

Health Maintenance Tool Module 5: Pain

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







Funded by



Second Edition 2023

This edition was developed as a part of the SCI Wellness Project.

Funder:

Insurance and Care (icare) NSW

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Suggested citation:

Middleton JW, Arora M and McCormick M (2023). Health Maintenance Tool: How to stay healthy and well with a spinal cord injury. A tool for consumers by consumers; *Module 5: Pain*; Ed. 2, NSW Australia.

ISBN: 978-1-921679-00-1

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

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 upto-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



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Summary of findings from the 2015 Rural Spinal Cord Injury Project

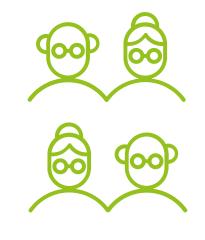
The project involved

681 people with spinal cord injury living in rural NSW





84% of individuals reported pain as an issue



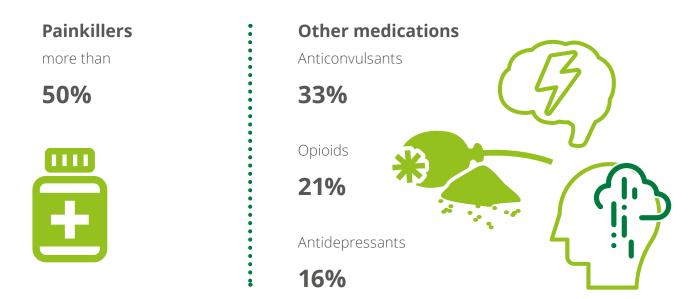
Musculoskeletal pain

is more prevalent in people with spinal cord injury who:

- Are older
 (aged over 60 years)
- Have been injured for less than 5 years or more than 20 years.

Pain management strategies used by people with a spinal cord injury included:

:



How to navigate this module



Know about your pain

Why do we experience pain?

Pain is normally generated when a potentially harmful stimulus (noxious), caused by heat, tissue damage or inflammation, activates high threshold receptors that send messages along the spinal cord to the brain. Different nerve pathways and chemical substances are involved with the control of pain, and the balance of these mechanisms often changes after a spinal cord injury.



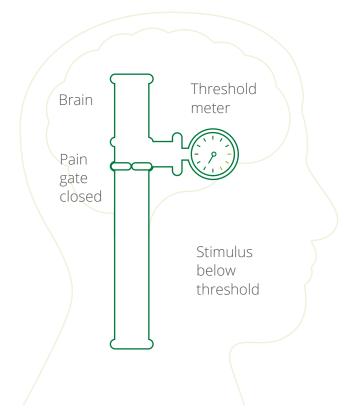
This is the point when you start experiencing PAIN

A strong stimulus triggers the nerve

A message reaches the spinal cord then travels to the brain

The messages are relayed to different parts of the brain

PAIN GATE MECHANISM



At various levels of the spinal cord and in the brain, there is a natural gate that filters information to ensure you only become aware of sensations when they reach a critical level or threshold.

The gates, when closed, help to turn down the volume of information received by the brain.

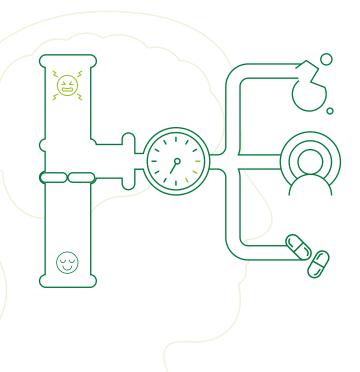
If these gates are not closed, your brain can become confused due to too much information.

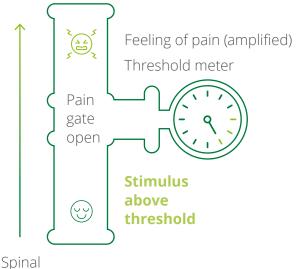
Effects of spinal cord injury on pain

Due to damage to the nerves after a spinal cord injury, the gates struggle to close. The spinal cord itself becomes sensitised or hyperexcitable to this sensory information.

The damaged spinal cord tries to reorganise and rewire itself after injury. Faulty rewiring at the injury site causes the nerves to fire off in an uncontrolled manner, even when triggered by a stimulus that is not usually painful.

For example, a light brushing touch may be experienced as an electric shock or burning pain.





cord

Good news!

The **pain gates** in your nervous system are found not only in the spinal cord but also in the brain.

You can **retrain the brain to turn down your pain**.

We know there are pathways coming down from the brain to the spinal cord that control these gates. The release of certain chemicals excites the pain pathways, so the gates open up. Other chemicals close the gates.

You can use physical, psychological and medical strategies to turn down the pain volume.

Nature of pain

Pain can be acute or chronic in nature



Acute pain

Pain that occurs immediately after an injury, disease or surgery. Acute pain can be severe, but usually gets better within about 3 months as the body heals itself from the trauma.

Acute pain is important for our survival because it helps to protect us from danger.

Important notes

Chronic pain is different to acute pain.

Chronic pain responds differently to treatments for acute pain. In fact, treating chronic pain the same way you treat acute pain doesn't work.





Chronic pain

When pain persists for longer than 6 months, we reclassify it as chronic pain. There are different mechanisms that generate and maintain chronic pain.

Chronic pain can be present even after injured tissues have healed.

Pain can be categorised as follows: Nociceptive pain and Neuropathic pain.

Nociceptive pain arises from tissue damage that is sensed by specific pain receptors, called nociceptors. There are several different types of nociceptive pain:

- Musculoskeletal pain, e.g., shoulder pain
- Visceral pain from internal organs, e.g., abdominal pain
- Other nociceptive pain, e.g., autonomic dysreflexia headache.

Neuropathic pain arises due to direct damage to the spinal cord and nerves resulting in:

- At-level neuropathic pain, e.g., band-like pain felt at level of spinal injury
- Below-level neuropathic pain, e.g., pain well below spinal level in your legs
- Other neuropathic pain, e.g., carpal tunnel syndrome due to median nerve compression at the wrist.

Types of pain

A. Musculoskeletal pain

Musculoskeletal pain refers to conditions affecting muscles, bones and joints.

Pain location: It is common to feel pain in an area where the nerves have not been damaged, either above the level of your spinal cord injury or below the level, if you have an incomplete injury with preserved sensation.

Pain description:

Dull, sharp, tender, aching.

Things that make pain worse:

Certain body positions or movement, such as lifting to transfer, driving, pushing a wheelchair, exercise or sport.

Things that reduce the pain:

Rest, changing position, certain medications, and equipment changes.

Common types of musculoskeletal pain

are shoulder pain, wrist arthritis, neck or back ache and muscle spasms.

B. Visceral (internal organ) pain

Pain location:

Abdomen, chest or pelvis.

Pain description:

Dull, cramping, aching, colicky (experiencing severe pain in the abdomen), comes and goes, poorly localised.

Things that make pain worse:

Bladder infection, bladder/kidney stones, constipation, gall stones, heartburn or acid reflux.

Things that reduce the pain:

Treating infections with antibiotics, adjusting your bowel regime to allow for proper emptying.

Causes of visceral pain include:

Bloating, constipation, cramping and bladder infection.

C. Neuropathic pain

Neuropathic pain refers to pain caused by damage or disease affecting the nervous system.

Pain location:

It is common to feel neuropathic pain at the level of your spinal cord injury and/or below the level of your spinal cord injury in an area of abnormal or absent sensation. Nerve pain may also occur above the level of your spinal cord injury due to direct nerve compression at your wrist or elbow from pressure and overuse. Pain may be felt in the feet, legs, buttocks, abdomen, trunk, hands, arms and shoulders, depending on the level of your spinal cord injury.

Pain description:

Hot, burning, shooting, stabbing, electric shocks, icy/cold, squeezing, constricting, crawling, tingling or pins and needles.

Things that make pain worse:

Bladder infection, constipation, fatigue, stress.

Things that reduce the pain:

Medications, being distracted, gentle exercise.

Do you know?

It is normal for pain to fluctuate in intensity during the day or from one day to the next. However, when pain suddenly intensifies or the location or characteristics change, it needs to be checked out.

Check if you have a problem

Pain Checklist



Consider the following questions when checking your pain:

Have you been experiencing pain that is:

- hot/burning, cold/freezing, pins and needles/tingling, squeezing, stabbing, shooting, electric shock-like or similar in quality in an area with altered or absent sensation?
- abnormally sensitive skin to touch or provoked by brushing, pressure or contact on painful area?
- is usually unchanged with movement of the painful area?

Have you been experiencing pain that is:

- dull, aching, cramping or tender in muscles and joints in an area of normal sensation?
- made worse by certain movements, postures or activities

Have you been experiencing pain that is is dull, vague, poorly localised or cramping in waves in the chest, abdomen or pelvis in an area with altered or absent sensation?

Has your pain impacting on your daily activities, mood or sleep?

Has your pain changed recently, or have you noticed any other changes, such as feeling unwell with fevers and chills or change in bladder or bowel function?

Have you had a recent fall or trauma prior to the pain developing?

Have you noticed any new signs or symptoms that are alarming associated with your pain, such as loss of muscle strength or sensation, increased spasms, episodes of autonomic dysreflexia?

What to do next

If you answer "**yes**" to any of the questions above, please refer to the Severity Scale (page 23) to see whether your problem is mild, moderate or severe, and Interference Scale (page 23) to decide on what management strategy to take.

Warning signs

Warning signs, also known as red flags,

refer to clinical indicators of possible serious underlying conditions associated with new pain or worsening of existing pain. Red flags require further medical investigation and possible specialist referral, and may include any of the following:

- New pain with different characteristics or a stable pain that suddenly gets worse without any obvious cause
- Any recent change in bowel function, such as nausea, bloating, abdominal pain, constipation, bowel accidents, rectal bleeding
- Changes in your level of sensation, loss in muscle strength or a marked increase in muscle spasm
- Pain associated with autonomic dysreflexia
- Any change in bladder function, e.g., frequent urinary tract infections, bladder leakage, difficulty emptying
- A new area of skin breakdown
- · Pain associated with fevers and chills
- A recent fall or trauma prior to the pain developing.

Yellow flags refer to psychological and social indicators suggesting increased risk of developing long-term distress, disability and pain affecting your independence, quality of life and ability to effectively manage and cope with your pain on a daily basis. These may include the following:

- Alcohol/substance abuse
- Depressive disorder
- Unhelpful thoughts
- Opioid overuse/dependence.



Prevention

Self-management tips for controlling your pain

Seek timely treatment for medical problems

Medical problems, such as urinary tract infections, constipation, poor sleep or spasms, can make pain worse and harder to treat.

Action: Be aware that early treatment for medical problems can help reduce pain.

Exercise regularly

Regular exercise can reduce pain as well as improve your mood and health. Physical activity and exercise are enjoyable and can distract you from pain.

Action: Seek advice from your healthcare professional to develop a suitable exercise program.

Get treatment for depression

Depression can make your pain worse and reduce your quality of life. It is best treated through counselling and medication.

Action: Seek help from your doctor and/or clinical psychologist. They can help you find ways to cope better with your chronic pain and improve your quality of life.



Reduce stress

Stress can make pain worse or make the pain harder for you to cope with. Learning techniques, such as relaxation training, biofeedback and hypnosis can decrease stress. Exercise also helps to reduce stress.

Action: Learn ways to manage stress through counselling and exercise.

Distract yourself

Distraction is one of the best methods for coping with chronic pain. When you are bored and inactive, you tend to focus more on your pain making your pain feel worse.

Action: Take part in enjoyable and meaningful activities to help you feel more in control of your life, especially when pain is at its worst.

Keep a pain diary

It is important to understand what makes you feel better and what makes pain worse. This will help you and your doctor find better ways to manage your pain.



Action: Keep a pain dairy to record how your pain interferes with your daily life (see page 30 for an example).

Get a wheelchair seating evaluation

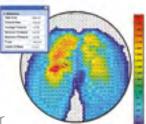
Poor posture and improper seating can contribute to pain problems.

Action: Have your wheelchair and seating evaluated by a specialist therapist.

Know your medications

It is important to understand how your pain medications work as well as their side effects. Using alcohol like a pain medication can lead to serious problems.

Action: Discuss with your doctor what pain medications you are taking and their possible harmful effects.



Ide Effect

1 | Pain

Pain management toolbox

Since there are different types of pain and a range of contributing factors, there is no one-size-fits-all approach. A single strategy, e.g., taking medications may not be as effective as when used in combination with other strategies. You and your doctor may need to try a combination of medications, exercise, pacing of activities, relaxation and other treatments, including psychological treatments, and this may take some time.

Think about using the below toolbox to manage your pain by combining a number of strategies.





Source: this section is adapted and modified from the existing NSW Agency for Clinical Innovation Pain Website for people with spinal cord injury.

1. Healthcare team approach

It is important to learn to work with the different members of your healthcare team to get the best results. When it comes to communicating with your team about pain, it is helpful to understand the type of information your healthcare professional needs to know. This information helps them to identify your pain to formulate your management plan.

A comprehensive interdisciplinary pain evaluation involves assessing the following factors:

- 1. Location and type of pain
- 2. Circumstances associated with pain onset
- 3. Rating of the intensity of your pain
- 4. Impact of pain on your daily activities, mood, rest and sleep
- 5. Any important medical history and presence of warning signs
- 6. Effectiveness of treatment (medications and other strategies) on your pain
- 7. Adverse effects from medications, e.g., nausea, constipation and poor concentration
- 8. Factors influencing your adherence to treatment
- 9. Goal planning to determine what you would like to do if your pain was better controlled.

Sometimes you need to educate your healthcare team about spinal-related health issues so it is important to know where to direct them. See further resources section on page 29.

Do you know?

It is normal for pain to fluctuate in intensity during the day or from one day to the next. However, when pain suddenly intensifies or the location or characteristics change, it needs to be checked out.



"I am going to start keeping a [Pain] diary [to record] as to what is going on."

- Consumer with a spinal cord injury



What does research tell you?

The assessment and treatment of pain in people with a spinal cord injury relies on a holistic, unified team approach to best utilise the full range of medical and non-medical strategies.

Members of your pain management team can include:

GP or local doctor

Your GP is often the first point of contact.

Physiotherapist

Gives advice regarding exercise, fitness, postural re-education and ways to relieve pain, and also provides training in community mobility skills.

Occupational therapist

Helps adapt your home and work environment and teaches you strategies to make daily functioning easier.

Clinical psychologist

Teaches you different strategies and techniques to think about and cope with pain, e.g., relaxation, mindfulness.

Medical specialists

They specialise in the diagnosis, treatment and/or management of pain, e.g., spinal rehabilitation specialist, pain specialist, neurologist, neurosurgeon or orthopaedic surgeon.

Social worker

Provides practical advice, support and help with different aspects of your life affected by your pain, such as work, relationships, family life, income and housing.

Recreational therapist

Plans, coordinates and implements recreation and leisure-based activity programs to support and enhance your psychological, social, emotional and physical wellbeing.

Nurse

Helps with troubleshooting bowel and bladder issues causing pain.

Other members

Include practitioners of complementary and alternative medicine. Techniques include acupuncture, chiropractic, massage therapy, naturopathic medicine and reiki. However, most techniques lack evidence in terms of effectiveness. It's important to be aware of the risks of natural, alternative or holistic treatments.

Please advise your clinician if you try a complementary therapy.

Important notes

Tips to get the most out of your consultation:

- You are likely to need more than one appointment to develop a pain management plan.
- Be clear about what you want to achieve regarding pain management, e.g., sit for longer periods, do more exercise or reduce your pain level by 50%?
- Prioritise your goals.
- Fill out the pain diary (see page 30).
- Take a list of questions.
- Make notes to help remember things or ask someone to go with you.

REMEMBER

- There is a risk of medications interacting with supplements or natural remedies.
- Take an active role in your health and pain self-management, by doing research to be prepared for a discussion with your healthcare providers.

2. Medications

Medications for musculoskeletal pain

Simple analgesics

Panadol works to reduce pain and fever by reducing the release of chemicals that are linked to pain and inflammation.

Non-steroidal anti-inflammatory drugs

Aspirin, ibuprofen and Naproxen reduce pain by modifying the inflammatory response and blocking the activity of a certain chemical in your body.

Muscle relaxant (anti-spasticity) medications

Diazepam (Valium), Baclofen (Lioresal) and Tizanidine (Zanaflex) can be effective for spasm-related pain.

Medications for neuropathic pain

Anticonvulsant medications

Pregabalin (Lyrica) and Gabapentin (Neurontin) work by reducing the excitability and the abnormal firing in damaged nerves after spinal cord injury.

Antidepressants

Duloxetine (Cymbalta), Venlafaxine (Effexor) and low-dose tricyclic drug Amitriptyline (Tryptanol, Endep), work by increasing the amount of chemicals responsible for closing the pain gate and ultimately reduce the volume of pain messages being sent to your brain.

Narcotics (Opiates)

Opiate medications, such as morphine and codeine, may be used to treat moderate to severe pain arising from musculoskeletal or neuropathic conditions. They bind to opioid receptors in the central nervous system which changes the way the brain perceives pain.

In people with a spinal cord injury, opioid medications become less effective over time and often result in unpleasant and severe side effects.

A common problem with opioid medications is the development of addiction and tolerance. Over time you no longer get the same pain-relieving effects – no matter how high the dose. Long-term, high-dose use can have the reverse effect.

Common side effects of opioids include:

- Constipation
- Drowsiness
- Blurred vision
- Dry mouth
- Headache
- Nausea
- Brain fog
- Memory loss.

Other serious side effects are breathing difficulty, worsening of snoring, lowered immunity, depression, overdose and death.

"Now I'm not on any pain medication, I'm much happier because I have a clearer head and my memory has improved." - Consumer with a spinal cord injury



What does research tell you?

A number of medications have proven effective in treating chronic pain disorders, and their use separately or in combination may help to control your pain.

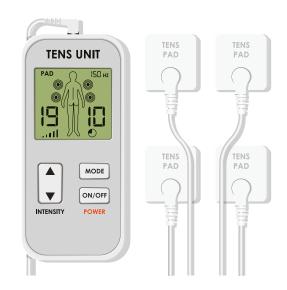
3. Physical treatment and exercise

It is essential to have a healthy body and mind for ultimate pain control. Exercise can help reduce both neuropathic and musculoskeletal types of pain by releasing natural opioid-like chemicals called endorphins. By using the body's own painrelieving chemicals, you can help reduce your pain and improve how you feel.

Exercise strengthens your muscles to help support your bones and joints. This, in turn, improves your posture and ability to perform everyday activities with less effort. After a spinal cord injury, regular exercise helps to maintain muscle conditioning, balance, strength and function. A physiotherapist can develop an individualised exercise plan for you, including:

- Modifying your activities
- Stretching
- Range-of-motion exercises
- Strengthening exercises for strong core and postural muscles.

A transcutaneous electrical nerve stimulator (TENS) has been shown to be effective for treating musculoskeletal pain as it blocks the pain signals from the areas of nerve damage.



Do you know?

Exercising for as little as 3-10 minutes at moderate to high intensity produces significant amounts of endorphins.

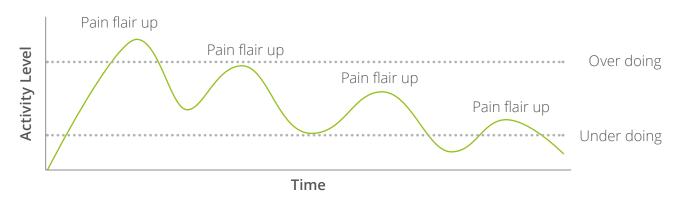


What does research tell you?

Engaging people with chronic pain in physical activity improves their pain, physical function as well as quality of life.

4. Pacing

Reduced activity leads to weakening of muscles, stiff joints and decreased fitness which results in pain flaring up more quickly. An unhelpful activity pattern involves cycles of over- and underdoing activities. Over-doing results in more pain so you have to cut back your activity level. The result is like being on a rollercoaster:



Activity pacing or pacing relates to planning for an activity. It is helpful to break down an activity into smaller chunks. The next step is to build up activities over time.

Important note

Keep an activity diary (page 31) to understand what influences your pain to be able to manage it better.

Planning to pace

- 1. Think about the things you enjoy doing but have had to cut back or stop due to pain. Brainstorm ways to gradually introduce them back into your daily routine.
- 2. Start small and build up gradually towards your goals. Increasing your activity by 10-20% per week will give you long-term results.
- Set a very specific routine and stick to it – this will help you achieve your goals.

5. Thoughts and emotions

The way we think and feel has a direct impact on our pain experience. The brain perceives information about pain location, type and intensity. At the same time, pain messages also travel to parts of the brain that deal with thoughts and emotions.

Your thoughts and emotions either increase or decrease your pain perception, acting like a volume control dial in your brain. If you feel unwell, anxious and stressed, messages from the brain cause the pain gates to open wide. As a result, more pain messages get through and your pain experience gets worse.

In some situations, your pain becomes less of an issue, especially when you focus on something else, e.g., your favourite hobby, watching a movie, listening to music or exercising. These activities help stimulate the body's natural feel-good chemicals and distract your mind. As a result, overactive nerve impulses are reduced and the pain gates close.

Unhelpful thoughts	Can make you feel worried, e.g., 'There must be something terribly wrong to cause this pain.' Negative thoughts can also undermine your confidence, e.g., 'I cannot cope with this.' Both are common in people experiencing chronic pain. Unhelpful thoughts make your pain worse and reduce your ability to cope with the pain.
	The good news is that thoughts can be changed which help reduce your pain and increase your coping ability. Two different ways to deal with unhelpful thoughts:
	 Challenge unhelpful thoughts, such as "I cannot manage my pain" or "My pain will only get worse in the future".
	 Adopt an accepting approach to thoughts and do not engage with them.
Planning and goal setting	Are important to help you achieve what is important, despite the pain. Work out what really matters to you then set achievable goals, break down your goals into smaller, bite-size pieces that are achievable in a daily or weekly timeframe.
Desensitisatior Relaxation and	 Involves learning to focus on the pain but then letting it blend into the background and not focussing your attention on it. Can assist in reducing muscle tension and stress that exacerbate pain by
meditation	activating pain-reducing brain chemicals.



What does research tell you?

Pain catastrophising (which refers to believing that something is far worse than it actually is) can magnify pain symptoms and increase depression, sense of helplessness, anxiety and loss of function.

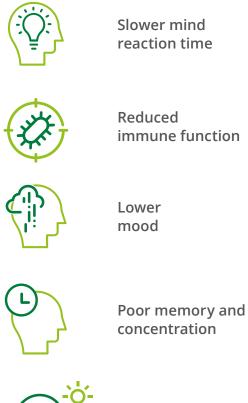
Important note

If you are experiencing substantial problems with your mood, keeping a Mood Diary (page 33) will help to inform your treatment.

6. Sleep

Chronic pain impacts your sleep. A lack of sleep affects your brain's ability to deal effectively with pain and has a negative effect on your mood, energy levels and ability to concentrate.

Effects of poor sleep



Daytime drowsiness

Do you know?

- During sleep many active processes occur that are essential for maintaining good health.
- Alcohol interrupts your sleep cycles and causes disrupted sleep and early awakening. Drinks like coffee and soft drinks cause problems with getting to sleep and staying asleep.

Sleep after a spinal cord injury

Sleep patterns often change after a spinal cord injury affecting the amount and quality of sleep. You might be awake longer, wake up more frequently and have reduced rapid eye movement (REM) sleep. REM sleep is the deep restful sleep when important body processes occur including body rest and repair – it is also when you dream.

Certain factors disrupt sleep patterns, such as spasms, changing position in bed and overnight bladder care.

People with higher injury levels are likely to have more problems producing a natural chemical known as melatonin. A lack in melatonin makes it difficult to get to sleep and/or stay asleep.

More than 60% of people with quadriplegia have obstructive sleep apnoea (OSA). Common signs and symptoms include:

- Daytime sleepiness
- Loud snoring
- Episodes of stopping breathing during sleep
- Sudden waking with gasping or choking
- Awakening with a dry mouth or sore throat
- Morning headache
- Poor memory
- Problem with concentration.

A respiratory and sleep physician treats OSA with the support of your GP.

Treatment options for sleep apnoea

- Healthy lifestyle changes
- Breathing devices
- Mouthpieces
- Therapy for mouth and facial muscles
- Implants
- Surgical procedures.



What does research tell you?

Sleep and pain are interrelated but research has shown that poor sleep is more strongly linked with chronic pain than the other way around.

Tips for having a good night's sleep

Good quality sleep is the result of good sleep habits, also known as sleep hygiene. Consider the following strategies to help you get a good night's sleep:

• Make your bedroom a **SANCTUARY** for sleeping

Don't set up your bedroom like an office or entertainment room. Instead, make sure you have good ventilation, fresh air, a constant comfortable temperature and you create a quiet space without TV or video games.

Have a set **ROUTINE** that symbolises sleep for you

Relax before going to bed, listen to relaxing music or do mindfulness exercises.

• Aim for gentle **EXERCISE**

Exercise every other day for good quality sleep. Avoid exercising just before bedtime.

Avoid CAFFEINE

Caffeine after 3pm can increase your alertness and make it more difficult to get to sleep. Avoid ALCOHOL

Alcohol initially makes you feel drowsy but then increases the likelihood of waking up in the early hours of the morning.

• Try RELAXATION STRATEGIES

Do deep breathing exercises, progressive muscle relaxation or mindfulness meditation for 15 minutes before going to bed to help you relax.

• **DISTRACT** your mind from the pain

Pain can be particularly severe overnight. Listen to music, the radio or an audiobook to keep your mind off the pain.

Practice **DESENSITISATION**

Learn to focus on the pain but teach yourself to let it blend into the background. As you change your focus, you will feel less distress. Desensitisation can be a particularly helpful strategy for coping with neuropathic pain.

Important note

If you are experiencing substantial problems with your sleep, keeping a Sleep Diary (page 32) will help to inform your treatment.



7. Fatigue

Things to consider in understanding and managing fatigue

The energy bank

You have a certain amount of energy in your energy bank so think carefully about how to spend your energy currency by planning your everyday activities.

Triggers

Understand what triggers fatigue as increased awareness will give you more control. Triggers of fatigue include overdoing an activity, eating an unhealthy diet and poor sleep patterns.

Reduce strain

Minimise physical stress and strain on your body.

It's a question of balance

Do not let your pain or fatigue levels dictate what you do. Balance periods of activity with rest. Stick to a level of activity you can easily cope with then gradually increase your activity level.

Communication

Be confident when communicating with others about your pain and fatigue and the impact on your everyday life.

Relaxation and meditation

Activate pain control pathways from the brain to reduce pain.

Planning tips

Take time to plan and order your activities. Perform more challenging tasks earlier in the day when you feel fresh and have more energy.

The right fuel

Eat a nutritious balanced diet to improve your energy levels.

Do you know?

Strategies for managing chronic pain, such as developing a pacing plan and activity plan, are also effective for managing fatigue.



8. Lifestyle and nutrition

Good nutrition is important so your body functions well. After a spinal cord injury your body's nutrition needs change and good nutrition becomes even more critical.

Benefits of having a good and healthy diet with good nutrition

- Stay healthy
- Keep your skin in good condition
- Improve bladder and bowel function
- · Maintain a healthy weight
- Reduce your pain.

Do you know?

Weight loss and good nutrition can reduce pain.

Maintaining a healthy weight is especially important after a spinal cord injury. It is also a crucial part of your pain management program. Gaining weight makes you feel lethargic and aggravates painful conditions such as arthritis, low back pain, shoulder, wrist and elbow pain, and carpal tunnel syndrome (nerve compression at wrist).

Being overweight causes problems with mobility and transfers, leads to muscle and joint strain, and changes the suitability and fit of your equipment. At its worst, being overweight impacts your ability to be independent when carrying out daily tasks.



Management index

The severity of your pain can vary depending on a range of factors.

To decide on the most appropriate management strategy, it is important to assess the severity of your pain and how much it interferes with your participation in everyday activities.

To work out the best management strategy, use the pain intensity and interference scales below.

Pain intensity scale

What is the intensity of your pain on a scale from zero (0) to ten (10)?

'0' me	ans 'no p	ain' and '	l0' means	'worst pa	ain you ca	n imagine	<u>,</u>			
No pain									1	bain you imagine
•	•	•	•	•	•	•	•	•	•	•
0	1	2	3	4	5	6	7	8	9	10

Pain interference scale

On a scale from zero (0) to ten (10), rate to what extent your pain is interfering with participation in your everyday activities.

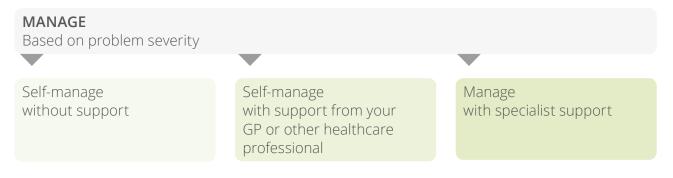
'0' means 'no interference' and '10' means 'extreme interference'

No interfe	erence									Extreme ference
0	1	2	3	4	5	6	7	8	9	10

The following index combines your self-assessment ratings on the pain intensity and interference scales to help you decide what level of support you need to most effectively manage your pain.

Intensity rating	Interference rating	Management strategies
Mild (1-3)	Mild (1-3)	Self-manage without support
Mild (1-3)	Moderate (4-6)	Self-manage without support
Mild (1-3)	Severe (7-10)	Self-manage with support from your GP or other healthcare professional
Moderate (4-6)	Mild (1-3)	Self-manage with support from your GP or other healthcare professional
Moderate (4-6)	Moderate (4-6)	Self-manage with support from your GP or other healthcare professional
Moderate (4-6)	Severe (7-10)	Self-manage with support from your GP or other healthcare professional
Severe (7-10)	Mild (1-3)	Self-manage with support from your GP or other healthcare professional
Severe (7-10)	Moderate (4-6)	Manage with specialist support
Severe (7-10)	Severe (7-10)	Manage with specialist support

Note: If you are self-managing without support and your pain has not resolved, seek help from your GP, other healthcare professional or involve a spinal cord injury specialist in your pain management plan.



What will happen if you do not manage your pain problem 'just-in-time'?

Serious complications can arise if pain-related problems are not managed in a timely way. In the long term, these issues can lead to:

- Physical deconditioning and reduced activity levels
- Interference with your mood and sleep
- Increased reliance on medications
- Resorting to unhelpful or destructive strategies, such as taking illicit drugs or excess alcohol
- Social withdrawal.

'Just-in-time', or the right care at the right place at the right time, helps you manage your pain. As a result you will maintain your quality of life, independence, health and wellbeing.

Be proactive and take responsibility for managing your own health risks

This involves:

- Education to help you understand how your spinal cord injury affects your pain perception and learn about the latest research findings.
- Becoming a partner in decision-making and learning to problem solve with your doctor and health professionals.
- Developing an individual pain selfmanagement program that works for you.
- Engaging in ongoing health and wellness activities. This includes:
 - Exercising regularly
 - Maintaining a healthy weight to reduce load on your shoulders, arms and hands
 - Using medications as instructed by your doctor
 - Incorporating regular relaxation, meditation and mindfulness techniques into your daily life.



Take home messages



Develop a pain

MANAGEMENT PLAN

that gets results



Be aware of all possible

SIDE EFFECTS of medications



Knowledge test

- 1. Which common types of pain are seen in people with a spinal cord injury?
- (a) Musculoskeletal pain.
- (b) Visceral pain.
- (c) Neuropathic pain.
- (d) All of the above.
- 2. Which type of pain is the least common cause of pain in people with a spinal cord injury?
- (a) Musculoskeletal pain.
- (b) Visceral pain.
- (c) At-level neuropathic pain.
- (d) Below-level neuropathic pain.

- 3. An example of neuropathic pain is:
- (a) Shoulder pain.
- (b) Bloating.
- (c) Electric shock pain in the legs.
- d Back pain.
- 4. Warning signs for pain include:
- (a) Red flags.
- (b) Yellow flags.
- C Both.

.

iv. ____

5. List four treatment strategies from the pain toolbox:

١.	
ii.	
iii	

For correct answers, please see page 29.

Glossary

Terms	Definition
Autonomic dysreflexia	An abnormal response to a problem in the body below a spinal cord injury. Most likely to happen if the spinal cord injury is at or above the sixth thoracic vertebra (T6).
Opioids	Depressant drugs that slow down the activity of the central nervous system and messages travelling between the brain and the body. Opioids cause sedative and euphoric feelings, and include pain medications and heroin.
Antidepressants	Medications to relieve symptoms of mild and chronic depression, social anxiety disorder, anxiety disorders, seasonal affective disorder and dysthymia, as well as other conditions.
Anticonvulsant	Drugs used for the treatment of epileptic seizures. Anticonvulsants are also used in the treatment of neuropathic pain and as mood stabilisers in the treatment of psychiatric disorders such as bipolar disorder.
TENS	TENS stands for transcutaneous electrical nerve stimulation. A TENS machine passes electricity across the skin to stimulate your nerves and relieve your pain.
Obstructive sleep apnoea	A sleep-related breathing disorder that involves a decrease or complete halt in airflow despite an ongoing effort to breathe. It occurs when the muscles relax during sleep, causing soft tissue in the back of the throat to collapse and block the upper airway.

Further resources

Reading resources for consumers

 Managing Pain for Adults with Spinal Cord Injury, New South Wales State Spinal Cord Injury Service (16 pages) Access at: https://www.aci.health.nsw.gov.au/__data/assets/pdf_file/0004/155173/sci_managing_ pain.pdf

Useful resources for consumers and medical professionals

- ACI Pain Management network website. Access at: https://www.aci.health.nsw.gov.au/chronic-pain/chronic-pain
- ACI: The SCI Pain Navigator Access at: https://www.aci.health.nsw.gov.au/chronic-pain/spinal-cord-injury-pain/sci-pain-navigator

Videos for consumers

- NSW Agency for Clinical Innovation Pain Management Network
 - Part 1: Introduction to spinal cord injury and chronic pain (19 minutes) Access at: *https://vimeo.com/102191972*
 - Part 2: Understanding pain after spinal cord injury (11 minutes) Access at: *https://vimeo.com/102098039*
 - Part 3: Getting help from your health care team (6 minutes) Access at: *https://vimeo.com/86952260*
 - Part 4: SCI and physical activity and exercise (11 minutes) Access at: *https://vimeo.com/102101565*
 - Part 5: Pain, lifestyle and nutrition (9 minutes) Access at: *https://vimeo.com/86952263*
 - Part 6: Pain and sleep (12 minutes) Access at: https://vimeo.com/86957197



Answers to knowledge test

1: a and c; 2: b; 3: c; 4: c; 5: i. Healthcare team approach, ii. Physical activities and exercise, iii. Pacing, iv. Thoughts and emotion;

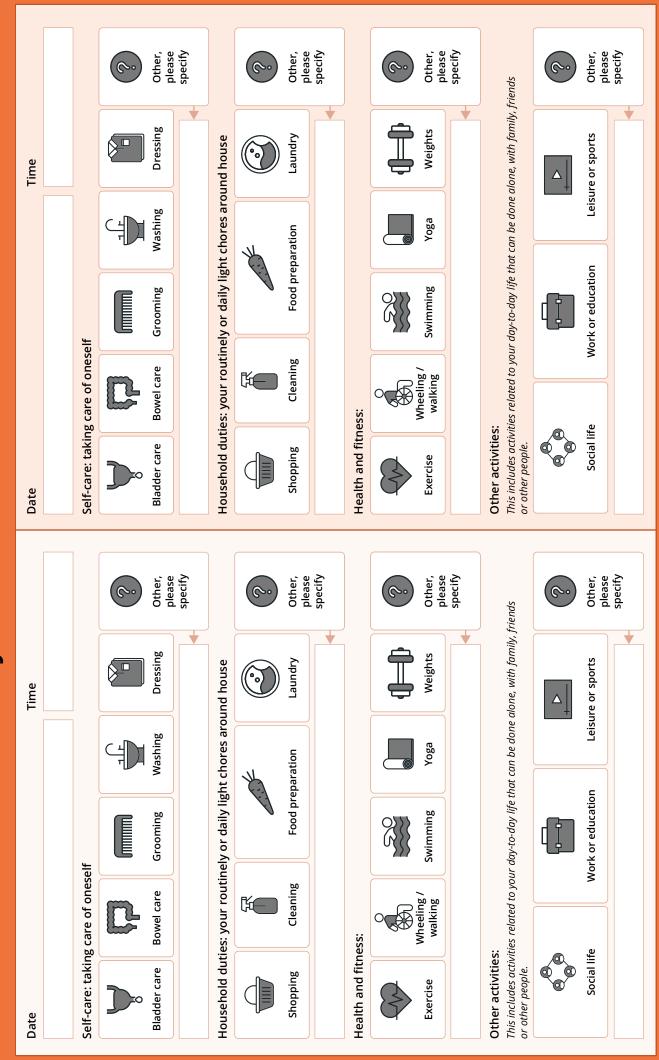
Diary
<u>بارا</u> Pain
Heageh Alintenance tool

Date		Time	Date	F	Time
Location of pain		Please specify other location	Location of pain Side	- - - - - - - - - - - - - - - - - - -	Please specify other location
	Left Right B	Both		Left Right Both	
Patterns of pain	Pain features	Please specify other feature	Patterns of pain	Pain features	Please specify other feature
How intense is your pain	How intense is your pain right now? (1 = very mild to 10 = worst pain imaginable)	0 = worst pain imaginable)	How intense is your pain right now? (1 = very mild to 10 = worst pain imaginable)	: now? (1 = very mild to 10 =	worst pain imaginable)
What makes your pain better? (select all applicable)	etter? (select all applicable)		What makes your pain better? (select all applicable)	? (select all applicable)	
Rest	Medications	Heat	Rest	Medications	Heat
Position/posture	Distraction	Other, please specify	Position/posture	Distraction	Other, please specify
Pacing activity	Meditation/mindfulness	dfulness	Pacing activity	Meditation/mindfulness	llness
What makes your pain worse? (select all applicable)	<pre>prse? (select all applicable)</pre>		What makes your pain worse? (select all applicable)	(select all applicable)	
Performing personal care (e.g., bowel care) Tranefers	e) Exercise/sports or leisure activities	ies Urine infection Other, please specify	Performing personal care (e.g., bowel care)	Exercise/sports or leisure activities	Urine infection Other, please specify
Pushing wheelchair	Stress		Pushing wheelchair	Stress	
Walking	Anxiety		Walking	Anxiety	
Spasms	Constipation/bloating	bating	Spasms	Constipation/bloating	ing
Notes (Record any other relevant info	rmation, such as use of medicat	Notes (Record any other relevant information, such as use of medications (what taken and when) and side effects.)	Notes (Record any other relevant informati	on, such as use of medicatior	Notes (Record any other relevant information, such as use of medications (what taken and when) and side effects.)
Pain interference in last 7	Pain interference in last 7 days with your: (0 = none to 10 = extreme interference)	o 10 = extreme interference)	Pain interference in last 7 days with your: (0 = none to 10 = extreme interference)	s with your: (0 = none to 1) = extreme interference)
Daily activity	Sleep	Mood	Daily activity	Sleep	Mood
Note: if more than 4 on any respectively.	r of the above, please comple	Note: if more than 4 on any of the above, please complete the activity, sleep or mood diary respectively.	Note: if more than 4 on any of the above, please complete the activity, sleep or mood diary respectively.	ie above, please complete	the activity, sleep or mood diary



C Activities Diary

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



Date	Date	Date	Date
What time did you go to bed (time)?	What time did you go to bed (time)?	What time did you go to bed (time)?	What time did you go to bed (time)?
How long did it take you to fall asleep? (minutes)	How long did it take you to fall asleep? (minutes)	How long did it take you to fall asleep? (minutes)	How long did it take you to fall asleep? (minutes)
How often did you wake up during the night?	How often did you wake up during the night?	How often did you wake up during the night?	How often did you wake up during the night?
How many hours did you sleep? (This may be different than the number of hours you spent in bed)	How many hours did you sleep? (This may be different than the number of hours you spent in bed)	How many hours did you sleep? (This may be different than the number of hours you spent in bed)	How many hours did you sleep? (This may be different than the number of hours you spent in bed)
Quality of sleep Very good Fairly bad Fairly good Very bad Fairly good Very bad 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 trailer passing a catheter pain)	Quality of sleep Pairly bad Very good Fairly bad Fairly good Very bad 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 cutherer and and	Quality of sleep Very good Fairly bad Fairly good Very bad 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 toller, passing a catherer balance	Quality of sleep Fairly bad Very good Fairly bad Fairly good Very bad 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 thilet passing a cutherer and

Keep this diary to record your daily

Heagth Contract Sleep Diary

Heagth 00 Moo	Mood Diary		Keep this diary to record your daily mood for a minimum of 14 days .
Date	Time	Date	Time
How are you feeling? (1 = terrible to 10 = great) How much pain do you have at the	How did you sleep last night? 1 = terrible to 10 = great) How much fatigue do you feel at the	How are you feeling? (1 = terrible to 10 = great) How much pain do you have at the	How did you sleep last night? 1 = terrible to 10 = great) How much fatigue do you feel at the
moment? (0 = none to 10 = extreme) m What makes you feel better? (select all applicable)	moment? (0 = none to 10 = extreme)	moment? (0 = none to 10 = extreme) m Mater? (0 = none to 10 = extreme) m Mhat makes you feel better? (select all applicable)	moment? (0 = none to 10 = extreme)
Rest Faith Eaith E	Faith Community Community Self-care contribution (including ce.g., mindfulness) Other, please specify Medication Doing housework	Rest Faith Socialising Self-care Exercise Medication Leisure Doing hous Work Work	Faith Community Community Self-care Contribution (including Ce.g., mindfulness) Cther, please specify Medication Doing housework
What makes you feel worse? (select all applicable)	ale)	What makes you feel worse? (select all applicable)	le)
Stress Not enou, Health problems (other Finance p than pain) Feeling ur Work-related problems excluded Lack of community Sorial & r.	Not enough sleep Other, please specify Finance problems Feeling unsupported or excluded	Stress Not enoi Health problems (other Finance than pain) Feeling L Work-related problems excluded Lack of community Social &	Not enough sleep Other, please specify Finance problems Feeling unsupported or excluded
formation, such	es es f medications, including side effects)	formation, such	estations including side effects)

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:
	 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

Frequency	Checks
Daily	• Self-skin check
-	Stay active
	Eat and drink responsibly
Monthly	• Women: Breast self-exam
5	• Men: Testicular self-exam
Yearly	 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	 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	 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	 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	 Tetanus booster Colonoscopy, which allows your doctor to examine your colon, beginning at 50 years of age (unless at high risk)
When required	Recognise and treat adverse health conditions early

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

Notes

Notes

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 tool.com

Website

The website has interactive elements that you can use anonymously.

Go to: www. healthmaintenance tool.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 "

> Tools to help you stay healthy and well with

a spinal cord injury

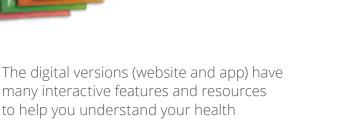
reate Profile



Apple



Google



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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Funding Organisation

• icare NSW

Partner organisations

- The University of Sydney
- John Walsh Centre for Rehabilitation Research, Northern Sydney Local Health District
- Royal Rehab
- NSW Agency for Clinical Innovation
- icare NSW

Informant group with Lived experience

- Cobie Moore
- Emily James
- Jonathan Tang
- Sue Jacobs

We would also like to acknowledge the contribution by Trudy McEnearney and Vanessa Gasiewski from Royal Rehab for Phase 1 of the project.



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