



Health Maintenance Tool

Module 1: Mental Health and Wellbeing

How to stay healthy and well with a spinal cord injury
A tool for consumers from consumers

A product of the SCI Wellness Project

A collaborative project between

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Royal Rehab
Empowering Independence



icare[™]
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DISCLAIMER

The strategies outlined in this module are provided for general information only. The module aims to help you work together with your doctor and health professional team to develop an effective self-management program, which best suits your living situation and maintains your health, independence, and quality of life. Clinical advice specific to your spinal cord injury, personal circumstances and lifestyle should be directed to the appropriate health professionals and services with the skills and expertise in managing people with spinal cord injury.

Foreword

The Health Maintenance Tool is a guide to help you understand and troubleshoot problems you may experience throughout your spinal cord injury journey.

Being a paraplegic for the last 34 years, I have learnt you can never have too many resources or information on hand to improve your knowledge and help you manage health issues associated with your spinal cord injury.

Health issues can pop up when least expected. The Health Maintenance Tool will prove to be an invaluable resource for you to find sound advice, take preventative measures and resolve issues related to your spinal cord injury as well as maintain your health and wellbeing.

– Tanya Fitch, Consumer with spinal cord injury

Spinal cord injury is associated with many challenges following injury. It is therefore important for people with spinal cord injury to self-manage their health-related needs and become the experts of their own care. People with spinal cord injury have complex health needs, not only following their spinal cord injury, but throughout their life. Here at icare we have been privileged to be involved in the development of the Health Maintenance Tool to empower people by providing guidance and recommendations for people to timely and proactively manage their spinal cord injury beyond the early days in the spinal injury unit.

The Health Maintenance Tool has been developed by people with spinal cord injury, GPs and expert clinicians to provide consistent evidence-based information to support proactive management of the health needs of people with spinal cord injury. It guides spinal cord injury-specific health maintenance in the following six areas: mental health, bladder, bowel, skin, pain and autonomic dysreflexia. The tool is easy to navigate and helps people understand common and potential issues, what's normal and what to look out for, lists recommended routine investigations, explains when to seek assistance and provides self-management tips.

Ultimately, we hope the Health Maintenance Tool empowers people with spinal cord injury to expertly and proactively manage their health needs leading to improved quality of life and health outcomes. I recommend this tool to those living with spinal cord injury and those who care and support them, their clinicians and their GPs.

– Suzanne Lulham, General Manager, Lifetime Schemes, icare NSW

Background

The Spinal Cord Injury Health Maintenance Tool

The Spinal Cord Injury Health Maintenance Tool (SCI-HMT) is a guide to help you understand and troubleshoot problems you may experience throughout your journey after your spinal cord injury. It is important for you to learn how to self-manage your health-related needs. Understanding your body, health and wellbeing and how to prevent potential health issues, will empower you to become an expert in your own care.

This tool has been developed by people with spinal cord injury, general practitioners and expert clinicians. The SCI-HMT provides evidence-based information, tips and tools to help you to proactively manage your health in six key areas – mental health, bladder, bowel, skin, pain and autonomic dysreflexia.

Behind the Spinal Cord Injury Health Maintenance Tool

The SCI-HMT is a product of the SCI Wellness Project*, based on the recommendation from a rural spinal cord injury clinic evaluation (2015) to develop a consumer-friendly Health Maintenance Tool supporting self-management. The content of the SCI-HMT was informed by up-to-date best-practice research and consumers' perceptions about their health. The tool is freely accessible to consumers with spinal cord injury, family members, carers and health professionals.

*The SCI Wellness Project consisted of two phases.

- Phase 1 (2018-2020) involved development of a pdf version (soft and hard copy) of the Health Maintenance Tool. The first phase was a collaborative project between the John Walsh Centre for Rehabilitation Research (The University of Sydney) and Royal Rehab, with financial support from Insurance and Care (icare) NSW.
- Phase 2 (2021-2023) involved development of a digital solution (website and a standalone app) of the Health Maintenance Tool. The second phase was a collaborative project between the John Walsh Centre for Rehabilitation Research (The University of Sydney), Royal Rehab and NSW Agency for Clinical Innovation, with financial support from Insurance and Care (icare) NSW.

“Well, I guess the number one motivation for taking care of my health is that I want to live a long life.”

– Consumer with spinal cord injury

Mental Health and Wellbeing

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Summary of findings

from the 2015 Rural Spinal Cord Injury Project

The project involved

681

people with spinal cord injury living in rural NSW



29%

of individuals reported issues with mental health and wellbeing



Depression/mood disorders, lack of motivation, anxiety, adjustment difficulties, poor coping, stress and grieving are some of the most common issues experienced



up to 40%

experience mental health issues in the first 5 years post spinal cord injury

25%

had mental health issues that remained prevalent till 20 years post spinal cord injury

Top three mental health management strategies used by people with spinal cord injury

44%

supportive counselling at clinic by social workers



22%

linking in with a peer support or general practitioner for resources and information



21%

referred for counselling



How to navigate this module

This module introduces ways to achieve good mental health. It describes factors that contribute to good mental health and lists the warning signs of poor mental health. This module also includes a toolbox of strategies for maintaining good mental health. A brief checklist is provided to gauge the level of your concerns and some ideas are offered on how to monitor your mental health. The module finishes with a list of on-line resources.

Remember

Please remember this module is only intended as a guide so if you are concerned about your mental health, or that of a family member, please get in touch with your GP ASAP to seek professional support.

KNOW About your mental health and wellbeing (page 5)
About your mental health and adjustment to SCI (page 8)

CHECK Refer to checklists (page 29)
and warning signs (page 31)

✓ Yes

✗ No

IDENTIFY PROBLEM

Look for important signs and symptoms:

- Depression (page 6)
- Anxiety (page 6)
- Suicidal thinking (page 7)
- Sleep disturbance (page 6)

Cognitive problems like:

- Troubles with memory (page 7)
- Adjustment, personality and relationships (page 6)
- Grief (page 6)
- Substance abuse (page 6)

OBSERVE

Refer to questions in checklist and warning signs

PREVENT

- Refer to:
Adjustment to SCI (page 8)
- Case studies (page 9)
- Tips for wellbeing (page 32)

MANAGE

Based on relevant sections of the toolbox (page 10)

EDUCATE

Refer to mental health toolbox (page 10)

Is this problem resolved? Have your goals been met?

✗ No

✓ Yes

RE-ASSESS

OBSERVE/PREVENT

Know about your mental health and wellbeing

Spinal cord injury and your mental health

Living with a spinal cord injury can be a huge challenge, testing your resilience and ability to cope with daily challenges. Following your injury, you may find that life roles have dramatically changed. Learning to live with your spinal cord injury involves a new and different way of life that can sometimes be challenging and confronting.

Most people with a spinal cord injury adjust and cope well, becoming more resilient. Being resilient means you get on with life, dealing with the injury as best you can in a positive manner. However, being resilient means you will still experience threats to your mental health, which is a normal reaction to SCI.



Possible challenges

Following a spinal cord injury people can experience increased challenges with their mental health. This might include sleep disturbance, cognitive problems, grief and depression.

Good News

It's important to remember that many of these experiences are very common and many people adjust and experience positive well-being over the long term.

"Life with a spinal cord injury is challenging but challenges can be rewarding, satisfying and fun. Lean into the discomfort and you will find your way, there are so many opportunities to find beauty and enjoyment."

– Consumer with spinal cord injury

Understanding your mental health

Common mental health challenges

Sleep disturbance

It is quite common for sleep patterns to become disrupted for many people with a spinal injury. Your injury can make it harder to get to sleep. This may include sleep interruption from obstructed sleep disorder, pain and spasticity. Feeling sleepy during the day can also be a problem. Sleep disturbance can disrupt your ability to work and be productive.

Grief

Grief is a natural and a common reaction. Grief can leave you feeling angry, anxious, sad, or strange. Research shows that it helps to accept that grief is a normal response following your injury, but don't mistake grief for depression. There is no right or wrong way to grieve and everybody can experience grief differently. When grieving, it is important to stay connected with family and friends and to take care of your health by managing your stress and still doing things that you enjoy.

Remember

As you learn to live with your spinal injury it is important to remember feelings of grief will often be experienced over the long term, and that this is quite normal! The effects of your injury on your life will change over time as you have new life experiences. You may feel your life is more challenging at certain times and other times less so.

Anxiety

Anxiety is the body's physical response to a threat or perceived threat.

Anxiety can be normal in stressful situations, such as speaking in public. Anxiety is a problem when your feelings are overwhelming and interfere with daily life. Anxiety presents in different ways. This may include feeling worried, nervous or tense, panicky, restless or fidgety. You may get a sense of doom, think the worst will happen or avoid social situations.

Feeling depressed

The traumatic nature of spinal cord injury and the huge change it brings can increase the chance of experiencing depression. Depression can make everything harder to deal with. If depressed, you may begin to feel helpless, neglect to look after yourself, and begin to have thoughts of self-harm or suicide. Depression is linked with a higher chance of urinary infections and pressure injuries, increased pain, sleep difficulties, relationship hassles, and increased social isolation. Taking care of your mental health is therefore critical for enjoying a good quality of life.

Relationships and life satisfaction

Physical impairments and health problems can introduce challenges to relationships and social participation. Relationship roles may change including learning different ways to be intimate. Efforts to create positive personal and social relationships involve communication, listening skills, understanding your body and being open to change. See Section 6 (page 25) of the Toolbox for more information and resources.

Substance misuse

Substance abuse/misuse can be dangerous to all of us, especially when combined with mental health problems, and also when taking prescribed anti-depressant or pain medications. Alcohol and substance abuse will also damage your physical health. If you believe you are using harmful amounts of alcohol, medication, or recreational drugs, then you most likely are. It is best to seek a referral for professional help or seek support from family or friends. The skills presented in Section 4 (page 22) will help you manage this problem.

Remember

Not all problems are experienced by everyone or are inevitable.

Other mental health challenges

Post-traumatic stress

If you sustained your injury as a result of a traumatic accident that was potentially fatal, such as a motor vehicle crash, a fall or assault, then this has the potential to cause post-traumatic stress, a condition that can develop into post-traumatic stress disorder (PTSD).

If you are experiencing high levels of stress related to your injury and symptoms such as nightmares, depression, high anxiety, avoidance of social contexts, numbness of emotions, then strategies for managing post-traumatic stress can be found in Section 4 (page 22).

Cognitive problems

Cognitive function includes brain activities like memory, attention and language. Fatigue, sleep disturbance, chronic pain, anxiety and/or depression affect your brain function. Even taking multiple medications can be problematic. If you notice forgetfulness or poor decision making and/or concentration, it is best to seek professional assessment and help.

Suicidal thinking

If you are having thoughts or ideas that life is no longer worth living and the possibility of ending one's own life. Help is available, speak with someone today.



"A meaningful life well lived is an essential component when considering the place of 'hope for better than now' in the lives of newly-injured individuals."

– Consumer with spinal cord injury

Adjustment to SCI

What is Adjustment

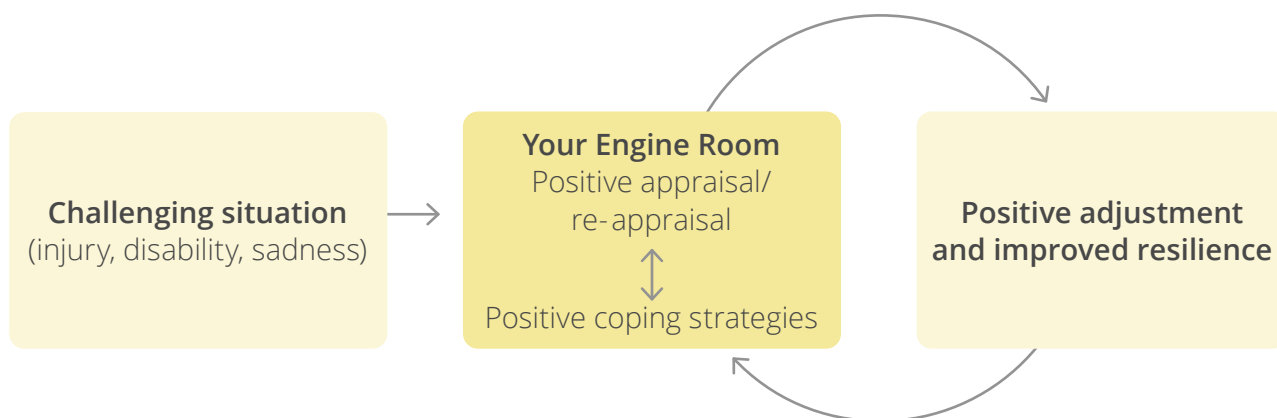
Simply put, adjustment is the process of becoming used to a new situation. Life following a spinal injury is often very different to your life before your injury and involves a great deal of adjustment as you negotiate a number of new challenges.

Good News

The way you perceive the world is not fixed – different situations can be viewed from a variety of perspectives. Research has found that how we explain events in our lives impacts how well (or poorly) we deal with those events.

For everyone adjustment involves a process of appraisal and re-appraisal. Appraisal refers to how you think about and evaluate yourself, your situation, challenges and solutions. Appraisals can be optimistic and realistic leading to good mental health through adopting positive coping strategies. Appraisals can also be pessimistic, leading to poor mental health through adopting poor coping strategies. The appraisal and coping process is called the “engine room” of adjustment and for maintaining good mental health because it is very important.

The following figure shows the relationship between a challenging situation, a positive appraisal/re-appraisal and coping process, and positive adjustment outcomes. Many things can challenge your resilience (time since injury, level of injury, negative thinking, poor social support, pain), however, **your engine room is very powerful**, and can help you adjust well regardless of what life can throw at you.



"Having a high quality of life following a spinal injury involves a sense of balance between your body, mind and your social context and environment. Understand your condition, take control and introduce order and predictability into your life. Learn what is possible, set goals, develop values that make sense of your disability, and search out resources to manage your life better."

– Consumer with spinal cord injury

Case studies illustrating adjustment

Neuropathic pain and mindfulness/thought training

Challenge

You are prescribed pain medication which causes side effects, like confusion, fatigue and weight gain.

You decide to try something different to cope.

Your doctor suggests reducing the dosage in combination with an online mindfulness App.

Positive adjustment

Learning mindfulness techniques gives you another strategy to manage pain.

Reducing medication improves your ability to think and you have more energy.

Reappraising your new situation you realise you have more positive resources than you realise.

Outcome

This new approach to managing your pain allows you to **focus on other activities** such as hobbies and socialising

You also have **improved self-esteem** due to the way you dealt with this challenge



Onset of anxiety and relaxation techniques

Challenge

You are beginning to experience serious anxiety and feelings of panic about dealing with your injury in the coming years. This has caused feelings of helplessness, sleep disturbance and a reluctance to mix socially. There is also an embarrassment and reluctance to talk to family and friends about it. You try to cope, hoping it will go away however it gets worse to cause nausea, fatigue, and depression.

Positive adjustment

The risk of not doing anything about your situation is a serious threat to your mental and physical health. You get advice from a trusted friend who has a spinal cord injury too. It is agreed that you must focus more on optimistic activities such as an online relaxation course, and regular exercise

Outcome

If you begin to develop positive coping strategies, this should encourage further positive changes, such as changes to medications, diet and social activities.

Note to self

Get a GP referral to a psychologist if these strategies are not working.

Remember

Transitioning from hospital back into the community can feel liberating. It will also be very challenging as you learn to be independent again. You will strengthen your adjustment if you set achievable goals, keep active, eat well, think optimistically and realistically, seek help when needed and maintain strong social ties.

Mental Health Self-Management Toolbox

Improving your ability to self-manage your health is an important objective of the Health Maintenance Tool. Self-management helps you be 'in control' of your behaviour, thoughts and emotions, placing you in the best position to look after your mental health.

The mental health toolbox shown below includes a range of strategies and activities to assist you in developing a personalised program that will support your mental health and wellbeing.

Each strategy is focussed on a particular set of skills that have an evidence-base as an effective psychological therapy. The key idea of this toolbox is to help you develop a sense of balance between your body, mind and your social and environmental context.

Remember

People often experience different issues and challenges with their mental health and a range of factors may be contributing. There is no one-size-fits-all approach!



1. Readiness to change

An important starting point is to explore how ready you are to plan and take action to make positive changes in your life. Which of the following statements best fits your current level of readiness to change?

Statement 1

I'm not really thinking about change, not interested in change.

Statement 2

I'm thinking about and interested in change, but I'm not entirely sure I want to change.

Statement 3

I've given the idea of change some thought and I'm preparing for action.

Statement 4

I've started to make some changes and I want to keep making these changes.

Statement 5

I've successfully made changes. I now need to maintain these changes

Check it out!

The following guide can assist you in selecting appropriate strategies within this toolbox program.

If you selected statement 1

We suggest you look at Section 3: Improving your knowledge and supported help (page 18).

If you selected statement 2

Please refer to section on values and personal responsibility (page 12).

If you selected statement 3

Please go to Section 4: Goal-setting and developing a plan (page 22).

If you selected statement 4

Please go to Section 2, 5, 6 and 7 where you can select strategies you think will help you change (page 13 and page 23).

If you selected statement 5

Please go to Section 5 (page 23) which will introduce you to develop an informed action plan. Action plan aims to help you sustain the positive changes you have made.

Remember

Managing your mental health is an ongoing process not a destination and for this reason it requires consistent attention and care.

"In terms of resistance to MH issues, we don't want to have to deal with pain, but I suddenly had to. We don't want to have to deal with different bowel and bladder issues but now we have to. AND I didn't want to feel like this, but now I do. So some people will just not want to confront it, but other people will and having something that helps them confront mental issues is great."

– Consumer with spinal cord injury

Values and personal responsibility

To help reflect on your readiness to change, and adjust to your injury, it may help to explore what things are important to you, and the type and size of any changes that might be required to ensure you live according to the values that matter to you.

Personal values are the things that we hold as most important to us. They can guide our actions and decisions. Values help to keep us grounded at times when we're struggling with decision-making. This is a struggle between doing what you know you need to do and what you want to do. An example is: I know I need help to manage my anxiety but the embarrassment makes me reluctant to do so.

An important personal value is to acknowledge personal responsibility for one's behaviour and actions. If you are interested in change, but not entirely sure you want to change, this inner conflict needs to be resolved. To help you resolve this conflict answer the following questions and reflect on your answers.

1. What kind of person do I want to become?
2. What do I really care about?
What matters to me?
3. What is stopping me from taking action to improve my mental health?
4. What in my life is most meaningful?
5. Are these barriers becoming more responsible for my mental health?
6. If I decide take personal responsibility for the way I live, what inner changes can I make?

You will find below some simple steps that will help you begin to build personal responsibility and resilience (the ABCDE of resilience):

Acceptance

You have to accept things in your life which are beyond your control with optimism. This does not mean you are giving up. It means going forward to change things that can be improved.

Belief

There is always some area of freedom in your life in which you can act responsibly. It involves upholding your values and personal strengths.

Commitment

This means taking action and moving forward, carrying out those things you are responsible for, regardless of your feelings or conditions.

Discovery

Involves learning about yourself and discovering your strengths and resources.

Evaluation and self-management

Involves monitoring and making necessary adjustments so you can move forward. If this is difficult and is not working, then make adjustments (re-appraise and employ new coping strategies).



Did you know

Beyond Blue provides many personal stories from people who have had to deal with their personal values and learn to adopt a responsible attitude toward their health. Use the following link to explore these encouraging stories:

<https://www.beyondblue.org.au/personal-best/pillar/wellbeing>

2. Managing your thinking

The way you think about life will influence your mood and frame of mind for better or worse. You need to ensure you are aware of whether your thoughts are helpful. Are your thoughts (optimistic, realistic, confident) or unhelpful (negative, irrational, pessimistic)?

Helpful thinking will boost your mental health. Unhelpful thinking will chip away at your mental health.

A helpful thought could be:

"This is really challenging! Its great though that I have lots of help and I seem to be managing well".

An unhelpful thought could be:

"This is really terrible! It's my fault I'm struggling to deal with this anymore. It is all too much."



Remember

While it is completely expected for people to have a range of positive and negative feelings, it is important that you do not allow too many unhelpful thoughts to take over and interfere with your adjustment

Catching unhelpful thinking traps

As humans we are all prone to thinking in ways that are unhelpful and can fall into “thinking traps”. By recognising these traps we can begin to manage our thinking more positively. Let’s look at some examples of common thinking traps:

Black and white thinking

It’s easy to see a situation as all good or all bad instead of a more balanced view of a situation. You may be better at some things than others and are able to improve.

Example:

I’m neither ‘perfect’ nor a complete ‘failure’.

Jumping to conclusions

Sometimes we think we know what another person is thinking (mind-reading). Or that we can predict what will happen in the future (predictive thinking).

Example:

Knowing some else’s thoughts or predicting the future is not possible, so it can be a mistake to accept such thinking is based on facts.

Catastrophising

You believe that what has happened or will happen will be so awful and unbearable that you won’t be able to stand it. Sometimes we predict the worst possible outcomes about the future.

Example:

If we overestimate the likelihood of a negative event occurring and underestimate our ability to cope, we can feel very anxious and depressed.

Mental filtering

This type of thinking happens when we adopt a single-minded approach. The information we see matches our existing beliefs and information that offers a different perspective is filtered out as if it doesn’t exist.

Example:

A tendency towards tunnel vision doesn’t let you see other points of view.

Personalising

You attribute a lot of the blame to yourself for your problems and fail to see that certain things are can be caused by others.

Example:

“It was all my fault the marriage ended.”

Blaming

You focus on the other person as the source of your unhelpful thinking and you refuse to take responsibility for changing yourself.

Example:

“She’s to blame for the way I feel now” or “My parents caused all my problems.”

Shoulds

You interpret events in terms of how things should be rather than simply focusing on what is.

Example:

“I must do well. If I don’t, then I’m useless and a failure.”

Regulating your emotions

To better regulate our emotions, it helps to take control of your thinking. With improved control of our thoughts, we improve awareness of our emotional state (see illustration below).



If you want to try to regulate your emotions, then consider the following approaches:

Self-awareness

You need to be aware of your emotional state. Check in from time to time and ask yourself how you are feeling: hopeful, anxious, happy, contented, angry, sad, or hopeless. Make sure you then explore these emotional states. Name the specific emotions that you can feel at that moment.

Mindfulness

Try one of the mindfulness techniques with your slow breathing to achieve an internal calmness. For more details see section on Relaxation techniques: slow breathing and mindfulness (page 17).

Appraisal and reappraisal

Try to use your 'engine room' process to manage your thoughts. This involves appraisal and re-appraisal of your thinking. See if you can direct those thoughts to become helpful and optimistic.

Adaptability

Try to become more adaptable. Attempt a straightforward problem-solving strategy to your current problem.

Self-compassion

Try to use the 'pleasant events' strategy and set aside time each day to enjoy yourself. This is a good way to build emotional regulation skills. Remind yourself of your talents and virtues and focus on these for a while each day.

Emotional support

Try to seek positive social and emotional support to help you regulate your emotions. With improved self-awareness it is possible to seek emotional support from within yourself. Of course, you may seek external help by engaging with others in a positive way.



"Learning to regulate my emotions helped me to grieve. And through grieving, through a process of acceptance, there was light at the end of the tunnel."

– Consumer with spinal cord injury

Relaxation techniques: slow breathing and mindfulness

Relaxation can help to reduce your anxiety or irritability and help you to manage and tolerate the stressful things that frequently happen.

There are many variations of relaxation exercises. It is important to find one that suits your preference. One of the simplest and effective relaxation exercises is slow diaphragmatic breathing.

You do this by:

- Placing one hand on your stomach and one hand on your chest.
- Slowly breathing in through the nose, drawing the breath from your stomach. The hand on your stomach should rise with your breath and your hand on your chest should not move.
Please note: If you are unable to do this, just imagine your breath expanding your belly as you breath in, and leaving the belly as you breathe out.
- When you exhale let the stomach fall and focus on letting your breath out through your nose as slowly as possible.
- Using this strategy, slow down your breathing rate to 6 times a minute, that 4 seconds breathing in (through the nose) and 6 seconds breathing out (through the mouth with pursed lips).
- You should practice this breathing exercise for 5-10 minutes, at least twice a day and try using this skill before a stressful event.



Another very effective relaxation strategy is called mindfulness.

Mindfulness builds on your slow diaphragmatic breathing. Mindfulness involves giving your attention to what is going on within you (your breathing) and around you, moment by moment. You focus on and enjoy feedback provided by your five senses: touch, smell, sight, sound and taste. You remain fully aware of your surroundings.

An example of a mindfulness exercise is to wheel into a garden where you are safe and in which you can enjoy multiple sensations: while slowing your breathing, smelling flowers, listening to birds signing, feeling the sun or breeze on your skin, observing all the colours around you.

During a mindfulness exercise, you learn to deliberately block any sad or stressful thoughts. You allow your senses to dominate. For example, distract yourself with the smell of a flower, focus on its colour, feel the leaves, and so on. We recommend this type of mindful exercise once a day as well as your slow breathing exercises.

Use the links below to see some mindfulness scripts:

You can use from the following websites:

<https://www.blackdoginstitute.org.au/wp-content/uploads/2020/04/7-mindfulnessineverydaylife-with-gp-notes.pdf>

<https://spinalis.se/the-art-of-healthy-living-with-physical-impairments/>



Positive thinking exercise

Sometimes we can find ourselves 'emotionally stuck' in harmful thinking patterns. This may prevent us from engaging in helpful action.

The following exercise explores Cognitive Defusion. Cognitive Defusion is a skill that, helps you to let go of negative thinking. It requires regular practice!

Remember

You are the observer and the boss of your thoughts, not the thoughts themselves. You can learn to give each thought a little bit of the attention it needs, allowing it to "float in and out" of your mind.



Let's try a visualisation exercise called Leaves on a Stream

- Sit in a comfortable position and close your eyes.
- Visualize yourself sitting beside a gently flowing stream with leaves floating along the surface of the water. Pause 10 seconds.
- For the next few minutes, take each thought entering your mind, whether pleasant, painful, or neutral, place it on a leaf and let it float by. Even if you have happy or excited thoughts, place them on a leaf and let them float by.
- If your thoughts momentarily stop, continue to watch the stream. Sooner or later, your thoughts will start up again. Pause 20 seconds.
- Allow the stream to flow at its own pace. Don't try to speed it up and rush your thoughts along. You're not trying to rush the leaves along or "get rid" of your thoughts. You are allowing them to come and go at their own pace.
- If your mind says "This is silly," "I'm really bored," or "I'm not doing this correctly" place those thoughts on leaves also, and let them pass. Pause 20 seconds.
- If a leaf gets stuck, allow it to hang around until it's ready to float by. If the thought comes up again, watch it float by another time. Pause 20 seconds.
- If a difficult or painful feeling arises, simply acknowledge it. Say to yourself, "I notice myself having a feeling of boredom/impatience/frustration." Place those thoughts on leaves and allow them float along.
- From time to time, your thoughts may hook you and distract you from being fully present in this exercise. This is normal. As soon as you realize that you have become side-tracked, gently bring your attention back to the visualization exercise.

How did you find it? Remember it takes practice to become skilled at managing your thoughts.

3. Improving your knowledge

Having a good understanding about your mental health is the foundation of self-management.

Check it out!

Connecting with other people who live with spinal cord injury, and their family and friends, can be a really valuable way for sharing your experience and learning practical tips on living well with your spinal cord injury.

Check out: <https://scia.org.au/peer-support/>

You can learn so much more by accessing the information about mental health and tips for supported change:

Grief and loss

Grief line

Tips, tools and articles to help you manage grief and loss. Supported by Rotary District 9800 as part of the G'day Network initiative.

<https://griefline.org.au/resources/>

Bare

Grief counselling and support Services Australia: resources for helping deal with grief and loss

<https://bare.com.au/grief-counselling-bereavement-support-services-in-australia/>

Depression, Anxiety and Stress Management

Moodgym

Moodgym is like an interactive self-help program that helps you to learn and practise skills which can help to prevent and manage symptoms of depression and anxiety. Moodgym has been shown to be effective in medical research by research groups around the world. Supported by Australian National University

https://moodgym.com.au/?gclid=EAlalQobChMlpqy0iOb29AIVLppmAh32GQEEAAYASAAEgLFtVD_BwE

This Way Up

Learn a step-by-step way of tackling feelings of stress, anxiety, and low mood with our clinically proven online courses. Select a course that is relevant to the difficulties you've been having or take our anonymous online test to see which course is for you. You can get instant access for \$59 or speak with your clinician (GP or psychologist) to enrol for free. Supported by UNSW and St Vincent's Hospital NSW.

<https://thiswayup.org.au/courses/>

A photograph of a man in a wheelchair sitting on a paved path in a park. He is wearing a blue denim jacket, blue jeans, and sunglasses. His arms are raised in the air, and he has a joyful expression on his face. The background shows lush green trees and a clear sky.

Prevention is better than cure

myCompass

myCompass allows you to track your thoughts, feelings, and behaviours in four areas – depression, anxiety, stress, and sleep. It provides graphical feedback to recognise patterns and triggers that impact your mental health. Designed and developed by researchers at the Black Dog Institute (UNSW), myCompass has been shown to significantly reduce mild-to-moderate symptoms of anxiety, depression, and stress, and significantly improve levels of work and social functioning in just seven weeks.

<https://www.blackdoginstitute.org.au/resources-support/digital-tools-apps/mycompass/>



**Black Dog
Institute**

The Generalised Anxiety Program

The Generalised Anxiety (GAD) Program is designed to help you understand the nature of anxiety and worry and to learn the skills and strategies that help manage anxiety and improve overall mental health and wellbeing. This program has been developed by psychologists and researchers from the National eTherapy Centre, Swinburne University of Technology.

<https://www.mentalhealthonline.org.au/pages/about-the-gad-online-program>

Beyond Blue

Beyond Blue provides information and support to help people achieve stable mental health.

<https://www.beyondblue.org.au/>

Substance misuse

SMART (Self Management and Recovery Training) Recover

A free group program assisting any problematic behaviours, including addiction to drugs, alcohol, cigarettes, gambling, food, shopping, Internet and others. SMART Recovery is a registered health promotion charity and a non-profit organisation.

<https://smartrecoveryaustralia.com.au/>



Health Direct Australia

Free health resource; Australian government-funded service, providing quality, approved health information and advice

<https://www.healthdirect.gov.au/alcoholism-at-home>

Relationships

Relationships Australia

A leading provider of relationship support services for individuals, families and communities. It offers services that include counselling, family dispute resolution (mediation) and a range of family and community support and education programs. We are a federation of service providers in each Australian state and territory and have a national office based in Canberra

<https://relationships.org.au/>

Medications

There are many prescribed medications that may help you to manage your mental health symptoms. But medications only is not always ideal. What appears to work best is the combination of medication and sensible changes to your behaviour, thinking and lifestyle. Below, you will find the major medications used for mental health management. You will need to weigh up the benefits versus the risks of taking medications. This exercise will help you make a more informed decision about what is right for you.

Types of medications used for mental health management

Used to treat	Possible side effects	Effectiveness
Depression Anxiety Obsessive compulsive disorder Post-traumatic stress disorder	Sexual dysfunction (including reduced sex drive, difficulty having an orgasm, problems ejaculating), nausea, loss of appetite, diarrhoea, insomnia	++
Depression Nerve pain Anxiety disorders	Headache, sweating, sexual dysfunction (including reduced libido, difficulty having an orgasm, problems ejaculating), nausea, diarrhoea, reduced appetite	+++
Depression	Insomnia, tiredness, nausea, constipation	+
Depression (can also help sleep)	Tiredness, dizziness. Blood tests are needed to check liver function	+++
Severe depression. Anxiety Chronic pain OCD can be treated with clomipramine	Dry mouth, blurred vision, constipation, sexual dysfunction (including reduced libido, difficulty having an orgasm, problems ejaculating), weight gain, sleepiness	++++
Major depression; depression with anxiety	Tiredness, dry mouth, constipation, weight gain. Blood tests needed with Mianserin, given its use has a very rare risk of causing blood disorder	++++
Anxiety, sleep disturbance	Highly addictive with prolonged use, withdrawal effects; drowsiness, confusion,	+

Types of medications used for mental health management

Types of medications used for mental health management	Used to treat	Possible side effects	Effectiveness
Mood stabiliser: Lithium	Bipolar disorder Depression	Tremor, hypothyroidism, weight gain, sedation, lithium toxicity, arrhythmia.	+++
Mood stabilisers/ anticonvulsants: Sodium Valproate (Epilim) and Lamotrigine (Lamactil)	Bipolar, depression	Drowsiness, nausea, abdominal pain, diarrhoea, vomiting, low platelet count, tremors, tiredness, and hair loss.	++
Anti-psychotics: Quetiapine (Seroquel) Clozapine (Clozaril), Risperidone (risperdal) and Olanzapine (Zyprexa)	Psychoses Sleep disorder Bipolar disorder	Weight gain, sweating, confusion, fast or uneven heartbeats, tremors, uncontrolled muscle movements, feeling light-headed, blurred vision, eye pain, increased thirst and urination, excessive hunger, fruity breath odour, weakness, nausea and vomiting.	++

+ Effectiveness shown by clinical trials; the more + the more effective generally

WARNING

An abrupt stop of your anti-depressants may cause serious withdrawal symptoms. If you want to stop a medication always reduce the dose slowly and in discussion with your specialist or GP. Always discuss possible alcohol and medication interactions too.



4. Goal setting & developing a plan

Setting goals can be a great way to improve your mental health and help you adjust to living with your injury. Goals provide you with targets and outcomes to work towards. Targets can motivate you to work harder to achieve those outcomes.

What is a goal?

A goal is an idea or a picture of where you would like to be in the immediate, near, or distant future. Your early or initial goals don't require great detail. But it is important to think about the direction you want to head in. Goals can be set for short, medium, and long-term periods.

Short, medium and long-term goals

Short-term and medium-term goals refer to what you want to achieve now or in the next 6-12 months or so. Short-term goals help you to get where you would like to be in the distant future (long-term goals). It is important to be able to set long-term goals, but not at the expense of shorter-term goals. If your initial goals are achievable the success you experience may motivate you. And your achievements may help you adjust to your injury and so improve your mental health.

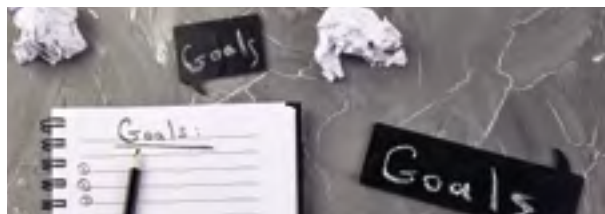
Writing goals down

If you write down your goals you are more likely to remember them and so achieve them. It is rewarding to achieve your goals and may give you back some sense of control over your life. In the table below, write down your short, medium, and long-term goals, and how you may achieve them.

Making a plan

Once you develop your goals you may find it helpful to create a plan. You can do this by dividing those goals into smaller steps. Write down each step, put it into your plan and set a deadline for its completion.

It is important to review your plan every month or so. When you complete a step along the way take a moment to acknowledge the milestone. Celebrate your progress and re-evaluate your plan. For example, is it still relevant or practical? Do I need to make any adjustments? The process of goal and plan completion can be very rewarding.



Goal planning exercise

An example has been provided below:

Short-term goals (daily, weekly, monthly)	Strategies to achieve these goals	Medium to long-term goals (6-12 months)	Strategies to achieve these goals
<ul style="list-style-type: none">Decrease anxiety and improve moodLose weight	Do 20 minutes of exercise daily 5 days every week	<ul style="list-style-type: none">Lose 5 kilograms in 12 monthsFeel relaxed most of the time and enjoy life	Continue active exercise for 20 minutes daily at least 5 days per week.

5. Problem solving

This section provides strategies to help you change your behaviour and so improve your mood and quality of life. Problems are an inevitable part of life. It is tempting to avoid problems because avoidance brings immediate relief. Facing problems can be difficult especially when you are in despair or overwhelmed. It can be hard to see problems clearly enough to consider effective solutions. We all have tendencies to see things a certain way that can cloud our thinking. This 'bias' can get in the way of effective problem solving. For this reason, a structured system can help.

The steps of structured problem solving are:

Define the problem

Rather than a general statement like, "My carers change too often and no one knows what they're doing." Try to be specific with something like, "I have had three carers change this month which has made it hard to establish a consistent approach to my personal care routine".

Identify contributing factors

Try to identify factors that contribute to the problem and those that maintain it. Was the change in the care team related to relationship factors? Are these going to continue to be a problem? Were there factors beyond your control like a change in management at the level of the care provider? Are these types of changes infrequent or regular?



Brainstorm solutions

The third step involves brainstorming. Try to think of as many possible solutions as possible. This is not a time to evaluate your solutions because you will rob yourself of ideas as you go. You just need to get as many ideas as you can think of onto paper or recorded using your voice on your laptop or mobile. You are not solving it all yet!

Compare the pros and cons

Once you have those potential solutions written down or recorded, you can do a pros and cons analysis of each potential solution. Consider the positive and negative outcomes that could result if you implemented each solution.

Develop an informed action plan

Pick a solution that has a higher number of pros than cons. Then develop a step-by-step plan to trial that solution. If a potential solution was to explore possible changes to your care provider you would list the steps involved in this: i) have a meeting with my care coordinator, ii) research or speak to others to find alternatives, etc.

Problem-solving is also the basis for resolving conflicts with others. Resolving conflicts will also require you to:

- Listen and not jump to conclusions
- Identify the problem and apply the above problem-solving strategy
- Regulate your emotions or behaviour that might make things worse, like anger, shouting, pointing your finger. Or avoidance.
- Be prepared to negotiate and agree on concessions.
- Work together to ensure positive outcomes for all parties.

Use this link to help you develop a pleasant event weekly calendar:

<https://emergingminds.com.au/resources/pleasant-events-schedule-completed/>

Check it out!

This template can help to create problem solving solutions.

The table below provides a template for your problem-solving cases.

Define the problem and potential contributing and maintaining factors

Definition

Contributing factors

Maintaining factors

Brainstorm possible solutions

Consider (analyse) pros and cons for each potential solution

Pros

Cons

Steps to put one of the solutions into action

Step 1

Step 2

Step 3

Step 4

Step 5

Step 6

Step 7

6. Scheduling pleasant events

Making time for you

An obvious symptom of poor mental health is a reduced ability to enjoy oneself. An effective way to counter this is to develop a 'pleasant events schedule'. Choose from a list of activities that are generally considered enjoyable. The creation of such a schedule may lead to greater enjoyment in life.

With planned pleasurable activities each day, you will realise that you can still enjoy yourself. By doing these activities, you can gain a sense of control over your mood and other aspects of your life.



Activity

List activities you enjoy doing. For example, visiting friends, going to the beach, shopping, fishing, reading, having a cup of coffee, listening to music, gardening, having a BBQ, movies, exercise, planning a holiday, going for a drive, and so on.

Make sure your list has something for every day, every week, every month and every 6 to 12 months. Even though you may not always feel like it, it is important to go ahead and do the chosen activity. You can learn how to enjoy yourself. For this strategy to help, frequency is key. Make sure you do some pleasurable activity every single day.

If you have trouble with ideas use the following link for a long list of things you may want to try:

<https://www.cci.health.wa.gov.au/-/media/CCI/Mental-Health-Professionals/Depression/Depression---Information-Sheets/Depression-Information-Sheet--06---Fun-Activities-Catalogue.pdf>



For more information and instructions on how to set goals and make plans, visit these:

University of Wollongong site:

<https://www.uow.edu.au/student/learning-co-op/effective-studying/goal-setting/>



Healthdirect: Goal setting

<https://www.healthdirect.gov.au/goal-setting>



7. Relationships and other social resources

Your spinal cord injury didn't happen to you alone. Your injury affected a wide range of people, especially your family and close friends. Your injury may affect your wider social networks. You may need to renegotiate pre-injury relationships as roles can change.

Remember

People often say that learning a new understanding of relationships is a journey and takes time. Clear communication and an openness to learning can help enormously.

Setting healthy boundaries

Boundaries are guidelines, limits, or rules about what you consider to be acceptable behaviour from other people. People who don't have boundaries might be considered 'push-overs' whereas people who have very strict boundaries might be considered aloof.

Look at the following chart and consider where you fit. Are your boundaries too tight, too loose; or just right?

Healthy boundaries

- Aware of your emotional needs and wants.
- Can tolerate disagreement and difference of opinions.
- Respect your own opinion as well as the opinions of others.
- Share personal information without over-sharing (e.g., telling everyone everything about yourself) or under-sharing (e.g., questioning others to avoid sharing anything about yourself).

Loose boundaries

- Inclined to accept abuse or disrespect.
- Become overly involved in other people's problems.
- Depend too much on what other people think of you and being quick to change what you do or think to please others, often to your own hurt.
- Fear rejection if you don't do what others ask/want you to do.
- Find it difficult to say no to others.

Strict boundaries

- Avoid close relationships or being uncomfortable with intimacy.
- Become overly protective of your personal information; not open or trusting.
- Have few close relationships.
- Solve problems on your own rather than asking for help when appropriate.
- Keep others at a distance to avoid the possibility of rejection.

To work on setting healthy boundaries, try these three steps.

1. Define your limits. Examine past experiences that involved you feeling angry, resentful, or uncomfortable.

What was the situation? Who was involved? Which personal standards or values were violated in these instances?

You feel awkward discussing certain topics or when people do things that affect you without first consulting you or asking for your opinion.

2. Determine how you know when your boundaries have been crossed. How do you feel about this (e.g., anger, annoyance, irritability, resentment)? Watch out for these negative feelings and when you are aware of them. Check whether one of your boundaries may have been violated.
3. Practise assertiveness when you become aware of a boundary violation. This will mean you will state how you feel, what objective facts contributed to these feelings, and request an alternative you consider to be more acceptable (e.g., I felt uncomfortable when you said I was being unreasonable the other day. So in the future it would be great if we could work towards accepting our differences).

Life with support workers

Some people after a spinal cord injury need to negotiate a new type of relationship. That of community support workers or carers. Support workers play a critical role to enable people with spinal injuries to live a meaningful life. They are often employed to assist with domestic tasks and personal cares. Tasks may include dressing, grooming, food preparation, travel, work, hobbies, and care of children and/or pets.

However, working together with support workers is much more than just completing tasks. There are many demanding factors at play, including trust, familiarity and privacy. To learn to ask for help can be weird and a huge challenge. People can feel awkward "asking carers to do stuff".

Remember

Clear and respectful communication has been identified as one of the most important aspects in determining successful support worker relationships. This may be communicating the details of tasks you need assistance with, and your general expectations regarding the scope and role of a support worker.

The quality of the relationship between you and your support workers can impact your quality of life (and that of your family). For best advice discuss this topic with your spinal cord injured peers. Or you may find community support group websites or social media platforms helpful. Check out <https://scia.org.au/>



Reaching out and developing a support network

Strong relationships you can count on are vital for your mental health. Develop a support network to include the people in your life that help you achieve your personal and professional goals. Tips on who can be part of your support network might include:

Family

Family is an important support network for you. If family are not an option, then it is important you develop networks from the following five sources.

Friends

Think about your friends, someone with whom you have an established relationship. Such a person is ideal for your support network. Do not be embarrassed about seeking support.

Colleagues

If you work, then colleagues can be a great source for social support.

Neighbours, acquaintances and friends of friends

Use your existing network to identify and build further connections with neighbours, acquaintances and friends of friends.

Social Media and Facebook/Meet-Up Groups

The internet provides many social support opportunities.

Local Community and advocacy groups

Become actively involved in your local community. It is a great way to develop social connections. Examples include community clubs, sporting groups and volunteer organizations. Of course, there are great opportunities within advocacy groups such as Spinal Cord Injuries Australia and Forward Ability Support.

Intimate relationships

It is common for intimate relationships to change after your injury. Interest in one's ability to have sex and be intimate raises big questions that are important. The impact of each spinal cord injury is different for each person. It is important to seek answers to your questions. With the right knowledge you can have a meaningful, pleasurable, and rewarding sex life.

Check it out!

Listen to a podcast by Spinal Cord Injuries Australia who interview psychosexual therapists Candice Unger and Arlyn Owens from Royal Rehab's Sexuality Service in Sydney:

<https://podcasts.apple.com/au/podcast/episode-ten-psychosexual-exploration-sexual-self-esteem/id1554797536?i=1000538457903>

To learn about intimacy, spend time getting used to your body after your spinal cord injury. See how it responds to touch and allow yourself to be open. To learn more, check out these resources and information:

<https://royalrehab.com.au/sexuality-service/>

<https://www.backuptrust.org.uk/support-for-you/information-section/sex-and-spinal-cord-injury>



Mental Health Checklists



It is important that you maintain your mental health management plan, so that you thrive into the future. This includes continuing to practise the skills and strategies presented in the Toolbox. You should also evaluate and re-evaluate your goals and plan every now and then, and don't neglect to discuss any changes with family, friends or a professional if needed. Continue to reward yourself when you successfully complete your goals.

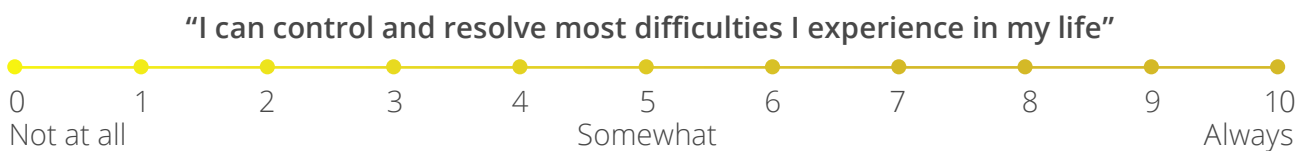
Remember, you will most certainly continue to experience stressful life events that will challenge you. The important thing to remember is that coping in the face of difficult circumstances proves you can be resilient and maintain balanced mental health.

Resilience relies on self-mastery (or self-efficacy).

Medical research has shown the way you think about your life and about your problems will help protect you from distress and depression. This is called self-efficacy.

A strong self-efficacy will help you deal better with anxiety and pain, and will strengthen your self-efficacy by practising your skills regularly.

Place a circle on the point of the line that you believe to be mostly true for yourself at this time. If you score above 5, then it suggests you have strong self-efficacy.



Check your mental health regularly, just like you monitor the health of your eyes or skin. The earlier you are aware of a problem, the quicker and the better it is to act and find a suitable solution.

Checklists can help you monitor your mental health. They provide a way for you to assess your mental health status. Relying only on your memory to assess your mental health status will result in memory gaps and may result in you focussing more on bad times.

Use the following set of questions to monitor your mental health. You could ask yourself these questions at the same time every week to start a healthy monitoring habit. For example, you could add up the number of times you ticked “agree” and compare week by week. This checklist may also provide direction for better self-management (refer to toolbox on page 10).

Tick “agree” or “disagree” that best suits how you are

1. I enjoy my life	<input type="radio"/> Agree	<input type="radio"/> Disagree
2. I rarely feel sad or depressed	<input type="radio"/> Agree	<input type="radio"/> Disagree
3. I can manage my problems like pain or anger	<input type="radio"/> Agree	<input type="radio"/> Disagree
4. I feel relaxed about things most of the time	<input type="radio"/> Agree	<input type="radio"/> Disagree
5. I do not depend on alcohol/illicit substances to get through the day	<input type="radio"/> Agree	<input type="radio"/> Disagree
6. I sleep well most nights	<input type="radio"/> Agree	<input type="radio"/> Disagree
7. I think life is worth living	<input type="radio"/> Agree	<input type="radio"/> Disagree
8. I am happy with my ability to remember things	<input type="radio"/> Agree	<input type="radio"/> Disagree
9. I look forward to mixing socially with friends and family	<input type="radio"/> Agree	<input type="radio"/> Disagree
10. I rarely dwell on what I have lost following my injury	<input type="radio"/> Agree	<input type="radio"/> Disagree

Understanding your answers to the Checklist

Your answers to the 10 questions will help you focus on where in this module you can seek answers. For example, if you ticked the "Disagree" for most of the 10 questions, it suggests you may have a problem with feeling depressed and anxious, and most sections of the toolbox (page 10) will help with this, as it contains strategies that can help you understand how best to manage mental health problems.

The following table provides where in this module you can seek answers and tailor strategies to your specific mental health needs.

Question	Problem	Relevant sections of Toolbox
1-10	Depression	1, 2, 3, 6, and 7
4	Anxiety	1, 2, 3, 5, 6, and 7
7	Suicidal thinking	Seek professional help
6	Sleep disturbance	2, 4, and 6
8.	Cognitive problems like troubles with memory	2, 4, 5, 6, and 7
3,9	Adjustment, personality, relationships	1, 2, 4, and 7
1,2,10	Grief	1, 2, 4, 6 and 7
5	Substance misuse	1, 4, 5 and 7



Staying on Track

Warning signs

How do I know if my mental health status is normal or problematic? While it is normal to feel angry, irritable, and sad from time to time, there are RED FLAGS to watch out for. RED FLAGS indicate possible worsening of a mental health problem. A list of potential red flags is found below. [You may use the following red flags as additional aides to regularly monitor your mental health.]

Red Flags

Constantly feeling stressed, sad and irritable

When you feel stressed and sad a lot of the time, you can be at greater risk of developing elevated anxiety and increased depressive mood symptoms. When people are anxious or depressed, they tend to see the negative side of things which can make them more irritable.

Feeling irritable is a state where you become easily frustrated, angry and upset. If you often feel irritable it could mean that you are using a lot of mental and/or physical energy to deal with stressful life events, leaving little energy for other things.

Fatigue and sleep problems

If you are tired a lot of the time, you should first see your GP to rule out any medical cause such as iron deficiency, sleep apnoea (excessive snoring and gasping for air during the night) or unwanted medication side-effects. If you are tired despite eating and sleeping well, this could mean you have problems with anxiety and a depressive mood.

Losing interest in activities that were once enjoyable

Losing interest in things that you enjoyed in the past is a possible symptom of depression. It could also mean an activity is not suitable for your age or energy levels. However, if you find yourself having little pleasure in almost all your activities then this is a red flag and needs to be addressed.

Problems with concentration and making decisions

Mental confusion and poor concentration can be symptoms of depression and anxiety. Increasing age, taking multiple substances or drugs (e.g. pain killers such as opiates/opioids, Lyrica, alcohol, cigarettes, and so on) will also cause these problems. If you find you are experiencing memory lapses, reduced concentration and attention, difficulty making decisions and so on, then this can be a red flag.

Withdrawing from people or activities

Avoiding and withdrawing from your social networks can be a red flag for mental health problems. You may have a good reason to withdraw for a time, but always withdrawing from family, friends and work is often a symptom of depression. If you believe this is happening, then address this quickly.

Thoughts of self-harm or suicidal ideation

See the following section for more helplines on issues of self-harm and suicidal ideation. Suicidal ideation involves a person constantly thinking about self-harm. If this occurs, it is a serious red flag that requires you to talk to trusted family and/or friends, and if required, immediate referral to a mental health professional.



Tips to maintain wellbeing

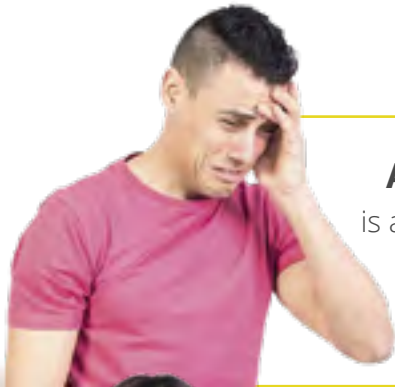
Be proactive and take responsibility for managing your own health risks

This involves:

- Educate yourself so that you understand how your spinal cord injury affects your mental health
- Keep you up-to-date about the latest research findings.
- Become a partner in decision-making and learning to problem solve with your family and health professionals.
- Develop an individual mental health self-management program that works for you.
- Engage in ongoing health and wellness activities. This includes:
 - Exercising regularly
 - Maintain a healthy weight to reduce load on your shoulders, arms and hands
 - Use medications only as instructed by your doctor(s)
 - Incorporate regular relaxation and mindfulness techniques into your daily life.



Take home messages



ACCEPT GRIEF

is a normal reaction
to change



TAKE CONTROL

and learn to
manage your
thinking



DEVELOP

a mental health
management plan



USE THE TOOLBOX

in this module to increase
your overall wellbeing



BE AWARE

of your
symptoms



HAVE REGULAR DISCUSSIONS

with your GP to discuss
medication options

Knowledge test

- When monitoring your mental health risk, you need to consider:
 - Underlying medical conditions.
 - Medications you are taking.
 - Whether I enjoy my life.
 - All of the above.
- List four treatment strategies from the mental health toolbox:

- To adjust positively to spinal cord injury means:
 - You analyse, evaluate, explore, and try to resolve life challenges and problems.
 - You never experience any serious life challenges after your spinal cord injury.
 - You are always resilient.
 - All of the above.
- The “engine room” of adjustment involves what? Check all of the correct answers.
 - Coping.
 - Appraising.
 - Re-appraising.
 - Improved resilience.
- When you are depressed and anxious, what is the most likely symptom you will experience?
 - Feel sad all the time.
 - Have trouble relaxing.
 - Experience moments of panic.
 - Frequently feel annoyed and angry.
 - All of the above.

For correct answers see page 35.

Glossary

Some mental health terms used in this module to be defined here:

Term	Definition
Depression	A mood (emotional) disorder that is marked by feelings of low self-esteem, guilt, a reduced ability to enjoy life, difficulty with relationships and wanting to avoid or participate in social activities.
Anxiety	A feeling/emotion involving worry, nervousness, or unease about something with an uncertain outcome. It is a response to a stress that is either real or imagined.
Post-traumatic stress	Involves acute distress and anxiety after having experienced a shocking, scary, or dangerous event. If not addressed, it can lead to post-traumatic stress disorder.
Grief	Involves feelings of intense sorrow and low mood after experiencing loss of some nature. It should not be confused with depression.
Substance abuse	Excessive use of psychoactive drugs, such as alcohol, pain medications or illegal drugs. It can lead to physical, social or emotional harm.
Adjustment	Involves the way you think about yourself and your life, and how you manage challenges and problems. To adjust you need to evaluate and re-evaluate how you handle your problems.
Self-efficacy	An individual's belief about their capacity to carry out behaviours necessary to produce a desired outcome. Self-efficacy will influence every area of life.
Resilience	The ability to mentally or emotionally cope with and adjust to an adversity and recover over time. Resilience occurs when a person uses their skills to protect them from the negative effects of an adversity



Answers to knowledge test

1: d;

2: any of the following: readiness to change; managing your thinking; improving your knowledge; goal setting; problem solving; pleasant events; relationships

3: a; 4: a, b, c; 5: e.

Further resources and help lines

Help lines

Telephone number of family member or friend

Local Ambulance Service or police emergency ring 000

Lifeline

13 11 14
www.lifeline.org.au

Mensline

1300 789 978
<https://mensline.org.au/>

Parentline

1300 1300 52
<https://kidshelpline.com.au/parents/issues/how-parentline-can-help-you>

Kids Helpline

1800 55 1800
<https://kidshelpline.com.au/parents/issues>

Salvo Care Line

<https://www.salvationarmy.org.au>

Useful SCI resources for consumers and medical professionals

Forward NSW, Ability Support Australia

(02) 8741 5674
<https://fas.org.au/>

Spinal Cord Injuries Australia

(02) 9661 8855
www.scia.org.au

Emotional Wellbeing Toolkit: A Clinician's Guide to working with Spinal Cord Injury ACI

https://aci.health.nsw.gov.au/resources/spinal-cord-injury/psychosocial_strategy/emotional-wellbeing-toolkit

Guide for Health Professionals on the Psychosocial Care of People with Spinal Cord Injury (updated 2014)

https://aci.health.nsw.gov.au/__data/assets/pdf_file/0019/155233/Guide-Psychosocial-Care.pdf

Psychosocial Adjustment after Spinal Cord Injury (updated 2014)

https://aci.health.nsw.gov.au/__data/assets/pdf_file/0010/155197/Psychosocial-Adjustment.pdf

Spinal Cord Injury Research Evidence (SCIRE)

<https://scireproject.com/evidence/rehabilitation-evidence/depression-following-spinal-cord-injury/>

Useful mental health resources for consumers and medical professionals

Australian Psychological Society Psychologist Referral Service

<https://www.psychology.org.au/Find-a-Psychologist>

SANE website

<https://www.sane.org/information-stories/facts-and-guides/spinal-cord-injury-and-mental-health>

Beyond Blue

www.beyondblue.org.au

Blue Pages

www.bluepages.anu.edu.au

Mental Help

www.mentalhelp.net

Reach Out

www.reachout.com.au

Black Dog Institute

<http://www.blackdoginstitute.org.au/>



Date	Time																		
<input type="text"/>	<input type="text"/>																		
<p>How are you feeling? <i>(1 = terrible to 10 = great)</i></p> <input type="text"/>	<p>How did you sleep last night? <i>(1 = terrible to 10 = great)</i></p> <input type="text"/>																		
<p>How much pain do you have at the moment? <i>(0 = none to 10 = extreme)</i></p> <input type="text"/>	<p>How much fatigue do you feel at the moment? <i>(0 = none to 10 = extreme)</i></p> <input type="text"/>																		
<p>What makes you feel better? <i>(select all applicable)</i></p> <table border="0"> <tr> <td><input type="checkbox"/> Rest</td> <td><input type="checkbox"/> Faith</td> <td><input type="checkbox"/> Community contribution (including caring for others)</td> </tr> <tr> <td><input type="checkbox"/> Socialising</td> <td><input type="checkbox"/> Self-care (e.g., mindfulness)</td> <td><input type="checkbox"/> Other, please specify</td> </tr> <tr> <td><input type="checkbox"/> Exercise</td> <td><input type="checkbox"/> Medication</td> <td><input type="text"/></td> </tr> <tr> <td><input type="checkbox"/> Leisure</td> <td><input type="checkbox"/> Doing housework</td> <td></td> </tr> <tr> <td><input type="checkbox"/> Food</td> <td></td> <td></td> </tr> <tr> <td><input type="checkbox"/> Work</td> <td></td> <td></td> </tr> </table>		<input type="checkbox"/> Rest	<input type="checkbox"/> Faith	<input type="checkbox"/> Community contribution (including caring for others)	<input type="checkbox"/> Socialising	<input type="checkbox"/> Self-care (e.g., mindfulness)	<input type="checkbox"/> Other, please specify	<input type="checkbox"/> Exercise	<input type="checkbox"/> Medication	<input type="text"/>	<input type="checkbox"/> Leisure	<input type="checkbox"/> Doing housework		<input type="checkbox"/> Food			<input type="checkbox"/> Work		
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<p>What makes you feel worse? <i>(select all applicable)</i></p> <table border="0"> <tr> <td><input type="checkbox"/> Stress</td> <td><input type="checkbox"/> Not enough sleep</td> <td><input type="checkbox"/> Other, please specify</td> </tr> <tr> <td><input type="checkbox"/> Health problems (other than pain)</td> <td><input type="checkbox"/> Finance problems</td> <td><input type="text"/></td> </tr> <tr> <td><input type="checkbox"/> Work-related problems</td> <td><input type="checkbox"/> Feeling unsupported or excluded</td> <td></td> </tr> <tr> <td><input type="checkbox"/> Lack of community access</td> <td><input type="checkbox"/> Social & relationship challenges</td> <td></td> </tr> </table>		<input type="checkbox"/> Stress	<input type="checkbox"/> Not enough sleep	<input type="checkbox"/> Other, please specify	<input type="checkbox"/> Health problems (other than pain)	<input type="checkbox"/> Finance problems	<input type="text"/>	<input type="checkbox"/> Work-related problems	<input type="checkbox"/> Feeling unsupported or excluded		<input type="checkbox"/> Lack of community access	<input type="checkbox"/> Social & relationship challenges							
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<p>Notes <i>(Record any other relevant information, such as use of medications, including side effects)</i></p> <input type="text"/>																			



Keep this diary to record your daily sleep patterns for a minimum of 7 days.

<p>Date</p> <input type="text"/>	<p>Date</p> <input type="text"/>	<p>Date</p> <input type="text"/>	<p>Date</p> <input type="text"/>
<p>What time did you go to bed (time)?</p> <input type="text"/>	<p>What time did you go to bed (time)?</p> <input type="text"/>	<p>What time did you go to bed (time)?</p> <input type="text"/>	<p>What time did you go to bed (time)?</p> <input type="text"/>
<p>How long did it take you to fall asleep? (minutes)</p> <input type="text"/>	<p>How long did it take you to fall asleep? (minutes)</p> <input type="text"/>	<p>How long did it take you to fall asleep? (minutes)</p> <input type="text"/>	<p>How long did it take you to fall asleep? (minutes)</p> <input type="text"/>
<p>How often did you wake up during the night?</p> <input type="text"/>	<p>How often did you wake up during the night?</p> <input type="text"/>	<p>How often did you wake up during the night?</p> <input type="text"/>	<p>How often did you wake up during the night?</p> <input type="text"/>
<p>How many hours did you sleep? (This may be different than the number of hours you spent in bed)</p> <input type="text"/>	<p>How many hours did you sleep? (This may be different than the number of hours you spent in bed)</p> <input type="text"/>	<p>How many hours did you sleep? (This may be different than the number of hours you spent in bed)</p> <input type="text"/>	<p>How many hours did you sleep? (This may be different than the number of hours you spent in bed)</p> <input type="text"/>
<p>Quality of sleep</p> <p><input type="checkbox"/> Very good <input type="checkbox"/> Fairly bad</p> <p><input type="checkbox"/> Fairly good <input type="checkbox"/> Very bad</p>	<p>Quality of sleep</p> <p><input type="checkbox"/> Very good <input type="checkbox"/> Fairly bad</p> <p><input type="checkbox"/> Fairly good <input type="checkbox"/> Very bad</p>	<p>Quality of sleep</p> <p><input type="checkbox"/> Very good <input type="checkbox"/> Fairly bad</p> <p><input type="checkbox"/> Fairly good <input type="checkbox"/> Very bad</p>	<p>Quality of sleep</p> <p><input type="checkbox"/> Very good <input type="checkbox"/> Fairly bad</p> <p><input type="checkbox"/> Fairly good <input type="checkbox"/> Very bad</p>
<p>Notes</p> <p><i>(Record any other relevant information, such as use of medications, including side effects; reasons for poor sleep, for example, feeling hot or cold, going to toilet, passing a catheter, pain)</i></p> <input type="text"/>	<p>Notes</p> <p><i>(Record any other relevant information, such as use of medications, including side effects; reasons for poor sleep, for example, feeling hot or cold, going to toilet, passing a catheter, pain)</i></p> <input type="text"/>	<p>Notes</p> <p><i>(Record any other relevant information, such as use of medications, including side effects; reasons for poor sleep, for example, feeling hot or cold, going to toilet, passing a catheter, pain)</i></p> <input type="text"/>	<p>Notes</p> <p><i>(Record any other relevant information, such as use of medications, including side effects; reasons for poor sleep, for example, feeling hot or cold, going to toilet, passing a catheter, pain)</i></p> <input type="text"/>

<p>Date <input type="text"/></p> <p>Location of pain <input type="text"/> Side <input type="checkbox"/> Left <input type="checkbox"/> Right <input type="checkbox"/> Both <small>Please specify other location</small></p> <p>Patterns of pain <input type="text"/> Pain features <input type="text"/> <small>Please specify other feature</small></p> <p>How intense is your pain right now? (1 = very mild to 10 = worst pain imaginable) <input type="text"/></p> <p>What makes your pain better? (select all applicable)</p> <p><input type="checkbox"/> Rest <input type="checkbox"/> Medications <input type="checkbox"/> Heat</p> <p><input type="checkbox"/> Position/posture <input type="checkbox"/> Distraction <input type="checkbox"/> Other, please specify <input type="text"/></p> <p><input type="checkbox"/> Pacing activity <input type="checkbox"/> Meditation/mindfulness <input type="text"/></p> <p>What makes your pain worse? (select all applicable)</p> <p><input type="checkbox"/> Performing personal care (e.g., bowel care) <input type="checkbox"/> Exercise/sports or leisure activities <input type="checkbox"/> Urine infection</p> <p><input type="checkbox"/> Transfers <input type="checkbox"/> Fatigue <input type="checkbox"/> Other, please specify <input type="text"/></p> <p><input type="checkbox"/> Pushing wheelchair <input type="checkbox"/> Stress <input type="checkbox"/></p> <p><input type="checkbox"/> Walking <input type="checkbox"/> Anxiety <input type="checkbox"/></p> <p><input type="checkbox"/> Spasms <input type="checkbox"/> Constipation/bloating <input type="checkbox"/></p> <p>Notes <i>(Record any other relevant information, such as use of medications (what taken and when) and side effects.)</i></p> <input type="text"/>	<p>Date <input type="text"/></p> <p>Location of pain <input type="text"/> Side <input type="checkbox"/> Left <input type="checkbox"/> Right <input type="checkbox"/> Both <small>Please specify other location</small></p> <p>Patterns of pain <input type="text"/> Pain features <input type="text"/> <small>Please specify other feature</small></p> <p>How intense is your pain right now? (1 = very mild to 10 = worst pain imaginable) <input type="text"/></p> <p>What makes your pain better? (select all applicable)</p> <p><input type="checkbox"/> Rest <input type="checkbox"/> Medications <input type="checkbox"/> Heat</p> <p><input type="checkbox"/> Position/posture <input type="checkbox"/> Distraction <input type="checkbox"/> Other, please specify <input type="text"/></p> <p><input type="checkbox"/> Pacing activity <input type="checkbox"/> Meditation/mindfulness <input type="text"/></p> <p>What makes your pain worse? (select all applicable)</p> <p><input type="checkbox"/> Performing personal care (e.g., bowel care) <input type="checkbox"/> Exercise/sports or leisure activities <input type="checkbox"/> Urine infection</p> <p><input type="checkbox"/> Transfers <input type="checkbox"/> Fatigue <input type="checkbox"/> Other, please specify <input type="text"/></p> <p><input type="checkbox"/> Pushing wheelchair <input type="checkbox"/> Stress <input type="checkbox"/></p> <p><input type="checkbox"/> Walking <input type="checkbox"/> Anxiety <input type="checkbox"/></p> <p><input type="checkbox"/> Spasms <input type="checkbox"/> Constipation/bloating <input type="checkbox"/></p> <p>Notes <i>(Record any other relevant information, such as use of medications (what taken and when) and side effects.)</i></p> <input type="text"/>
<p>Pain interference in last 7 days with your: (0 = none to 10 = extreme interference)</p> <p>Daily activity <input type="text"/> Sleep <input type="text"/> Mood <input type="text"/></p> <p>Note: if more than 4 on any of the above, please complete the activity, sleep or mood diary respectively.</p>	<p>Pain interference in last 7 days with your: (0 = none to 10 = extreme interference)</p> <p>Daily activity <input type="text"/> Sleep <input type="text"/> Mood <input type="text"/></p> <p>Note: if more than 4 on any of the above, please complete the activity, sleep or mood diary respectively.</p>

Ageing with your spinal cord injury

Ageing is a process that affects us all and involves changes to our body systems with functional decline, along with shifts in social roles, financial situation and supports.

However, in a person with spinal cord injury, ageing becomes more complicated as the changes that occur as part of the normal ageing process are overlaid on top of the effects of having a spinal cord injury. As a result, you may experience the effects of ageing faster in some body systems and new health problems developing at a younger age.

Due to the spinal cord injury, there is an immediate reduction in functional reserves and capacities of certain body systems. With loss of capacity in some systems, other systems have to compensate, often performing near maximum capacity. In combination, this change may lead to overloading of some body systems and functions with premature (earlier) or accelerated ageing.



What does research tell you?

- Premature ageing is more likely to occur in your muscles, joints, bones, heart and glands.
- There is evidence that urinary (bladder and kidneys), gastro-intestinal (bowel and digestive system), skin and respiratory (lungs) systems may be prematurely ageing.
- People with SCI are more likely than the general population to experience urinary tract infections, kidney and bladder stones, chronic pain, pressure injuries, and bone loss with fractures.



Issues with ageing with spinal cord injury

Body System	Issues with ageing with SCI
Bladder and kidneys	Age-related changes are intensified by the type of bladder problem, how you manage your bladder and length of time after injury. Potential backflow of urine with kidney damage can result from an overactive bladder and poor emptying.
Bowel and digestive system	The function of your digestive system naturally declines with age and spinal cord injury makes slowing of the gut worse.
Endocrine (glands)	The secretion of hormones is vital for metabolism, growth, sleep and tissue healing and repair. People with a spinal cord injury have lower levels of certain hormones that decrease with age, including growth hormone and testosterone leading to changes in body composition, obesity and metabolic disorders, with impaired glucose tolerance and higher rates of diabetes.
Heart	Heart disease may occur as the metabolism slows down, with weight gain over time (may eventually become obesity), reduced exercise tolerance, changes in lipid profile (increase in “bad” cholesterol or LDL with decrease in “good” cholesterol or HDL), and diabetes.
Lungs	Worsening lung function due to respiratory or abdominal muscle weakness, spinal curvature or spasms with increased risk respiratory tract infections and clots. Risk of obstructive sleep apnoea increases with age, more so in people with tetraplegia.
Mental health	People usually live fulfilling and pleasurable lives without experiencing major emotional problems as they age. In fact, most older adults, with and without a spinal injury, are resilient and adjust well to changes in their physical abilities. They also note improved relationships with loved ones, increased appreciation for life, and changes in priorities.
Muscles, joints and bones	Overuse (‘wear and tear’) of muscles, tendons and joints occurs particularly in the upper limbs (shoulders, arms, and hands) due to the demands of everyday living, leading to injuries (e.g., shoulder rotator cuff tears), inflammation (e.g., tendonitis), arthritis and pain. These changes impact on level of functioning and independence in performing daily activities (such as transfers and wheelchair mobility).
Skin	People with spinal cord injury are already susceptible to pressure injuries due to altered sensation and mobility. In addition, with progressive tissue thinning due to ageing, becomes even more prone to breakdown and harder to heal once a pressure injury has developed.
Spinal cord and nerves	Late onset weakness or sensory loss, increasing muscle weakness, pain or spasticity can occur with ageing due to normal nerve drop out or problems from: <ul style="list-style-type: none"> • over- or misuse of muscles and bones leading to nerve damage. • changes within the spinal cord itself (such as a cyst).

Recommendations for ageing with spinal cord injury

These may vary by age, gender, ethnic background, family history, and other factors.

Frequency	Checks
Daily	<ul style="list-style-type: none"> • Self-skin check • Stay active • Eat and drink responsibly
Monthly	<ul style="list-style-type: none"> • Women: Breast self-exam • Men: Testicular self-exam
Yearly	<ul style="list-style-type: none"> • Vital signs / measures including pulse, blood pressure (in sitting and supine lying positions), vital capacity, weight/waist circumference • Blood tests including full blood count, biochemistry (electrolytes, Liver function, renal function, blood sugar level), HbA1c, Cholesterol, Vitamin D level. • Women (40 years and older): mammography • Men (50-69 years): may have digital rectal exam and prostate specific antigen (PSA) test • Flu vaccination, especially for people with injuries at T8 and higher • Renal/Bladder ultrasound
1- to 2-yearly	<ul style="list-style-type: none"> • Comprehensive Health Evaluation reviewing all body systems • Faecal occult blood test (50-74 years) • 55 years and older: comprehensive eye exam • Cystoscopy (in those with long-term indwelling urethral or suprapubic catheters > 10 years)
3- to 5-yearly	<ul style="list-style-type: none"> • Women: breast cancer exam by a doctor • Women: gynaecological exam and Pap smear • Assess adaptive equipment and posture • Assess range of motion, contractures, and function • Bladder exam; also do this each year for the first 3 years after any major change in urologic management (including Videourodynamics) • Bone Health - DEXA scan, performed in first year post-injury (baseline reading) then repeat every 3-5 years)
5-yearly	<ul style="list-style-type: none"> • Motor and sensory testing • Multidisciplinary clinic review (of function, participation, ADL, community mobility and lifestyle demands, equipment and care assistance requirements) • Pulmonary (Lung) function test
10-yearly	<ul style="list-style-type: none"> • Tetanus booster • Colonoscopy, which allows your doctor to examine your colon, beginning at 50 years of age (unless at high risk)
When required	<ul style="list-style-type: none"> • Recognise and treat adverse health conditions early

The Spinal Cord Injury Health Maintenance Tool

The Spinal Cord Injury Health Maintenance Tool (SCI-HMT) is a guide to help you understand and troubleshoot problems you experience in managing your life after a spinal cord injury. It is important for you to learn how to self-manage your health-related needs. This tool has been developed by people with spinal cord injury, general practitioners and expert clinicians. The SCI-HMT provides evidence-based information, tips and tools to help you proactively manage your own health in six key areas – mental health, bladder, bowel, skin, pain and autonomic dysreflexia.

To improve accessibility and cater for a range of learning styles and user preferences, the SCI-HMT has been developed as three free and complementary products:

Booklets

You can ask for printed versions of the booklet from your spinal service provider.

OR

Access and download the PDF versions at: www.healthmaintenance.com



Website

The website has interactive elements that you can use anonymously.

Go to: www.healthmaintenance.com



Smartphone App

The app keeps all your personal information secure within your phone and is not shared with anyone else. You can get it from the Apple Store or Google Play Store by scanning these QR codes on your smartphone.

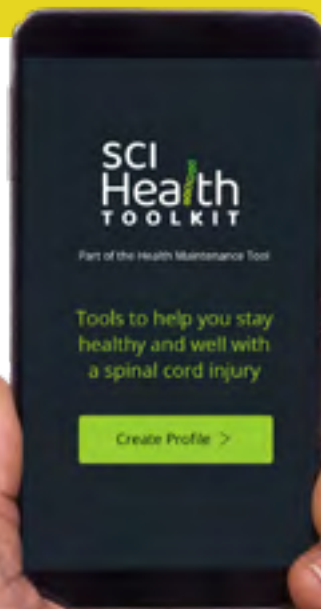
Or search "SCI Health Toolkit"



Apple



Google



The digital versions (website and app) have many interactive features and resources to help you understand your health maintenance needs.

The website includes below elements:

- Search tab
- Quick links
- Videos
- Downloadable interactive diaries
- Customisable care plan
- Quick Health Check
- Quizzes
- Glossary
- Further reading

Acknowledgements

The project team would like to thank all the consumers with SCI, healthcare professionals and staff of the three spinal cord injury units in NSW for their contribution to the SCI Wellness Project.

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- Mohit Arora
- Ashley Craig

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- icare NSW

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