressure, digestion and pupil dilation, without conscious effort. These neural arcs maintain homeostasis by regulating internal organs via sympathetic ("fight-or-flight") or parasympathetic ("rest-and-digest") pathways

Autonomic Standards

Autonomic Standards are international standards to document autonomic function. The Standards provide a format for documenting the impact of SCI in the autonomic nervous system (ANS) neural control of cardiovascular, thermal, sudomotor (sweating), bronchopulmonary and sacral organ function, which includes the urinary tract, gastrointestinal tract and genitalia and reproductive organs.

Axon

An axon is the process of the nerve cell (neurone) that transmits the nerve impulse to another cell or to an effector organ, such as muscle. An axon is also called a nerve fibre.

Axon terminal

The axon terminal is the end portion of the axon (nerve fibre) of a neurone that stores and releases neurotransmitters and which interacts with another neurone or organ. An axon terminal is sometimes called a synaptic bouton (button).

B-lymphocytes (B-cells)

B-lymphocytes, or B-cells, are white blood cells (WBCs) essential for the body's adaptive immune system response, which is responsible for producing antibodies (immunoglobulins) against pathogens (antigens). Originating in bone marrow, they mature into plasma cells (secreting antibodies) or memory cells (providing long-term immunity, so the next immune response against that specific antigen is quicker than the first antigen exposure). Vaccinations generally prompt a B-cell response, so there are memory cells for the next time you encounter that antigen.

Battery

In legal terms, battery is an intentional act of interference with the bodily integrity of the person experiencing the battery. Often accompanying an assault, an intentional act which causes the person to anticipate and fear imminent physical interference, battery does not have to cause injury to lead to a claim in tort law. Obtaining the person's consent is a defence to a claim of battery.

Behavioural therapy

Behavioural therapy is an umbrella term for types of therapy that treat mental health disorders. It is based on the idea that all behaviours are learned and that behaviours can be changed.

Below-level or distant pain

'Below level' pain, also known as distant pain, relates to loss of the usual feedback pathways within the spinal cord that filter pain sensations. These are often experienced more vaguely and unpredictably in a wide variety of ways (aching, numbness, a feeling of swelling or tightness, sharp prickles or electric shocks, etc). Below-level pain can be a false positive, i.e. a normal sensation that is experienced as pain. An analogous example in non-SCI is tooth sensitivity or 'brain freeze' from cold foods or a false negative, i.e. serious pain that is experienced as another sensation. This is one reason that people with SCI present late with serious conditions below the level of injury, such as appendicitis.

Bi-level Positive Airway Pressure (BiPAP)

BiPAP (bi-level positive airway pressure) is a non-invasive ventilation device used to assist breathing in obstructive sleep apnoea, by delivering pressurised air through a mask.

Bioelectrical impedance

Bioelectrical impedance refers to how different body tissues resist low-level, imperceptible electrical current. Lean tissue (high water or electrolyte content) conducts electricity better than fat tissue. Bioelectrical Impedance Analysis (BIA) measures bioelectrical impedance. BIA is used in health, fitness and clinical settings to monitor body fat, muscle development and hydration status.

Bioelectrical impedance analysis (BIA)

Bioelectrical impedance analysis (BIA) estimates body composition, in particular body fat and muscle mass. A weak electric current flows through the body and the voltage is measured to calculate the impedance (resistance and reactance) of the body. Most body water is stored in muscle. Thus, if a person is muscular, there is a high chance that they will also have more body water, which leads to lower impedance.

Bisphosphonates

Bisphosphonates are a class of prescription medications used to strengthen bones by slowing down bone breakdown or resorption.

Bladder dysfunction

Bladder dysfunction is a problem with the way the bladder stores or releases urine, which can lead to issues like leaking urine, difficulty emptying the bladder or a strong, sudden urge to urinate. This aligns with medical descriptions showing that bladder dysfunction includes conditions, such as urinary incontinence, overactive bladder, underactive bladder or trouble emptying due to neurological or other health conditions.

Body mass index (BMI)

Body mass index, or BMI, provides an indication of body size. BMI is calculated using weight and height (weight divided by height squared). Along with several other factors, such as blood pressure and cholesterol, BMI can help estimate the risk of a heart attack or stroke. BMI has several limitations and is not accurate for some people. A GP and an Accredited Practising Dietitian can help one maintain a healthy weight.

Bone mineral density (BMD)

Bone mineral density (BMD) is a measurement of the amount of mineral (calcium) contained in a small volume of bone, which is used to assess bone strength and diagnose conditions, such as osteoporosis.

Borderzone or At-level pain

'At level' pain (often called 'border zone' or 'on level' pain) is due to permanent damage at the level of injury. Because it relates to a nerve root, it is experienced as a horizontal band-like pain in one or more dermatomes.

Brain-computer interface (BIC) technology

Brain-computer interface (BIC) technology is a system that determines functional intent - the desire to change, move, control or interact with something in your environment directly from your brain activity. In other words, BCI allows you to control an application or a device using *only your mind*.

Cardiac muscle

Cardiac muscle is the muscle of the heart. It is highly specialised and is found nowhere else in the body.

Cardiac stress test

A cardiac exercise stress test shows how well your heart handles exercise. This can take various forms, including a stress ECG (an electrocardiogram that measures your heart's electrical activity) and a stress echocardiogram (a heart test using ultrasound to see how your heart functions at rest and during exercise or stress, checking for blockages or problems, such as coronary artery disease, heart valve issues or cardiomyopathy by comparing heart images before and after increased demand. After the test, you are monitored until your heart rate returns to normal. For individuals living with SCI, the test is modified as it is usually done on a treadmill.

Caries

Caries are the cavities (holes) in teeth that develop from tooth decay. 'Carious teeth' translates into teeth with cavities.

Cauda equina

The *cauda* (tail) *equina* (horse) is a bundle of spinal nerves at the lower end of the spinal cord that looks like a horse's tail. *Cauda equina* syndrome (CES) is a rare, severe medical emergency caused by compression of the nerve roots at the base of the spine, often from a massive herniated lumbar disc, tumour or infection. It requires urgent decompression surgery, typically within 24-48 hours, to prevent permanent neurological damage.

Central cord syndrome

Central cord syndrome (CCS) is the most common incomplete cervical SCI, which is characterised by disproportionate, severe weakness in the arms or hands compared with the legs, often with bladder dysfunction and variable sensation loss. It is caused by traumatic neck hyperextension or underlying cervical stenosis. It frequently affects older adults. Recovery prospects are generally good.

Central nervous systems (CNS)

The central nervous system (CNS) comprises the brain and the spinal cord, both of which coordinate the various functions of the body.

Cerebral cortex

The cerebral cortex, also called gray matter, is the brain's outermost layer of nerve cell tissue. It has a wrinkled appearance from its many folds and grooves. The cerebral cortex plays a key role in memory, thinking, learning, reasoning, problem-solving, emotions, consciousness and functions related to the senses.

Chondroitin sulphate proteoglycans (CSPGs)

Chondroitin sulphate proteoglycans (CSPGs) are molecules made by a combination of proteins and carbohydrates, generally found in cartilage. In terms of SCI, these CSPGs are a byproduct of myelin sheath damage as a result of SCI.

Circadian rhythm

A circadian rhythm is the natural cycle of physical, mental and behavioural changes that the body goes through in a 24-hour cycle. Circadian rhythms are mostly affected by light and darkness and are controlled by a small area in the mid-brain called the hypothalamus.

Circadian rhythm sleep–wake disorders

Circadian rhythm disorders are conditions that disrupt or affect the body's natural sleep-wake cycle. These disruptions affect how well we sleep, when we sleep and how we function while awake. They're also known as "circadian rhythm sleep disorders" or "circadian rhythm sleep-wake disorders."

Cis-gendered

Cis-gender is often shortened to cis. It describes a person whose gender identity corresponds with their sex assigned at birth, i.e. someone who is not transgender. Derived from this, then are cis-males and cis-females.

Cognitive behavioural therapy (CBT)

Cognitive behavioural therapy (CBT) is a form of psychological treatment that has been demonstrated to be effective for a range of problems, including depression, anxiety disorders, alcohol and drug use problems, marital problems, eating disorders and severe mental illness. CBT involves interventions to change thinking patterns.

Cognitive behavioural therapy for insomnia (CBT-I)

CBT-I uses a range of approaches to assist individuals in achieving better sleep. It examines thoughts, behaviours and other processes that contribute to insomnia. The main parts of CBT-I are:

Education: Learning about sleep and insomnia.
Behavioural interventions: Changing habits to improve sleep.

Cognitive restructuring

Cognitive restructuring is the therapeutic process of identifying and challenging negative and irrational thoughts, such as those described in the birthday example. These thoughts are called cognitive distortions. Although everyone has some cognitive distortions, having too many is closely linked to poor mental health conditions, such as depression and anxiety.

Colonic transit time (CTT)

Colonic transit time (CTT) is the time taken for food or waste to travel through the colon (large intestine) from entry to elimination.

Colonoscopy

A colonoscopy is an examination used to look for changes such as swollen, irritated tissues, polyps or cancer in the large intestine (colon) and rectum. A tube with a camera is inserted into the rectum.

Colostomy

A colostomy is a surgical procedure that creates an opening (stoma) in the abdominal wall, connecting the colon to the surface to divert stool into an external, wearable pouch.

Complete spinal cord injury

A complete SCI is any injury that fully severs the spinal cord at the injury site. A complete SCI results in the loss of all feeling and function for anything connected to nerves below the injury site. The higher up on the SCI, the more severe the symptoms tend to be. Thus, a person with a complete SCI at the lower lumbar spine might lose feeling and function in their hips and legs, becoming paraplegic. A complete injury in the cervical spine (the neck) can cause someone to lose all function in their arms and legs (quadriplegic). They may also need mechanical assistance to breathe.

Congenital abnormalities

Congenital abnormalities, also known as birth defects or congenital disorders, are structural or functional anomalies present at birth that can affect a child's appearance, development or bodily functions. They may be structural, such as heart or limb defects, or functional or metabolic, such as enzyme deficiencies, which can impact physical, cognitive and/or developmental health.

Consumer packaged goods (CPGs)

Consumer packaged goods (CPGs) are essential, non-durable products that consumers purchase regularly, typically with a short decision-making process. The market is highly competitive, so companies rely heavily on branding and marketing to gain shelf space and customer loyalty.

Continuing professional development (CPD)

Continuing professional development (CPD) is the ongoing learning of a professional to ensure that they are familiar with the current evidence and that their skills are up to date.

Continuous Positive Airway Pressure (CPAP)

CPAP, or Continuous Positive Airway Pressure, involves air being blown through a mask by a CPAP machine to keep your airway open at night.

Cortico-spinal tract or pathway

The cortico-spinal tract is the primary descending white matter motor pathway for voluntary movement, originating in the cerebral cortex and travelling to the spinal cord. It descends through the internal capsule, brainstem and medulla, where ~90% of the fibres cross to form the lateral tract (distal limbs) and 10% remain ipsilateral (same side of the body) as the anterior tract (proximal muscles).

Cranial nerves

The cranial nerves comprise 12 pairs of nerves emerging directly from the brain (mostly the brainstem) that manage sensory and motor functions for the head, neck and torso, including smell, vision, eye movement and facial sensations. They are classified as sensory (I, II, VIII), motor (III, IV, VI, XI, XII) or mixed (V, VII, IX, X).

Cultural safety

Cultural safety requires healthcare professionals and their associated healthcare organisations to examine themselves and the potential impact of their own culture on clinical interactions and healthcare service delivery. This requires individual healthcare professionals and healthcare organisations to acknowledge and address their own biases, attitudes, assumptions, stereotypes, prejudices, structures and characteristics that may affect the quality of care provided. In doing so, cultural safety encompasses a critical consciousness where healthcare professionals and healthcare organisations engage in ongoing self-reflection and self-awareness and hold themselves accountable for providing culturally safe care, as defined by the patient and their communities, and as measured through progress towards achieving health equity. Cultural safety requires healthcare professionals and their associated healthcare organisations to influence healthcare to reduce bias and achieve equity within the workforce and working environment.

Culturally and Linguistically Diverse (CALD)

CALD refers to individuals and communities whose cultural background, language or heritage differs from the dominant Anglo-Australian culture. The term is often used in policy, health and education.

CXCL1, CXCL2: C-X-C Motif Ligands 1 and 2

CXCL1 and the other named molecules play a key role in the immune response, particularly in recruiting neutrophils to sites of inflammation and injury.

Cytokines

Cytokines are chemicals produced by cells that promote tissue repair.

Cytotoxic T-cells

Cytotoxic T-cells are one of the main types of immune cells produced in the thymus. When one has an infection, helper T-cells activate cytotoxic T-cells to fight the infection. These T-cells are an important part of the adaptive immune system, as opposed to the innate (inborn) immune system.

Deep vein thrombosis (DVT)

A deep vein thrombosis (DVT) occurs when a blood clot (thrombus) forms in one or more of the deep veins in the body, usually in the legs. Immobility is a risk factor for DVT. DVTs can cause leg pain or swelling. Sometimes there are no noticeable symptoms. A DVT can lead to pulmonary embolism if the clot travels to the lungs.

Delphi study

A Delphi study is a method to gather expert opinions through rounds, named after the Oracle of Delphi, to achieve consensus.

Demylination

The axons (fibres) of some neurones, particularly the large ones, in the central nervous system (CNS) and the peripheral nervous system (PNS) are ensheathed by cells that wrap around the axon to increase the speed at which the axon potential travels down the axon. This is called the myelin sheath. Demyelination involves the unwrapping of these cells, which slows down the nerve transmission. Multiple sclerosis (MS) is an example of a demyelinating disease. If a nerve cannot transmit an impulse to the muscle, the muscle no longer works, leading to weakness and fatigue. The muscle will atrophy (become smaller) as a result.

In the central nervous system (CNS), oligodendrocytes form the myelin sheath. In the peripheral nervous system (PNS), Schwann cells are responsible for myelination.

Dendrites

Dendrites are branched, tree-like extensions of neurones that receive electrochemical signals from other neurones. They are involved in information processing and synaptic integration. They act as input sites, transmitting signals to the cell body (soma) and often feature dendritic spines to enhance connection.

Dendritic cells

A dendritic cell is a special immune cell that is found in tissues, such as the skin. It boosts immune responses by showing antigens on its surface to other cells of the immune system.

Dermatome

A dermatome is an area of skin that is mainly supplied by afferent nerve fibres from the dorsal root of any given spinal nerve. There are 30 dermatomes. You can watch a short video: https://www.youtube.com/watch?v=GqGsj4B6MoQ

Dermis

The dermis is the middle layer of skin that supports the outermost layer, the epidermis, which is responsible for protecting the body from harm, feeling different sensations and producing sweat and has hair follicles. Below the dermis is the hypodermis.

Descending motor pathways

Descending motor pathways are neural tracts carrying signals from the brain to spinal cord lower motor neurones (LMNs), controlling voluntary (pyramidal) and involuntary (extrapyramidal) muscle movement. Major tracts include the cortico-spinal (voluntary limb/trunk movement) and brainstem pathways (posture, balance), which are vital for motor control and, if damaged, such as in SCI, lead to severe motor deficits

DEXA (Dual-Energy X-ray Absorptiometry)

DEXA is a quick, non-invasive, low-radiation imaging test that measures bone mineral density to diagnose osteoporosis and assess fracture risk.

Diaphragm pacing

Diaphragm pacing is a procedure that stimulates the phrenic nerve to induce contraction of the diaphragm, thereby improving breathing and speech.

Diffusion Tensor Imaging (DTI)

Diffusion tension imaging (DTI) is an MRI-based technique that maps the CNS's white matter by measuring the diffusion of water molecules. By analysing how the water moves, DTI can track neural fibre pathways, assess tissue integrity and identify microstructural changes in the brain or spinal cord.

Dorsal columns

The dorsal (or posterior) columns of the spinal cord are key sensory pathways in the nervous system responsible for transmitting fine touch, vibration and proprioceptive information from the body to the brain. *There are two main tracts:* One carries sensory information

from the lower body (below T6) and the other transmits information from the upper body (above T6). The tracts ascend the spinal cord and synapse with the medulla oblongata. The medulla oblongata controls vital autonomic functions, including cardiovascular control, respiratory control and reflexes.

Dorsal root

The dorsal roots are bundles of nerve fibres (axons) that emerge directly from the posterior side of the spinal cord. Each spinal nerve typically has a dorsal root and a ventral root, with the dorsal root characterised by an oval swelling called the dorsal root ganglion. Dorsal roots, also known as posterior roots, are dedicated to carrying sensory information into the spinal cord from the body. These roots contain afferent nerve fibres, meaning that they transmit signals from the periphery towards the central nervous system (CNS).

Dysreflexic

Dysreflexic is an adjective to describe a process that is no longer reflexive. 'Dys' means abnormal or out of kilter. With SCI, this relates to autonomic dysreflexia (AD), in which the normal processes responsible for automatically regulating the heart, blood pressure and in some instances, breathing, have been disrupted.

Dystonia

Dystonia happens when the muscles receive mixed or excessive messages after SCI, making parts of the body pull into positions the person does not intend and cannot easily relax.

Eco-anxiety

Eco-anxiety was recognised by the American Psychological Association in 2017 and was defined as a sense of 'environmental doom' in relation to climate change, environmental destruction, etc.

Eczematous changes

Eczematous changes are chronic skin conditions characterised by inflammation, intense itching, dryness and rash, often referred to as dermatitis

Electroconvulsive therapy (ECT)

Electroconvulsive therapy (ECT) is a procedure performed under general anaesthesia during which time small electric currents pass through the brain, intentionally causing a brief seizure. ECT seems to change brain chemistry. The changes can quickly improve symptoms of certain mental health conditions.

Electrode array

An electrode ray is a device with multiple small electrodes arranged in a specific pattern to deliver electrical impulses.

Electroejaculation (EEJ)

Electroejaculation (EEJ) is an outpatient procedure used to retrieve sperm from men who cannot ejaculate due to SCI, multiple sclerosis (MS) or nerve damage.

Electromyograph (EMG)

Neurologists use electromyography (EMG) to help diagnose injuries and conditions that affect muscles and the nerves that control them, such as carpal tunnel syndrome, nerve root compression and muscular dystrophy. They often use this test with nerve conduction studies.

Motor neurones transmit electrical signals that cause muscles to contract. An EMG uses tiny devices called electrodes to translate these signals into graphs, sounds or numerical values that are then interpreted. During a needle EMG, a needle electrode inserted directly into a muscle records the electrical activity in that muscle.

A nerve conduction study, another part of an EMG, uses electrode stickers applied to the skin (surface electrodes) to measure the speed and strength of signals travelling between two or more points.

Embodiment

Embodiment is the understanding that the body actively shapes thoughts, feelings and interactions with the world, and that mind and body are inseparable in these lived experiences. To be 'embodied' refers to the feelings and sensations that are experienced of being in one's body. Embodiment shapes identity.

Endocrine

Endocrine, as in the endocrine system, relates to the glands and organs that make hormones and release them directly into the blood so they can travel to tissues and organs of the body. The hormones released by the endocrine system control many important functions in the body, including growth and development, metabolism and reproduction.

Endorphin

An endorphin is a natural pain reliever (small protein) released from the brain which creates feelings of well-being and happiness by binding to opioid receptors to block pain and reduce stress. You can think of them as endogenous opioids.

Enduring power of attorney

Enduring power of attorney is a legal instrument that enables a person to appoint another person to make decisions on their behalf, in anticipation of a future loss of decision-making capacity.

Energy density

Energy density refers to the number of calories in a given volume or weight of food or fluids. Reducing energy density helps you eat satisfying portions while keeping calorie intake in check, which is especially important if your energy needs are lower. It supports a healthy weight, better nutrition and long-term health.

Enteric

Enteric is an adjective that relates to the intestines. The term is often used in contexts like the *enteric nervous system* (the network of nerves in the gut).

Enteric nervous system (ENS)

The enteric nervous system (ENS) controls the digestive system, connecting through the central (CNS, brain and spinal cord) and sympathetic nervous system. In particular, the enteric nervous system determines the movements of the gastrointestinal tract, regulates gastric acid secretion, changes in local blood flow and the release of gut hormones and interacts with the immune system in the gut.

Enterocystoplasty

Enterocystoplasty is a surgical procedure in which a segment of bowel (usually ileum or colon) is used to enlarge or reconstruct the urinary bladder. It is performed to increase bladder capacity, reduce intravesical pressure and improve urinary continence, commonly in patients with neurogenic bladder dysfunction.

Environmental factors

The term, environmental factors, covers a range of external factors. In terms of disability, environmental factors, which may be barriers or enablers, include physical surroundings (inaccessible buildings and transport), societal attitudes (stigma and discrimination), policies (services and laws), technology (assistive devices), natural elements (climate, pollution) and social support (family, friends, health professionals).

Environmental sustainability

'Environmental' has been added to sustainability to ensure that everyone is on the same page. Sustainability has been used to infer longevity. This is confusing. For instance, if a new education program is being proposed at a university, someone may ask, "*How sustainable will it be?*" They are asking whether students will still want to study the course five or 10 years down the track, which implies financial sustainability. Qualifying sustainability with 'environmental' means considering the impact on the natural environment in terms of resources used, emissions and waste produced.

Ependymal cells

Ependymal cells are epithelial cells that line the ventricles of the brain and produce cerebrospinal fluid (CFS).

Epidermis

The epidermis is the outermost layer of the skin, which protects the body from abrasion and also makes the skin 'waterproof'. The epidermis is supported by the dermis, which contains nerves, sweat glands and blood vessels, amongst other structures.

Epidural space

The epidural space is the potential space between the vertebrae of the spine and the innermost layer (dura mater) of the meninges, the covering of the spinal cord and brain.

Excitatory neurotransmitters

Excitatory neurotransmitters increase the likelihood of a post-synaptic neurone firing an action potential by causing depolarisation, typically through the influx of positively charged ions like sodium. Glutamate is the primary excitatory neurotransmitter in the central nervous system (CNS), crucial for learning and memory. Other examples include acetylcholine, adrenaline and noradrenaline.

Excitotoxicity

Excitotoxicity is the pathological process in which neurones are damaged and killed by excessive stimulation from neurotransmitters, primarily glutamate, causing a massive influx of calcium into nerve cells (neurones).

Extra-pyramidal pathways

Extrapyramidal pathways are complex, polysynaptic motor pathways originating in the brainstem (not the cerebral cortex) that regulate involuntary motor functions, including postural tone, balance and automatic movements. They modulate lower motor neurones (LMNs) to ensure smooth, controlled movement.

Extreme Citizen Science (ExCiteS)

Extreme Citizen Science is a situated, bottom-up practice that takes into account local needs, practices and culture and works with broad networks of people to design and build new devices and knowledge creation processes that can transform the world.

Exudate

Exudate is the fluid that leaks from blood vessels into nearby tissue. The fluid comprises cells, proteins and other solid material. Exudate also oozes from wounds or areas of infection.

Fascia

The word, fascia, is used to describe the web-like network of connective tissue that surrounds and holds every muscle, organ, bone, nerve and blood vessel in the body.

First Nations people

The term refers to Aboriginal and Torres Strait Islander peoples in Australia.

First-order neurones

First-order neurones are the initial point of contact for sensory information, acting as the first cells in a sensory pathway. They are specifically designed to detect stimuli originating from the external environment or from within the body's internal environment.

Flexion

Flexion is the bending of a joint to bring body parts closer together.

Flow cytometry

Flow cytometry is a technique that rapidly measures the physical and chemical properties of individual cells or particles in a fluid sample. It uses lasers and detectors to analyse light scattering and fluorescence from stained cells, allowing for cell counting, characterisation and identification based on their size, granularity and specific protein expression.

FODMAP

FODMAP stands for ‘fermentable oligosaccharides, disaccharides, monosaccharides and polyols'. These are foods that produce more gas on interaction with gut microbes.

Forced expiratory volume (FEV)

Forced expiratory volume (FEV) is a measurement in pulmonary function testing that quantifies the volume of air a person can forcibly exhale from the lungs within a specific time frame following maximal inhalation.

Functional ability

Functional ability is about having the capabilities that enable all people to be and do what they have reason to value. This includes a person’s ability to: Meet their basic needs, learn, grow and make decisions, be mobile, build and maintain relationships and contribute to society.

Functional Electrical Stimulation (FES)

Functional electrical stimulation (FES) involves a range of rehabilitation tools that use low-level electrical currents to activate nerves in muscles that have become paralysed or weakened due to central nervous system damage (brain or spinal cord).

Functioning

Functioning is a comprehensive health indicator describing how well a person carries out daily activities and participates in life situations, taking into account physical, psychological and social abilities (International Spinal Cord Injury (InSCI) Community Survey).

Gastroenterologist

A gastroenterologist is the medical specialist who deals with issues relating to the gastrointestinal system (gut).

Generative Co-design Framework for Healthcare Innovation

The three major stages of the Generative Co-design Framework for Healthcare Innovation are:

Pre-design (Step 1: Contextual inquiry; Step 2: Preparation and training)
Co-design (Step 3: Framing the issue; Step 4: Generative design; Step 5: Sharing ideas)
Post-design: (Step 6: Data analysis; Step 7: Requirements translation)

Genomics

Genomics is the branch of molecular biology that studies an organism's entire set of genetic instructions, known as the genome. Unlike genetics, which examines individual genes, genomics analyses all genes, their interactions, structure, function and evolution to understand how they influence health, disease and environmental responses.

Ghrelin

Ghrelin is a peptide (almost a protein) hormone, often called the 'hunger hormone', primarily produced in the stomach and stimulates appetite, increases food intake and promotes fat storage.

Gingival bleeding

The gingiva are the gums, so gingival bleeding is when the gums bleed. This often happens when the bristles of the toothbrush are too hard, but it could also be an indication of a sign of gingivitis (early gum disease) caused by plaque build-up or periodontitis (advanced gum disease).

Gland

A gland is a structure or organ in the body that makes and releases substances such as hormones, sweat and saliva. Endocrine glands release their secretions into the blood so that hormones, such as insulin, can be transported to distant tissues and cells around the body. Exocrine glands release their secretions locally. Sweat is produced onto the skin surface for evaporative cooling, while saliva is released into the mouth to assist with digestion.

Glial cells

Glial cells are cells that support neurones in the central nervous system (CNS), such as oligodendrocytes, astrocytes and microglia.

Glioma

A glioma is a tumour that forms in the brain or spinal cord involving the cells that support neurones (glia). There are several types, depending on the cell involved, such as astrocytoma (involving astrocytes) and oligodendroglioma (involving oligodendrocytes). Some grow very quickly. Treatment involves a combination of surgery, radiation therapy and chemotherapy, depending on the location and the size.

Good Manufacturing Practice (GMP)

Good Manufacturing Practice is a system of quality control that ensures products are consistently produced and controlled according to quality standards appropriate for their intended use.

Growth factors

Growth factors are molecules secreted by the cells that promote or inhibit cellular growth (or mitosis) or affect cellular differentiation.

Hazard ratio

A hazard ratio is a measure of how often a particular event happens in one group compared with another group over time. A hazard ratio of 1 means that there is no difference in survival between the two groups. A hazard ratio of >1 means that survival was better in one group.

Helper T-cells

Helper T-cells (CD4+ T-cells) are critical regulators of adaptive immunity, acting as coordinators that activate B-cells to secrete antibodies, guide macrophages to destroy pathogens and trigger cytotoxic T-cells to kill infected cells. They function via cytokines (chemicals) following activation by antigen-presenting cells (APCs) in lymphoid tissues.

Homeostasis

Homeostasis refers to the body's ability to keep its internal environment relatively stable, despite significant changes that may be occurring externally or within specific parts of the body. Many of the body’s processes operate within normal ranges to function. Exceeding these ranges could be life-threatening, such as with temperature and blood pressure.

Hormones

Hormones are chemical messengers produced by the endocrine organs of the body that travel through the bloodstream to regulate physiological processes.

Hyperexcitable

Hyperexcitation describes a state in which the neurones become overly active, similar to an engine revving too high. In this state, neurones fire signals more frequently and easily than normal, disrupting neurla communication patterns in the brain and body.

Hyperextension

Hyperextension is the bending of a joint backward beyond its normal range.

Hyperglycaemia

Hyperglycaemia is when there is too much glucose (sugar) in blood. A blood glucose level above 15 mmol/L is considered hyperglycaemia. In Type 2 diabetes, hyperglycaemia can happen for a range of reasons, including:

Not enough or missed insulin or diabetes medication
Taking some medicines, such as steroid medicines
Unsuitable food choices
Drinking a lot of alcohol
The amount of physical activity done.

The opposite situation is hypoglycaemia, which is when the glucose level is low, which may lead to fainting, unconsciousness or coma if insulin is not administed.

Hyperkeratosis

Hyperkeratosis refers to the increased thickness of the outer, protective layer (stratum corneum) of the epidermis of skin. Hyperkeratosis is due to chronic physical or chemical damage, such as friction or the use of aggressive soaps, but can also be caused by chronic inflammation or a side-effect of some drugs, including chemotherapy.

Hypermetabolic state

Hypermetabolism is when one's metabolism is extremely fast. This means calories (or energy) are burned fast. It can cause weight loss, fatigue, anaemia and other symptoms. It typically occurs when the body is trying to repair or heal itself. Eating disorder recovery, burns and sepsis are common causes of a hypermetabolic state.

Hypersensitivity

Hypersensitivity is an immune response characterised by mechanisms that cause significant tissue damage or physiological dysfunction, whether directed against pathogens,

harmless environmental antigens or self-antigens, that is reproducible upon re-exposure to the antigen.

Hypertensive episode

A hypertensive episode is a sudden, severe increase in blood pressure of 180/120 mm Hg or greater. A hypertensive crisis is a medical emergency. It can lead to a heart attack, stroke or other life-threatening health problems. A hypertensive episode is also referred to as a hypertensive crisis.

Hyperthermia

Hyperthermia is a medical term that means that the internal body temperature is higher than normal, which is dangerous as it can lead to heat stroke, which is characterised by confusion, seizures and coma.

The opposite of hyperthermia is hypothermia, when body temperature drops too low. This is equally dangerous as one can become unconscious and stop breathing.

Hypertrophy

Hypertrophy can lead to a relative increase in the volume of a tissue or organ and contributes to the overall growth of an organism. It is often used in relation to skeletal and cardiac muscle.

The opposite is atrophy, when muscle wastes if not used. Without innervation from motor neurones following SCI, skeletal muscles will atrophy.

Hypodermis

The hypodermis is the innermost layer of skin found below the dermis. It contains fat for insulation, protection and as a source of energy.

Hypoexcitable

Hypoexcitability describes a state in which nerve cells are less responsive or active than normal, requiring more stimulation to fire.

Hypothalamus

The hypothalamus is a small, almond-sized region of the brain located below the thalamus. It serves as the primary link between the nervous and endocrine systems, maintaining bodily homeostasis by regulating vital functions like hunger, thirst, body temperature, sleep-wake cycles and hormone release from the pituitary gland

Hypothermia

Hypothermia is when the body temperature is below normal. This too can be medically dangerous as it can lead to confusion, drowsiness, slow breathing and coma.

The opposite is hyperthermia, when the body temperature rises too high, leading to confusion, delirium and coma.

Hypoventilation

Hypoventilation is a serious condition in which breathing is shallow or slow, causing dangerous carbon dioxide build-up and low blood oxygen. Common causes include obesity, opioid or sedative misuse and neurological or muscle disorders. Symptoms include extreme fatigue, morning headaches and daytime sleepiness. Diagnosis involves sleep studies and blood gas tests, with treatments focused on assisted breathing (CPAP/BiPAP) and lifestyle changes.

Hypoxia

Hypoxia is a condition in which the body or a region of the body is deprived of an adequate oxygen supply at the tissue level.

Idiopathic

Idiopathic relates to or denotes any disease or condition that arises spontaneously or for which the cause is unknown.

Ikigai

Ikigai is a Japanese concept of an individual's definition of the meaning of their life. Ikigai can be about having a sense of purpose in life, as well as being a source of motivation.

IL-1RA (Interleukin-1 receptor antagonist)

IL-1RA (Interleukin-1 receptor antagonist) is a naturally occurring protein that acts as an anti-inflammatory agent by blocking the activity of the pro-inflammatory cytokines IL-1alpha and IL-1beta. It binds to membrane-bound IL-1 receptors without triggering a signal, thereby preventing inflammation.

Immuno-inflammatory shock

Immuno-inflammatory shock is often seen in conditions such as sepsis or severe systemic inflammatory response syndrome (SIRS), which is a life-threatening cascade that occurs when inflammatory chemicals (cytokines) damage tissues, causing blood vessels to leak and dangerously low blood pressure (shock, organ failure and potential death). Triggers for this cascade are often infections, severe trauma and major surgery.

Immunofluorescence

Immunofluorescence is a technique that uses fluorescent-labelled antibodies to detect and visualise specific molecules (antigens) in cells and tissues.

Immunomodulation

Immunomodulation is a process in which the host immune response is altered to a desired level. Parasites are capable of modulating the response of the host immune system to allow them to establish themselves.

Incomplete spinal cord injury

An incomplete SCI only partially severs the spinal cord, allowing some signals to pass through the level of injury. The individual might still retain some function and feeling below the site of the injury, whereas someone with a complete SCI would not have any feeling or function because the link between the nervous system and the brain is completely severed.

Indirect calorimetry

Indirect calorimetry is a non-invasive method of measuring energy expenditure using oxygen consumption and carbon dioxide production.

Inhibitory synaptic input

Inhibitory synaptic input suppresses neurone excitability, preventing action potential generation by moving the membrane potential away from threshold. This mechanism controls excitation spread, balances network activity and allows for precise neural coding.

Injury-induced immune depression syndrome (IDS)

SCI-induced immune depression syndrome is a severe, rapid decline in immune function following acute SCI, causing high susceptibility to infections (pneumonia, sepsis) and increased mortality.

Innate immunity

Innate immunity is the protective defence mechanism against antigens (foreign particles) that is present when we are born. Macrophages (big eaters or phagocytes) and neutrophils are part of innate immunity.

Insomnia

Insomnia is the inability to sleep. It is debilitating for the individual as sleep serves to recharge the brain and the body.

Interneurone

Interneurones are special neurones found in the spinal cord that connect two neurones. They commonly form an important part of the reflex arc by connecting a sensory neurone with a motor neurone in the grey matter of the spinal cord.

Intersectionality

Intersectionality is the complex distributions of social, economic, cultural and ecological forces that shape the identity of individuals and groups, such that unique individuals are produced.

Intrathecal baclofen pump (ITB)

An intrathecal baclofen (ITB) pump is a surgically implanted device that delivers baclofen, a muscle relaxant medication, directly into the spinal fluid to treat severe spasticity and dystonia. It is generally used in individuals living with cerebral palsy, multiple sclerosis or SCI. A small, hockey puck-sized pump is placed under the skin of the abdomen, connected to a catheter that delivers the medication directly to the intrathecal space surrounding the spinal cord.

Ionic imbalance

An ionic imbalance is a change in the normal amount of minerals in the body or within cells. Examples of minerals include sodium, potassium, calcium, magnesium, chloride and phosphate.

Ischaemia

Ischaemia is a condition characterised by reduced or restricted blood flow to tissues or organs. This causes a shortage of oxygen and nutrients, which are necessary for cellular metabolism. Ischaemia is often caused by artery blockages, plaque build-up or blood clots. Tissue damage and dysfunction usually follow. Common examples include myocardial (heart) and cerebral (brain) ischaemia. Tissues cannot function without oxygen.

Langerhans cells

Langerhans cells are specialised dendritic cells (immune cells) found in the epidermis, the top layer of skin, and the underlying dermis. These cells recognise foreign pathogens, process antigens and migrate to lymph nodes to activate T-cells (T-lymphocytes).

Leptin

Leptin is a protein hormone predominantly made by adipocytes (cells of adipose tissue). Its primary role is likely to regulate long-term energy balance.

Lived and living experience (LLE)

Lived and living experiences (LLEs) are the first-hand stories that individuals share about their experiences of life events that offer unique insights that cannot be captured through external observation or theory.

Locked-in syndrome

"Locked-in persons are quadriplegic and lack articulate speech but have normal visual perception and bodily sensations, as well as consciousness and cognitive functions. They are able to make decisions and understand their consequences; they can consciously assume responsibility, be held accountable for their own actions, and perform acts of legal and civic import, such as expressing treatment preferences, entering into contracts, owning property, or voting. For that, however, they need human or technological assistance to transmit their views, wishes, and decisions." (Vidal, 2025)

Low-density lipoproteins (LDLs)

Low-density lipoproteins (LDLs) are lipoprotein particles that transport cholesterol in the blood. LDL cholesterol or "bad" cholesterol carries cholesterol to tissues, where high levels cause plaque build-up in arteries, increasing the risk of heart disease and stroke.

Lower motor neurones (LMNs)

Lower motor neurones (LMNs) are motor neurones of the peripheral nervous system (PNS) that originate in the brainstem and spinal cord and directly innervate skeletal muscles, acting as the "final common pathway" for all voluntary movement. They transmit signals from upper motor neurones (UMNs) to muscles, using acetylcholine (a neurotransmitter) to trigger contractions.

Macronutrients

Macronutrients are nutrients the body needs in large quantities. The three main macronutrients are carbohydrates, proteins and fats.

Macrophages

Macrophages are cells that engulf (phagocytose) foreign particles, often referred to as antigens, in the body. The macrophages process the engulfed particles and then present to other immune cells to mount an immune response.

Magnetic Resonance Imaging (MRI)

Magnetic resonance imaging (MRI) is a medical imaging technique used in radiology to generate pictures of the anatomy and the physiological processes inside the body.

Mast cells

Mast cells are a type of tissue-resident white blood cell (WBC) that serve as immune guards to protect the body from invaders and toxins. Located in tissues surrounding blood vessels, nerves and mucosal surfaces, they mature in tissues and contain granules packed with mediators like histamine, which they release during allergic reactions or to fight infections

Matched case-control study

A matched case-control study in one in which an affected individual is matched with an unaffected individual for gender and age.

Meninges

The meninges comprise the three protective layers of tissue that cover the brain and spinal cord. From the inside out, they are the pia mater, arachnoid mater and the dura mater.

Mesenchymal stromal cells

Mesenchymal stromal cells are embryonic cells that have the potential to become different types of cells in the body.

Meta-analysis

Meta-analysis is the examination of data from several independent studies of the same subject to determine overall trends.

Metanoia

Metanoia is a change in one's way of life resulting from penitence or spiritual conversion.

Micronutrients

Micronutrients are vitamins, such as Vitamin C, and minerals, such as iron, zinc, and calcium, that are needed in small amounts for vital functions, including growth, development and disease prevention. As the body cannot produce them, we rely on our diet to provide them.

Mindful eating

Mindful eating is the practice of paying full, non-judgmental attention to the sensory experience of food, in terms of taste, smell, texture and appearance while eating, rather than consuming mindlessly. It involves listening to internal hunger and satiety cues to reduce overeating, improve digestion and foster a healthier relationship with food.

Mindful plating

Mindful plating is the intentional, artistic arrangement of food on a dish to foster appreciation, encourage slower consumption and enhance the overall dining experience. Mealtimes become sensory, meditative and nourishing rituals. Prompting engagement with the food's colours, textures and aromas leads to healthier portion sizes and better digestion

Mindfulness- and acceptance-based interventions (MABIs)

Mindfulness- and acceptance-based interventions (MABIs) comprise methods that emphasise present-moment awareness, non-judgment and values-based living. They operate by teaching individuals to cope with stressful thoughts, emotions and physical sensations.

Moral injury

Moral injury is the damage done to one's conscience or moral compass when that person perpetrates, witnesses, or fails to prevent acts that transgress one's own moral beliefs, values or ethical codes of conduct. In the context of military service, particularly regarding the experience of war, *moral injury* refers to the lasting emotional, psychological, social, behavioural and spiritual impacts of actions that violate a service member's core moral values and behavioural expectations of self or others (Moral Injury Project).

Motor

Motor, as an adjective, relates to movement. Motor neurones, for example, carry signals from the brain or spinal cord to muscles. The opposite would be sensory, in which stimuli are picked up and sent to the brain or spinal cord.

Motor cortex

The motor cortex is a region in the brain's frontal lobe (precentral gyrus) responsible for planning, controlling and executing voluntary skeletal muscle movements. It comprises the primary motor cortex, pre-motor cortex and supplementary motor area, which together coordinate complex, skilled actions.

Motor evoked potential (MEP)

Motor evoked potentials (MEPs) are electrical signals generated by stimulating the motor cortex of the brain and recording the responses in nerves or muscles. They are used to assess the motor pathways leading from the brain to the muscles.

Motor nerves

Motor nerves carry signals to your muscles or glands to help you move and function.

Motor pathway

A motor pathway comprises a functional bundle of nerve axons that descend through the spinal cord, from the brain or brainstem. These pathways are involved in controlling the activity of lower motor neurones (LMNs).

Motor signals

Motor signals are primarily transmitted by motor neurones, which are specialised nerve cells responsible for conveying messages from the central nervous system (CNS) to muscles and glands.

Mucosal tissue

Mucosal tissue is an epithelium and its underlying supportive connective tissue that lines the internal surfaces of the body, including digestive, respiratory and reproductive tracts. We might then talk about the gastrointestinal or respiratory mucosa.

Multidisciplinary team

A multidisciplinary team comprises a range of health professionals, such as doctors, nurses, physiotherapists, pharmacists, and other team members, such as support workers. Different teams will oversee different phases of a person's healthcare journey. In the case of SCIs, this team will change, depending on need. In the case of a traumatic spinal cord injury (TSCI), as soon as someone arrives in the Emergency Department, there will be a specialist multidisciplinary team to deal with the urgent, acute injury. During surgery, there will be another multidisciplinary team, and so on.

Muscle fibre

A muscle fibre is another name for a muscle cell.

Muscle reflex

A muscle reflex is an involuntary, nearly instantaneous movement of a muscle in response to a stimulus, mediated by a reflex arc without conscious brain input.

Muscle spindles

Muscle spindles are specialised sensory receptors in skeletal muscles that detect changes in muscle length and contribute to proprioception, playing a crucial role in motor control and reflexes.

National Disability Insurance Scheme (NDIS)

In Australia, the NDIS provides funding to eligible people with disability so that they gain greater independence, have access to programs to develop new skills, are supported to study and find employment, receive quality healthcare, become volunteers in their com-

munity and spend more time with family and friends. All of these lead to an improved quality of life.

Nationally Determined Contributions (NDCs)

Nationally Determined Contributions (NDCs) are at the heart of the 2015 Paris Agreement and the achievement of its long-term climate goals. NDCs represent each country's efforts to reduce national emissions and adapt to the impacts of climate change. Countries report regularly on their NDCs. https://unfccc.int/process-and-meetings/the-paris-agreement/nationally-determined-contributions-ndcs

Natural killer (NK) cells

Natural killer (NK) cells are cytotoxic lymphocytes of the innate immune system, which act as a rapid, first-line defence against virally infected cells and tumours without prior sensitisation (exposure) to antigens, such as viruses.

Nature prescribing

Nature prescribing involves a health professional giving patients a recommendation to spend time in nature. It may also encompass a written prescription, verbal counselling or a referral to another provider. Nature prescribing may include prescribing nature-based activities that enhance physical activity and improve social connection, well-being and mental health. Nature therapy is sometimes referred to as ecotherapy, forest bathing or forest therapy.

Nerve bridges

Nerve bridges are three-dimensional cellular constructs for neurological applications. In this context, the ‘nerve bridge’ is a term used by the inventor team at the Clem Jones Centre to describe a novel, award-winning technology for creating scaffold-free 3D cellular structures.

Neurodivergent (ND)

Neurodivergent is a non-medical term that describes people whose brains develop and work differently. This means the person has different strengths, but they struggle in some areas compared with people whose brains work more typically. While some individuals who are ND have medical conditions, this is not always the case.

Neurogenic bladder

Neurogenic bladder is a condition in which the nerves controlling the bladder are damaged, leading to problems with urine storage and release. Causes include multiple sclerosis (MS), spina bifida, SCI, stroke and diabetes.

Neurogenic bowel

Neurogenic bowel is the loss of normal bowel function caused by a nerve problem. Many different and unrelated conditions can cause neurogenic bowel disorder. A SCI or a nerve disease, such as Parkinson's disease, multiple sclerosis (MS) or diabetes, may damage the nerves that help control the lower part of the colon (large intestine). This is the part of the body that sends solid waste out of the body. This condition gets in the way of the normal ability to store and get rid of faecal waste. It often causes constipation and stool leakage.

Neurogenic bowel dysfunction (NBD)

Neuogenic bowel dysfunction (NBD) is a condition in which damage or disease of the nervous system disrupts normal bowel function, leading to problems such as constipation, faecal incontinence or irregular bowel movements. This is common with SCI.

Neurogenic heterotropic ossification (NHO)

Neurogenic heterotopic ossification (NHO) is the abnormal formation of mature lamellar bone in soft tissues, commonly complicating central nervous system injuries, such as traumatic brain (5-20% incidence) or SCI (20-30% incidence).

Neurogenic obesity

Neurogenic obesity is obesity that develops as a result of nervous system dysfunction, commonly seen after SCI.

Neurogenic shock

Neurogenic shock is a life-threatening, distributive shock caused by sudden loss of sympathetic nervous system signals following severe central nervous system (CNS) damage, typically SCI at or above T6.

Neuroinflammation

Neurogenic inflammation is an inflammatory response in the brain or spinal cord. Neuroinflammation is caused by the brain's immune system (microglia and astrocytes) reacting to pathogens, injuries or chronic stressors, leading to immune cell activation and the release of inflammatory chemicals. Key causes include traumatic brain injury (TBI), infections (viruses or bacteria), chronic stress, poor diet, neurodegenerative diseases and systemic peripheral inflammation.

Neuromuscular electrical stimulation (NMES)

Neuromuscular electrical stimulation (NMES) is a therapy that uses small, controlled electrical pulses to activate the nerves that make muscles contract. These gentle signals mimic the messages normally sent from the brain and spinal cord, helping the muscle work even when a person cannot move it fully on their own. NMES is commonly used to strengthen

weak muscles, maintain muscle shape and prevent muscle wasting and improve circulation, supporting recovery after injury or illness affecting movement. It is a well-established therapy used by physiotherapists and rehabilitation teams.

Neuromuscular junction

A neuromuscular junction is where a motor neurone meets a muscle fibre to trigger muscle contraction when a chemical signal (neurotransmitter) is converted to an electrical impulse.

Neurone

A neurone is a nerve cell. It sends and receives electrical signals in the body. The neurone is the functional cell of the nervous system.

Neuropathic pain

Neuropathic pain is chronic, often severe pain caused by damaged or dysfunctional nerves, typically described as burning, shooting or electric shock-like sensations. It can also arise from underlying conditions, such as diabetes, shingles or trauma. Treatments focus on reducing symptoms through anti-convulsants, anti-depressants and topical agents, in combination with physical exercise.

Neurophysiology

Neurophysiology is a branch of physiology and neuroscience that studies the functional properties of the nervous system, focusing on the electrochemical, biochemical and electrical activity of neurones, glia (supporting cells) and neural networks.

Neurostimulation

Neurostimulation is a therapeutic technology that uses targeted electrical currents or magnetic fields to modulate, activate or inhibit nerve activity in the central nervous system (CNS) or peripheral nervous system (PNS). It is used to treat chronic pain and neurological disorders, such as epilepsy and SCI.

Neurotransmitter

A neurotransmitter is a chemical messenger that transmits signals between nerve cells (neurones) or between nerve cells and muscle cells and glands.

Neurotrophic factors

Neurotrophic is derived from the term ‘neurotrophin’, which refers to proteins that support the development, maintenance, repair and survival of neurones.

Neutrophils

Neutrophils are the most abundant type of white blood cell (WBC), acting as the primary, first-line immune defence against bacterial and fungal infections. They are produced in the bone marrow and are capable of phagocytosis.

Nociceptive pain

Nociceptive pain is the most common type of pain, caused by tissue damage, such as cuts, burns and bruises. These injuries activate specialised nerve endings called nociceptors. This type of pain acts as a protective, acute warning system, signalling injury and is often described as aching, throbbing or sharp. It typically resolves as the tissue heals.

Nociplastic pain

Nociplastic pain is pain that is mechanistically different from nociceptive pain and neuropathic pain. It can be defined as chronic pain, leading to an altered nociceptive function, resulting in increased sensitivity as a result of the altered function of pain-related sensory pathways in the periphery and the central nervous system (CNS). It consists of multifactorial processes from different inputs, which could be either a bottom-up response to a peripheral nociceptive or neuropathic stimulus (known as central sensitisation) or a top-down CNS-driven response. encompassing pain from dysfunctional pain or medically unexplained somatic syndromes.

Conditions that fall under the umbrella of nociplastic pain include fibromyalgia, complex regional pain syndrome and other musculoskeletal pain, such as chronic low back pain and visceral pain disorders, such as irritable bowel syndrome (IBS) and bladder pain syndrome.

Nocturia

Nocturia is when you wake up more than once during the night because you have to pee. Causes can include drinking too much fluid, sleep disorders and bladder obstruction. Treatments for nocturia include restricting fluids and medications that reduce symptoms of overactive bladder.

Non-invasive ventilation

Non-invasive ventilation is a method of providing ventilatory support through a mask or helmet, avoiding intubation while improving gas exchange and reducing respiratory muscle workload.

Non-steroidal anti-inflammatories (NSAIDs)

Non-steroidal anti-inflammatory drugs (NSAIDs) are a class of medications that reduce pain, fever and inflammation by blocking COX enzymes and decreasing prostaglandin production. Commonly used for arthritis, headaches and menstrual pain, they include ibuprofen (Nurofen), naproxen and aspirin. While effective, they can cause serious side-effects,

particularly gastrointestinal bleeding and increased cardiovascular risk. They should always be used under the direction of a health professional who can prescribe.

Non-traumatic spinal cord injury (NTSCI)

A non-traumatic SCI injury (NTSCI) is an injury to the spinal cord caused by disease, such as a tumour or degeneration.

Oedema

Oedema is swelling caused by excess fluid accumulating in the tissues, often seen in the feet, ankles and legs.

Olfactory

Olfactory is an adjective describing our sense of smell. The noun is olfaction.

Olfactory ensheathing cell (OEC)

Olfactory ensheathing cells (OECs), also known as olfactory ensheathing glia or olfactory ensheathing glial cells, are a type of macroglia (radial glia) found in the nervous system. They are also known as olfactory Schwann cells, because they ensheath the non-myelinated axons of olfactory neurones in a similar way to how Schwann cells ensheath non-myelinated peripheral neurones. They also share the property of assisting axonal regeneration.

Oligodendrocyte

An oligodendrocyte is a type of glial cell that forms the myelin sheath around the neurones of the brain and spinal cord in the central nervous system (CNS).

Osteoporosis

Osteoporosis causes bones to become weak and brittle so that a fall or even mild stresses, such as bending over or coughing, can cause a break. Osteoporosis-related breaks most commonly occur in the hip, wrist or spine.

Oxidative stress

Oxidative stress is the imbalance between harmful molecules (free radicals) and protective molecules (antioxidants) in the body that leads to cell and DNA damage.

Paired associative stimulation (PAS)

Paired associative stimulation (PAS) is slow-rate repetitive low-frequency median nerve stimulation combined with transcranial magnetic stimulation (TMS) over the contralateral motor cortex.

Parasympathetic nervous system

The parasympathetic nervous system works opposite to the sympathetic nervous system in that it is the ‘rest and digest’ part of the autonomic nervous system (ANS). The sympathetic NS is the 'fight or flight' part of the ANS.

Participatory action research (PAR)

Participatory action research (PAR) is an approach to research rather than a research method that seeks to situate power within the research process with those who are most affected by a program. The intention is that the participant is an equal partner with the researcher.

Penile vibratory stimulation (PVS)

Penile vibratory stimulation (PVS) is an effective, safe and first-line, non-invasive method for inducing ejaculation in men with SCI, particularly those with injuries at T10 or above.

Peptide YY

Peptide YY is a 36-amino-acid hormone released by endocrine L-cells in the distal small intestine and colon in response to food intake. It serves as a key satiety signal, reducing appetite and inhibiting food intake.

Percutaneous Endoscopic Gastronomy (PEG) feeding

PEG is a method of long-term enteral nutrition in which a feeding tube is inserted directly into the stomach through the abdominal wall using endoscopic guidance. PEG feeding is used when oral intake is inadequate or unsafe, such as in patients with neurological impairment, dysphagia or prolonged reduced consciousness, while maintaining a functioning gastrointestinal tract.

Perineum

The perineum is the anatomical region located between the anus and the genitals, specifically the vulva in females and the scrotum in males.

Periodontitis

Periodontitis is a severe gum infection that damages soft tissues and destroys the bone supporting teeth.

Peripheral nerves

Peripheral nerves are a vast network of nerves outside the brain and spinal cord (central nervous system, CNS) that act as an electrical communication system, sending signals between the brain, spinal cord and the rest of the body. They control voluntary muscles,

relay sensory information and regulate involuntary functions, such as digestion and heart rate.

Peripheral nervous system (PNS)

The peripheral nervous system comprises all parts of the nervous system outside of the central nervous system (CNS: brain and spinal cord).

Personal health record (PHR)

A personal health record (PHR) is a secure, comprehensive, and often electronic collection of an individual's medical information, managed by the patient rather than a provider. A carer could also manage the PHR.

Phagocytic cells

Phagocytic cells are specialised white blood cells (WBCs), primarily macrophages, neutrophils, monocytes and dendritic cells. They protect the body by engulfing and destroying foreign particles, bacteria and dead cellular debris. They are critical to innate immunity, using phagocytosis to engulf and digest the pathogen.

Phagocytosis

Phagocytosis literally means ‘big eating’. Cells that are phagocytic (phagocytes) often engulf damaged tissue and cellular components after injury or bacteria during an infection.

Pharmacology

Pharmacology is the science that examines the effects of drugs on biological systems, from understanding the molecular level interactions by which drugs work, to their effects on people.

Phase II-A (of a clinical trial)

Phase II-A of a clinical trial is a pilot study, usually enrolling a small group of patients with the targeted disease to evaluate preliminary efficacy, safety and optimal dosing. It serves as a ‘proof of concept’ to determine if a drug or procedure works before advancing to larger, more rigorous Phase II-B (pivotal) trials

Phrenic nerve

The phrenic nerve is a nerve that originates in the neck from the C3, C4 and C5 spinal nerves and controls the diaphragm, the primary muscle of respiration.

Physical medicine and rehabilitation (PM&R)

Physical medicine and rehabilitation (PM&R) is also called physiatry. It is a medical specialty in the US that involves restoring function to a person who has been disabled as a result of

a disease, disorder or injury. Physiatry provides integrated, multidisciplinary care aimed at recovery of the whole person by addressing the individual's physical, emotional, medical, vocational and social needs. A doctor who specialises in physical medicine and rehabilitation is called a physiatrist.

Physiology

Physiology is the study of the normal physical and chemical functions of living organisms, their cells, organs and systems and how they interact to maintain life.

Pineal gland

The pineal gland is a tiny endocrine gland in the middle of the brain that helps regulate the body's circadian rhythm by secreting the hormone, melatonin.

Planetary boundaries

Planetary boundaries are defined for the nine biophysical systems and processes that regulate the functioning of life support systems on Earth and ultimately the stability and resilience of the Earth system. Nine planetary boundaries have been described, and include climate change, freshwater change, land system change and novel entities, which are the thousands of chemicals we have made. As of June 2025, the safe operating spaces of six planetary boundaries had been crossed, meaning that the health of the planet is considere as 'code red'. For more information, the Potsdam Institute has a Q&A page.

Pluripotent stem cells

Pluripotent cells are cells that have the potential to differentiate into different types of cells.

Pneumococcal disease

Pneumococcal disease is caused by *Streptococcus pneumoniae*, a bacterium found in most of our noses. Under some circumstances, it can cause disease. Severe invasive diseases include meningitis, pneumonia and bacteraemia, while non-invasive diseases include otitis media.

In children, it can cause ear or sinus infections. The bacterium can sometimes enter the lungs, bloodstream or the coverings of the brain, leading to serious diseases, such as pneumonia, sepsis or meningitis. Children with SCI, especially those with weak respiratory muscles, impaired cough or a reduced ability to clear mucus, are at higher risk of pneumococcal chest infections. Vaccination is an important preventive measure. The Australian Department of Health, Disability and Ageing has a webpage for pneumococcal disease immunisation.

Polyp

A polyp is a small growth on the inner lining of the bowel. Most polyps are harmless, but some can slowly develop into bowel cancer if they are not found and removed. Polyp detection simply means identifying these growths during the procedure. The higher the polyp detection rate, the better the colonoscopy is at identifying early changes that could become serious.

Polypharmacy

Polypharmacy is a term used when people are using five or more medicines at the same time. It is common in older people because they often have several chronic conditions that need several medicines. About two-thirds of Australians aged 75 years+ take five or more medicines.

Post-injury bone marrow failure syndrome

Post-injury bone marrow failure syndrome is an acquired, often transient, suppression of blood cell production following severe trauma or injury.

Post-sepsis syndrome (PSS)

Post-sepsis syndrome (PSS) affects up to 50% of sepsis survivors. It can affect sepsis survivors of any age, including children. Recent research confirms that many sepsis survivors experience new or worsened physical, cognitive and psychological problems for months to years after hospital discharge, whether they were treated in an intensive care unit (ICU) or in a general ward or unit.

Post-traumatic stress disorder (PTSD)

Post-traumatic stress disorder (PTSD) is a mental health condition caused by an extremely stressful or terrifying event, either being part of it or witnessing it. Symptoms may include flashbacks, nightmares, severe anxiety and uncontrollable thoughts about the event. Most people who go through traumatic events may experience difficulty adjusting and coping in the short-term. Over time and by taking good care of themselves, they usually improve. If, however, the symptoms get worse, last for months or years and affect their ability to function daily, they may have PTSD, which needs to be treated.

Practitioner

A practitioner is someone who practices something, especially an occupation, profession or technique. For the purposes of this resource, it is appropriate to talk about 'a health practitioner'. Mostly, however, you will read about health professionals, which is the term we have used. The title of this Chapter is 'health professions education' as the training and education involve professional and ethical considerations, not just the ability to complete a psychomotor skill.

Preventative care

Preventative care is aimed at preventing diseases by detecting health concerns early. Some examples of preventative care include routine health screening, vaccinations and health education.

Primary injury

The primary injury is the injury that is sustained directly. In SCI, this relates to the acute stage. Also see secondary injury, which relates to subsequent pathology arising from the impacts of the primary injury.

Primary sleep disorders

Primary sleep disorders can be divided into parasomnias and dyssomnias. *Parasomnia* sleep disorders cause abnormal activities during sleep, such as sleep terrors or sleepwalking. *Dyssomnia* sleep disorders involve trouble falling asleep or staying asleep. Perhaps the most well-known dyssomnia is obstructive sleep apnoea (OSA).

Progenitor cells

Progenitor cells are cells with the ability to differentiate into a specific type of mature cell. They are similar to stem cells, but with a limited capacity for proliferation and a more specific scope for differentiation.

Proprioception

Proprioception is the body's sense of its own position, movement and force in space.

Prucalopride

Prucalopride is used to treat chronic idiopathic (unknown cause) constipation (CIC). It works by increasing peristalsis (contractions) in the colon, leading to an increase in bowel movements.

Psychogenic

Psychogenic describes conditions that originate from psychological factors, not from physical disease. These conditions are often related to anxiety or stress and can mimic biological illnesses.

Pulmonary embolism

Pulmonary embolism is when a blood clot (embolus) blocks and stops blood flow to an artery in the lung. In most cases, the blood clot starts in a deep vein in the leg and travels to the lung. Rarely, the clot forms in a vein in another part of the body. When a blood clot forms in one or more of the deep veins of the body, it is called a deep vein thrombosis (DVT).

Purulent

Purulent describes an exudate that is a thick, white, yellow or brown fluid. It is a sign of infection and needs medical attention.

Pyelonephritis

Pylonephritis is a kidney infection in which bacteria move from the bladder up to one or both kidneys during a urinary tract infection (UTI), causing inflammation, pain, fever, chills, etc. This can lead to permanent kidney damage if not treated with antibiotics.

Pyramidal tract

The pyramidal tract (cortico-spinal and cortico-bulbar tracts) is the primary descending motor pathway for voluntary movement, originating from Layer V pyramidal cells in the cerebral cortex. It carries signals for skilled motor function, passing through the medullary pyramids and decussating (crossing) in the medulla, with 85-90% forming the lateral cortico-spinal tract.

Qualitative research

Qualitative research is the opposite of quantitative research. Qualitative research gathers non-numerical data to understand attitudes, beliefs and motivations of people. Interviews, focus groups and direct observation are the most common forms of collecting data.

Quality of Life

Quality of Life (QoL) is defined by the World Health Organization (WHO) and researchers as an individual's overall well-being and satisfaction with life, encompassing physical health, psychological state, social connections and personal circumstances. It is a subjective measure of how people perceive their lives in relation to their culture, goals and values, generally assessed across health, environmental and social domains.

Randomised control trial (RCT)

A randomised control trial is a scientific experiment that randomly assigns participants to an experimental group or a control group to test the effectiveness of an intervention.

Receptors

Receptors are specialised structures or proteins on the surface of cells that respond to specific signals, such as neurotransmitters, chemicals, temperature changes or pH changes. When specific receptors on a cell are stimulated, a biochemical cascade is triggered in the cell.

Red-flag symptoms

Red-flag symptoms refer to specific clinical indicators that suggest the presence of serious underlying conditions requiring immediate medical attention, such as severe pain following trauma, sudden weight loss or new-onset neurological deficits.

Reflex

A refelx is an automatic, involuntary (no conscious thought) and rapid response to a stimulus, such as the rapid withdrawal of the arm when a finger is burnt.

Reflex circuit or arc

A reflex or circuit is the pathway that a nerve impulse follows during a reflex action. It typically involves the following components:

Stimulus: Any change in the environment that triggers a response, such as touching a hot surface.
Receptor: Specialised sensory neurones that detect the stimulus and convert it into a nerve impulse.
Sensory neurone: Carries the impulse from the receptor to the spinal cord or brain.
Interneurone: A neurone that connects sensory and motor neurones within the spinal cord, allowing for processing and integration of the signal.
Motor neurone: Transmits the impulse from the spinal cord to the effector (muscle or gland).

Reflexive

A type of physical movement performed without one's conscious control.

Resilience

The American Psychological Association describes resilience as: *The process and outcome of successfully adapting to difficult or challenging life experiences, especially through mental, emotional, and behavioural flexibility and adjustment to external and internal demands. A number of factors contribute to how well people adapt to adversities, predominant among them (a) the ways in which individuals view and engage with the world, (b) the availability and quality of social resources, and (c) specific coping strategies.*

Psychological research demonstrates that the resources and skills associated with more positive adaptation (i.e. greater resilience) can be cultivated and practiced. Also called psychological resilience.

Respiratory syncytial virus (RSV)

Respiratory syncytial virus (RSV) is a virus that causes chest infections. It usually looks like a cold, but children with SCI can have trouble clearing mucus, making the infection more serious and harder to manage.

Resting metabolic rate (RMR)

The resting metabolic rate (RMR) is the energy (calories) your body burns at complete rest to maintain vital functions like breathing, circulation and organ function, making up the largest part of your daily calorie burn, typically measured under awake, post-absorption and thermoneutral conditions and which is influenced by factors such as body size and composition, age and sex.

Restless legs syndrome (RLS)

Restless legs syndrome (RLS) is characterised by the compelling urge to move the legs, particularly when in bed and trying to sleep. The cause is unknown, but it is thought to involve a malfunction of the nervous system. It follows then that the RLS is relatively frequent in people with SCI. It responds to dopaminergic treatment.

Restorative justice

Restorative justice is a system that focuses on the rehabilitation of wrongdoers by facilitating communication between the parties and encouraging wrongdoers to accept responsibility for their wrongdoing. It contrasts with more traditional punitive theories of justice, which focus instead on deprivation of liberty, financial penalties and other punitive measures as a way of signalling the unacceptable nature of the wrongdoer's acts or conduct.

Retrospective case control longitudinal cohort study

A retrospective case control longitudinal study is a complex study design that blends several features. It looks back (retrospective) at existing data for a defined group (cohort) sharing a past exposure, comparing those who have the disease, condition or injury (cases) with individuals who are unaffected (controls). The outcomes are analysed over time (longitudinal) to see how risk factors correlate with long-term effects. This means diseases, conditions or injuries can be studied using existing data rather than collecting new information.

Sarcopaenia

Sarcopaeia is the age-related progressive loss of muscle mass and strength. The main symptom of the condition is muscle weakness. Sarcopenia is a type of muscle atrophy primarily caused by the natural aging process. There is accumulating evidence that being physically inactive and eating an unhealthy diet can contribute to the disease.

Saturated fat

A saturated fat is a type of dietary fat found predominantly in animal food sources and in palm and coconut oils.

Schwann cells

Schwan cells are cells that form the myelin sheath of neurones in the peripheral nervous system (PNS).

SCI-Induced Immune Deficiency Syndrome (SCI-IDS)

Patients recovering from severe SCI can develop an immune deficiency that puts them at risk of developing life-threatening infections. Monocytes, which are white blood cells (WBCs) required to fight bacterial infections, are deactivated shortly after SCI. There are also reductions in the blood level of antibodies and immunoglobulins, which are part of the body's 'learned' or adaptive immunity.

Scoliosis

Scoliosis is when the spine curves sideways because the muscles that normally hold it straight are not getting the right signals after SCI. Over time, this imbalance can make the spine bend or twist, especially while a child is still growing.

Seborrheic dermatitis

Seborrheic dermatitis is a common, chronic inflammatory skin condition causing itchy, scaly, red or greasy patches, often appearing on the scalp (dandruff), sides of the nose, eyebrows and ears, as well as the chest.

Second-order neurones

Second-order neurones receive the information from the preceding neurones and deliver it to the third-order neurones.

Secondary injury

A secondary injury refers to the progressive damage and dysfunction to nervous tissue beginning minutes after initial trauma that lasts for weeks or months. It is caused by many factors, including inflammation, ischemia (lack of blood and oxygen), oedema (fluid build-up) and excitotoxicity (too much excitatory neurotransmitter release).

Secondary symptoms

Secondary symptoms are the medical issues that arise indirectly due to an underlying primary health condition, injury or disease, rather than directly from the condition, injury or disease.

Sensorimotor loop

A sensorimotor loop is the continuous, closed-loop process in which sensory input from the environment or body, such as touch and proprioception, guides motor output (movement), which in turn alters future sensory input. This cycle, involving brain-to-spinal path-

ways, is essential for motor control, skill learning and adapting to and interacting with the environment.

Sensory

Sensory relates to feeling or detecting changes, such as touch, pain or temperature and sending the information to the brain.

Sensory nerves

Sensory nerves carry signals to the brain to about sensations of touch, taste, smell and sight.

Sensory neurones

Sensory neurones, also known as afferent neurones, convert a specific type of stimulus, via their receptors, into action potentials or graded receptor potentials.

Sensory pathway

A sensory pathway comprises a functional bundle of axons (nerve fibres) that ascend the spinal cord, relaying sensory information (e.g. touch, pain, pressure, temperature) from the body towards the brain.

Sensory receptors

Sensory receptors are specialised nerve endings or cells that act as transducers, which convert external and internal environmental stimuli, such as light, sound, heat or chemicals into electrical signals (action potentials).

Sensory signals

Sensory signals are electrical impulses (action potentials) generated when specialised sensory receptors convert environmental stimuli, such as light, sound, touch or heat, into neural data. These signals travel via nerves to the brain for interpretation, enabling perception of both the external environment and internal body states.

Skinfold measurement

Skinfold measurement estimates body fat % by measuring subcutaneous fat thickness at specific body sites, such as the triceps and thigh, using specialised callipers. It is non-invasive and cost-effective and can be used to track body composition changes, typically on the right side of the body, with a 3.5-5% margin of error.

Smooth muscle

Smooth muscle lines many of the tracts of the body, including the gastrointestinal, respiratory and urinary tracts and larger blood vessels. This muscle regulates the diameter of

the lumen of blood vessels to regulate blood pressure. The uterus also comprises smooth muscle.

Social determinants of health

The social determinants of health are broadly defined as the conditions in which people are born, grow, live, work and age and people's access to power, money and resources. They have a powerful influence on health inequities. These are the unfair and avoidable differences in health status seen within and between countries. Addressing the social determinants of health equity is fundamental for improving health and reducing long-standing inequities in health. It requires action by all parts of government, the private sector and civil society. The WHO is committed to supporting countries in developing and implementing key policies that address the social determinants of health to reduce health inequities.

Socialisation

Socialisation is the process by which, throughout life, individuals learn and internalise the socio-cultural elements of their environment, integrate them into their personality and adapt to the social context in which they live (Serpa, 2019).

Somatic

The term, somatic, refers to the physical body, distinct from the mind, spirit or soul, often focusing on the body's structure, movement and sensations.

Somatic reflexes

Somatic reflexes are motor responses to specific stimuli, primarily involving skeletal muscles and mediated by the somatic nervous system (voluntary movements).

Somato-Sensory Evoked Potential (SSEP)

The Somato-Sensory Evoked Potential (SSEP) test measures the electrical activity of the nervous system in response to sensory stimuli to assess the integrity of the somatosensory pathway from the body to the brain.

Spasticity

Spasticity is a disruption in muscle movement patterns that causes certain muscles to contract all at once when you try to move or even at rest. The muscles remain contracted and resist being stretched. It interferes with movement and can also affect speech and gait (walk).

Spasticity is usually caused by damage to nerve pathways in the brain or spinal cord that control movement and stretch reflexes. Spasticity may occur due to several conditions, including:

Spinal cord injury
Multiple sclerosis (MS)
Cerebral palsy
Stroke

Spatial methods

Spatial techniques are used for processing and analysing spatial data, which includes data with a spatial frame of reference such as points, lines and polygons. These methods are essential for managing relationships among spatial objects and optimising queries within spatial databases.

Specialist Disability Accommodation (SDA)

Specialist Disability Accommodation (SDA) is NDIS-funded housing for people with extreme functional impairment or very high support needs.

Spina bifida

Spina bifida literally means 'split spine'. It is a birth defect in which the spinal cord and vertebrae do not close completely during early pregnancy, leaving the nerves exposed and potentially damaged.

Spinal circuits

Spinal circuits are local neural networks in the spinal cord that coordinate movement, process sensory feedback and manage involuntary reflexes. They function independently of the brain for rapid responses, such as reflexes (via reflex arcs) and locomotion, modulated by descending signals from higher brain centres.

Spinal Cord Independence Measure (SCIM)

Spinal Cord Independend Measure (SCIM) is a tool used to assess the functional abilities of people living with SCI.

Spinal cord stimulation (SCS)

In spinal cord stimulation (SCS), a spinal cord stimulator, a small, implantable medical device designed to manage chronic pain, particularly when other treatments like medications, physical therapy or injections have failed. The device sends mild electrical pulses to the spinal cord, which interfere with the transmission of pain signals to the brain. Patients often describe the sensation as a gentle tingling or buzzing that masks the pain, similar to a 'white noise' effect for the nervous system

Spinal cord stimulator

A spinal cord stimulator is an implanted medical device that sends low-voltage electricity to the spinal cord to mask pain signals. It is often used for chronic back or leg pain, includ-

ing cases where previous surgery failed. There is often a trial period followed by potential permanent implantation. While it can significantly reduce pain and reliance on medication, it does carry risks of infection, hardware failure and further surgeries.

Spinal motor neurones

Spinal motor neurones are specialised lower motor neurones (LMNs) located in the ventral horn of the spinal cord that directly control muscle contraction for movement. They receive signals from upper motor neurones (UMNs), acting as the final common pathway for transmitting commands to skeletal muscles. Acetylcholine is the main neurotransmitter.

Spinal shock

Spinal shock is a temporary loss of all sensation, muscle tone and reflex activity below the level of a severe, acute SCI. This lasts from days to several weeks and is characterised by flaccid paralysis. It commonly causes autonomic dysfunction, including hypotension and bladder and/or bowel dysfunction, until the reflexes return. This signals the end of the 'shock'.

Spino-thalamic tract

The spino-thalamic tract is an ascending sensory pathway in the spinal cord that transmits pain, temperature and crude touch to the thalamus and ultimately the somatosensory cortex.

Stockholm syndrome

Stockholm syndrome is a psychological response to being held captive. People with Stockholm syndrome form a psychological connection with their captors and begin sympathising with them.

Stoma

A stoma is a small opening in the abdomen used to remove faeces or urine into a collection bag. A stoma might be required if part of the bowel is removed. Most stomas are temporary, but some may be permanent. Stomal therapy nurses help a person learn to manage their stoma.

Stretch reflexes

Stretch reflexes are automatic muscle contractions in response to stretching, crucial for maintaining posture and protecting muscles from injury.

Suicidal ideation (SI)

Suicidal ideation refers to thoughts, ruminations or planning regarding ending one's own life, ranging from fleeting, passive desires to die to detailed, active plans. It is a symptom

of severe distress, not a diagnosis. It is considered a significant risk factor for suicide that requires immediate professional attention

Superior mesenteric artery (SMA) syndrome

Superior mesenteric artery (SMA) syndrome is a rare condition that involves compression of the third portion of the duodenum, which is the upper part of the small intestine just past the stomach. This condition occurs when the third part of the duodenum is compressed between two arteries, the main artery of the body called the abdominal aorta (AA) and one of its branches called the SMA. Compression of the SMA against the AA can prevent duodenal contents from draining into the jejunum (upper part of the small intestine), leading to inadequate nutrition, weight loss and malnutrition. Pain from the compression can be debilitating, causing 'food fear' and aggravating the condition.

Supraspinal control

Supraspinal control refers to the function of the neural structures in the brain found above the spinal cord. This system governs several bodily functions, from conscious movements to involuntary processes. It forms the highest level of control within the nervous system, orchestrating complex operations. The brain's influence ensures coordinated and adaptable responses throughout the body.

Sweat glands

Sweat glands are exocrine glands in the skin that produce sweat for cooling through evaporation.

Sympathetic nervous system

The sympathetic nervous system is the body's internal alarm system, a key part of the autonomic nervous system (ANS) that is responsible for the 'fight-or-flight' response that prepares one for action during stress, danger or intense physical activity by increasing heart rate, blood pressure, alertness and diverting energy to muscles.

Synapse

A synapse is a transmission site from the pre-synaptic to the post-synaptic neurone. The structures found on either side of the synapse vary depending on the type of synapse. Some synapses are on muscle while others are on glandular tissue.

Syrinx and tethered cord

A syrinx is a fluid-filled cavity (cyst) within the spinal cord, while a tethered cord is a condition in which the spinal cord is abnormally attached to the spinal canal, often causing a syrinx. Tethered cord causes tension on the cord, leading to progressive injury and often requires surgical untethering (surgically) to resolve the associated syrinx

Systematic review

A systematic review is a rigorous research method that finds, evaluates and synthesizes all available evidence on a specific, clearly defined question.

T-lymphocytes (T-cells)

T-lymphocytes (T-cells) are white blood cells (WBCs) of the adaptive (acquired) immune system that identify and destroy infected or cancerous cells. They develop in the thymus, differentiate into specialised types to target specific threats and establish long-term immune memory. Key functions include direct killing of abnormal cells, helper cell activation and immune regulation.

Tethered cord syndrome

A tethered spinal cord occurs when the spinal cord abnormally attaches to the spinal canal. As children grow, a tethered spinal cord stretches and restricts blood flow. This may lead to numbness, muscle weakness or issues with motor control.

Thalamus

The thalamus is a structure of the brain that processes and transmits sensory (except for smell) and motor information from the body to the cerebral cortex. It is often described as the brain's relay station as much of the information that reaches the cerebral cortex first stops in the thalamus before being sent to its destination.

Third-order neurones

Third-order neurones transmit the sensory signals from the thalamus to the ipsilateral primary sensory cortex of the brain. They ascend from the ventral posterolateral nucleus of the thalamus, travel through the internal capsule and terminate at the sensory cortex of the brain.

Tinea pedis

Tinea is a common skin or nail infection caused by a fungus. The tinea fungus grows well in warm, moist places, such as the feet, groin and scalp. Types of tinea include:

Nail infection (onychomycosis): Toes or fingernails
Athlete's foot (tinea pedis): Skin on feet
Ringworm of the scalp (tinea capitis)
Ringworm of the body (tinea corporis)
Jock itch (tinea cruris): A rash in the moist, warm areas of the groin

Tipping points

In climate science, a tipping point is a critical threshold that, when crossed, leads to large, accelerating and often irreversible changes in the climate system

Tracheostomy

A tracheostomy is a small surgical opening that is made through the front of the neck into the windpipe or trachea.

Trans fat

A trans fat is a type of unsaturated fatty acid that increases bad cholesterol.

Transanal irrigation

Transanal irrigation is a medical procedure in which water is used to evacuate faeces from the rectum and descending colon via the anus.

Transcranial magnetic stimulation (TMS)

Transcranial magnetic stimulation (TMS) is a non-invasive brain stimulation technique using magnetic pulses from a coil on the scalp to activate nerve cells. rTMR is repeated TMS.

Transcutaneous Electrical Stimulation (TENS)

Transcutaneous electrical stimulation (TENS) uses low-voltage electrical currents to relieve pain. A TENS unit is a small device that delivers current to or near nerves to block or change the perception of pain. Health providers use TENS to treat a range of conditions, including osteoarthritis, tendinitis and fibromyalgia.

Transverse myelitis

Transverse myelitis is a rare inflammatory condition that affects both sides of part of the spinal cord. The inflammation can damage the myelin sheath, which is the protective covering nerve axons (fibres), disrupting communication between the spinal cord and the rest of the body. The symptoms include weakness, sensory changes and bladder and bowel dysfunction.

Traumatic spinal cord injury (TSCI)

Traumatic spinal cord injury (TSCI) to the spinal cord is caused by trauma such as falls, motor vehicle and sports accidents.

Tumour necrosis factor-α (TNF-α)

Tumour necrosis factor-alpha (TNF-α) is a potent, pro-inflammatory cytokine primarily produced by activated macrophages, T-lymphocytes and natural killer (NK) cells. It acts as a critical regulator of immune responses, driving inflammation in autoimmune diseases and has dual roles in cancer by promoting tumour proliferation and metastasis

Type 2 diabetes (T2D)

Type 2 diabetes is a metabolic condition in which the body does not produce enough insulin or is resistant to the insulin produced, leading to high blood glucose. T2D is a risk factor for damage to many organs and organ systems, such as the cardiovascular system.

Ultra-processed foods (UPFs)

The term 'ultra-processed foods' (UPFs) originated from the Nova food classification system, which defines food in four categories, ranging from least to most processed:

Unprocessed or minimally processed foods like fruit, vegetables, milk or fish.
Processed culinary ingredients, such as salt, sugar, olive oil and butter.
Processed foods, such as jam, pickles or canned fruit.
Ultra-processed foods, such as energy drinks, instant oatmeal, sliced bread and hot dogs.

Further information can be found on the Johns Hopkins Bloomberg School of Public Health website.

Upper motor neurones (UMNs)

Upper motor neurones (UMNs) are specialised motor neurones originating in the cerebral cortex and brainstem that initiate and modulate voluntary movement by sending signals down to lower motor neurones. They represent the primary motor system, controlling muscle activity and maintaining muscle tone. UMN damage causes spasticity, weakness and hyperreflexia.

Urinary sphincters

Urethral sphincters are specialised muscles in the urinary system that control urine flow from the bladder. These structures maintain continence, allowing urine storage until release. They coordinate storage and controlled elimination of urine. The urethra carries urine from the bladder out of the body. The urethral sphincters are positioned along its length. In both males and females, two distinct types of sphincters regulate urine flow: The internal urethral sphincter and the external urethral sphincter. The internal urethral sphincter is located at the bladder neck, where the bladder connects to the urethra. This sphincter is composed of smooth muscle, meaning its function is involuntary. It operates automatically to prevent urine leakage, particularly during bladder filling. Further down the urethra, the external urethral sphincter is found. This sphincter comprises skeletal muscle, allowing for voluntary control over its actions. Individuals can consciously tighten this muscle to hold urine, even when the bladder feels full, providing an added layer of continence.

Urinary tract infection (UTI)

A urinary tract infection (UTI) UTI occurs when bacteria enter the urinary tract through the urethra and begin to spread in the bladder. The urinary system is designed to keep out

bacteria. Sometimes the defences fail. When that happens, bacteria may take hold and grow into a full-blown infection in the urinary tract. Risk factors are numerous, including constipation and incomplete bladder emptying as well as blockages of the urinary tract.

Utilitarian

Utilitarian means it has been designed to be useful or practical.

Venous thromboembolism (VTE)

Venous thromboembolism (VTE) is a serious, preventable condition comprising deep vein thrombosis (DVT), a blood clot in deep veins, typically legs and pulmonary embolism (PE), where that clot travels to the lungs. Symptoms include leg pain, swelling or redness (DVT) and chest pain or shortness of breath

Ventilator-associated pneumonia (VAP) care bundle

Ventilator-associated pneumonia (VAP) develops in a patient after about 48 hours of intubation with an endotracheal or tracheostomy tube. A VAP care bundle prevents the development of VAP when a patient is intubated and ventilated. There are eight elements in the care bundle, such as suctioning of the endotracheal or tracheostomy tube, and the patient should be nursed in a greater than 30-degree reclining position. For more information: vap_care_bundle__final.pdf

Ventral root

Ventral roots, or anterior roots, are responsible for carrying motor commands away from the spinal cord to the muscles and glands. These roots contain efferent nerve fibres, which transmit signals from the central nervous system (CNS) to the body's effector organs, such as muscles and glands. While dorsal roots bring in information about our surroundings and internal state, ventral roots enable us to respond by controlling movement and glandular functions.

Vertebrae

The vertebrae are the bones that make up the spine or backbone. Singular is vertebra.

Vesicoureteric reflux (VUR)

Vesicoureteric reflux (VUR) is a condition in which urine flows backward from the bladder up into one or both ureters, and sometimes all the way to the kidneys, instead of staying in the bladder and emptying normally.

Virtual reality (VR)

Virtual reality (VR) is the use of computer modelling and simulation that enables a person to interact with an artificial three-dimensional (3-D) visual or other sensory environment

VO2 max

VO_2 max is the maximum rate of oxygen the body can consume and utilise during intense, incremental exercise, serving as an indicator of aerobic fitness, cardiovascular health and endurance.

Voluntary assisted dying (VAD)

Voluntary assisted dying (VAD) is the assistance provided by a health professional to a person with a terminal illness, disease or medical condition to end their life. 'Voluntary' means it is the person's voluntary choice. The person must have decision-making capacity to decide to access VAD. VAD includes:

Self-administration, in which the person takes the VAD medication themselves, and
Practitioner administration, in which the health professional administers the medication.

White blood cells (WBCs)

The cells in blood are divided into red blood cells (RBCs, also called erythrocytes) and white blood cells (WBCs). While RBCs carry oxygen and carbon dioxide around the body, WBCs are involved in immunity and protecting the body from pathogens, such as viruses, bacteria and fungi. WBCs include:

Monocytes, which become macrophages in the tissues (phagocytic cells that engulf antigens and process them) as part of the innate (present at birth) immune system
Neutrophils (also phagocytic, particularly of bacteria), eosinophils (deal with parasites, such as worms) and basophils
B- and T-lymphocytes, which are part of the adaptive (acquired) immune system.

White matter

White matter is the part of the brain or spinal cord consisting primarily of myelinated axons (fibres) that connect one part of the nervous system to other parts. The grey matter of the brain is where neuronal cell bodies (soma) are located.

Xerostomia

Xerostomia is the sensation when you don't have enough saliva (spit) as the salivary glands in your mouth are not producing saliva to lubricate your mouth and help keep it clean. Occasional dry mouth is normal, e.g. if you are dehydrated. Chronic dry mouth, i.e. when your mouth is dry all the time, could indicate an underlying health condition. It is more likely, however, that xerostomia is a side-effect of medications, including anti-histamines, decongestants and some anti-depressants.

Contributing Editors, Contributors and Reviewers

All chapters in this resource have been reviewed by at least one reviewer. In some instances, chapters have been reviewed by two or three reviewers, either with a lived experience of SCI or content expertise. All contributing editors reviewed at least one chapter. They also oversaw the final editing of each chapter, with assistance and guidance from the Bond Library team of Antoinette Cass, Emmy Peterson and Bronwyn Linthwaite.

Contributing Editors

Michelle McLean, PhD, MEd, Professor, Medical Education, Faculty for Health Sciences & Medicine, Bond University, Gold Coast, Queensland

After more than 35 years of experience in medical education on three continents, mainly involved in problem-based learning and teaching Histology, I have gone back to my ecology roots and now focus on Planetary Health, which has been integrated across the Bond University Medical Program. An area of my research was the importance of professional identity. As I gather information through researching existing literature and talking to people (and their family, friends, carers and support workers) with an SCI, I have come to appreciate the importance of 'identity' as value-based and motivating. It is what gets us up every day to do what we do, whether as an educator, carer, researcher, driver, support person or an advocate for better services or policies.

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My expertise includes management, education, quality assurance, research, policy, advocacy, and regulation across South Africa, New Zealand, and Australia. My work spans medicine, allied health, secondary and special needs education, vocational training, and higher education, giving me a uniquely integrated perspective on systems, people, and the structures that shape their experiences. My passion though lies in medical education, health regulation and, more recently, disaster management, along with advocating for people, including those with disabilities, and widening access to safe healthcare services through capacity development and empowerment. Throughout my career, I have worked to drive systemic change at strategic governance and policy levels with key decision makers, while also empowering individuals and their support networks to live their best lives.

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I am an Assistant Professor of Professionalism and Medical Education at Bond University, with nearly two decades of experience across health sciences, clinical physiotherapy, research and medical education. As a Registered Physiotherapist, I have supported individuals with complex conditions, including SCI, in hospital, community and in-home settings, with a strong focus on holistic, evidence-based and patient-centred care. My early work with the MacWheelers Rehabilitation Program (McMaster University, Canada), where I facilitated upper body training and biopsychosocial support for people living with an SCI, shaped my enduring commitment to patient advocacy and the integration of lived experience into health professional education. As an active member of Bond University's Collaboration for Research in Understanding Stigma in Healthcare (CRUSH), my work is grounded in equity, inclusion and respect for the whole person, with a collaborative, culturally responsive approach to both education and care.

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I am a clinical anatomy lecturer and educator with a background as a surgical trainee. I have been involved with teaching medical students for the last twenty years, both in the University environment and in the operating theatre. My research interests lie in integrating traditional anatomy teaching with newer multimodal technologies, such as augmented and virtual reality. I am currently involved as a surgical assistant in spinal surgery and research in the diagnosis and therapies for spinal discogenic pain.

Priya Iyer, PhD, MSc Nutr & Diet, MSc Food Sc & Nutr, BSc, Lecturer (Post doc B), Dietetics and Food Science | Accredited Practising Dietitian (APD) I Susan Wakil School of Nursing & Midwifery, Sydney Nursing School, Faculty of Medicine and Health, The University of Sydney, New South Wales

I am an experienced clinician and researcher with over 20 years in SCI and traumatic brain injury rehabilitation, most of which I have spent as a clinical lead at a major facility in New South Wales. One of my patients inspired me to explore the role of nutrition in rehabilitation and recovery, which ultimately led me to pursue a PhD. While working full-time, I completed my doctorate in 2022, focusing on the interplay between hospital food services, patient food choices, and cardiometabolic health in spinal rehabilitation. My research is driven by a desire to transform nutrition care through innovation, equity, and co-design with consumers and clinicians.

I want to shift the next generation of research to focus on improving health trajectories in people with spinal cord injuries, not just documenting the negative consequences of secondary conditions. One of my core goals is to move away from the 'one-size-fits-all' approach to nutrition care in spinal cord injury. I want to dismantle the persistent and unhelpful rhetoric around 'overeating and weight gain' in this community. Instead, I advocate for a more nuanced, per-

son-centred approach that respects individual needs and supports sustainable, empowering care.

Tanisha Jowsey, PhD, MA, BA (Hons), FANZAHPE, Associate Professor, Faculty for Health Sciences & Medicine, Bond University, Gold Coast, Queensland

I am a New Zealand-born social scientist and medical educator, now based in Queensland, Australia. I have a deep commitment to reporting and improving people's experiences of health and care, particularly within healthcare systems. My research explores how people navigate illness, care, and recovery, with a particular focus on the social and cultural dimensions of health. My research outputs have informed the World Health Organization and the National Institute for Health and Care Excellence (NICE) UK Guidelines. I have been involved in spinal cord research for several years. I am passionate about amplifying the voices of patients, clinicians and health professions students, translating research into meaningful and quality healthcare for communities and practitioners.

Thomas Titus, MBBS, MD, MRCP, D.Phil, FRACP, Senior Staff Specialist, Nephrology, Gold Coast University Hospital.

I would describe myself, first and foremost, as a doctor caring for patients in the real world, a teacher and a researcher. Caring for patients with spinal cord injury who, unfortunately, developed end-stage kidney failure needing dialysis, made me realise the difficulties they go through every day. Spinal cord injury is not just about paralysis or disability due to lack of movement, although this stands out. Changes are happening throughout the body. It was obvious that both patients and health professionals needed education about their specific needs. There are knowledge gaps. We realised that if we were able to collate a broad knowledge resource for people living with spinal cord injury, as a minimum, it would improve the quality of their lives. This resource is the outcome of that endeavour and the tireless effort of all the contributors. The hope is that it will also serve as a springboard for people to collaborate to create a Spinal Cord Injury Register, which will collate long-term health data for these individuals. This, in turn, can become a repository of knowledge which can open the door to better care, drive research and further improve the lives of people living with spinal cord injury.

Dinesh Palipana (OAM), MD, CertEM, GAICD, LLB, GradDipLP, Assistant Professor, Faculty for Health Sciences & Medicine, Bond University, Gold Coast, Queensland

I am a doctor, a lawyer, a disability advocate and a researcher. Born in Sri Lanka, my family moved to Australia during the civil war when I was 10. While studying medicine, a 2010 car accident left me with quadriplegia. I completed my medical studies and became the first quadriplegic medical intern in Queensland. I was the Queensland Australian of the Year for 2021, and, in 2022, I was listed as #33 on the Courier Mail's top 100 power list for Queensland's most influential in health and well-being. Currently, I work in the Emergency Department at the Gold Coast University Hospital, Queensland. I have flown a modified plane, parachuted from an aeroplane and climbed the Story Bridge in Brisbane. In 2024, I published an autobiography, *Stronger*.

Contributors

Denis Bartrum, MBBS(UQ), MSc(Cardiff), MMed(UQ), DRCOG, DTMH, Dip.Derm, FRACGP, FACTM, FACRRM-GEM, Cert Bioethics, JP(Q), OSIS.

I am a recently retired clinician with a broad background as a country obstetric GP, then later an emergency medicine consultant and retrieval specialist. I am currently an Adjunct Assistant Professor at Bond University. I have completed a two-year course of study with One Spirit Interfaith Seminary in the US and qualified as an ordained interfaith minister. I am a military veteran and minister to other veterans. I am currently a voluntary interfaith chaplain to Ipswich Hospice.

Wendy Bonython, PhD JD, BSc (Hons), GDLP, GCTE, Associate Dean, Learning and Teaching, Faculty of Law, Bond University, Gold Coast, Queensland

As a researcher and educator working across medicine, health sciences and law, my work focuses on areas of intersectionality and overlap, including human rights and tort (personal injury) law and regulation of health and medical services and technologies. I have a longstanding teaching and research interest in how illness and disability shape interactions between people and legal systems, particularly in terms of legal capacity and compensation. My professional work experience before joining academia full-time includes clinical research, health administration and governance, research ethics and public sector legal practice.

Belinda Craig, PhD, MProfPsyc, BPsySc(Hons), Assistant Professor, Bond University Medical Program, Gold Coast, Queensland

I am a researcher and educator working in medical education. Before this, I completed my undergraduate and postgraduate studies in psychology. My research interests include topics in the areas of emotion, well-being and person perception. I have been part of an Autism Research Group, as I have an interest in neurodiversity. I am also a member of the Rainbow community. I am interested in ways that we can improve the delivery of culturally safe, neuroaffirming care in health contexts.

Perry Cross (AM), Founding Director and CEO, Accessible Homes Australia, Executive President and Founder, Perry Cross Spinal Research Foundation, Gold Coast, Queensland

A C2 injury while playing rugby at 19 changed my life, leaving me with quadriplegia and needing to be ventilated. That moment ignited a lifelong mission, which was to help find a cure for paralysis and to make the world more inclusive, accessible, and empowering for people living with disability. I founded and sit as the Executive President of the Perry Cross Spinal Research Foundation to fast-track SCI research, support groundbreaking projects, and connect people with purpose. I also founded Accessible Homes Australia, where we are transforming the housing landscape by delivering Specialist Disability Accommodation (SDA) that supports independence, dignity and choice. Whether through advocacy, speaking, entrepreneurship or col-

laboration, I work to bring real change to people's lives and to create a future where paralysis is no longer permanent. Everyone has the opportunity to live without limits.

Sara Dalton, MSc (ExSc) PGCertTertT&L BPE ADSpSc CertCoachProf AEP, Student Support Academic, Bond Medical Program, Gold Coast, Australia

I am an academic in Medicine at Bond University, where I have specialised in medical education since 2007. As an Accredited Exercise Physiologist with over 40 years of experience in health, education, and exercise science, I bring clinical and educational expertise to capability development, curriculum design, and assessment. My teaching focuses on reflective practice, learning literacies, self-care, and communication skills such as motivational interviewing and person-centred communication. I work with students to develop personal behaviour change strategies and professional identity formation for their clinical careers. I am passionate about evidence-based practice and the role of exercise in health and well-being. My work integrates clinical exercise physiology with educational pedagogy to equip medical students with adaptive skills for supporting patients facing complex health challenges.

Dean Durman, Dip Technical Engineering, Information and Technology, counsellor, podcaster, and speaker, Gold Coast, Queensland

I am a seasoned technology professional with a strong background in designing and architecting solutions that help organisations achieve their strategic business objectives. I served as Manager, ANZ Presales Centre of Excellence at Dell Technologies, where leadership and innovation were central to driving customer success. In 2011, my life changed dramatically after an SCI caused by a motor vehicle accident. This experience shaped a new perspective and purpose. By 2024, my focus became men's mental health, pursuing formal studies in Counselling and launching a podcast dedicated to reaching individuals who find themselves in moments of loneliness and despair, offering encouragement, hope and a reminder that they are not alone. My journey reflects resilience, empathy and a commitment to making a positive impact, both in the technology space and in mental health advocacy.

Jacqueline Durman, Nat. Dip Radiography, Diagnostic Radiographer, Mammographer, Gold Coast, Queensland

Born in Durban, South Africa, I grew up in very challenging circumstances, learning to develop mental and emotional fortitude through hard work and overcoming adverse circumstances in life. After finishing school, I studied Diagnostic Radiography, later qualifying in Mammography. I am now studying Breast Ultrasound. I am the wife of Dean, a proud mom and a volunteer at our local church, where I often take young ladies under my wing to help them navigate life's challenges.

Halima Goss, PhD, MBBS, Grad Dip Mgt, B App Sci, Dip Teach, Academic Lead, Advanced Clinical Skills Rotation, MD Program, Bond University, Gold Coast, Queensland

I am a medical doctor, educator and Lead of the Advanced Clinical Skills Rotation of the Bond University Medical Doctorate Program. My involvement with the Spinal Cord Injury project

came about after a career trajectory from teaching in Human Movement studies through my career as a medical doctor in a range of locations. On a personal level, I bring the lived experience of being a family member and grateful aunt of a girl with Rett's syndrome who lived her life without movement, speech or the ability to swallow, but who enriched our lives fully with her smiles and eyes that were the window to her heart. I am dedicated to bridging medical practice with wellness practice and supporting others who are like-minded. I am grateful to be a part of an international family of practitioners transcending the boundaries of borders in order to practice and promote the scholarship of wellness as a means to elevating our humanity for enriching lives, environments and cultures irrespective of disability.

Adeline Green, PhD, DPhty, BAppSci (Exercise & Sport), Athlete Identification and Development Lead, Australian Institute of Sport, Gold Coast, Queensland

In my role as Athlete Identification and Development Lead at the Australian Institute of Sport, I work with Olympic and Paralympic sports to enhance athlete identification and development and performance pathways across Australia's high-performance sport system. An experienced physiotherapist, I bring a strong applied understanding of health and performance to my work. My research lies in understanding the factors that influence athlete pathways, particularly in para-sport and talent transfer contexts. I have previously worked with the Queensland Academy of Sport and Paralympics Australia to deliver initiatives that enhance participation opportunities through to high-performance in both para- and non-para-sport. I am passionate about implementing evidence-informed practices that support athlete development and optimising sport systems to facilitate greater opportunities for athlete success.

Shane Hearn, PhD, MPH, BAppSci, Associate Dean and Professor, First Nations Health, Bond University, Gold Coast, Queensland

I am a proud Whadjuk, Ballardong, Noongar man, who is a highly experienced leader in First Nations health, education and community engagement. I bring more than 25 years of expertise in designing, implementing and evaluating culturally safe programs, research initiatives and policy frameworks across health, education and not-for-profit sectors, with a focus on co-designed, inclusive approaches. I have led national-level campaigns, developed strategies for Aboriginal and Torres Strait Islander participation and successfully guided multi-sector collaborations to deliver measurable outcomes, including in terms of disability for First Nations communities.

Justin Keogh, PhD, Associate Professor, Faculty for Health Sciences & Medicine, Bond University, Gold Coast, Queensland

I have worked at Bond University since 2012 and am currently Head of Discipline, Exercise and Sport Science and the Faculty's Associate Dean of Research. I am an Accredited Sport Scientist with Exercise and Sport Science Australia (ASpSc2) and an accredited ASCA Strength and Conditioning Coach (Level II). I also worked part-time for Paralympic New Zealand for several years as the Paralympic Powerlifting Coach and travelled to multiple competitions, including the 2008 Paralympics in Beijing as head coach. Much of my exercise and sport science research and that of my higher degree research students, is industry-embedded. Recent and current

research projects have focused on developmental and elite sports, including Australian football, rugby league, swimming and triathlon, as well as improving the physical function and overall health and well-being of older Australians living in the community and residential aged care. As I strongly believe that physical and social activities should be accessible and available to all members of the community, I will continue to dedicate much of my work to further improving outcomes for groups that have found such access more challenging.

Megan Lee, PhD, Assistant Professor, School of Psychology, Faculty of Society and Design, Bond University, Gold Coast, Queensland

I specialise in Positive Psychology, focusing on human strengths, wellbeing and happiness. My research portfolio spans health promotion, lifestyle medicine and nutrition and mental health. My work is dedicated to understanding and improving mental health resilience, mindfulness and personal fulfilment, with a strong emphasis on translating research into practical, evidence-based strategies to promote mental wellness in everyday life.

Rhea Liang, BA(Ed), MBChB, MSurgEd, FRACS, FACS, FFSTEd, FRCSEng (Hon), FAcadME. Consultant Breast and General Surgeon, Medical Educator, Gold Coast Hospital and Health Service; Doctor of Medicine (MD) Curriculum Lead, Bond University.

I am a general and breast surgeon and medical educator with a passion for diversity, inclusion and belonging. My clinical and academic work focuses on equity in breast cancer care and surgical education, with a particular focus on problematising 'the way things have always been done'. My personal positionality is as a person of Chinese heritage who grew up in Aotearoa New Zealand and is now an Australian citizen, navigating the world through the additional lens of being autistic. My advocacy covers a broad range, including issues of gender, sexuality, race, disability, neurodiversity, structural inequity and unequal distribution of resources. I chaired the curriculum development group for the federally funded Better Culture project. I am also the Vice-Chair of the Education Subcommittee of the International Relations Committee of the American College of Surgeons and President-elect of the ANZ Chapter of the American College of Surgeons. I serve on the *British Journal of Surgery* Editorial Board. In recognition of my work over more than two decades, I was the first Australian woman to be conferred an honorary Fellowship of the Royal College of Surgeons in England in 2023.

Neelam Maheshwari, MBBS, MD-Gen. Pathology (India), FRCPath(UK), FRCPA-Microbiology/Virology (Australasia), M. Clinical Edu. Associate Professor & Clinical Microbiologist, Faculty for Health Sciences & Medicine, Bond University, Gold Coast University Hospital, Gold Coast, Queensland

I have international experience as a medical specialist, including in India, the United Kingdom, Saudi Arabia and Australia. I am passionate about global health with environmental sustainability (theatre surgical waste) and have a research interest in anti-microbial stewardship, emerging infections, interactive educational tools and setting up international electives in resource-restricted regions. I have publications in several peer-reviewed medical journals, including *Lancet* and book chapters in Emergency Medicine and Planetary Health. I serve on the editorial boards of two open-access medical journals and the organising committee for confer-

ences. I feed my soul through chanting, community dancing for ISKCON (International Society of Krishna Consciousness), gardening, cooking and painting. My spiritual upbringing empowers me to be a counsellor.

Richard Matthews, PhD, Associate Professor, Faculty of Medicine & Health Sciences, Bond University, Gold Coast, Queensland

I am a clinical and public health bioethicist with many years of teaching experience in philosophy, social justice, and medicine. I also worked clinically as a bioethicist in First Nations health at the Meno Ya Win Health Centre in Northwestern Ontario, as well as in several aged care and complex care facilities in the Thunder Bay, Ontario region. As a researcher, I focus on violence in healthcare. Planetary Health is an area where this focus is particularly important, especially given the emergence of ecocide as a legal and moral category and the growing recognition of the roles played by various forms of systemic violence in driving the triple planetary crisis. I have published a book, *The Absolute Violation: Why Torture must be Prohibited* (Montreal & Kingston: MQUP, 2008) and articles on bioethics and genocide of First Nations, conscientious provision of healthcare and related articles in medical ethics.

Sarah McGuigan, AEP, AES, Senior Teaching Fellow, Faculty for Health Sciences & Medicine, Bond University, Gold Coast, Queensland

I am an Accredited Exercise Physiologist with over seven years of experience working as the Team Lead in a specialised clinic that focuses on people with neurological and neuromuscular conditions, as well as physical disability. Through this role, I developed a deep commitment to empowering individuals, particularly those with an SCI, to reclaim their independence and improve their quality of life. My approach is grounded in the belief that there is always hope and potential for change, even the smallest change in muscular activation or sensation makes the biggest difference. Seeing the amazement in clients when they achieve a movement they thought was lost forever is the most rewarding feeling. I am inspired by the adaptability of the brain and nervous system and strongly advocate for early and active intervention to maximise recovery. My work is driven by the respect for my clients' journeys and a dedication to helping them become the best versions of themselves through movement, exercise and fun.

Treasure McGuire, PhD, B Pharm, B Sc (Pcol), Grad Dip Clin Hosp Pharm, GCHEd, FACP, FPS, FANZCAP (Edu, ObsGynae), Assistant Director of Pharmacy (Practice and Development), Mater Health, South Brisbane in a conjoint appointment as Associate Professor of Pharmacology, Faculty for Health Sciences & Medicine, Bond University, Gold Coast, Queensland and Associate Professor (Honorary), School of Pharmacy and Pharmaceutical Sciences, The University of Queensland

I am an experienced clinical pharmacist, pharmacologist, educator and researcher. I have a deep commitment to educating future prescribers to share medication decision-making with their patients, particularly in areas of uncertainty such as pain management, to improve safe and effective medication use. My research explores consumer help-seeking behaviours to understand what motivates people to seek health and medicines information, whether for themselves as the patient or for a significant other (client, family or friend). My research has

identified that a critical gap exists in understanding the dynamics of patient-based benefit-risk assessment of medicines in chronic conditions such as SCI during the disease journey. Only by understanding the medication attributes that are important to the patient and their loved ones can healthcare professionals support patients in medication decision-making.

Beth Mozolic-Staunton, PhD, MS OTR/L, Grad Dip Acad Pract, Associate Professor, Occupational Therapy, Faculty of Health Sciences & Medicine, Bond University, Gold Coast, Queensland

I am an Associate Professor in the Master of Occupational Therapy program at Bond University. I am an experienced occupational therapist with expertise across a broad range of practice settings, including paediatrics, rural health, aged care, rehabilitation, as well as school and community-based practice. My early clinical work focused on collaborating with individuals to live life to the fullest and engage meaningfully in outdoor leisure and recreational activities in the Rocky Mountains of Colorado. The connections made with clients, the community and our natural environment through skiing, biking, horse riding, camping and so much more were invaluable influences on my career. My research interests include health service delivery and health workforce development, health promotion and topics related to promoting occupational participation for individuals across the lifespan.

Susan Moloney, MBBS, FRACP, Honorary Adjunct Professor, Faculty of Health Sciences & Medicine, Bond University. Professor, Griffith University School of Medicine. Director of Paediatrics, Gold Coast University Hospital

I am a General Paediatrician and Pre-Eminent Staff Specialist with Queensland Health. I have been involved with numerous national and international paediatric organisations and am a previous President of the Paediatric Division and Board Member of the Royal Australasian College of Physicians. I am a Board member of Life Education Queensland and undertake volunteer work overseas for Operation SMILE.

Christian Moro, PhD, MBus, BSc, BEd, Associate Professor, Biomedical Sciences and Medicine, Faculty of Health Sciences & Medicine, Bond University, Gold Coast, Australia**.**

I am an experienced educator and researcher in the field of health professions education. As a teaching academic, I have developed and evaluated educational interventions, apps, games and software and have created a range of novel technological tools that enhance learning, participation and interaction across both university and clinical settings. As an active laboratory researcher, I work on projects exploring urinary structure and function, as well as cell regeneration and immunology.

Michelle Myburg, BOccThy, OT, Spinal Outreach Program, Queensland Health, Brisbane, Queensland

I am an OT with 22 years of experience, having worked across all services within the Queensland Spinal Cord Injuries Service (QSCIS), including the inpatient unit, Transitional Rehabilitation Program and Spinal Outreach Team and SCI research initiatives. In my current role with

the Spinal Outreach Team (SPOT), I deliver specialist-level knowledge, expertise and skills to people living with an SCI. I also work part-time in private practice, supporting individuals with a wide range of physical and neurological disabilities in the community. I am passionate about helping people with neurological conditions achieve their goals and reach their full potential in everyday life.

Bradley Ng, MBCHB, MHL, FRANZCP, FACLM, Consultant Psychiatrist, Private Practice and Interdisciplinary Persistent Pain Centre, Robina Campus, Gold Coast Hospital and Health Service.

I am a specialist psychiatrist trained in both New Zealand and Australia. I am currently in private practice on the Gold Coast, Queensland and Tweed Heads, New South Wales. I am the psychiatrist with the Interdisciplinary Persistent Pain Clinic, Gold Coast Hospital and Health Service. I have post-graduate qualifications in pain management and cognitive behavioural therapy and a Masters in Health Law from the University of Sydney. I am an editor with the journal *Psychiatry, Psychology and Law*.

Rachael Norman, MBChB (Otago University, NZ), RNZCGP, RACGP, BSc (Neuroscience), Assistant Professor, Bond University, Gold Coast

I am a New Zealand-trained GP, now practising in Queensland, Australia, and have been teaching clinical reasoning to third-year medical students at Bond University since 2021. My contributions relate to my short-term experiences as a junior doctor working at the Christchurch-based Burwood Hospital and Spinal Unit back in the mid-2000s. In particular, my lack of prior knowledge, which would have been invaluable to have learned before attending to some of the more challenging acute problems specific to spinal cord injury patients, before the era of the Internet and mobile phones. I had moved one hour south of Christchurch before the significant earthquakes in September 2011 and February 2012. The damage and human displacement affected the service and delivery of health care on much of the South Island.

Chithrani Palipana, MASRC, MIPA, Grad Cert Case Mgt, Principal Rehabilitation Counsellor (Disability/Vocational), Plan Manager NDIS

I am a Vocational Rehabilitation Counsellor, Plan Manager (NDIS) and Disability Advocate (pro bono) with professional experience in rehabilitation, case management and disability systems navigation. My professional practice is informed by lived experience as a full-time carer for my son, which provides a unique and critical perspective on person-centred service delivery and long-term disability support. My primary area of academic and professional interest is post-spinal cord injury care, with particular emphasis on adjustment to injury, vocational rehabilitation, continuity of care and optimisation of functional and psychosocial outcomes.

Andrew Rayfield, BSc (Hons), PhD (UQ), Research Development Manager, Clem Jones Centre for Neurobiology and Stem Cell Research, Griffith University, Gold Coast, Queensland, Australia

I am the Research Development Manager at Griffith University's Clem Jones Centre for Neurobiology and Stem Cell Research. A trained neuroscientist with a specialisation in molecular

biology and glial cells, my primary focus is translating preclinical research into tangible, high-impact outcomes. A key achievement has been leading the management and operationalisation of a human clinical trial for a novel cell therapy and intensive exercise rehabilitation program aimed at repairing the injured spinal cord ("Olfactory cell transplantation and intensive rehabilitation to repair chronic spinal cord injury (GUSIP03) clinical trial"). This has involved managing complex logistics over many years to make this Phase I clinical trial a reality in 2026. I have also played a significant role in fostering the Centre's growth through strategic development initiatives and guiding the development of intellectual property strategies. I have established strategic relationships with biotechnology industry leaders and have been key in establishing community outreach relationships through events such as laboratory tours for politicians, philanthropists and people with lived experience of SCI. The laboratory has had over 1000 visitors in the last eight years.

Ronak Reshamwala, MBBS, MMST, PhD; NIISQ Senior Research Fellow, translational and clinical research in the Spinal Injury Project at Clem Jones Centre for Neurobiology and Stem Cell Research, Institute for Biomedicine and Glycomics, Griffith University, Gold Coast, Queensland.

I am a medical doctor who is registered in India. I am also an experienced clinical-translational researcher with a strong focus on regenerative neurology and spinal cord injury repair. In my current capacity as Senior Research Fellow at the Clem Jones Centre for Neurobiology and Stem Cell at Griffith University, Australia, I lead the translational and clinical research arms of the Spinal Injury Project (SIP), including the neurosurgery research team.

I received my medical degree (MBBS) from Sardar Patel University, India, and a Master of Medical Science and Technology (MMST) from the Indian Institute of Technology, Kharagpur. I later completed my PhD at Griffith University, focusing on the transplantation of 3D cellular constructs into the injured spinal cord to promote structural and functional recovery. I am particularly passionate about bridging the gap between bench and bedside by developing clinically viable surgical techniques and behavioural assessment tools for spinal cord injury models. My work has contributed significantly to the recent launch of the world-first clinical trial testing the cellular nerve bridge transplantation therapy for spinal cord injury repair.

In 2024, I was awarded a three-year fellowship by the National Injury Insurance Scheme Queensland (NIISQ) to develop the next generation of our nerve bridge technology. This project aims to enhance the therapeutic potential of our spinal cord repair strategy and ensure it aligns with the expectations of both clinicians and the community. Beyond the lab, I am deeply committed to consumer and community engagement. I work closely with people living with spinal cord injury, clinicians, and support networks to co-design clinical applications and trial methodologies that are meaningful, ethical, and impactful.

Katrina Reynolds, DipHthSc(Pod), BSC(Pod), GCDiabEd, MHthSc(Ed), PhD, Associate Professor, Faculty of Medicine, Nursing, Midwifery & Health Sciences, The University of Notre Dame Australia, Sydney, New South Wales

I am a clinical podiatrist with over 34 years of experience across private and public practice in metropolitan, rural and regional settings. I have been an academic for 18 years, having worked

at several Australian universities. Key contributions to the profession include the development and delivery of the inaugural podiatry program at Central Queensland University, where I served as an Associate Professor in the School of Health Sciences. My PhD (Bond University) focused on preparedness for practice in podiatry.

I have also held senior higher education management roles, including my current position as an Associate Professor at the University of Notre Dame, leading Program Development, Quality and Assessment in the School of Health Sciences. As a qualitative researcher, I enjoy contributing to research and developing curricula that reflect real-world practice and draw on people's experiences to improve outcomes. Early in my career, providing home-visit care to an 18-year-old who became a quadriplegic following a rugby ruck injury, shaped my commitment to supporting people living with chronic conditions. Collaborating in multi-disciplinary teams to deliver optimal care remains central to my clinical practice and teaching. I am dedicated to highlighting the vital role podiatry plays in supporting people living with an SCI and other complex conditions affecting lower limb and foot function.

Chelsea Ribeiro, DPT, BSc (Active Health & Rehab), Sessional Teacher, Bond University, Physiotherapist for Paediatrics (APA Level 2), Gold Coast, Australia

I completed a Bachelor of Science at Simon Fraser University in my home country (Canada) prior to moving to Australia to study a Doctor of Physiotherapy at Bond University. Over my years of working in paediatric private practice, I took numerous courses to expand my knowledge in paediatrics and a variety of disabilities. I have a passion for supporting children and adolescents living with disability to achieve meaningful, lifelong outcomes. With a background in community private practice, I bring a holistic, family-centred approach to continuity of care across the rehabilitation journey. My career encompasses clinical practice, sessional teaching at Bond University, and community advocacy for enhanced access and inclusion in sport for young people with disabilities across the Gold Coast.

Shashikala Ramakrishna, PhD, MD (Anaesthesia), MBBS, Faculty for Medical and Health Sciences, University of Auckland, New Zealand

I am an anaesthesiologist and a medical researcher. I trained and worked as an anaesthetist in India. I am pursuing a fellowship in solid organ transplant and vascular anaesthesia in the USA. I earned a PhD in Medicine in 2025 from the University of Auckland. My research focused on spinal cord stimulation therapy for chronic pain of various aetiologies, including SCI and refractory angina pectoris. My research has laid the groundwork for establishing a spinal cord stimulation therapy registry in New Zealand. Also, it informs the regulatory framework for stimulator implantation and maintenance and provides a nuanced understanding of the long-term effectiveness of the therapy. My research interests include pain medicine, spinal cord stimulation, patient safety, and patient experiences. In addition to clinical and research pursuits, I am committed to medical education.

Elizabeth Thomas, MD, DPhil. Paediatrics Registrar, Queensland Health, Adjunct Associate Lecturer, University of Queensland.

I am a paediatric registrar and medical researcher. I completed my medical degree at Bond University in 2018. I then completed a DPhil (PhD) at the Centre for Evidence-Based Medicine, University of Oxford. I am passionate about health equity and improving the quality of care for children and their families.

Jacob Thorstensen, PhD, BExSc (Hons 1), Faculty of Health Sciences & Medicine, Bond University, Gold Coast, Queensland

I am a teaching and research academic within the Faculty of Health Sciences & Medicine at Bond University. I have a PhD (Griffith University, Gold Coast, Australia) and postdoctoral training (The University of Queensland, Brisbane, Australia) in neurophysiology. My research spans both discovery and clinical neuroscience, neuropharmacology, and exercise physiology. I am particularly interested in studying the neural control of movement in healthy and clinical populations (including spinal cord injury). In addition to research, I have taught anatomy, physiology, neuroscience and pharmacology across three leading Australian universities (Bond University, The University of Queensland, and Griffith University) to students enrolled in clinical and science programs. I am an Editorial Board Fellow at The Journal of Physiology and sit on the editorial board for the Journal of Applied Physiology.

Simone Van Groningen, MHML, BOccThy, Medical Student at Bond University, Gold Coast, Australia

A career in Occupational Therapy spanning more than 20 years has seen my involvement in public and private hospitals, tertiary education and private practice. This has facilitated a broad range of expertise in delivering healthcare to people with learning difficulties and behavioural problems, neurological, orthopaedic, cardiac, spinal cord injury, work readiness and employment rehabilitation. A sound state of health is fundamental for achieving a fulfilling life. Accessibility, health literacy and education are central tenets of this and precipitated my move to a career in Medicine.

Other contributors include:

Teresa Blair (First Nations Student Success & Wellbeing Officer at the Nyombil Centre, Bond University at the time of writing, **Daniel Boardman** (Perry, Cross' long-standing NDIS-registered support worker), **Genny Kohler** (Director, Clinical Operations Manager, Making Strides, Burleigh), **Dr Kieran Le Plastrier** (Gold Coast GP and Bond academic), **Jemma Matthews** (podiatrist servicing remote communities) and **Emma Simpson** (a former support worker, but now an occupational therapist).

Reviewers

Bruce Baer Arnold, JD, GCTE, PhD, Associate Professor (Law), University of Canberra, Canberra

I manage the undergraduate Law program at the University of Canberra. I also convene Priestley and elective units. I have been a member of high-level international health and data working parties. My research addresses questions about regulation, human rights, personhood and new technologies.

Jo Bishop, BSc (Hons), PhD, PGCertEd, FANZAHPE, Associate Professor and Head of Curriculum, Bond University Medical Program, Gold Coast

I am dedicated to enhancing student and staff well-being through evidence-informed curriculum design. My research centres on embedding wellbeing meaningfully within health professions education. I contributed to the *Medical Student Wellbeing – A Consensus Statement* for Australia and New Zealand and led the Learner Wellbeing chapter in *Understanding Medical Education: Evidence, Theory and Practice*. I am passionate about fostering supportive, connected learning environments that enable people to thrive. I am the deputy chair of the National Leadership Alliance, established in April 2023, which is dedicated to translating the Every Doctor Every Setting (EDES) Framework from theory into Action, with a mission to *Empower a Healthier Future for Doctors.*

Joseph Coyne, PhD, AEP. Senior Teaching Fellow, Faculty for Health Sciences & Medicine, Bond University, Gold Coast, Queensland

At the time of reviewing this article, I was a Senior Teaching Fellow at Bond University with a keen interest in research outputs on training load and international Olympic athlete performance, which was the subject of my PhD. Alongside academic work, I also work as the strength and conditioning coach for Bond University Swimming and Elite Sports Program and have over 15 years' experience working with professional and Olympic athletes, across several sports (including UFC, Chinese Athletics Association and Chinese Olympic Committee).

Kate Desneves, PhD, MHumNutr, GDip Dietetics, BSc, AdvAPD, Senior Clinician Victorian Spinal Cord Service, Nutrition & Dietetics Department, Austin Health, Clinical Associate Dietetics, Swinburne University of Technology, Melbourne, Victoria

I am the Research and Workforce Education lead in the Nutrition and Dietetics Department at Austin Health. I have also been working with individuals with spinal cord injury for >30 years. My research interests include energy requirements, body composition and pressure injury management in people with a SCI.

Connie Cai Ru Gan, PhD, MPH., Lecturer in Planetary Health, School of Medicine and Dentistry; Griffith Institute for Human and Environmental Resilience (GIHER), Gold Coast, Australia

Before moving into academia, I worked in hospitals supporting frontline healthcare workers responding to health emergencies while caring for both people and the environment. My work now brings me to coastal communities across the Indo-Pacific that face the greatest risks from climate change. I am fortunate to work alongside healthcare workers, community leaders, older people, those living with disabilities and many others navigating daily challenges. Time and again, I witness how climate disasters hit those already facing health issues and social dis-

advantages the hardest. I am on a humbling journey working *with* and being *led by* communities, learning from lived experiences and wisdom. I am a strong believer in creating spaces where everyone's voices matter in shaping climate solutions that are meaningful, practical, and grounded in care, equity, and respect for Country.

Adrienne Graham, Retired, but former Pastoral Carer, Princess Alexander Hospital, Brisbane, Queensland

Born and grew up in Wales with Greek heritage. Always one for adventure, I left the old country to move to Australia as an adult, travelling and living all over the country and working in various fields before settling in Queensland. I volunteered and then worked as a Pastoral Carer for the Anglican Church for 30 years at the Princess Alexandra Hospital (PAH) before an accident at home, which landed me in the PAH as a patient with a traumatic SCI. I spent 12 months under the care of Spinal Care Unit before returning to her partner, menagerie and island home. I returned to offer pastoral care at the PAH before retiring in 2024. I would like to believe that I am a living example of what can be achieved each day with an SCI.

Tamara Flynn, Dip Counselling, Manager Empowerment & Engagement, Empower Autism, Brisbane, Queensland

I am an experienced engagement specialist who, for the past 20 years, has focused on building community engagement capacity across Australia to empower communities to create sustainable change. My passion is to centre community ideas at the heart of decision-making processes and to ensure that safe and accessible engagement opportunities are available for everyone. During my time as Director, Community Engagement for the Disability Royal Commission and as a Director supporting the delivery of Australia's Disability Strategy, I had the opportunity to lead engagement processes that focused on translating diverse voices into practical, evidence-informed advice that supported and continues to support meaningful and lasting reform. I have very much appreciated the time I have been able to spend in the community, learning and driving change for and with people with an SCI, their families, supporters and care networks.

Sule Gunter, PhD (Med Physiol), MSc (Ex Physiol), BSc (Sport Sci), Assistant Professor, Bond Medical Program, Gold Coast, Queensland

I teach foundational sciences, including physiology, pathology and anatomy in the Bond Medical Program. I have a background in exercise physiology and a strong interest in health and nutrition. I have worked in sports medicine settings, supporting athletes during rehabilitation following sports-related injuries. I also completed a Master's degree in neuromuscular control and proprioception in long-distance athletes.

Peter Jones, MBBS, PhD, FRACP, DCH, GAICD, Professor of Paediatrics**,** Faculty of Health Sciences & Medicine, Bond University, Gold Coast, Queensland

I am a career clinical academic whose focus has been on the development of new and innovative clinical training opportunities for medical students. I established the University Depart-

ment of Rural Health and the Rural Clinical School for the University of Newcastle between 2002 and 2008. I was the program director of the Ochsner Program and Partnership for the University of Queensland and established the first transnational medical program in which USA citizens could complete the first two years of their medical program in Brisbane and the final two years in New Orleans and graduate with the option of practising in either Australia or the USA on graduation. I was Dean of Medicine from 2011 to 2018 at Bond University and developed the curriculum that has allowed direct school-leaver students to graduate with an MD in 4 years and 8 months. Since stepping down as Dean, I have led the development of international medical student placements in 'resource-poor' communities around the world on behalf of Bond University, for which the team received an Australian National Teaching Award for Global Citizenship and Internationalisation in 2019. In addition to my academic work, I practice as a consultant paediatrician at a private practice on the Gold Coast.

Linday Nott, My C5 Life content creator**,** Brisbane, Queensland

I sustained an SCI several years ago, so I now get around on four wheels instead of two legs! My injury has not stopped me from making the most out of this beautiful life. I call myself an explorer because I love travelling and adventures, which I have done for more than 30 years.

My journey began on the last day of Grade 12 at the age of 17 when I went for a celebratory swim at Southbank, Brisbane and broke my neck at C5. My world changed at this point. While in the hospital recovering from my injury, my family and I learnt a lot. Once discharged from the hospital, it was such a big learning curve for us.

Since my accident, I love sharing my tips and tricks. I am an advocate for disability awareness. My goal is to help people and their families who are in similar situations, as well as healthcare professionals. I am currently a member of the Princess Alexander Hospital (Brisbane) consumer reference group, a peer mentor and a guest lecturer for occupational therapy and exercise physiology students at the University of Queensland. I am also affiliated with the Perry Cross Spinal Research Foundation and Wings for Life World Run.

Charlotte Phelps, PhD, BBioSci (Hons), Assistant Professor, Foundation Sciences, Faculty of Health Sciences and Medicine, Bond University, Gold Coast, Queensland

I am an early-career academic in the Medical Program at Bond University. I teach across foundation science disciplines, including histology, physiology, pathology and planetary health. My research focuses on urinary bladder projects in the laboratory and health professions education, with a strong track record in publishing medical education research.

Cheryl Selvage, MEd *Counselling, USQ,* Grad Cert Mental Health, Monash; Certificate in Palliative Care for Chaplains, California; Bachelor of Theology, BCT; C. P. E. AL 2 Supervisor 2016; Cert Expressive Therapies, Rev'd Canon, Pastoral Care Co-ordinator, Princess Alexander Hospital, Brisbane, Queensland

I am currently employed as Head of Department, Pastoral Care, Princess Alexandra Hospital (PAH) and the Diocesan Hospital Ministry Manager for Anglicare, South Queensland. I have 30

years of experience in education, including at a tertiary level, which includes pastoral care, ministry, educational counselling and special needs education. My Ministry for the past 15 years at PAH has offered a daily learning of journeying with many trauma patients, including the privilege of those with an SCI. With a lifelong commitment to facilitating the growth of others, I am always eager to continue journeying with people as they experience and holistically interpret life and assist them in their spiritual learning.

Jonathan Tang, BPhty (Hons), MD, FRACGP, practising General Practitioner in Sydney, New South Wales

I am a researcher and clinician who has incomplete quadriplegia. I sustained a C5 SCI during elite gymnastic training when I was a medical student. After graduating in 2020, I completed my internship and residency at Royal Prince Alfred Hospital. I completed my fellowship training in General Practice in 2026. I am an advocate for inclusion and diversity in the health workforce. My research interests are in clinical trials and registries. In my spare time, I enjoy wheelchair racing, having competed in marathons in Australia and internationally.

Siobhan Tierney, B Int Global Stud, M. Human Rights, Director, *IncludeAbility*-Equality at Work

I am the current Director of *IncludeAbility* (Equality at Work), an Australian Human Rights Commission initiative focused on promoting equal opportunities and outcomes in employment for people with disability. Before this, I led a policy team at the Disability Royal Commission, where I developed findings and recommendations to address employment barriers faced by people with disability. With extensive experience in policy development and project management across government and non-profit sectors, I have a strong track record of creating better outcomes for people and communities.

Rani West, PhD, BExSS, Assistant Professor, First Nations Health, Faculty of Health Sciences and Medicine, Bond University, Gold Coast

Ngatha djirangang Birrbay (*I am a proud Biripi woman*), descendant of the Gathang-speaking people, early-career researcher, Adjunct Research Fellow with the Poche Centre for Indigenous Health at the University of Queensland and Assistant Professor of First Nations Health at Bond University. I am deeply committed to social justice and passionate about fostering collaborations and knowledge sharing that are led by, and responsive to, Community priorities. My work is grounded in ethical approaches that centre Aboriginal Ways of Knowing, Doing and Being, including strong advocacy and leadership in *Ngaanaguba* (*Indigenous Data Sovereignty, meaning belonging to/associated deeply with*) and Governance.

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