Health Maintenance Tool

How to stay healthy and well with a spinal cord injury

A tool for consumers from consumers

A product of the SCI Wellness Project

An initiative of

Royal Rehab
Empowering Independence

Partnering with

THE UNIVERSITY OF SYDNEY

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Authors:
James Middleton, Clinical Director, State Spinal Cord Injury Service, Agency for Clinical Innovation; Professor of Rehabilitation Medicine, John Walsh Centre for Rehabilitation Research, The University of Sydney.

Mohit Arora, Postdoctoral Fellow, John Walsh Centre for Rehabilitation Research, The University of Sydney; Project Officer, NSW Spinal Outreach Service, Royal Rehab.

Melissa McCormick, Manager, NSW Rural Spinal Cord Injury Service, Royal Rehab.

Dimity O'Leary, Manager, NSW Spinal Outreach Service, Royal Rehab.

Contributors:
Tony Jones, Advocacy Services Manager, Spinal Cord Injury Australia.

Tanya Fitch, Rural Consumer Representative.

Tony Lembke, General Practitioner, Alstonville Clinic.

Selina Rowe, General Manager Community Services and Director of Allied Health, Royal Rehab.

Gerard Weber, Spinal Cord Injury Rehabilitation Specialist, Royal Rehab.

Suzanne Lulham, General Manager, Care, Innovation and Excellence, icare NSW.

Jacqueline Scott, Service Development Manager, Care, Innovation and Excellence, icare NSW.

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Contents

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 five areas: 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, Care, Innovation and Excellence, icare NSW

Acknowledgements

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Steering committee

James Middleton
Mohit Arora
Melissa McCormick
Dimity O'Leary
Tony Jones
Tanya Fitch
Tony Lembke
Selina Rowe
Gerard Weber
Suzanne Lulham
Jacqueline Scott

Partner organisations

- Royal Rehab
- icare NSW
- John Walsh Centre for Rehabilitation Research, The University of Sydney

Consumer representatives and contributors

Cobie Moore
Emily James
Jonathan Tang
Sue Jacobs

Marketing and communication team, Royal Rehab

Vanessa Gasiewski
Trudy McEnearney

Background

What is the SCI Wellness Project?

The SCI Wellness Project is an initiative of Royal Rehab in partnership with the John Walsh Centre for Rehabilitation Research at the University of Sydney with financial support from Insurance and Care (icare) NSW. The primary aim of the SCI Wellness Project, which was undertaken in 2018-19, is to develop a Health Maintenance Tool incorporating current best practice and to provide guidance and recommendations to assist people living with spinal cord injury to self-manage their spinal needs over their lifetime.

In addition, the project aims to:

- Guide primary healthcare professionals and others in the management of spinal cord injury.
- Inform and guide lifelong health promotion and early intervention to maintain consumer health, wellbeing and social participation.
- Involve stakeholders during development to facilitate clinical decision-making and provide consensus on statewide health management recommendations.
- Inform the Lifetime Care Scheme of essential health management pathways.
- Plan and support the implementation of the tool with flexibility to suit different practice requirements.

Why is a Health Maintenance Tool needed in NSW?

The SCI Wellness Project was undertaken following the 2015 Lifetime Care and Support funded project 'Health Assessment and Risk Management in people with spinal cord injury in rural NSW'. The 2015 project collated and reviewed data from the Rural Spinal Cord Injury Service clinics from 2007 to 2012, providing detailed information on the problems that affect people living with spinal cord injury in rural NSW, particularly as they age with their disability.

The report strongly recommended to develop a Health Maintenance Tool to support regular health management. In addition, the project highlighted a lack of consumer-friendly tools that provide consistent evidence-based information to people living with spinal cord injury to self-manage their complex health needs.

"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

What is the Health Maintenance Tool?

The Health Maintenance Tool is a guide and a compendium of health-related information to assist people living with spinal cord injury to self-manage their spinal needs over their lifetime. The content has been developed by spinal cord injury experts including consumers with spinal cord injury, healthcare providers, researchers and other stakeholders. The content has been informed by the most up-to-date spinal cord injury research and consensus statements from healthcare practitioners. The tool is based on effective learning principles.

Development of the Health Maintenance Tool involved a literature review, establishing statewide consensus on management recommendations through consultation with clinical experts and services, and consumer engagement in the tool's design and content.

What is the scope?

The Health Maintenance Tool was developed as a spinal-specific health maintenance schedule for five priority issues:

1. Bladder and its associated problems
2. Bowel and its associated problems
3. Skin and its associated problems
4. Pain
5. Autonomic dysreflexia.

While the tool's focus is on the five priority areas, it is recognised that other issues arise for people living with spinal cord injury, such as equipment or mental health concerns. However, these issues are not covered in this tool.

The project incorporated consumers' perceptions about their health and health needs, and includes current best practice and expert consensus for consumers and their general practitioners to use to proactively manage their health. In addition, the tool aims to guide primary healthcare professionals and non-specialist clinicians in the management of spinal cord injury. The tool is accessible to consumers and clinicians, and can be used to inform essential health management plans.

Background

How to read this tool?

This tool has been written through the eyes of a person living with a spinal cord injury, so you can learn what to do to stay well and know what actions to take when health issues arise. The first step is usually to self-manage, but if this approach doesn't work, an appropriate healthcare professional can help.

The tool has several features to give you plenty of opportunity to self-manage:

- Practical solutions
- Links to further reading
- Interactive elements
- Screening tools
- Easy-to-understand language
- Use of illustrations
- Highlighted key facts.

Each health module has a 'How to navigate' page to guide you to the most relevant sections. The starting point is to understand how your health works after a spinal cord injury then build on that knowledge by asking yourself if there is a problem when you experience a specific health issue.

The navigation tree helps you decide if you only need prevention strategies because you're tracking well, or, if there is an issue, what the cause might be and how to deal with it.

This type of problem solving can help you proactively manage your own health risks, which in turn improve your skills and build your confidence to handle future issues.

"I think knowledge is everything... having access to knowledge."

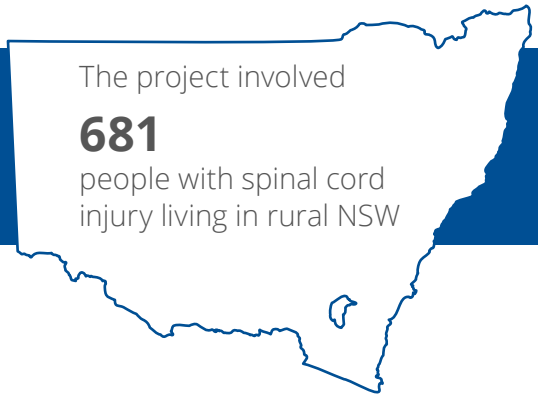
– Consumer with spinal cord injury

The bladder

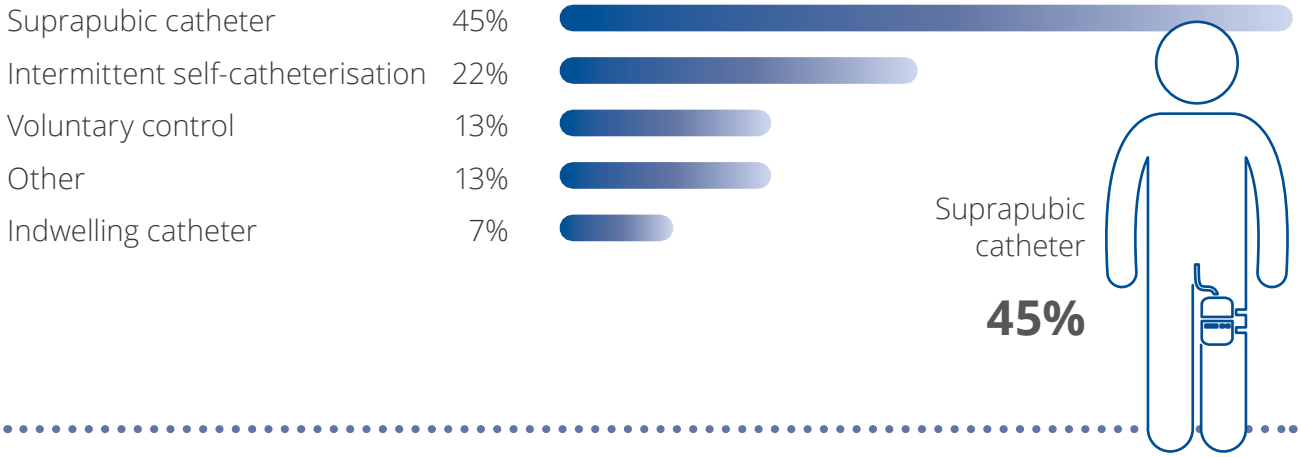
and its associated problems

Contents

Summary of findings
from the 2015 Rural Spinal Cord Injury Project



Methods used for bladder management

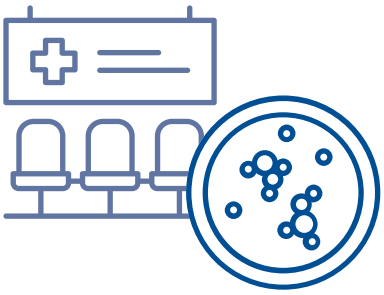


The three most common problems related to the bladder

33%

of individuals performing intermittent self-catheterisation reported

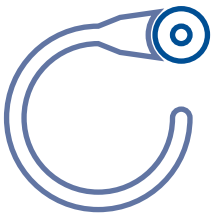
Urine leakage



67%

of individuals hospitalised were admitted primarily for treatment of a

Urinary tract infection



20%

of individuals using a permanent suprapubic or indwelling urethral catheter reported

Blocked catheters

How to navigate this module

KNOW How your bladder and kidneys work (page 5)

CHECK Do you have a problem with your bladder or kidneys?
Refer to checklist and warning signs (page 13)

Yes

IDENTIFY PROBLEM
Look for important signs and symptoms:

- Urinary tract infection (page 19)
- Catheter blockage (page 20)
- Difficulty inserting an intermittent catheter (page 21)
- Urine leakage (page 22)
- Bladder and kidney stones (page 23)
- Blood in urine (page 24)
- Other problems (page 25-27)

CHECK SEVERITY
Based on the management index:

- Severity scale (page 28)
- Interference scale (page 29)

MANAGE
Based on problem severity and interference (page 28-29)

- Self-manage without support
- Self-manage with support from your GP or other healthcare professional
- Manage with specialist support

Is this problem resolved? Have your goals been met?

No

RE-ASSESS

Yes

OBSERVE/PREVENT

No

OBSERVE
Refer to questions in checklist and warning signs

PREVENT
Refer to:

- Self-management tips (page 15)
- Urinary tract infection (page 16)
- Bladder and kidney stones (page 17)
- Routine follow-up and tests (page 18)

EDUCATE
Refer to bladder management (page 19)

What will happen if you do not manage your problem 'just-in-time'? (page 30)

Know about your bladder and kidneys

How the bladder normally works

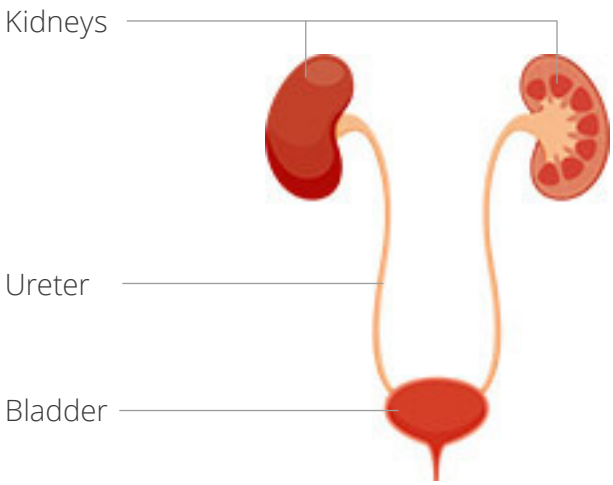
Urine forms as the blood filters through the kidneys. The urine drains down through tubes called ureters for storage in the bladder.

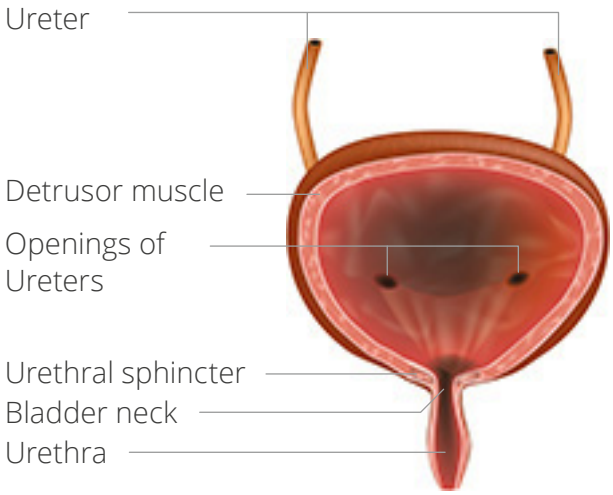
When your bladder is full of urine, it causes the bladder wall muscles to stretch. Nerve impulses or messages travel from your bladder to your brain via your spinal cord. You become aware of how full your bladder is and can decide whether to urinate or to wait until later. You have control over when you go to the toilet.

If you choose to pass urine, your brain sends a message down the spinal cord to the bladder to contract its muscles. As the bladder contracts, the bladder outlet or sphincter muscles relax for coordinated emptying. The urine passes through the urethra to outside of the body.

If you choose not to pass urine, your bladder will keep holding urine until you decide to go to the toilet.

This is how your bladder works to store and then pass urine when you do not have a spinal cord injury.



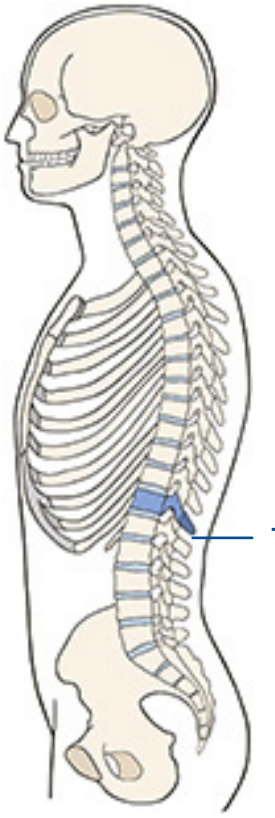


Effects of a spinal cord injury on bladder and kidney function

After injury, spinal nerves carrying messages from the brain to your bladder do not work in the usual way.

This type of bladder is often referred to as a neurogenic bladder.

There are two main types of neurogenic bladder depending on where your injury is:



Overactive bladder
At and above T12 vertebral level
(sacral nerves are intact): Overactive or spastic (hyperreflexic) bladder

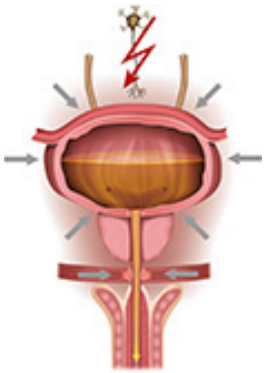
Underactive bladder
Below T12 vertebral level
(sacral nerves are damaged): Underactive or flaccid (areflexic) bladder

Note: Sacral nerves are responsible for controlling the bladder.

The two main types of neurogenic bladder are:

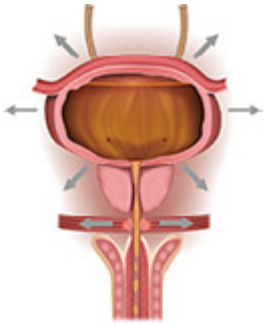
Overactive or spastic (hyperreflexic) bladder

- Bladder muscles get very excited due to lack of control by the brain.
- Bladder holds less urine and bladder muscle spasms as bladder fills up.
- Results in high pressure as the bladder fills with more frequent but poorer urination.



Underactive or flaccid (areflexic) bladder

- Bladder muscles are sluggish or do not work due to damage to the sacral nerves.
- Loss of the ability to contract and bladder is easily stretched.
- Bladder can overfill and leak.



Note: Due to the level of spinal cord injury, some bladders may have a mixed pattern, with some features of both main types.

When you have a neurogenic bladder, you may experience problems with storing urine and/or completely emptying your bladder.

Problems with storing urine

This is a common problem in an overactive bladder that empties too soon and often without any warning as it fills with urine. This usually occurs in people with spinal cord injury above the T12 level.

It can cause:

- Urine to leak (incontinence)
- Passing urine more often
- A strong sense of need to pass urine (urgency)
- High back pressure on the kidneys as the bladder is filling up.

Leakage of urine can also occur in an underactive bladder due to overflow (see 'Problems with emptying your bladder').

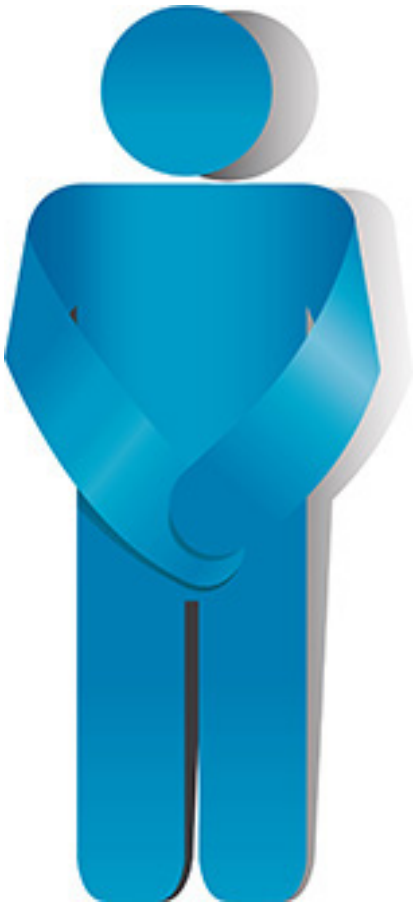
Your doctor may recommend taking an oral tablet to relax your bladder. The most common anticholinergic medication is Oxybutynin (sold as Ditropan). If tablets do not work, a Botulinum toxin injection into the bladder wall may help. This aims to increase the urine storing capacity of an overactive bladder.

Problems with emptying your bladder

This is a common problem in an underactive bladder that does not empty well and retains urine. It can stretch and fill up too much, causing urine to leak when it overflows.

Failure to empty well can also occur in an overactive bladder. This is due to the bladder outlet or sphincter muscles spasming as the bladder empties. This can cause difficulty inserting a catheter or prevent emptying of the bladder completely. There is an increased chance of infection if the amount of urine remaining in the bladder is 100ml or more.

Your specialist may recommend taking an oral tablet (alpha-adrenergic blocker) to relax your sphincter muscles. Botulinum toxin injection into the sphincter muscle or surgery called a sphincterotomy are other options.



Bladder and kidney problems

Common problems

- Urinary tract infection (UTI)
- Catheter blockage
- Difficulty inserting a catheter (this may be due to an overactive sphincter muscle, damage and narrowing of urethral passage or enlargement of prostate gland)

Other problems

- Bladder and kidney stones
- Blood in the urine
- Infection and swelling of the testicles (known as epididymo-orchitis)
- Inflammation of the prostate glands (prostatitis)
- Kidney infection (known as pyelonephritis)
- Widening of the tubes draining your kidneys (ureter/s) and enlargement of the kidney/s (due to high pressures in the bladder causing urine to flow backwards, referred to as hydronephrosis)
- Narrowing (or stricture) of the urethra
- Problems related to pregnancy, menstruation, menopause and sexual activity
- Autonomic dysreflexia in person with spinal cord injury at/or above T6 level (please refer to Autonomic dysreflexia module for further information)

Uncommon problems

- Bladder cancer (in those using a permanent suprapubic or indwelling urethral catheter)
- Prostate cancer (risk is no different from general population, but may be picked up later)
- Purple urine bag syndrome (very rare)

"I know I can get a urinary tract infection if I don't do a hygienic procedure."

- Consumer with spinal cord injury

Ways to empty your bladder

There are three common ways to empty your bladder:

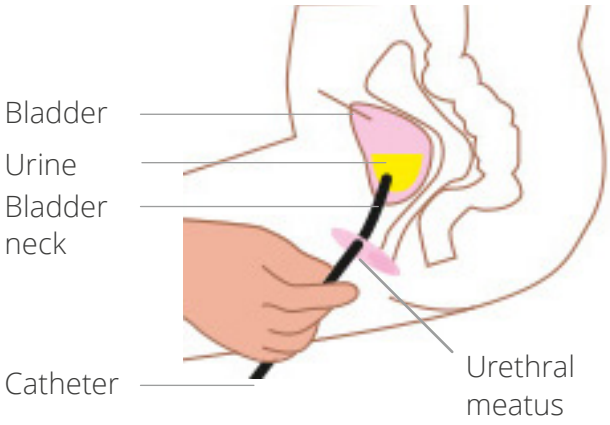
- Intermittent catheterisation
- Permanent catheterisation
- Reflex voiding.

The choice of method depends on factors such as level of injury, lifestyle and gender.

Reflex voiding is no longer recommended due to associated risks. The two most common methods are explained below.

Intermittent catheterisation

- This is the preferred method for people with enough hand function.
- Using this method, drain the bladder for 5 minutes or so by inserting a catheter at regular intervals.
- Drain the bladder every 4 to 6 hours, but this depends on the amount and type of fluid you drink.
- Recommended catheter size is 14, but for people with prostrate problems, use 16 gauge instead.



Important notes

Intermittent catheterisation is not recommended when you have:

- Abnormal urethral anatomy (such as stricture, false passages, and bladder neck obstruction)
- Reduced bladder capacity (less than 200ml)
- Poor decision-making, lack of motivation, inability or unwillingness to adhere to the catheterisation time schedule
- Persistently high fluid intake
- Adverse reaction to passing a catheter into the genital area multiple times per day
- Tendency to develop episodes of autonomic dysreflexia with bladder filling despite treatment.

What does research tell you?

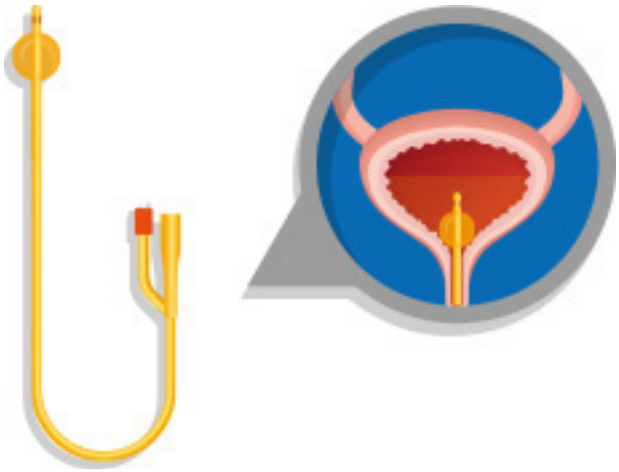
- Clean intermittent self-catheterisation is the preferred method of bladder management for people with spinal cord injury who have enough hand function.
- The use of single-use hydrophilic catheters lowers the risk of a urinary tract infection.

Permanent catheterisation

There are two types of permanent catheterisation:

- Indwelling catheter (IDC): this catheter drains urine from your bladder via the urethra. Recommended catheter size is 12 to 16 gauge.
- Suprapubic catheter (SPC): this type of catheter is inserted into the bladder through a small cut in the lower abdominal wall. Recommended catheter size is 18 to 24 gauge.

In both types, there is continuous drainage with the urine draining into a urinary drainage bag.



Important notes

Reflex voiding involves passing urine by triggering an automatic response using a technique like tapping over the bladder or stroking the inner thigh.

Reflex voiding is no longer recommended because of the long-term risk of high pressure being placed on the kidneys as the bladder fills against resistance which may lead to kidney failure in the long term.

Reflex voiding may also lead to other potential problems such as catheter leakage or skin breakdown of the penis. Using a condom catheter may result in recurrent symptomatic UTI, poor bladder emptying, and autonomic dysreflexia.

Do you know?

Some people use a flip-flo valve attached to their permanent catheter and/or bag, which is not continuous and NOT recommended for people at risk of autonomic dysreflexia.

What does research tell you?

- People with an overactive bladder using a permanent suprapubic or indwelling urethral catheter are recommended to take an anticholinergic medication.
- Reflex voiding should no longer be used because it can cause too much pressure in the bladder and damage to the kidneys.

Recommendations for selecting a catheter

When selecting a catheter that works best for you, consider the following:

- Your level of injury
- Degree of hand function and dexterity
- Your lifestyle (includes school, work and social activities)
- Cost and ease of use
- Other existing medical conditions
- The availability and expertise of your caregiver.

Do you know?

A single-use, disposable catheter may help reduce the chances of bladder infection, especially with a catheter tip that remains sterile (closed 'no touch' system). This type of catheter may be preferred, particularly when you are experiencing frequent urinary tract infections.

Advantages and disadvantages of different types of catheters

Type of management	Advantage	Disadvantage
Intermittent catheterisation	Reduced infection.	Usually need to take anticholinergic medications which are costly and you may require assistance with insertion.
Permanent catheter	Reduces pressure in your bladder and often recommended with limited hand function. Convenience and less caregiver assistance.	Increased risk of infection, problems with blockage. May need to access external providers for catheter changes.

Bladder management supplies

Eligibility for continence supplies

You may be eligible (certain criteria apply) for continence supplies under various schemes, as summarised in the table below:

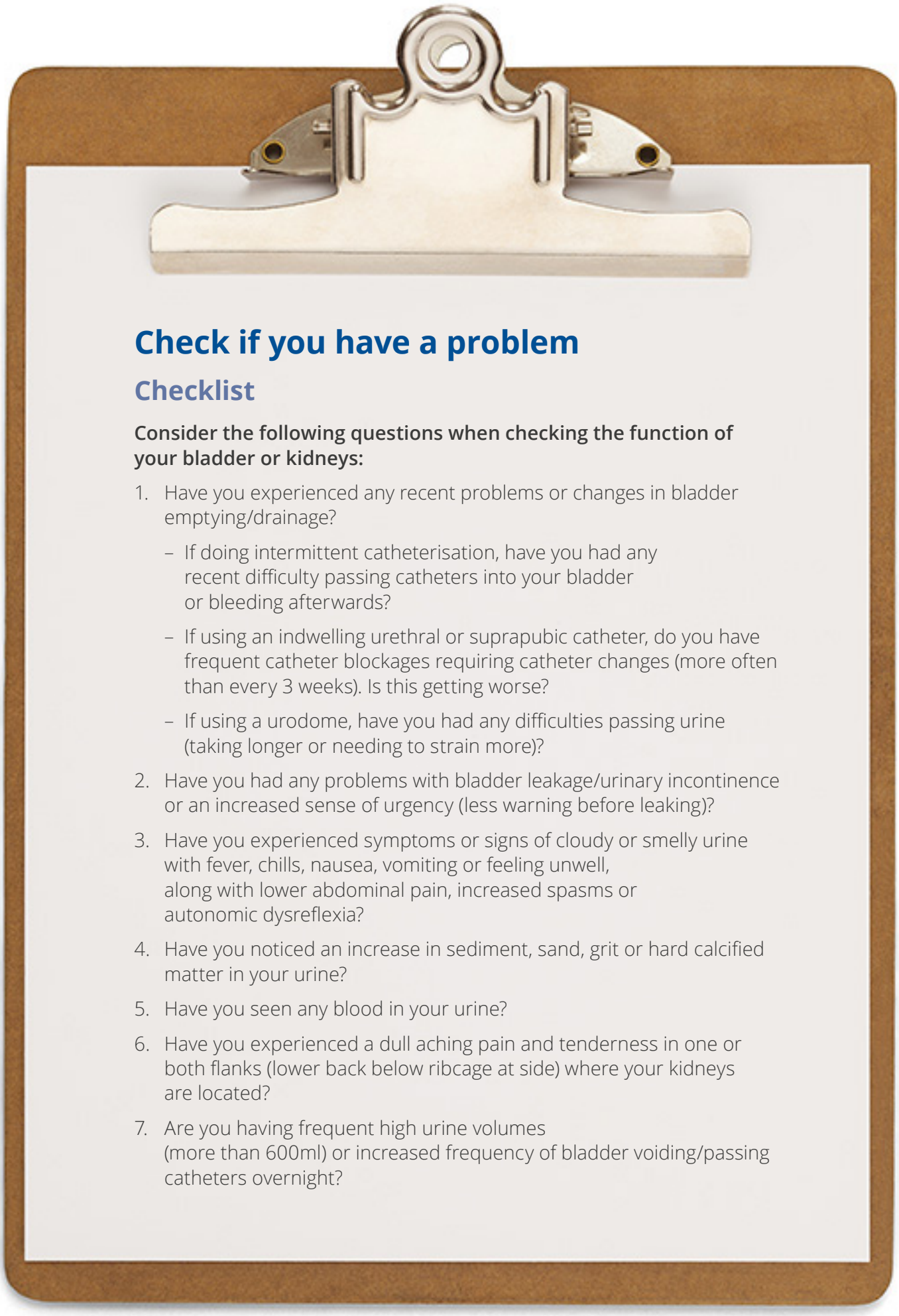
Schemes/ Programs	Under 65 years	65 years and over
National Disability Insurance Scheme (NDIS)	✓	✗ $
My Aged Care	✗	✓ *
Continence Aids Payment Scheme (CAPS)	✓	✓
EnableNSW	✓	✓
icare NSW #	✓	✓

$ Unless you have accessed scheme prior to turning 65 years.
* Your package may not include your bladder supplies.
# For eligible participants only.

Please talk to the relevant organisation/s or your healthcare provider for details about eligibility and further information.

Schemes/ Programs	Website*	Contact details
National Disability Insurance Scheme (NDIS)	**www.ndis.gov.au/people-disability**	1800 800 110
My Aged Care	**www.myagedcare.gov.au**	1800 200 422
Continence Aids Payment Scheme (CAPS)	**www.bladderbowel.gov.au/caps**	1800 239 309
EnableNSW	**www.enable.health.nsw.gov.au**	1800 362 253
icare NSW	**www.icare.nsw.gov.au**	1300 738 586

* Last verified on 27 March 2020



Check if you have a problem

Checklist

Consider the following questions when checking the function of your bladder or kidneys:

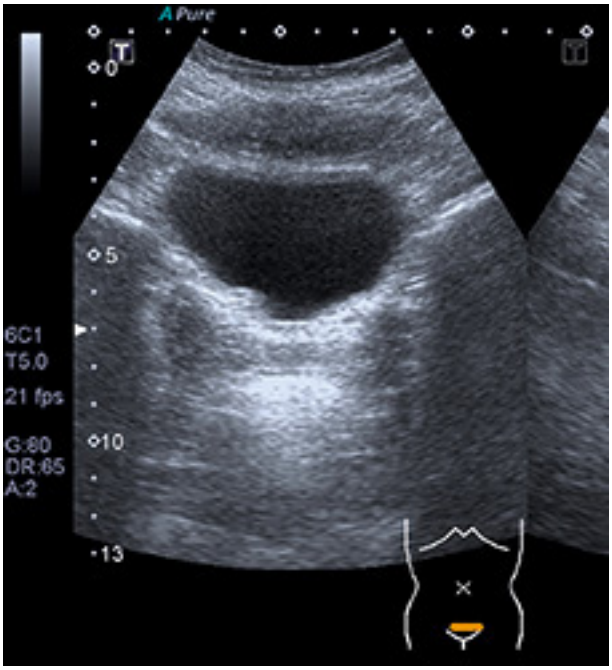
1. Have you experienced any recent problems or changes in bladder emptying/drainage?
   - If doing intermittent catheterisation, have you had any recent difficulty passing catheters into your bladder or bleeding afterwards?
   - If using an indwelling urethral or suprapubic catheter, do you have frequent catheter blockages requiring catheter changes (more often than every 3 weeks). Is this getting worse?
   - If using a urodome, have you had any difficulties passing urine (taking longer or needing to strain more)?
2. Have you had any problems with bladder leakage/urinary incontinence or an increased sense of urgency (less warning before leaking)?
3. Have you experienced symptoms or signs of cloudy or smelly urine with fever, chills, nausea, vomiting or feeling unwell, along with lower abdominal pain, increased spasms or autonomic dysreflexia?
4. Have you noticed an increase in sediment, sand, grit or hard calcified matter in your urine?
5. Have you seen any blood in your urine?
6. Have you experienced a dull aching pain and tenderness in one or both flanks (lower back below ribcage at side) where your kidneys are located?
7. Are you having frequent high urine volumes (more than 600ml) or increased frequency of bladder voiding/passing catheters overnight?

Warning signs

If you experience any of the following issues, these are the warning signs indicating there may be a serious problem requiring further investigation and/or treatment:

- Recurrent urinary tract infections (3 or more in last 6 months)
- 'Grit' or urinary sediment
- Blood in urine
- Changes on ultrasound or other x-ray imaging, including;
  - Presence of kidney and/or bladder stones OR
  - Hydronephrosis (swollen kidney/s because your urine is backing up under pressure from your bladder and filling it with urine)
- Deterioration in blood tests for renal (kidney) function. See page 18 for more details.

Ultrasound of a kidney



Ultrasound of the bladder

Prevention

Self-management tips to maintain a healthy bladder and kidneys

Learn how to identify a likely bladder infection

Urine that is smelly, dark in colour and/or cloudy without other signs (such as fever, increased spasms) rarely needs any treatment. Look for the presence of blood, sediment or other debris that may indicate an infection or other problems.

Action: Drink plenty of fluid, unless you are told not to drink a lot of fluid for other reasons. Aim to drink 6-8 glasses per day or drink the maximum amount you are allowed.

If you feel ill, have a raised temperature or experience other symptoms, such as increased spasms, pain or autonomic dysreflexia, seek medical help immediately.

Organise your bladder equipment

Make sure you know which equipment comes from where, the cost and who's paying for it.

Check your eligibility for bladder supplies (refer to page 12).

Action: Always have at least 3 months' supply on hand in case your order is delayed.

Change your catheter regularly

Ensure your suprapubic catheter or indwelling catheter is changed every 4 weeks.

Action: Always have contact details of your healthcare professional handy (especially when being discharged after your spinal cord injury) to arrange a catheter change, or know where to go in an emergency.

Be prepared for the unexpected

Ensure you have an 'emergency' supply of basic equipment – catheters, drainage bags, and so on.

Action: Make sure to always take a few extras in case you are held up and don't get back when you thought you would.

Know your medications

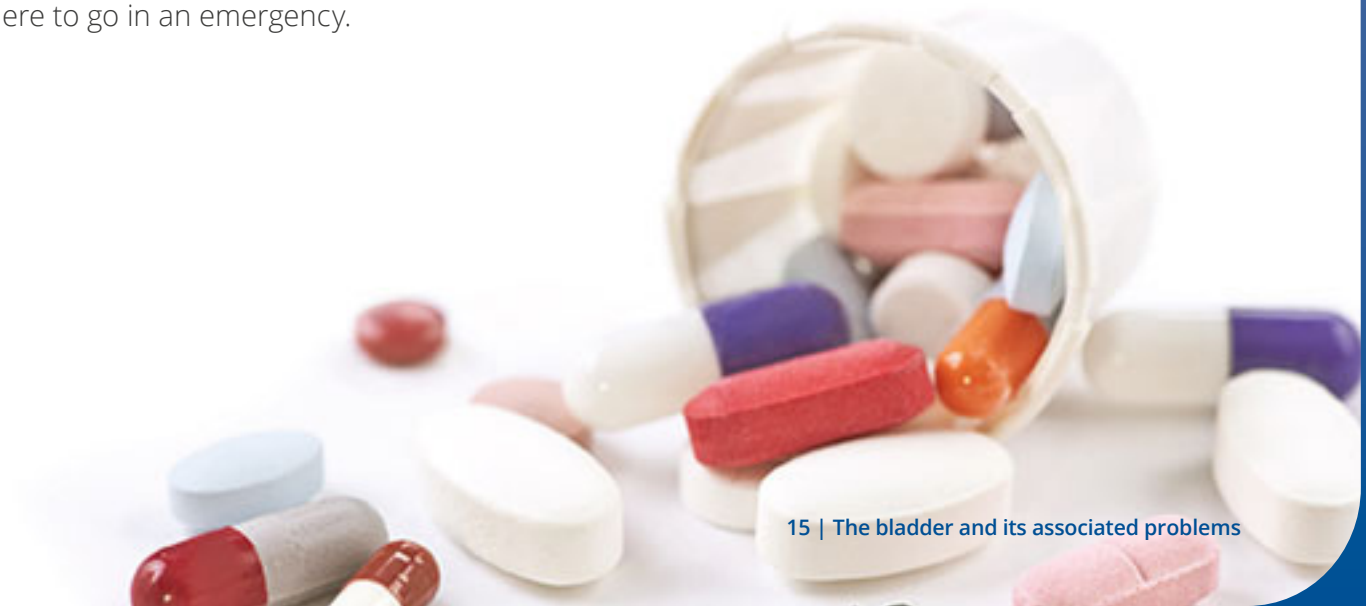
Know which medications you are taking for your ongoing bladder management. It is important that you understand how each medication works, why you are taking them and the possible side effects.

Action: Ask your GP to explain your bladder medications and why you need to take them.

Know who to call if you need advice

Make sure you know who is available to give you advice. Bladder problems can be really frustrating and interfere with many aspects of your life, if they remain unresolved.

Action: Always have a contact list handy. Your community nurse, GP or other healthcare providers such as a urologist should be able to assist you. Carry your AD Emergency Treatment card (for more details, read the Autonomic dysreflexia module) and medications.



How to prevent a urinary tract infection

Empty your bladder at regular intervals to prevent it from getting too full

- If you do intermittent catheterisation, do it regularly (usually every 3-4 hours).
- If you use an indwelling catheter, change it every month.

Drink plenty of water to flush out the bacteria

- The colour of your urine can help guide you to drink enough water.
- Your urine should be yellow or golden in colour.
- You may need to drink more water if your urine is darker.

Cut down on drinking liquids such as alcohol, caffeine and sugar drinks

Eat a healthy diet and exercise

- This can help to boost your immune system and fight off infections.

Maintain good hygiene

- Maintaining good hygiene and keeping the area clean is a good way to stop the infection from spreading further.

Use of antiseptics (to weaken and slow the growth of bacteria)

- Current research does not support taking Hiprex with vitamin C or cranberry as an effective treatment of urinary tract infection.
- If you think cranberry helps, take tablets instead of drinking the juice which has added sugar.

Use of antibiotics

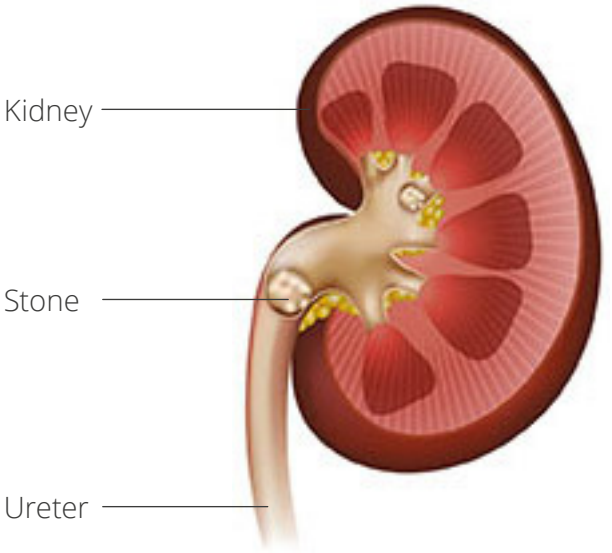
- Take the antibiotics exactly as prescribed and over the prescribed time frame.
- Do not stop taking them when you begin to feel better but finish the full course.
- If you have frequent UTIs, your doctor may recommend continuing to take a low dose antibiotic. A decision should balance the benefits of this against the risk of developing a drug resistant bacteria.

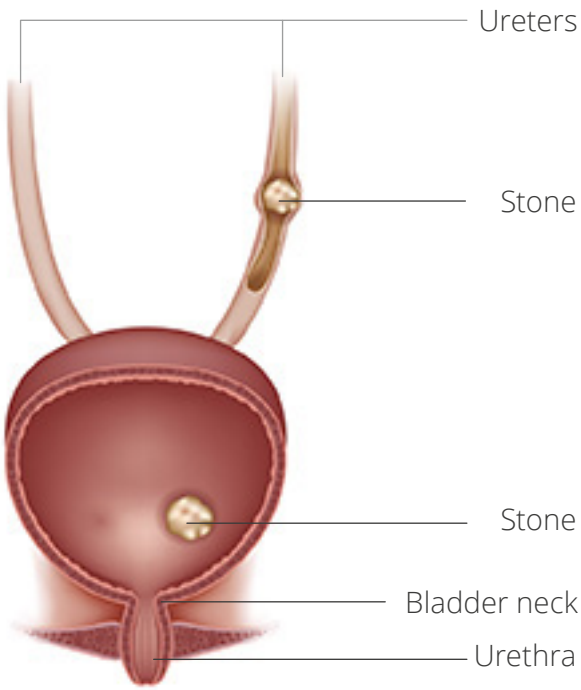
What does research tell you?

Cranberry products, such as tablets, capsules or juice, are not effective in preventing urinary tract infections in people with neurogenic bladders managed with intermittent or permanent catheterisation.

How to prevent bladder and kidney stones

- Pass intermittent catheters at regular intervals using the correct technique. This will prevent urine staying in the bladder for too long.
- Drink plenty of fluid (6-8 glasses of water is recommended per day) to avoid urine becoming too concentrated.
- Do or engage in as much exercise as possible.
- Changes in diet may help reduce some types of stones.
- Consume a high-protein diet. This reduces the level of chemical (citrate) in urine, which prevents stone formation.
- Limit or cut down foods with high amounts of oxalate. Food such as spinach, beetroot, sweet potato, grapes, capsicum, celery and liquids such as black tea.
- If your blood phosphate level is low, you will need supplementation.
- Request a kidney (renal) ultrasound every year to check for stones or other problems.





What does research tell you?

Increase your water intake and add lemon juice to the water. Lemon juice is high in citrate, a chemical, which may stop calcium from binding to other stone constituents thus preventing stone formation and recurrence. While the evidence on diet is mixed, the experts agree that a normal calcium intake and a low salt intake may help prevent stone recurrence.

Routine follow-up and tests

In general, your GP or continence nurse is the first point of contact for most bladder-related problems. You may also want to contact your community nurse or case coordinator.

It is recommended to have a ROUTINE FOLLOW-UP with your GP once a year to check your bladder and kidney health; more often if you have bladder problems.

As part of the **yearly review** of your upper and lower urinary tract function, you should have the following tests done:

Ultrasound

- An ultrasound of your bladder and kidneys is a useful, cost-effective, non-invasive method for long-term routine follow-up.

Blood tests

- Electrolytes, urea and creatinine (EUC)
- Estimated glomerular filtration rate (eGFR).

Urine test

- Urine albumin to creatinine ratio (ACR).

Other tests may be ordered **less often** or as needed. These may include:

X-ray or CT scan

- An x-ray or CT scan of kidneys, ureters and bladder (KUB).

Renal (isotope) scan

- A nuclear medicine test that uses small amounts of radioactive material to see how urine flows through the kidneys, ureters and bladder.

Videourodynamic study

- A test assessing pressure and flow in the lower urinary tract when your bladder is filling and emptying.

What does research tell you?

- It is recommended to have annual monitoring of upper and lower urinary tracts by performing an ultrasound.
- Ultrasound has a good sensitivity for detecting problems with the upper urinary tract. If an ultrasound is abnormal, further testing needs to be done.

Management of bladder and kidney problems

Urinary tract infection

Urinary tract infection (UTI) is an infection of the urinary system (including kidneys, ureters, bladder and urethra). It is a very common problem after spinal cord injury. Most infections involve the lower urinary tract — the bladder and the urethra. UTI occurs when bad bacteria enter and multiply in the bladder.

General signs and symptoms of UTI may include:

- Fever and chills
- Feeling unwell and lethargy
- Nausea and vomiting
- Blood in urine.

Note: Cloudy or smelly urine alone does not need antibiotics or urine testing.

Spinal cord injury specific signs and symptoms of UTI may include:

- Abdominal discomfort or flank pain, as well as
- Increased spasms, autonomic dysreflexia or sense of unease.

Note: Due to your spinal cord injury, you may not experience common signs and symptoms of urinary tract infection such as a burning sensation when urinating.

How to treat a urinary tract infection

- Collect a urine sample from a fresh catheter change (or from an indwelling catheter if changed within a week). Do this before starting treatment.
- Increase fluid intake as this helps to dilute urine and flush out bacteria.
- Take antibiotics as prescribed – usually for 7-10 days and do not stop when feeling better. Send another urine specimen for analysis 48 hours after finishing your course of antibiotics to check if your urine infection has cleared.
- You may need to take a second course of antibiotics if it takes a few days before you start to feel better.
- If you are not feeling better, check with your doctor if you are taking the right antibiotic.
- If you experience frequent infections, presence of grit or blood in your urine, you may need an ultrasound. You may also need a referral to a urologist or your spinal specialist for a medical review.

What does research tell you?

Long-term use of antibiotics is not encouraged as it results in reduced effectiveness of that antibiotic.

Catheter blockage

This problem occurs in people using suprapubic or indwelling urinary catheters. Flow of urine can be blocked by:

- Kinks in the catheter
- Kinks in the tube of the drainage bag
- Debris or grit building up in the catheter.

Note: Catheter blockage is an emergency and needs fixing as soon as possible.

What to do if there is no urine draining into your bag

- Check and remove any kinks in the catheter or drainage bag tubing. Wearing loose fitting underwear may help.
- Check that the drainage bag is always positioned below the level of your bladder.
- Check that the leg bag straps are not obstructing drainage.
- Unless you experience signs of a full bladder, such as abdominal discomfort, increased spasms or autonomic dysreflexia, drink 1-2 glasses of water to help your urine flow.
- If there is still no urine draining after 30 minutes or you have an episode of autonomic dysreflexia, your situation has now become an emergency. Call 000 for an ambulance.

Note: Increasing the size of the balloon holding the catheter in place is not advised.

Another problem is urine leaking around the blocked catheter, also called bypassing. Bypassing can also result from bladder spasms.

What does research tell you?

The most common cause of autonomic dysreflexia is a distended bladder.

Difficulty inserting an intermittent catheter

If you cannot get the catheter in, do not force it and follow the steps below:

- Ensure adequate lubrication.
- Try a slight cough or bear down as this may help to open the bladder neck.
- Check you have inserted your catheter in the right place.
  - For females: check you have not inserted the catheter into your vagina by mistake. If you have, discard this catheter and try again using a new catheter to avoid transferring germs from the vagina to the bladder.
  - For males: ensure you have inserted the catheter about 18-25cm into your penis.
- Take an extra Oxybutynin tablet and try inserting the catheter again in about half an hour.
- Use of anaesthetic gel (2% lignocaine) inserted into the urethra 5 minutes prior to passing a catheter may help.
- If the catheter seems to be in the right place but not draining, the lubricating gel may be blocking the catheter drainage holes. Wait for several minutes as the gel is water-based and may take a little time to dissolve in the urine.

If your bladder is still full and you are feeling sick and uncomfortable, your situation has now become an emergency. Call 000 for an ambulance.

Important note

If you have recurrent problems with inserting a catheter, other associated medical conditions may be the cause and must be ruled out by consulting your doctor.

Medical conditions may include an overactive sphincter muscle, damage and narrowing of the urethral passage or enlargement of the prostate gland.

Urine leakage

After spinal cord injury, leakage of urine can happen as the bladder fills and stores urine. This is also known as incontinence.

There are several different types of incontinence:

- **Stress incontinence** occurs when the pelvic muscles cannot hold the urine as bladder pressure increases. For example, this may happen during a transfer, exercise, coughing or sneezing.
- **Overactivity incontinence** occurs when the bladder automatically contracts while it is filling.
- **Urge incontinence** can also occur in an overactive bladder. This happens when there is a sudden desire to pass urine and you can't hold on long enough to get to the toilet.
- **Overflow incontinence** occurs when urine leaks from a bladder that is always full.

How to treat urinary leakage

The choice of treatment depends on the type of urinary leakage problem and the severity. It can be helpful to keep a daily diary recording how much you drink, how often you pass urine and the amount of urine leakage. The treatment may include:

- Using medications:
  - To calm an overactive bladder (anticholinergic) or
  - To tighten lax bladder neck/sphincter muscles (alpha-adrenergic).
- Losing weight and making lifestyle changes. This includes quitting smoking and reducing alcohol, coffee and tea. These are diuretics that promote urine production.
- Managing your bowel care well to prevent constipation or straining to empty.
- Injecting a substance called macro-plastique to bulk up the soft tissues around the urethra. This procedure is performed by a urologist and helps narrow the bladder opening.
- Performing pelvic muscle exercises with biofeedback, if there is some muscle control.
- Undergoing surgery:
  - To place a mesh strip or "sling" around your urethra to lift up and support the bladder neck or;
  - Inserting an artificial urinary sphincter.

Important note

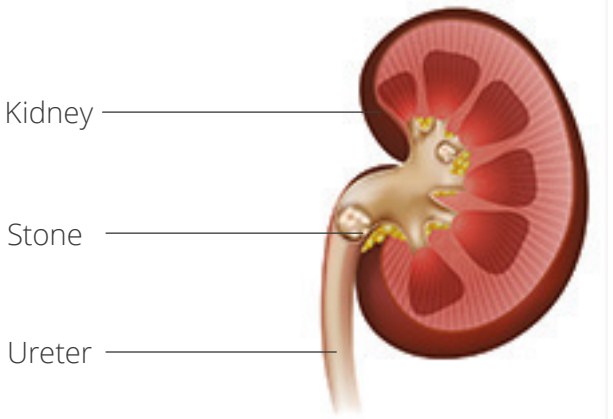
Keep a bladder diary to record fluid intake, frequency of bladder emptying (day and night), amounts emptied, episodes of leakage, amount of leakage/pad usage, and other information such as a sudden desire or urge to pass urine and medication use (see page 35).

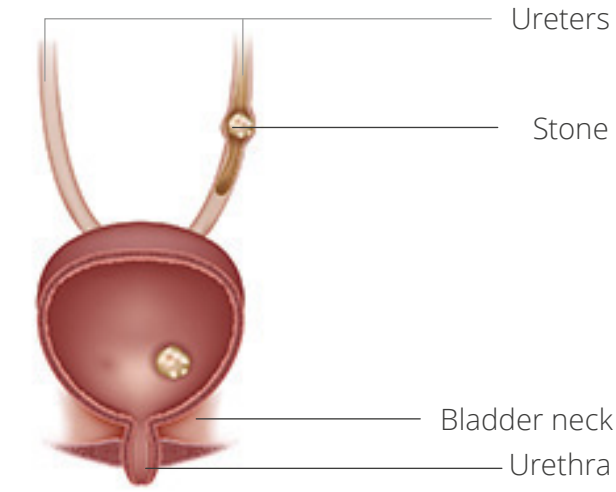
Bladder and kidney stones

Bladder and kidney stones are hard crystals made up of minerals and proteins found in urine. They can cause serious problems, including blocking the flow of urine into or out of the bladder and recurring infections.

After a spinal cord injury, the chances of developing a stone increase because of:

- Changes in how well your bladder drains
- Use of catheters
- Recurring urinary tract infections
- Concentration of urine from not drinking enough
- Higher levels of calcium from your bones.





Signs and symptoms of a stone may include:

- Pain in the lower abdomen or lower back, if some sensation is present
- Recurrent urinary tract infections
- Increased urge to pass urine or bladder overactivity
- Increased spasms
- Increased sweating
- Blood in the urine
- Seeing stones passed in the urine
- Autonomic dysreflexia – in people with injury at T6 level or above, for more details see the Autonomic dysreflexia module.

How to treat bladder and kidney stones

- Small stones may be passed by drinking a lot of water.

If this does not help, your doctor may refer you to a urologist for treatment.

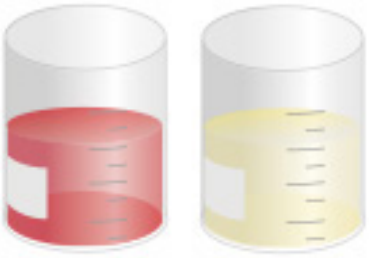
- A common treatment involves passing a telescope-like device, called a cystoscope, into the bladder. The stones are then crushed or broken up with a laser into smaller pieces and flushed out.
- Another common treatment, called lithotripsy, uses shock waves to break up kidney stones.
- Sometimes larger stones need removal with open surgery.

What does research tell you?

Ninety-eight percent of stones are less than 5mm in diameter and likely to be passed spontaneously. This percentage decreases as the stone diameter increases.

Blood in urine

Blood in the urine, called haematuria, can be either visible to the eye or only seen through a microscope. Blood that is visible can vary in appearance from light pink to deep red with clots. People who can see blood in their urine will visit their doctor with this obvious problem. However, people who have microscopic haematuria will not realise they have it until found during a routine health check.



Visible haematuria | Microscopic haematuria

Causes of blood in urine

Visible and microscopic haematuria result from bleeding anywhere along the urinary tract. Your doctor should investigate any amount of blood in the urine. The causes of visible and microscopic haematuria are similar:

- Urinary tract infection
- Kidney and bladder stones cause irritation and abrasion of the urinary tract which leads to blood in the urine
- Trauma to the urethra, prostate or suprapubic tract, which is the opening to the bladder in the lower abdomen
- Kidney disease
- Use of certain medications such as aspirin that can increase the risk of bleeding
- Cancer somewhere along the urinary system, though this is rare.

How to treat blood in urine

Treatment for haematuria will vary depending on the reason for the bleeding. Many episodes of haematuria will settle down without any specific treatment with no cause found. You can reduce the risk of haematuria by maintaining a healthy urinary tract as follows:

- Drink about 6-8 glasses of water of fluid daily, more during hot weather.
- Avoid smoking cigarettes, which increases the risk of bladder cancer.
- For men over 50 years – check with your doctor for an annual prostate examination and prostate-specific antigen (PSA) blood test. This is important to rule out prostate cancer, which is sometimes associated with haematuria.
- If your haematuria does not resolve within 1 or 2 days or recurs, a review is required.

Your urologist will be responsible for recommending any further investigations or treatment.

What does research tell you?

A urological referral is recommended for people with spinal cord injury presenting with visible haematuria, persistent microscopic haematuria, abnormal urine tests showing abnormal cells or recurrent urinary tract infections.

Epididymitis and epididymo-orchitis

Epididymitis is the inflammation of the epididymis, the tube at the back of the testicle. Epididymo-orchitis refers to inflammation of both the epididymis and testicle.

Signs and symptoms may include:

- Swelling and tenderness of the affected epididymis, testicle or scrotum
- Fluid around the testicle called a hydrocoele
- Fever and generally feeling unwell.

The pain may become constant and severe. If the cause is a sexually transmitted disease, a discharge from the penis may be present.

How to treat epididymitis and epididymo-orchitis

- Bed rest
- Oral antibiotics and pain killers
- Ice packs applied to the scrotum
- Immobilising scrotum with a jockstrap to decrease pain from movement
- Drainage of pus by a qualified medical practitioner.

If not treated properly, this condition can lead to permanent infertility.

Prostatitis

Prostatitis refers to swelling and inflammation of the prostate gland. This can develop gradually or suddenly. It often affects young or middle-aged men. There can be pain in the lower abdomen or when passing urine (burning) if sensation is present. There may be problems with urination, difficulty passing catheters or painful ejaculation.

Chronic prostatitis can also lead to recurring urinary tract infections. Your doctor may recommend you to take antibiotics to treat the infection. Antibiotic treatment without symptoms is usually not necessary.

Pyelonephritis

Pyelonephritis is a severe kidney infection, which usually comes on suddenly. It can start as an infection in the lower urinary tract. People with backflow of urine from the bladder, called reflux, are at greater risk.

Symptoms and signs may include:

- Fever and chills
- Pain in your back, side or groin
- Nausea and vomiting
- Cloudy, dark, bloody or foul-smelling urine.

How to treat pyelonephritis

Treatment often requires admission to hospital, involving intravenous antibiotics as well as an extended course of oral antibiotics for 10-14 days. Surgery may be necessary to drain the pus that does not respond to antibiotics.

Hydronephrosis

Hydronephrosis is swelling of one or both kidneys from a build-up of urine. This can be due to:

- Obstruction of the tubes, called ureters, draining the kidney, or
- Backflow of urine already in the bladder.

Common causes of hydronephrosis:

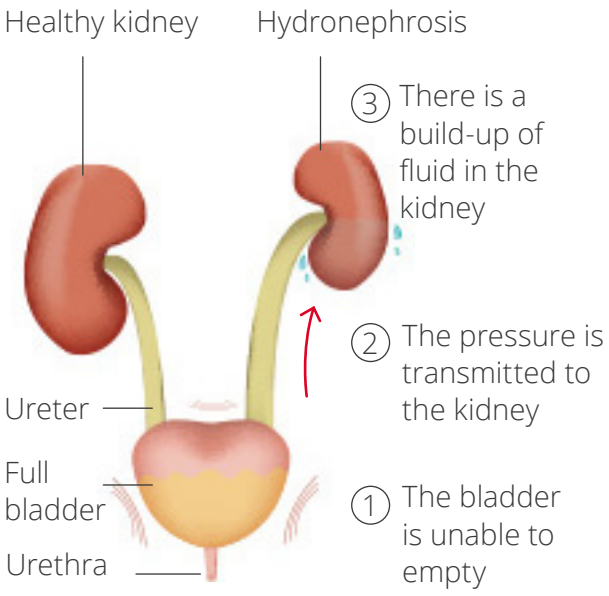
- A kidney stone blocking the ureter
- High pressure in an overactive bladder
- An enlarged prostate.

In a person with a spinal cord injury, the usual signs and symptoms may not be obvious. An ultrasound of the kidneys can detect hydronephrosis at an early stage.

How to treat hydronephrosis

Treatment involves addressing the cause, e.g. removing a stone from the ureter.

You may need to change the way you manage your bladder. A temporary procedure to drain the kidney, known as nephrostomy, may be necessary. **It is critical to deal with this problem as soon as possible**. Severe urinary blockage and hydronephrosis can lead to kidney failure.



Urethral stricture

A urethral stricture is a constriction or narrowing of the urethra. It occurs in a small number of men who perform intermittent self-catheterisation. Urethral stricture results from trauma, tissue inflammation and scarring.

Treatment usually involves:

- Incision of the stricture in an operation called urethrotomy or
- Sometimes a repair of a defect within the urethral wall by urethroplasty.

Bladder cancer

People with a long-term spinal cord injury have an increased risk of bladder cancer, 5 to 7 times higher than the general population. The condition is considered rare among the general population. People using urethral or suprapubic catheters for more than 15 years are most at risk. Cigarette smoking increases the risk by about 4 times compared to a non-smoker. Other risk factors may include frequent urinary tract infections and bladder stones. Although the value of routine screening is still unknown, it is recommended for a regular cystoscopy and bladder biopsy to be performed by a urologist in people most at risk.

Purple urine bag syndrome

Purple urine bag syndrome is caused by a bacterial infection. The bacteria produces a chemical, called indoxyl phosphatase, causing purple discolouration of the urine within the bag. This can be of concern for people with spinal cord injury and their family members and carers. The treatment involves drinking plenty of water to flush out bacteria, changing the catheter and taking appropriate antibiotics.

Bladder problems related to pregnancy, menstruation, menopause and sexual activity

After a spinal cord injury, women report a significant increase in bladder and catheter-related problems associated with gynaecological and reproductive health issues. A large survey reported women experience 4 times more urinary tract infections after their injury (86%) than before (22%), as well as an increase in vaginal yeast infections (59% versus 45%). Other key findings from the survey include:

Pregnancy

- Complications related to pregnancy were uncommon except for a significant increase in urinary tract infections.
- One quarter of the women reported they had to change their usual bladder management method during their pregnancy. Between 10-15% reported having new leakage around their indwelling urinary catheter and new bladder spasms. Among those women using intermittent catheterisation, 27% had to catheterise more frequently during the day.

Menstruation

- Around one fourth of all women had exacerbations of autonomic symptoms (i.e., sweating, headaches, flushing, or goose flush), bladder spasms, or muscle spasms, which were associated with a certain time in their cycle.
- Difficulties can be associated with catheterisation, as well as the use of tampons and pads, which can press on the urethra and bladder and interfere with catheter drainage.

Menopause

- Conditions such as spasticity, autonomic dysreflexia and bladder spasms were reported by some women to increase during menopause.

Sexual activity

- Bladder incontinence was reported as a problem in 17% of women with spinal cord injury during sexual intercourse.
- Problems with Foley catheters were described more often (12%) during sexual intercourse by women with a longer injury duration of 11 years or more.

What does research tell you?

Women with a spinal cord injury experience a range of problems related to pregnancy, menstruation, menopause and sexual activity, which are unique to this group of people. They require greater recognition by health professionals to provide self-management education and support for women adapting to a new life situation after a spinal cord injury.

Management index

The severity of your bladder and kidney problems can vary depending on the underlying cause.

To decide on the most appropriate management strategy, it is important to assess how severe your problem is and to what extent it interferes with your participation in everyday activities.

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

Severity scale

To check the severity of your problem, consider the intensity, duration and frequency of your signs and symptoms using this table.

Problems	Mild	Moderate	Severe
Urinary tract infection (UTI)	1 or 2 UTIs per year	3 to 4 UTIs per year	3 or more episodes of UTI in last 6 months.
Catheter blockage	Less than once a month	1-2 times per month	Weekly or more often
Difficulty inserting a catheter	Once in a while	Frequently	Always
Urine leakage	Once a month or less AND/OR few drops only	Once a week or less AND/OR one pad per day	Several times a week to once daily or more AND/OR flooding wetness
Bladder and kidney stones	_	Able to pass	Unable to pass
Blood in urine	_	Microscopic	Visible

Important note

Any bladder-related symptoms of any severity associated with autonomic dysreflexia are considered **SEVERE** and require **URGENT MEDICAL ATTENTION**.

Interference scale

To determine to what extent your problem interferes with participating in everyday activities, use the scale below:

The following index provides a way to combine your self-assessment ratings on both severity and interference scales to help you decide what level of support you may need to most effectively manage your problem.

Severity rating	Interference rating	Management strategies
Mild problem	(0) Not at all	Self-manage without support
Mild problem	(1) A little of the time	Self-manage without support
Mild problem	(2) Some of the time	Self-manage with support from your GP or other healthcare professional
Mild problem	(3) A lot of the time	Self-manage with support from your GP or other healthcare professional
Moderate problem	(0) Not at all	Self-manage with support from your GP or other healthcare professional
Moderate problem	(1) A little of the time	Self-manage with support from your GP or other healthcare professional
Moderate problem	(2) Some of the time	Self-manage with support from your GP or other healthcare professional
Moderate problem	(3) A lot of the time	Manage with specialist support
Severe problem	(0) Not at all	Manage with specialist support
Severe problem	(1) A little of the time	Manage with specialist support
Severe problem	(2) Some of the time	Manage with specialist support
Severe problem	(3) A lot of the time	Manage with specialist support

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

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

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

- Recurrent infections
- Stones in the bladder or kidneys
- Kidney damage and chronic renal failure
- Bladder cancer.

Just-in-time, or the right care at the right place at the right time, will reduce risk and prevent complications. 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 about how your spinal cord injury affects your bladder and what research tells us.
- Becoming a partner in decision-making with your doctor and health professionals.
- Developing an individualised bladder plan
- Engaging in ongoing health and wellness activities for a healthy bladder:
  - Exercising regularly
  - Watching your weight
  - Drinking more water
  - Taking medications as directed
  - Scheduling an annual check-up.

Take home messages

Ensure your bladder is

EMPTIED FULLY

every 4 to 6 hours

ANTIBIOTIC USE

Finish the entire course of prescribed antibiotics

Organise an annual check-up for

BLADDER & KIDNEYS

QUIT

smoking

Maintain good

HAND HYGIENE

when catheterising

AVOID

straining to empty your bowel as this can weaken the sphincter muscles and cause leakage

DRINK

plenty of water

Knowledge test

1. The main job of your bladder is to:
   - (a) Store urine.
   - (b) Get rid of urine.
   - (c) Both.

2. How frequently should clean intermittent self-catheterisation normally be done?
   - (a) Every 2 hours.
   - (b) Every 4-6 hours, depending on fluid intake.
   - (c) Three times a day.
   - (d) Twice a day.

3. If you are experiencing signs and symptoms of a urinary tract infection, what should you do?
   - (a) Start antibiotics straight away and send a urine sample if you feel better in a few days.
   - (b) Collect a clean sample of urine and send to lab for testing – if results are positive, indicating an infection, start antibiotics as prescribed.
   - (c) Start antibiotics straight away and stop taking them when you are feeling better.

4. Reflex voiding is no longer recommended because it can cause too much pressure in the bladder and damage the kidneys.
   - (a) True
   - (b) False

5. Signs and symptoms for bladder or kidney stones can include:
   - (a) Grit in the catheter.
   - (b) Blood in urine.
   - (c) Recurrent urinary tract infections.
   - (d) All of the above.

6. Urine leakage may be due to:
   - (a) Stress when you laugh or sneeze.
   - (b) An overactive bladder.
   - (c) Overflow from a full bladder.
   - (d) All of the above.

For correct answers, please see page 34.

Glossary

Term	Definition
CT scan: kidneys, ureters and bladder	CT scans use a combination of x-rays and computer technology to create three-dimensional images. CT scans can help identify stones in the urinary tract, infections, cysts, tumours and traumatic injury to the kidneys and ureters.
Cystoscopy	Cystoscopy is used to diagnose, monitor and treat conditions affecting the bladder and urethra. Your doctor might recommend cystoscopy to investigate causes of signs and symptoms. Signs and symptoms can include blood in the urine, incontinence, overactive bladder and painful urination.
Electrolytes, urea and creatinine	Electrolytes and urea are the most commonly requested biochemistry tests. They provide essential information on renal function, principally in excretion and homoeostasis. Creatinine levels are a major factor in determining the estimated glomerular filtration rate, which is the gold standard marker of kidney health.
Estimated glomerular filtration rate	Estimated glomerular filtration rate (eGFR) is the best test to measure your level of kidney function and determine your stage of kidney disease. Your doctor can calculate it from the results of your blood creatinine test, your age, body size and gender.
Microscopy, culture sensitivity	The urine culture is used to diagnose a urinary tract infection (UTI) and to identify the bacteria or yeast causing the infection. It may be done in conjunction with susceptibility testing to determine which antibiotics will inhibit the growth of the microbe causing the infection.
Renal (isotope) scan	A renal nuclear medical scan is used to diagnose certain kidney diseases. In this test, images are made to see how blood flows into and out of the kidneys. It shows how urine flows through the kidneys, ureters and bladder and estimates how much each kidney is helping to clean your blood.
Ultrasound	A kidney ultrasound, also called a renal ultrasound, uses sound waves to examine the kidneys and also looks at the bladder. Doctors order ultrasounds when there is a concern about bladder problems. A bladder ultrasound can show how much urine the bladder holds when it is full and whether someone completely empties the bladder when urinating.
Urinary albumin to creatinine ratio	Albumin is one of the first proteins to be detected in the urine with kidney damage. A urine albumin test and albumin to creatinine ratio (ACR) are used to screen for kidney disease in people with chronic conditions, such as diabetes and high blood pressure, also called hypertension.
Videourodynamic study	The digital equipment used in this test can measure urine flow and pressure in the bladder and rectum by using x-rays or ultrasound. Pictures and videos are taken of the bladder during filling and emptying. Video urodynamic tests provide useful information about bladder and urethral function.
X-rays: kidneys, ureters and bladder	A kidney, ureter, and bladder (KUB) study is an X-ray study that allows your doctor to assess the organs of your urinary and gastrointestinal systems. Doctors can use it to help them diagnose urinary disorders and causes of abdominal pain.

Further resources

Reading resources for consumers

- Bladder Management Following Spinal Cord Injury: What You Should Know - A Guide for People with Spinal Cord Injury (36 pages)
  Access at: **https://pva-cdnendpoint.azureedge.net/prod/libraries/media/pva/library/publications/consumer_guide_bladder_071410.pdf**
- Staying Healthy After a Spinal Cord Injury: Bladder Management (2 pages)
  Access at: **http://sci.washington.edu/info/pamphlets/bladder_manage.pdf**
- Bladder Care (Website)
  Access at: **https://www.myshepherdconnection.org/sci/bladder-care**

Useful resources for consumers and medical professionals

- Management of the Neurogenic Bladder for Adults with Spinal Cord Injuries (18 pages)
  Access at: **https://www.aci.health.nsw.gov.au/__data/assets/pdf_file/0010/155179/Management-Neurogenic-Bladder.pdf**
- Bladder Management for Adults with Spinal Cord Injury: A Clinical Practice Guideline for Health-Care Providers (61 pages)
  Access at: **https://pva-cdnendpoint.azureedge.net/prod/libraries/media/pva/library/publications/cpgbladdermanageme_1ac7b4.pdf**

Videos for consumers

- How Does Spinal Cord Injury Effect the Bladder? (duration: 16 minutes)
  Access at: **https://youtu.be/kmcsrNxWEQo**
- Bladder Management (duration: 2 minutes)
  Access at: **https://youtu.be/8GrtS2wWJlo**
- Spinal Cord Injury and Bladder Management: Catheter Management (duration: 2 minutes)
  Access at: **https://youtu.be/uj1mJNST9sw**
- Bladder Management After a Spinal Cord Injury (duration: 6 minutes)
  Access at: **https://youtu.be/LmqvAopeOEo**

Answers to knowledge test

1: c; 2: b; 3: b; 4: a; 5: d; 6: d;

Bladder diary

Keep this diary accurately each day, for at least 3 days. It is recommended to complete this over 3 consecutive days.

Date and time/s of urine being passed (or episodes of urine leakage).	**Amount of urine passed** (half a glass = 125 ml).	**Did you feel the urge to go?** Yes/No Urgency 1-10 (10 is severe urge).	**Leakage episodes** (small, medium or large).	**Fluid intake** (record types of drinks and amount consumed over 24 hrs)	**Notes** Record any other relevant information, such as: • Use of medications (what taken and when) and its associated side effects • Pad usage • Urge or strong desire to urinate • Time when bowel emptied • Activities at the time when leakage occurred.

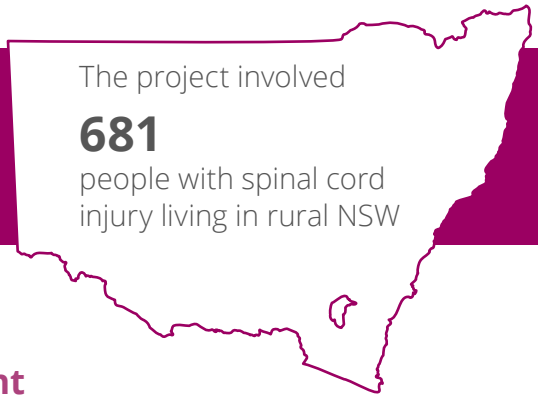
Notes

The bowel

and its associated problems

Contents

Summary of findings
from the 2015 Rural Spinal Cord Injury Project



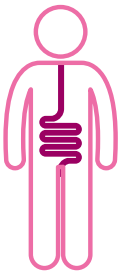
The main techniques used for bowel management

Enemas were used more often in people with tetraplegia, whereas digital stimulation with or without using an enema was more common in people with paraplegia.

15%

of people with an incomplete spinal cord injury had enough control to empty their bowel voluntarily.

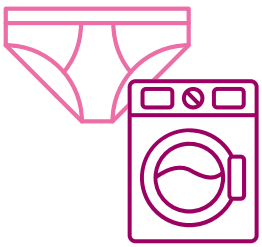
The three most common problems related to the bowel



19%

Constipation

The occurrence of CONSTIPATION was 21-28% from 6 to 20 years post-injury



16%

Faecal incontinence

Duration of BOWEL CARE was observed to be longer, more than 30 minutes, in people with spinal cord injury who were more than 15 years post-injury

14%

Haemorrhoids

The presence of HAEMORRHOIDS was highest (25%) in people with spinal cord injury who were over 10 years post-injury

How to navigate this module

KNOW How your bowel works (page 41)

CHECK Do you have a problem with your bowel?
Refer to checklist and warning signs (page 44)

Yes

IDENTIFY PROBLEM
Look for important signs and symptoms:

- Constipation (page 64)
- Diarrhoea (page 65)
- Alternating constipation and diarrhoea (page 66)
- Haemorrhoids (page 67)
- Other problems (page 68-70)

CHECK SEVERITY
Based on the management index:

- Severity scale (page 71)
- Interference scale (page 72)

MANAGE
Based on problem severity and interference (page 71-72)

- Self-manage without support
- Self-manage with support from your GP or other healthcare professional
- Manage with specialist support

Is this problem resolved? Have your goals been met?

No

RE-ASSESS

Yes

OBSERVE/PREVENT

No

OBSERVE
Refer to questions in checklist and warning signs

PREVENT
Refer to:

- Self-management tips (page 46)
- How to prevent constipation (page 47)
- How to prevent haemorrhoids (page 47)
- Routine follow-up and tests (page 48)

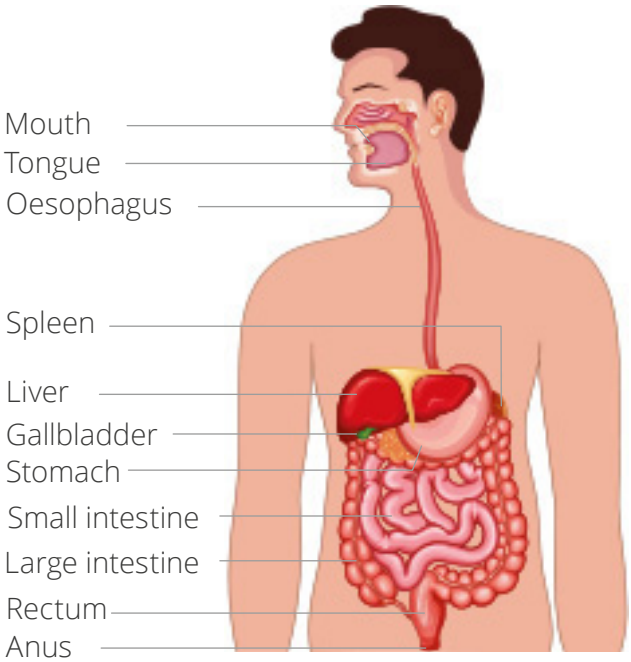
EDUCATE
Refer to bowel management toolbox (page 51)

What will happen if you do not manage your problem 'just-in-time'? (page 73)

Know about your bowel

How the bowel normally works

The digestive system includes the mouth, oesophagus, stomach, small intestines and colon, rectum and anus. When food or drinks are consumed, they travel through the digestive system and are eliminated as faeces in a bowel motion or stool from the anus.



Do you know?

The term "bowel" is used collectively to refer to the small intestine, colon and rectum.

It can be further categorised into:

Small bowel: small intestine
Large bowel: colon and rectum

When the stool reaches your lower colon and rectum, nerve impulses travel from your rectum via the sacral nerves and along the spinal cord up to your brain. Your brain tells you your bowel is ready to be emptied.

If you decide to delay your bowel movement, a message is sent from your brain to the spinal cord to tell the sphincter muscle, which is located near your anus, to stay closed until there is a better time to empty.

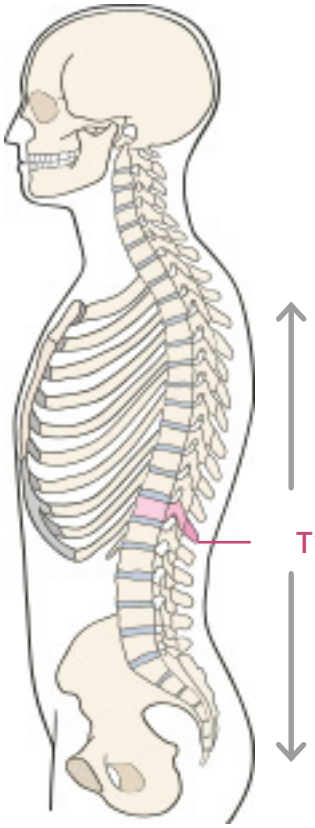
If you decide to empty your bowel, a message is sent back down your spinal cord to the sphincter muscle, telling it to relax and pass the stool.

This is how your bowel works when you do not have a spinal cord injury.

Effects of a spinal cord injury on bowel function

After spinal cord injury, your bowel will usually not work like it did before the injury. This type of bowel is often referred to as a neurogenic bowel.

There are two main types of neurogenic bowel depending on where your injury is:



Reflex bowel
At and above T12 vertebral level sacral nerves are intact

Non-reflex bowel
Below T12 vertebral level sacral nerves are damaged

Note: Sacral nerves are responsible for controlling the bowel.

The two main types of neurogenic bowel are:

Reflex bowel

Due to the spinal cord being injured, the message does not reach the brain, but remains in the spinal cord. The brain does not send a message down the spinal cord about whether or not it is a good time to empty your bowel.

The reflex activity generated in the sacral spinal cord causes the sphincter muscle to open when the rectum is full, and may be triggered by digital or chemical stimulation.

Non-reflex bowel

Due to nerve damage at a lower spinal level, the message is not able to reach the spinal cord. No reflex contraction can occur, and the bowel does not squeeze to empty its content.

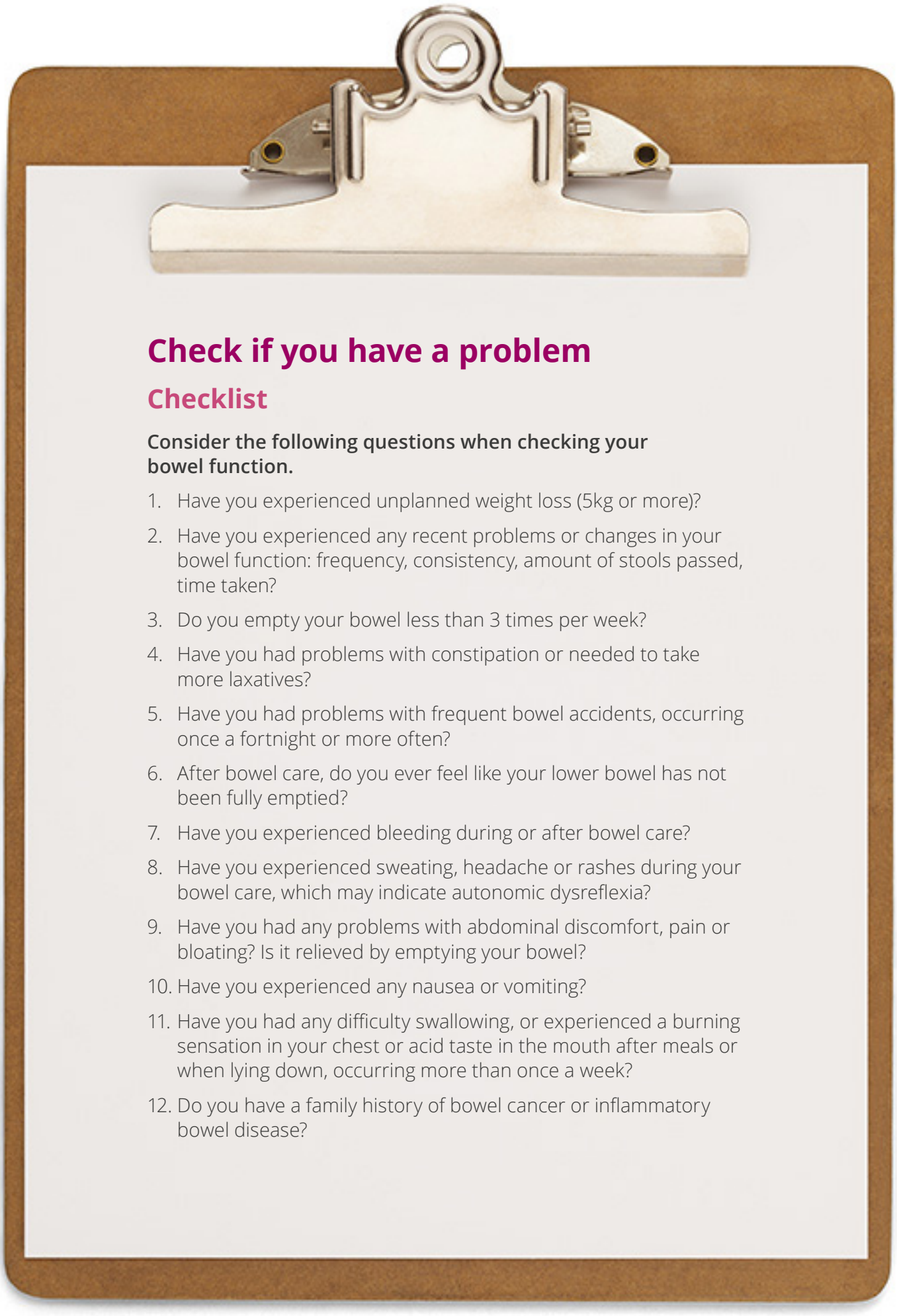
The sphincter muscle remains loose all the time and if too much stool collects in the rectum, it will come out causing a bowel accident.

Bowel problems

Common problems	• Constipation • Diarrhoea • Alternating constipation and diarrhoea • Haemorrhoids
Other problems	• Abdominal bloating and discomfort • Faecal impaction/pseudo-bowel (false) obstruction • Autonomic dysreflexia in person with spinal cord injury at above T6 level (please refer to Autonomic dysreflexia module for further information)
Uncommon problems	• Gallstones • Heartburn • Bowel cancer

What does research tell you?

Effective treatment of common bowel complications in individuals with a spinal cord injury, such as chronic constipation, faecal impaction and haemorrhoids, is necessary to minimise potential long-term harmful effects.



Check if you have a problem

Checklist

Consider the following questions when checking your bowel function.

1. Have you experienced unplanned weight loss (5kg or more)?
2. Have you experienced any recent problems or changes in your bowel function: frequency, consistency, amount of stools passed, time taken?
3. Do you empty your bowel less than 3 times per week?
4. Have you had problems with constipation or needed to take more laxatives?
5. Have you had problems with frequent bowel accidents, occurring once a fortnight or more often?
6. After bowel care, do you ever feel like your lower bowel has not been fully emptied?
7. Have you experienced bleeding during or after bowel care?
8. Have you experienced sweating, headache or rashes during your bowel care, which may indicate autonomic dysreflexia?
9. Have you had any problems with abdominal discomfort, pain or bloating? Is it relieved by emptying your bowel?
10. Have you experienced any nausea or vomiting?
11. Have you had any difficulty swallowing, or experienced a burning sensation in your chest or acid taste in the mouth after meals or when lying down, occurring more than once a week?
12. Do you have a family history of bowel cancer or inflammatory bowel disease?

Warning signs

The following symptoms are warning signs indicating there may be a serious problem that requires further investigation and/or treatment:

- Severe sweating or headache (autonomic dysreflexia) during or after bowel care
- Significant rectal bleeding, passing dark tarry stools or vomiting of blood
- New rectal bleeding of unknown cause
- Unexplained weight loss
- If you are feeling unwell due to having not opened your bowels and are experiencing symptoms such as bloating, nausea, vomiting or abdominal pain
- A major change in your bowel habit, including:
  - Severe constipation, incontinence or altered stool consistency
  - Prolonged time for bowel care
- Reduced ability or endurance to self-manage bowel care.

Prevention

Self-management tips to maintain a healthy bowel

Stick to a routine

Ensure you stick with a routine and try to go to the toilet at the same time every day.

Action: Develop a successful routine that is regular, reliable and completed within a reasonable length of time.

Avoid major changes to bowel care

Ensure consistency in your diet and avoid making major diet changes, take your medications and moderate your alcohol intake.

Action: Only change one thing at a time when adjusting your routine at home. Wait about 7-10 days before making another change.

Maintain a good diet and exercise program

Ensure you have a good healthy diet with plenty of fluid and regular exercise.

Fluid is good for your bladder too, and exercise helps you to maintain a healthy bowel as well as a healthy heart.

Food with poor nutritional value or low in fibre, as well as too much alcohol, contribute to bowel problems.

Actions: Eat a balanced high-fibre diet, drink well and avoid too much alcohol.

Go around the block or do a workout in a gym.

Some foods may increase the risk of bowel problems

Some spicy food, fruits and certain vegetables can cause stomach and bowel problems.

Action: Vegetables such as Brussels sprouts, broccoli, cabbage, asparagus and cauliflower are known to cause excess gas, so eat them in moderation.

Know about your gastrocolic reflex

Know how your gastrocolic reflex works to stimulate your bowel activity.

Action: Having a warm drink or a light breakfast before your routine can help stimulate the bowel, helping you to complete your routine successfully.

Recognise an unhealthy bowel routine

Look for signs of a routine that needs adjusting, including frequent bowel accidents, diarrhoea, constipation, prolonged routines, regular poor bowel results and rectal bleeding.

Action: See TOP goals (page 53) to establish regular and predictable bowel emptying.

What does research tell you?

Changing a bowel care program should be done one element at a time and maintained for 3-5 bowel care cycles, or 7-10 days, before making more changes.

How to prevent constipation

There are a number of things you can do yourself to try to avoid or relieve constipation:

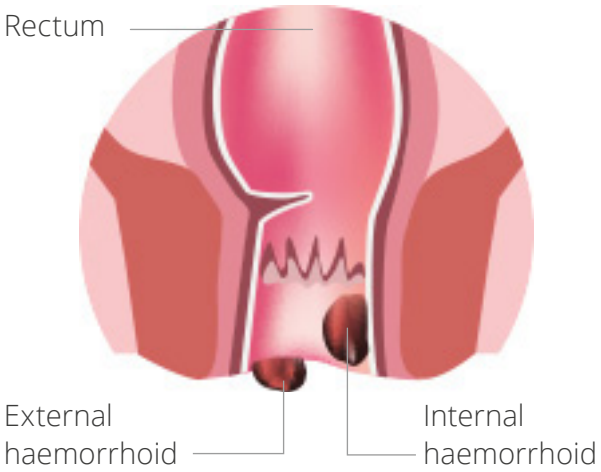
- Drink plenty of water.
- Eat foods containing fibre, such as high-fibre breakfast cereals, wholemeal bread, fruit and vegetables, and beans and pulses.
- Keep as active as possible – even gentle movement can help to keep your bowels moving.
- Try to develop a regular routine for going to the toilet and do not rush – give your bowels enough time to work.
- If you need help from a carer, friend or family member to go to the toilet, talk to them about what kind of help you would like.
- If you have been prescribed laxatives, take them as directed by your doctor or specialist nurse.

How to prevent haemorrhoids

Haemorrhoids or piles are swollen or inflamed veins in your bottom, due to increased pressure inside your rectum. They are due to an increased pressure in your rectum. Haemorrhoids can occur inside, known as internal, or outside of the anus, known as external.

The best way to avoid haemorrhoids is to prevent constipation. Take stool softeners to help stools to move with ease and drink plenty of water. Reduce your time sitting over the toilet and do not strain to empty. Be as gentle as possible when using digital stimulation or manual evacuation.

- Do not overuse laxatives as this can worsen your haemorrhoids.
- Ensure you have enough fibre in your diet and/or take fibre supplements.
- Control your weight, as obesity can increase the risk of haemorrhoids.
- Get as much exercise as possible.



Routine follow-up and tests

In general, your general practitioner or continence nurse is the first point of contact for most bowel-related problems. You may also want to contact your community nurse or case coordinator.

It is recommended to have a ROUTINE FOLLOW-UP with your GP once a year to check your bowel health; more often if you have bowel problems.

As part of a yearly review of your bowel function, particularly when experiencing problems or your bowel pattern has changed, you may require further tests. The different tests available are outlined below:

Rectal examination

External inspection of your bottom and palpation in your rectum by your doctor with a lubricated gloved finger, looking for haemorrhoids, fissures, skin tags, blood or discharge.

Stool sample

A stool sample is collected and sent to the laboratory for culture to detect infection which can be caused by parasites, viruses or bacteria. This test is used to rule out the presence of certain bacteria, for example, Clostridium difficile (in diarrhoea associated with recent antibiotic use) or Helicobacter pylori (associated with stomach ulcers).

Blood tests

Tests can include a full blood count and a multi biochemical analysis to assess whether you are anaemic, possibly caused by bleeding from the bowel, and give you clues about your overall health such as blood sugar level, and kidney and liver function.

Blood tests can show whether you have an infection or inflammation somewhere in your body. Your doctor may also test your blood for a chemical sometimes produced by colon cancers, called carcinoembryonic antigen or CEA.

Abdominal ultrasound

This test uses sound waves to capture the internal organs in your abdomen and pelvis: intestines, liver, gallbladder, bile ducts, pancreas, spleen, kidneys and urinary bladder. An ultrasound can be used to show gallstones or sludge in the gallbladder as well as cysts or abnormal growths in the liver, spleen or pancreas.

Imaging techniques

There are three main imaging techniques:

1. X-rays
2. Computed tomography (CT) scan which takes multiple X-ray images from different angles
3. Magnetic resonance imaging scan uses a large magnet and radio waves to create a detailed image on a computer.

Imaging techniques can help detect problems of the stomach, small bowel, colon as well as other internal organs involved in breaking down your food, such as the liver, gallbladder and pancreas. For example, a plain abdominal X-ray may be ordered to look at whether your bowels are full of stools, causing impaction, or if there is and obstruction or blockage. A CT or MRI scan of the abdomen and pelvis may be used as a way to find growths or lumps in organs such as your stomach, bowels and pancreas.

Hydrogen breath test

This simple, non-invasive test done after a short period of fasting is used to diagnose small intestine bacterial overgrowth and problems with the digestion or malabsorption of sugars, such as lactose, sucrose, fructose, and sorbitol.

Faecal occult blood test

A faecal occult blood test (FOBT) is a test to screen for bowel cancer or polyps, tiny growths on the bowel that can turn into cancer. A FOBT involves collecting a small sample of faeces and testing it for tiny amounts of hidden, also called occult, blood in your stool. **National guidelines recommend that Australians aged 50-74 complete an FOBT every two years for those at average risk and without any symptoms.** People aged 40-49 with moderate to high risk are recommended a FOBT every two years then a colonoscopy every 5 years from 50 to 74 years of age.

People with a spinal cord injury are no more likely than anyone else in the community to develop bowel cancer. However, lack of sensation may hide symptoms from early detection while chronic rectal bleeding, either due to haemorrhoids or regular digital stimulation/manual extraction, may lead to a false positive (wrong) FOBT result.

Screening is therefore even more important. FOBT is feasible for people with a spinal cord injury to complete but a full examination of the large bowel by colonoscopy may be necessary (see next page for further information).

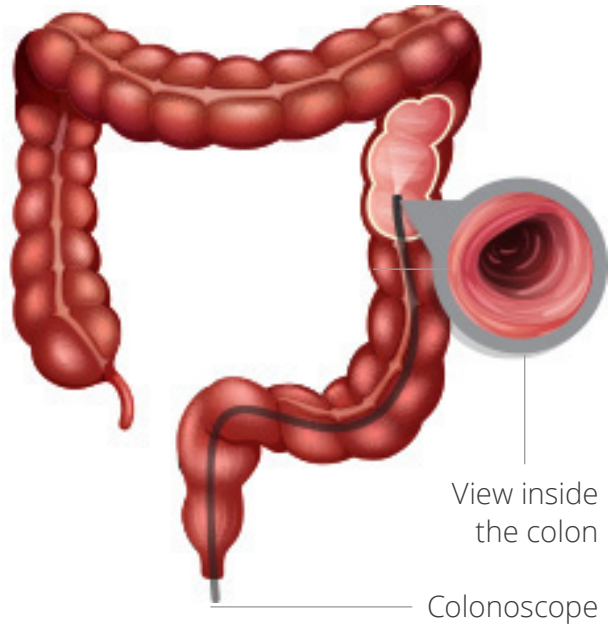
Endoscopy

This tube is passed through your throat and oesophagus, the canal carrying food from your mouth to your stomach, down into your stomach and the first part of the small intestine, called the duodenum. This test can be used to identify inflammation of your oesophagus, called oesophagitis, which is the result of acid reflux from your stomach or ulcers in your stomach or duodenum. This instrument allows your doctor to view any abnormalities and remove tissue samples, called a biopsy.

Colonoscopy

This is a procedure used to visually examine your lower digestive tract for screening and diagnostic reasons. A thin, flexible fibre optic tube, which transmits light and is equipped with a tiny camera, called an endoscope, is passed through the anus and manoeuvred through the large bowel and the last part of the small bowel. This instrument allows your doctor to view any abnormalities and remove tissue samples, called a biopsy.

Note: The recommended frequency of a colonoscopy for screening purposes will vary based on findings and level of risk. Level of risk depends on your family history and is related to the number of first-degree and second-degree relatives with colorectal cancer as well as their age at diagnosis (less than 55 years vs older).



Bowel preparation for colonoscopy

Adequate bowel preparation is important for not missing polyps or possible cancerous lesions. A modified bowel cleansing regime with a longer preparation time is recommended in people with a spinal cord injury to allow for slower colonic movements to pass faecal matter through the intestines. Admission to hospital prior to the procedure is often needed, particularly for people who are more dependent and need assistance with frequent toilet transfers, skin care or monitoring for autonomic dysreflexia. A colonoscopy may be arranged during an unrelated admission.

You should be on a low residue/low-fibre diet and clear fluids earlier than normal to achieve adequate cleansing for a colonoscopy. Solutions, such as Picoprep, have been shown to be safe, effective and better tolerated than polyethylene glycol electrolyte lavage solutions, such as ColonLYTELY. The latter is possibly the safest option but is often poorly tolerated by people with a spinal cord injury due to the large volume (2-4 litres) required to be consumed. Split dosing of this medication has been shown to improve tolerance and effectiveness.

What does research tell you?

A colonoscopy should be performed in individuals with a spinal cord injury over the age of 50, who have a major change in bowel function that cannot be resolved or an unexplained positive faecal occult blood test, to rule out possible colorectal cancer.

Bowel management toolbox

Management of a bowel problem can be challenging because there are many factors that can cause problems. A single strategy, for example, adjusting your diet and fluid intake, may be less effective than a combination of bowel management strategies. Your specialist nurse or doctor may need to try a combination of treatments and this may take some time.

Think about using the bowel management toolbox to help solve your bowel problem. The toolbox is made up of 8 components as seen in the picture below. An individualised approach to bowel management is needed and includes:

- Modifying diet and lifestyle
- Adjusting medications
- Employing assistive techniques.

Consider this 8-step toolbox when managing your bowel care.

Important note

It is unlikely that changing just one component will fix a bowel problem.

What does research tell you?

Create an individualised bowel program using a multifaceted, stepwise treatment approach. The following components are considered essential: appropriate diet, fluid intake and physical activity, timed bowel care routine, manual evacuation or digital stimulation with or without an enema or suppository, bowel medications, appropriate positioning over the toilet and the use of assistive techniques.

1. Assessment

For solving day-to-day bowel problems, it is helpful to have a way to assess the different types of bowel motion or stool consistency and where it is located in your gut.

Consistency

The Bristol Stool Chart is commonly used for describing the consistency of your bowel motion and identifies 7 types of stools.

Bristol Stool Chart

Type 1 	Separate hard lumps	Severe constipation
Type 2 	Lumpy and sausage like	Constipation
Type 3 	A sausage shape with cracks in the surface	Firm
Type 4 	Like a smooth, soft sausage or snake	Normal
Type 5 	Soft blobs with clear-cut edges	Lacking form
Type 6 	Mushy consistency with ragged edges	Mild diarrhoea
Type 7 	Liquid consistency with no solid piece	Severe diarrhoea

By Cabot Health, Bristol Stool Chart – http://cdn.intechopen.com/pdfs-wm/46082.pdf, CC BY-SA 3.0, https:// **commons.wikimedia.org/w/index.php?curid=41761316**

Location

The stool is normally stored down in the rectum before it is pushed out of your body or ready to empty. However, a person with a spinal cord injury has slower bowel movements so the stool sometimes stays higher up in your colon and is not ready to empty.

Assessment

Establishing goals for an effective bowel management program begins with a thorough assessment. This can be done in collaboration with your healthcare team, including specialist nurse, GP, spinal specialist and allied healthcare professionals.

Assessment should include the following factors:

- Bowel type: reflex or non-reflex
- History and outcomes of your past bowel management routine
- Personal and lifestyle factors such as diet and fluid intake, activity levels, exercise patterns and pre-injury bowel pattern
- Functional ability, particularly strength, ability to transfer, arm reach and hand function
- Body size
- Sitting tolerance, balance and posture
- Presence of spasms and/or contractures (causing restricted movements in your joints)
- The medications you are taking (and their side effects)
- Problem-solving skills and motivation
- Availability of a carer with the required knowledge and skills
- Ability to direct others appropriately.

2. Bowel care routine

Bowel management aims to establish regular and predictable bowel emptying. This should be at a time and place that suits your lifestyle.

The TOP goals

Timing:

- A bowel care program is most effective and reliable when you follow a regular routine.
- Empty your bowel at set times.
  - Reflex bowel – every 1 or 2 days, ideally 20-45 minutes after a meal to use the gastrocolic response.
  - Non-reflex bowel – occurs a little more often, typically once or twice daily.

Outcomes:

- Achieve complete emptying of your bowel within 30 minutes or less, and no more than 1 hour.

Prevention:

- Reduce and, if possible, prevent problems, such as bowel accidents, constipation and bowel-related autonomic dysreflexia. For more information on autonomic dysreflexia, please read the Autonomic dysreflexia module.

How to achieve the TOP goals

Have a regular bowel care **program**

Eat a well-balanced, healthy **diet** with enough fibre

Drink the recommended amount and type of fluids (6-8 glasses of water)

Be **active** and **exercise** regularly

Take your bowel **medications** regularly

Maintain a **soft, well-formed stool** or a firmer stool for a non-reflex bowel type.

"If I had to advise younger people with spinal cord injury, I would say 'stick to the rules'."

– Consumer with spinal cord injury

3. Diet and fluid intake

Two important factors for effective bowel movements are:

- Consuming food with an adequate amount of FIBRE, and
- Drinking enough FLUID.

Diet

Fibre holds fluid and is important for:

- Improving your bowel movements by adding bulk and form to the stool
- Moving your stool smoothly through the bowels
- Assisting evacuation with well-formed stools.

There are three types of fibre and your body needs them all.

Insoluble Fibre does not dissolve in water. This type of fibre adds bulk to the stool allowing active movement through the gut. This is beneficial in preventing constipation. See examples of insoluble fibre in the table on page 56.

Soluble Fibre is a gentler bulking fibre which forms a gel by absorbing water. This type of fibre is helpful in managing both constipation and diarrhoea. Consume this type of fibre when you have a loose stool. See examples of soluble fibre in the table on page 56.

Resistant starch is a prebiotic and a fibre which feeds the gut bacteria. Resistant starch promotes bacteria growth to maintain a healthier gut and reduces the risk of medical conditions such as bowel cancer and diabetes. Examples of resistant starch are whole grains, nuts and legumes, starchy vegetables, unripe bananas and some seeds.

Do you know?

- Most foods with fibre contain a mixture of soluble and insoluble fibre in different amounts.
- The amount of fibre in foods does not change with cooking, so food can be consumed raw or cooked.
- Your diet helps you to firm up or soften your stool.

What does research tell you?

- Individuals with a spinal cord injury should not necessarily be placed on a high-fibre diet, as this may further increase colonic transit time.
- Aim for a diet containing no less than 15 grams of fibre daily, with fibre intake gradually increased up to 30 grams, from a wide variety of sources.
- Symptoms of intolerance should be monitored, and fibre adjusted accordingly.

How to boost your fibre intake

Replace this		With this		To boost your fibre intake
35g oats	= 2.4g	40g high-fibre oats	= 7.3g	**+ 4.9g**
				
1 slice white	= 0.7g	1 slice multigrain	= 1.8g	**+ 1.1g**
				
½ cup cooked white rice	= 0.8g	½ cup cooked brown rice	= 2g	**+ 1.2g**
				
½ cup mashed potatoes	=1.1g	1 jacket potato	= 3.5g	**+ 2.4g**
				
1 cup of pear juice (240mL)	= 4g	1 pear	= 6g	**+ 2g**
				

Important notes

- Consume at least **25-30 grams** of fibre each day.
- If your fibre levels are not high, increase the amount gradually over a few weeks while drinking adequate fluids at the same time.

Fibre content in commonly eaten foods

Food category	Foods that harden stool (Soluble fibre)	Foods that soften stool (Insoluble fibre)
Dairy	Milk, yoghurt made without fruit, cheese, cottage cheese or ice cream	Yoghurt with seeds or fruit
Bread and cereals	White bread or rolls, crackers, refined cereals, pancakes, waffles, bagels, biscuits, white rice or noodles	Whole grain breads or cereals
Fruits and vegetables	Strained fruit juice or apple sauce	All vegetables except potatoes without the skins
Meat or legumes	Any meat, fish, or poultry	Nuts, dried beans, peas, seeds, lentils or crunchy peanut butter
Soups	Any creamed or broth-based without vegetables, beans, or lentils	Soups with vegetables, beans, or lentils
Fats	None	Any
Desserts and sweets	Any without seeds or fruits	Any made with cracked wheat, seeds, or fruit

See fibre calculator in the Further resources section at the end of this module.

Fluids

- National guidelines recommend an average intake of 2.1 litres for women and 2.6 litres for men.
- Fluid requirements can also be calculated using 30-35mL/kg body weight.
- **Water** is the best fluid of choice.

Do you know?

About half a glass (125mL) of juice provides energy equal to one serve of fruit. Limit your consumption of fruit juices.

Have a whole piece of fruit instead of juice.

4. Medications

Medications to manage your bowel can be:

- Taken by mouth, known as oral laxatives or oral stimulants.
- Inserted into the anus, known as rectal stimulants. Often both ways are needed.

Type of medication	Action	Common medications
Oral		
Bulk-forming laxatives	Add bulk to stool. You will need to drink extra fluid.	Agiofibe, Agiolax, Benefiber, Fybogel, Metamucil, Mucilax, Normafibe, Nucolax, Psyllium husks
Osmotic laxatives	Increase stool bulk by pulling water into the colon. You will need to drink extra fluid.	Actilax, Duphalac, Epsom salts, Movicol, Osmolax, Picolax, Sorbilax
Stool softeners	Help stool retain fluid, stay soft and slide through the colon.	Coloxyl tablets or drops, Duphalac, Lactulose, Parachoc
Stimulants	Increase the wave-like action of peristalsis to move stool through the bowel faster and keep it soft.	Coloxyl with Senna, Agarol, Durolax tablets, Normacol, Normacol Plus, Senokot granules or tablets
Rectal		
Suppositories	Increases colon activity by stimulating the nerves in the lining of the rectum.	Bisacodyl or Durolax
	Stimulates peristalsis in the colon and lubricates the rectum to help pass stool.	Glycerine
Enemas	Lubricates the intestine and causes fullness in the rectum.	Microlax
	Stimulates the rectal lining and softens stool.	Bisalax

Note: This is not an exhaustive list of medications.

What does research tell you?

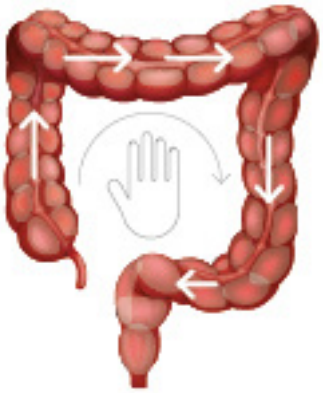
Expert opinion strongly suggests avoiding the long-term use of Senna, although robust evidence is lacking to support this concern.

5. Assistive techniques

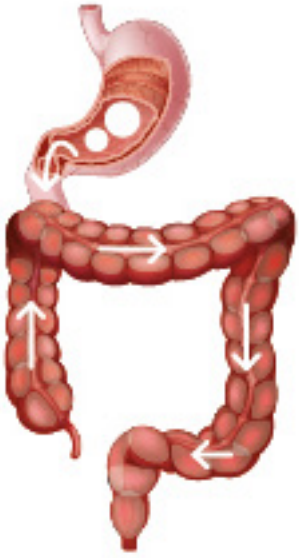
Assistive techniques can increase the speed of bowel care routines by promoting wave-like movements of your bowel, called peristalsis, which help to improve your bowel management.

The commonly used techniques are:

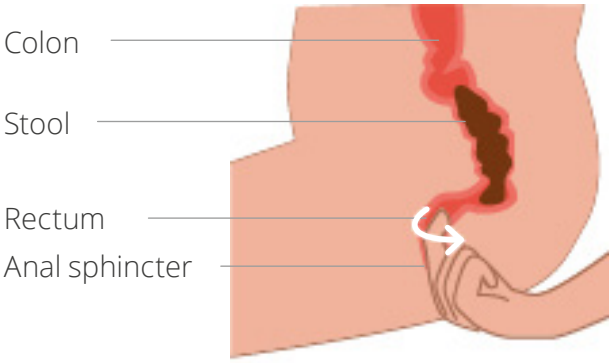
Abdominal massage uses a firm, slow and rhythmic action in a clockwise motion from the lower right side of the abdomen, across the top to the left and continuing down the left side of abdomen to assist the stool move along the large bowel towards the rectum and anus.



Gastrocolic reflex is an automatic response triggered by eating and drinking, particularly the first meal of the day, which stimulates the digestive process and causes contractions in the large bowel, helping to propel the formed stools down towards the rectum, ready for evacuation.



Digital stimulation involves gently inserting a gloved and well-lubricated finger into the rectum, up to the second finger joint. Rotate the finger in a gentle sweeping motion against the rectal wall. While digital stimulation can be repeated every 5-10 minutes until the bowel has evacuated, each stimulation usually takes only 15-20 seconds to perform and no longer than 1 minute. No more than 5 stimulations per bowel care routine should be required.



Manual removal involves the use of one or two gloved lubricated fingers to break up or hook stool and remove it from the rectum.

Optimal positioning for bowel care is with the knees bent and placed higher than the hips with the upper body bending forward, supported by elbows or hands on knees, if your balance allows this.

What does research tell you?

- Expert opinion recommends bowel care to be performed 30-45 minutes after a meal to take advantage of the gastrocolic reflex, which increases colonic activity.
- Expert opinion recommends the use of assistive techniques, such as abdominal massage and a seated or forward-leaning position (with foot stool) if mobility permits, to help the bowel to empty.

6. Lifestyle factors

Our lifestyle choices can affect the function of our digestive system and bowel habits. For example, the gut can be easily upset by factors such as stress, alcohol and smoking.

Exercise regularly

Exercise helps your bowel to function better. Try to exercise regularly but do not overdo it. For example, pushing in a wheelchair, lifting weight through the arms when in a wheelchair and standing may help increase pressure in the abdomen and aid movement of stool through the bowel. Doing something you enjoy will keep you motivated. You should aim for 30 minutes of moderate activity at least 5 times a week. Drink plenty of water while exercising.

Regular sleep routine

Our sleep patterns can also affect our bowel habits. Ensure you get enough rest. Having regular times for going to bed and getting up each day can help your digestive system work more effectively and improve the regularity of your bowels.

Avoid stress

Stress is a common problem in today's busy society. When life becomes too busy and stressful, our digestive system is one of the first parts of the body to react. Long-term stress can lead to changes in gut functioning over time which can cause your bowel to become more irritable.

Quit smoking

Smoking is bad for your health in every way, including your gut health. Smoking can affect the functioning of your gut, including decreased mucus production, altered gut bacteria and compromised immunity, and may contribute to problems such as heartburn and stomach ulcers.

Restrict or reduce alcohol intake

Drinking too much alcohol can cause irritation and inflammation of the lining of the gut, particularly the stomach. National guidelines recommend 2 standard drinks a day with no more than 4 standard drinks at any given time. One or two alcohol-free days in a week is recommended. For more information, check the 'Standard drink guide' in the Further resources section at the end of this module.

Getting older

As you get older, your bowels tend to become more sluggish. This is due to many factors including changes in our diet and less exercise.

7. Carer competence

Make sure your care provider or agency can provide the bowel care you need. Some agencies have restrictions in relation to specific procedures, such as inserting an enema or performing manual evacuation, per-rectal (PR) checks or digital stimulation. It is important to ensure your carer is competent and familiar with your specific bowel care needs.

- It is your responsibility to instruct your carer.
- You need to be adequately prepared to teach your carer to carry out your bowel care program. Don't hesitate to ask your nurse for help.
- If you feel your carer does not have the right skills or knowledge, talk to your case manager or coordinator.
- Make sure your carer is using the stimulation technique that is most effective for you.
- Ask your carer to tell you what they can feel when they are doing digital stimulation or a bowel check so you can decide what further action to take.
- Access resources to help educate your carers. Check the Further resources section at the end of this module.

What does research tell you?

Expert opinion recommends the assessment of the knowledge, ability and confidence of people with a spinal cord injury and their carer in performing the advised bowel care program at each follow-up visit.

8. Surgical treatment

Colostomy

A colostomy involves an operation to cut the colon and bring its end out through the abdominal wall. The bowel contents can then pass out through an artificial opening, called a stoma, bypassing the rectum and anus. Stool collects in a waterproof bag worn over the stoma. The bag is adhesive and sticks to the area reducing the risk of leakage and protecting the skin.

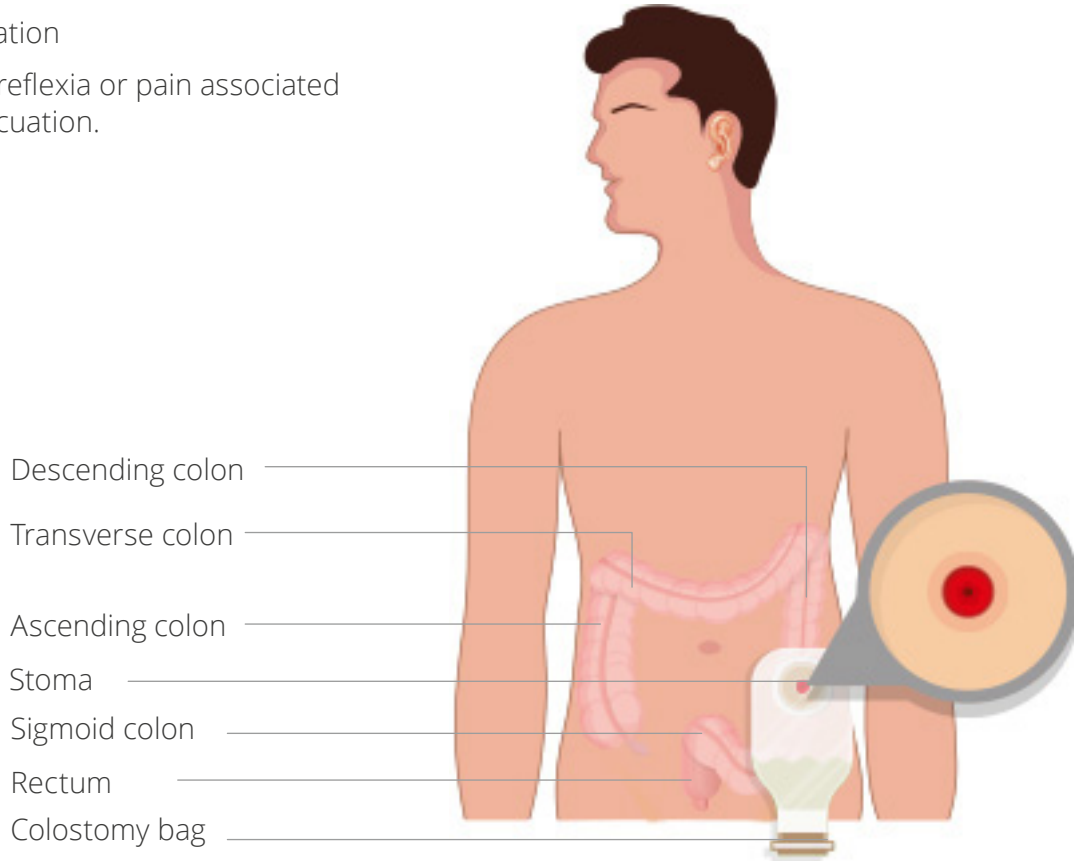
Common reasons for a person with spinal cord injury to consider a colostomy include:

- Lengthy episodes of bowel management
- Unmanageable faecal incontinence
- Severe constipation
- Autonomic dysreflexia or pain associated with bowel evacuation.

Colostomy greatly reduces bowel care time, laxative use, accidents and bowel-related autonomic dysreflexia. Colostomy also leads to improved independence and better quality of life.

The common problems with a stoma include:

- Rectal mucous discharge
- Ballooning of the stoma bag
- Stoma bag sticking together called pancaking, preventing stool from moving to the bottom.



What does research tell you?

Expert opinion recommends:

- A colostomy be considered at an earlier stage for an individual experiencing severe bowel problems despite comprehensive management.
- The decision to have a permanent colostomy should be based on a detailed assessment and the individual's expectations.

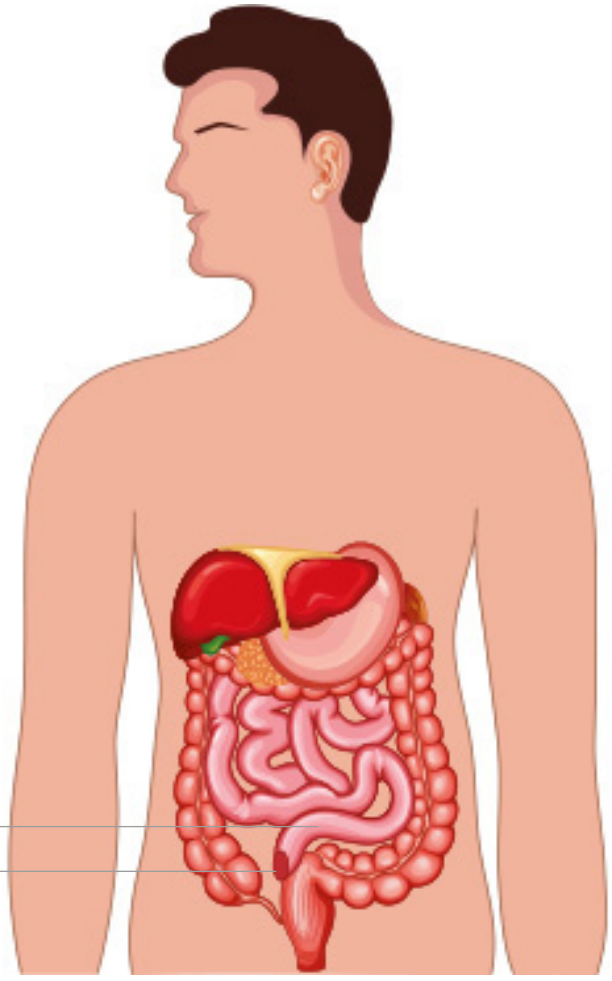
There is no agreement about when to have a colostomy. It is often only considered as a last resort when all other methods have failed. Yet, in most cases after having a colostomy, people report wishing they had had the procedure much earlier. It can be very helpful to talk to a peer who has already had a colostomy to find out more about how it has worked for them.

The stoma nurse plays an important role as your key contact during treatment. The nurse will meet with you before surgery to discuss positioning of the stoma and liaise with your surgeon and health professional team. The nurse will provide education and training in:

- Applying and removing your stoma bag
- Purchasing supplies (such as stoma bags, adhesive remover wipes, and so on)
- Providing dietary advice to minimise bowel problems
- Promoting healthy skin care.

Ileostomy

An ileostomy is like a colostomy. It involves bringing the ileum, the last part of the small intestine, out of the right side of your abdomen to form a stoma. As the waste material has not been through the colon, there will be a lot of water that has not been absorbed. Faeces will therefore be runny with some wind. The stoma will appear to look like the inside of your mouth. Ileostomy surgery is usually chosen when the colon is so damaged that it cannot be treated any other way.



My bowel care plan

It is important to use a comprehensive approach when developing your bowel plan, considering the following:

Medication

Be aware that certain medications may cause constipation, such as painkillers, anticholinergics (given for bladder management) or iron supplements.

Diet

Ensure you are eating a healthy and well-balanced diet with enough fibre.

Enemas and suppositories

Use an appropriate enema or suppository.

Bowel care routine

- Develop a regular routine – typically once or twice a day.
- Allow enough time on the toilet or commode, particularly if you rely on a carer. Do not hurry bowel care as it may result in an accident later in the day.
- If you think there are stools higher in the rectum, wait until the next scheduled bowel care to evacuate.

Important note

Keep a bowel diary to record the frequency (date and times) of your bowel movements. Record stool consistency, episodes of soiling or bowel accidents, fluid intake and other information such as medication use, diet and other symptoms (see page 78).

Assistive techniques

Combine the techniques below for best results:

- Timing of bowel care to use gastrocolic reflex
- Manual evacuation
- Abdominal massage
- Digital stimulation
- Forward and bending position.

Carer competence

Remember it is your responsibility to instruct them.

For more details about developing a specific bowel management program, please see 'Solving Common Bowel Problems' in the Further resources section on page 77.

Do you know?

Your digestive functions, particularly the emptying of your rectum, are more sluggish after a spinal cord injury.

Management of bowel problems

Constipation

Everyone's bowel habits are a little different. One person might go to the toilet as often as 3 times per day, while another goes just 3 times per week.

Constipation includes:

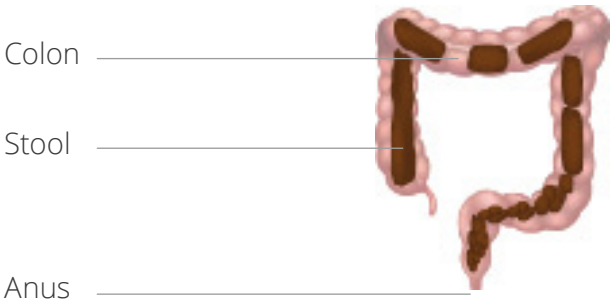
- Less frequent bowel movements
- Hard stools
- Difficulty opening your bowels.

What causes constipation

After a spinal cord injury, constipation can happen for several reasons:

- Loss of control and coordination of peristalsis (propulsive bowel waves) and abdominal wall contractions, leading to a delay in food emptying from your stomach and slower transit through bowel.
- Medications – constipation is a side effect of some commonly used medications, such as opioids for pain.
- Not drinking enough fluids – being dehydrated can make the stool harder and difficult to pass.
- Not eating a balanced diet with enough fibre or missing meals.
- Being less active than before – exercise stimulates the bowel and can help you go to the toilet more often.

It may not always be recommended to increase the amount of fibre in your diet, for example, if your appetite is poor or you aren't drinking enough. Always check with your nurse or doctor.



You should talk to your nurse or doctor if you:

- Have longer-than-usual periods of not going to the toilet (for example, more than three days) or problems with evacuating your stool
- Have pain in your stomach or bottom
- Feel sick or have been sick
- Have bleeding from your bottom
- Pass a watery stool after having constipation.

A nurse or doctor can assess what the cause may be and give you advice about the need for treatment.

Taking laxatives

Laxatives, also called aperients, are a type of medication that can help you to open your bowels. There are different types of laxatives, which work in slightly different ways to draw in water, form or loosen the stools and/or stimulate bowel movements.

It might take a while to find the right type and amount of laxative for you. Talk to your doctor or specialist nurse if your constipation doesn't improve.

If you are taking opioids – such as morphine, codeine or oxycodone – you can take laxatives at the same time to prevent constipation occurring as an unwanted side effect.

If you are prescribed laxatives, it is important to keep taking them regularly, even after you have had a bowel movement. This will help to stop you getting constipated again.

Do you know?

Occasionally, long-term constipation can lead to faecal impaction. This occurs when your colon becomes blocked by a mass of very hard stool and your bowel movements cannot propel along your colon.

Faecal impaction can cause pain and/or vomiting, and this may require urgent hospital treatment.

Diarrhoea

Diarrhoea can mean either very loose, wet stools or opening your bowels more often than usual. If you have diarrhoea you may also have:

- Abdominal (tummy) pain
- The need to go to the toilet urgently
- Nausea or vomiting
- Headaches
- Loss of appetite
- Feeling thirsty or dehydrated
- Loss of control over when your bowels open (faecal incontinence).

What causes diarrhoea

There are many causes of diarrhoea, including:

- An acute or chronic infection
- Side effects of medications, including taking too many laxatives
- Overflow diarrhoea, particularly if you have been constipated before
- Anxiety
- Food intolerances
- Diseases, including inflammatory bowel disease, bowel cancer and diabetes.

How to treat diarrhoea

Most cases of diarrhoea will clear up within a few days without any specific treatment. But if you have frequent or ongoing diarrhoea, or if you see blood or pus in your stool, you should talk to your nurse or doctor. You may need to provide a stool sample to be tested for different causes. It is not recommended to take an anti-diarrhoeal medication without first seeing a doctor or nurse. In some cases, these medications can make things worse.

Diarrhoea can dehydrate so drink plenty of fluids. Eat solid foods as soon as you feel able to. Start with small amounts and avoid fatty, spicy or heavy foods.

Overflow diarrhoea

Severe constipation can cause a blockage in your bowel. As a result, the bowel begins to leak watery stools that flow around the blockage from higher up in the bowel. The leak from the bowel can look like diarrhoea. It is called overflow or spurious diarrhoea.

If you have had severe constipation and then develop diarrhoea, you should talk to your doctor or nurse before taking any more medicine for constipation or diarrhoea.

Alternating constipation and diarrhoea

Episodes of alternating constipation and diarrhoea can result from severe constipation with episodes of bowel impaction and overflow but may sometimes indicate another problem, such as irritable bowel syndrome.

Signs and symptoms may include:

- Abdominal pain or cramping that is often relieved by passing wind or faeces
- A sensation that your bowel is not emptied after passing a bowel motion
- Abdominal bloating
- Mucus present in the stools
- Nausea.

How to treat alternating constipation and diarrhoea

Diet

Review your diet and consider:

- Increasing the amount of vegetables, fruits and nuts.
- Reducing foods that make the stools too hard, such as large amounts of meat or dairy products.

Note: Be aware that too much fibre can also be a problem, making the stools either too hard or soft.

Stool bulking and softening agents

You may consider modifying your bowel medications by:

- Adding or increasing the amount of fibre supplement, and/or
- Adding or increasing the amount of a stool softener.

Fluids

- Increase the amount of water you drink (aim to drink 6-8 glasses of water per day in addition to other beverages).
- Moderate the number of drinks you have that contain caffeine, such as tea or coffee, as well as your alcohol intake. These drinks have a diuretic effect causing your body to produce urine, which may make your constipation worse.

Bowel care routine

You may need to modify your bowel routine and/or the use of assistive techniques to avoid having accidents in between bowel evacuations.

Carer competence

Check that your carers are performing your bowel care correctly.

"I am more regular now than I was before, after taking the advice from the nurses."

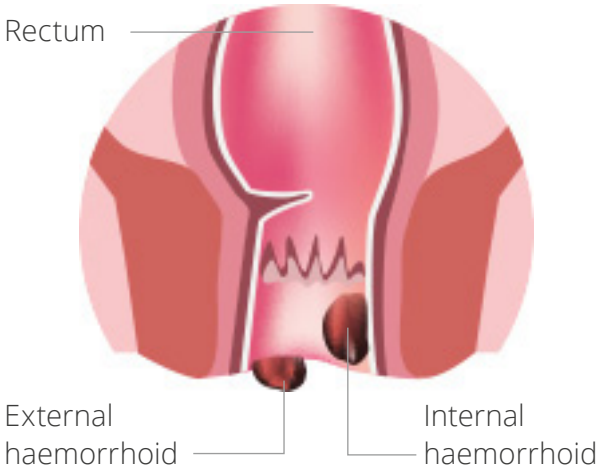
– Consumer with spinal cord injury

Haemorrhoids

Haemorrhoids or piles are swollen or inflamed veins in your rectum and anus. They are due to increased pressure in your rectum. Haemorrhoids may occur inside your rectum (known as internal) or outside of the anus (known as external).

Signs and symptoms of haemorrhoids may include:

- Pain or discomfort when sitting for a long time
- Pain or sweating during bowel movements, (a symptom of mild autonomic dysreflexia)
- Bright red blood on the outside of your stools, toilet paper or in the toilet bowl
- Irritation or mucus around your anus
- One or more swellings near your anus.



How to treat haemorrhoids

- Non-prescription ointments, creams and suppositories
- Cold compresses to relieve swelling
- Non-surgical procedures, which can include:
  - Applying a rubber band, called ligation, to cut off the blood flow to the haemorrhoids. The haemorrhoids will then shrivel and dry up.
  - Injection of a chemical solution into the haemorrhoid to cause it to harden, shrink and drop off.
- Surgery under general anaesthetic to remove the haemorrhoid/s, known as a haemorrhoidectomy.

Note: Haemorrhoids can recur after treatment, particularly if you remain constipated.

Precaution: Bleeding during bowel movements is the most common sign of haemorrhoids. However, rectal bleeding can also flag a more serious problem, such as bowel cancer.

You should consult your doctor if:

- Your haemorrhoids bleed often or a lot.
- Your haemorrhoids do not improve with self-management.
- Bleeding is associated with a major change in your bowel habits.
- You pass black, tarry stools, that can be caused by bleeding.
- Blood is mixed in with your stool.

Abdominal bloating and discomfort

Bloating occurs when part of your bowel fills with air or gas, causing the abdomen to become distended and uncomfortable. Constipation can often worsen symptoms of bloating. You may also experience dyspepsia (indigestion), acid reflux and early satiety, a feeling of fullness when eating. In addition, abdominal bloating can affect your breathing with shortness of breath from a distended bowel pressing up on your diaphragm, a muscle that draws air into your lungs.

Causes of bloating may include:

- Consuming gas-producing goods that are high in sugar, fizzy or carbonated drinks, or taking certain medications, e.g., Lactulose
- Swallowing air while chewing gum, drinking through a straw and eating while talking or eating too quickly
- Snoring
- Irritable bowel syndrome
- Food allergies and intolerances, including lactose, fructose, wheat, gluten and eggs
- Infections, such as from helicobacter pylori, responsible for most stomach ulcers.

How to treat bloating

The following strategies may help relieve wind, gas and bloating:

- Taking over-the-counter gas-reducing medications, such as simethicone tablets or digestive enzymes (for example, lactase for lactose intolerance).
- Avoid taking pain medications, such as aspirin, ibuprofen, and other non-steroidal anti-inflammatory drugs called NSAIDs if you have an abdominal condition, such as a stomach ulcer or a blockage of your bowels.
- Slowly increasing the amount of fibre in your diet and checking if gas and bloating become worse.
- Trying to eat smaller portions or adding an extra meal, if you feel uncomfortable after a large meal.
- Keeping a food diary to work out if certain foods seem to make you more gassy or bloated.
- Avoid foods containing FODMAPs. Both lactose and fructose are a part of a larger group of indigestible carbohydrates known as FODMAPs. FODMAP intolerance is one of the most common causes of bloating and abdominal pain. Foods to avoid include wheat, onions, garlic, broccoli, cabbage, cauliflower, artichokes, beans, apples, pears and watermelon. It may be helpful to see a dietitian.
- Taking a probiotic supplement may help to improve the bacterial environment in your gut and reduce symptoms of gas and bloating.
- Using peppermint oil has been shown to be effective against bloating.

Gallstones

The gallbladder's function is to store bile, a substance secreted by the liver to assist with digestion of fats and the absorption of certain vitamins. Gallstones are small stones made up of a mixture of cholesterol, bile pigment and calcium salts that form in the gallbladder. They often cause no symptoms and may be discovered by accident through an ultrasound or CT scan performed for another reason. Gallstones occur more often after spinal cord injury due to the sluggish movement of the bile along its tract called stasis. Other risk factors for gallstones include diabetes, obesity and/or family history.

Signs and symptoms may include:

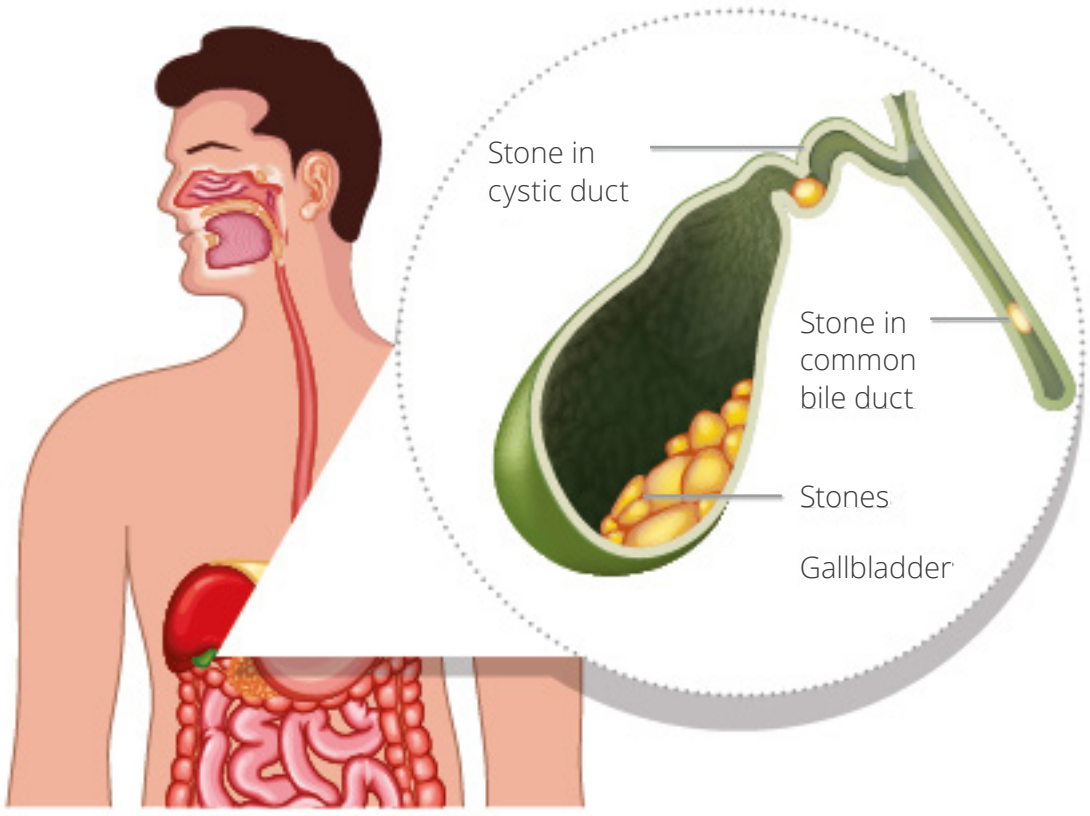
- Sudden severe pain or discomfort in your upper right abdomen – just below the rib cage – or right shoulder.

  Note: Your symptoms may be less localised with dull aching or colicky type of visceral pain when you have a higher level of injury.

- Pain, bloating or discomfort may increase after eating a fatty meal.
- Yellowing of your skin or eyes, called jaundice, occurs when bile pigments spill over into your bloodstream from blocked gallbladder and ducts.
- Nausea and vomiting.
- Fever and pain if gallbladder, bile ducts or pancreas become inflamed or infected.
- Changes to the colour of bowel motion (clay colour).

How to treat gallstones

- Surgery to remove the gallbladder, called a cholecystectomy, if severe or current attacks occur. This is usually done by laparoscopic or keyhole surgery.
- Lithotripsy is a procedure using sound waves via a focused ultrasound from outside the body to shatter the gallstones into pieces to pass safely down the bile duct. Lithotripsy may be used alone or along with a tablet containing bile acids that helps dissolve cholesterol. Unfortunately, gallstones are likely to recur.



Heartburn

Depending on the level of your spinal cord injury, you may or may not have heartburn or oesophagitis, experienced as pain in your chest, especially after bending over, lying down or eating. Heartburn is more common after a spinal cord injury due to reduced movement of the upper digestive tract resulting in delayed emptying of the stomach.

Other common symptoms are burping, a burning sensation in the throat, a sour or acidic taste at the back of the throat, a dry cough, hoarse voice or sore throat. Factors increasing your chances of heartburn include slower emptying of your stomach, lying down, immobilisation and certain drugs, such as anticholinergics used for your bladder. Heartburn is treated with a medication that blocks acid production.

Bowel cancer

The risk of developing bowel cancer is NOT increased after sustaining a spinal cord injury. Your genetic makeup, however, can play a big role in bowel cancer. About one in five people who develop bowel cancer have a relative with the disease. For this reason, it is important to find out if any of your relatives have had bowel cancer or polyps, which are growths in the colon or rectum, and if so, how old they were when they were diagnosed. Studies have shown that people with spinal cord injury are less likely to have routine tests done for bowel screening and may therefore be at risk of a delayed diagnosis.

Important notes

- Schedule an annual check-up to get screened. Most bowel cancers develop slowly from pre-cancerous growths called polyps. Early detection and removal of these pre-cancerous polyps prevents the development of bowel cancer.
- Reduce consumption of red and processed meat, and avoid charred meat.
- Drink alcohol in moderation.
- Know your family history.

Management index

The severity of your bowel problems can vary depending on the underlying cause.

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

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

Severity scale

To check the severity of your problem, consider the intensity, duration and frequency of your signs and symptoms by using this table.

Problems	Mild	Moderate	Severe
Constipation	<3 bowel movements per week; firm to hard stools (BSC* type 2-3) <25% of time	<3 bowel movements per week; hard stools (BSC* type 2) ≥25% of time	<3 bowel movements per week; prolonged (>1 hour) or incomplete evacuation, very hard stools (BSC* type 1-2) ≥50% of time
Bowel accidents	Occasional – once or twice a year	Every few months	Once or more a month
Alternating constipation and diarrhoea	Occasional – once or twice a year	Every few months	Once or more a month
Haemorrhoids	Bleeding occurs less than once a month	Bleeding occurs several times a month	Bleeding occurs more than once a week AND/OR large amounts of blood
Abdominal bloating and discomfort	Infrequent – less than once every few months	Occurs some of the time	Occurs most of the time
Heartburn	Infrequent – less than once every few months	Occurs some of the time	Occurs most of the time

*BSC: Bristol Stool Chart

Important note

Any bowel-related symptoms of any severity associated with autonomic dysreflexia are considered **SEVERE** and require **URGENT MEDICAL ATTENTION**.

Interference scale

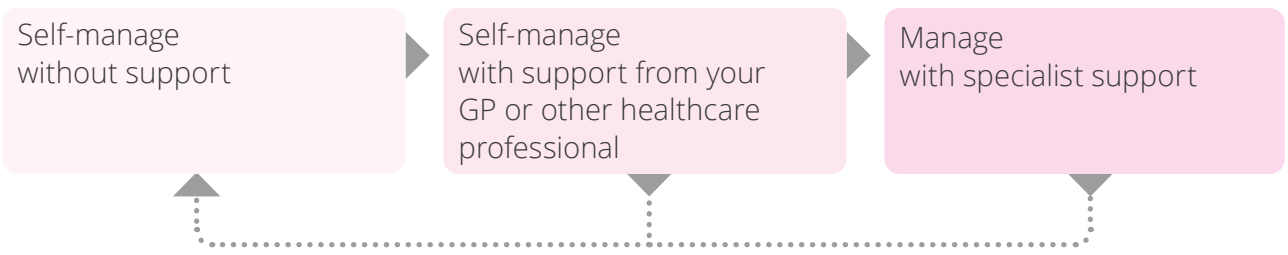
To determine to what extent your problem interferes with participating in everyday activities, use the scale below:

0	1	2	3
Not at all	A little of the time	Some of the time	A lot of the time

The following index provides a way to combine your self-assessment ratings on both severity and interference scales to help you decide what level of support you may need to most effectively manage your problem.

Severity rating	Interference rating	Management strategies
Mild problem	(0) Not at all	Self-manage without support
Mild problem	(1) A little of the time	Self-manage without support
Mild problem	(2) Some of the time	Self-manage with support from your GP or other healthcare professional
Mild problem	(3) A lot of the time	Self-manage with support from your GP or other healthcare professional
Moderate problem	(0) Not at all	Self-manage with support from your GP or other healthcare professional
Moderate problem	(1) A little of the time	Self-manage with support from your GP or other healthcare professional
Moderate problem	(2) Some of the time	Self-manage with support from your GP or other healthcare professional
Moderate problem	(3) A lot of the time	Manage with specialist support
Severe problem	(0) Not at all	Manage with specialist support
Severe problem	(1) A little of the time	Manage with specialist support
Severe problem	(2) Some of the time	Manage with specialist support
Severe problem	(3) A lot of the time	Manage with specialist support

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



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

Serious complications can arise if bowel problems are not managed in a timely way. In the long term, you could experience:

- Severe constipation, which can contribute to other unpleasant complications, such as haemorrhoids, bloating, worsening of pain or spasms.
- Rectal prolapse, a medical condition that occurs when part of your lower intestine pushes out through the anus from too much straining.
- Bowel obstruction with a severely dilated and distended colon, called a mega colon.
- Polyps and cancer.

'Just-in-time', or the right care at the right place at the right time, will reduce risk and prevent serious bowel complications. 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 understand how your spinal cord injury affects your bowel functioning and what research tells us.
- Becoming a partner in decision-making and learning to problem solve with your doctor and health professionals.
- Developing an individual bowel program that works for you.
- Engaging in ongoing health and wellness activities for a healthy bowel:
  - Exercising as much as you can.
  - Watching your weight, since obesity is linked to bowel cancer, especially in men.
  - Drinking more water.
  - Eating a healthy high-fibre diet with a variety of fruit vegetables and grains.
  - Reducing saturated fats, found in animal products, processed foods and takeaway.

Take home messages

DEVELOP

a regular bowel routine and don't rush

TROUBLESHOOT

if you have a bowel problem

EAT

a balanced diet with enough fibre

QUIT

smoking

MAINTAIN

a healthy lifestyle and exercise program

AVOID

constipation

DRINK

plenty of water

Knowledge test

1. You achieve a better bowel emptying result with your knees bent and placed higher than the hips.

   (a) True (b) False

2. You achieve better bowel emptying when a meal or hot drink is consumed up to 30 minutes before bowel care.

   (a) True (b) False

3. You achieve better bowel emptying when an abdominal massage is done 1 hour before the bowel movement.

   (a) True (b) False

4. What might help to ensure successful bowel management?

   (a) Eating a balanced diet, which includes fruit, vegetables, bread and cereals.

   (b) Consuming excessive amounts of fibre to bulk the stools.

   (c) Eating a lot of foods that contain fats and sugars.

   (d) Eating meals at any time during the day.

5. If constipation occurs, you should:

   (a) Decrease the amount of fibre in your diet.

   (b) Increase fluid intake and the amount of fibre in your diet.

   (c) Increase bowel evacuation from once to twice a day.

   (d) Decrease stool softeners if already using them.

   (e) All of the above.

6. Which of the following can cause a bowel accident?

   (a) Constipation with overflow.

   (b) Not emptying the bowel properly so that some stool remains.

   (c) Taking too many bowel stimulant tablets.

   (d) Diarrhoea.

   (e) All of the above.

For correct answers, please see page 77.

Glossary

Term	Definition
Faecal incontinence	The inability to control bowel movements, causing stool (faeces) to leak unexpectedly from the rectum. Also called bowel incontinence, faecal incontinence ranges from an occasional stool leakage while passing gas to a complete loss of bowel control.
Colonoscopy	A procedure carried out to screen for colon cancers and other problems as well as explore the cause of unexplained changes in bowel habits.
Fissure	An anal fissure is a small, oval-shaped tear in the skin that lines the opening of the anus. Fissures typically cause severe pain and bleeding with bowel movements. Fissures are often confused with other causes of pain and bleeding such as haemorrhoids.
Faecal occult blood test (FOBT)	A simple test that looks for the early signs of bowel cancer. Blood is usually caused by something less serious than cancer. However, it may be a sign of an early bowel cancer or a polyp, a growth on the inside of the bowel that could develop into cancer.

Further resources

Reading resources for consumers

- Solving Common Bowel Problems (13 pages)
  Access at: **https://www.continence.org.au/data/files/Factsheets/Solving_Common_Bowel_Problems.pdf**
- Neurogenic Bowel: What You Should Know – A Guide for People with Spinal Cord Injury (55 pages)
  Access at: **https://pva-cdnendpoint.azureedge.net/prod/libraries/media/pva/library/publications/consumer-guide_neurogenic-bowel.pdf**
- Fibre calculator: your actual fibre intake every day
  Access at: **http://www.benefiber.com.au/fibre-calculator**
- Standard drink guide
  Access at: **https://www.nhmrc.gov.au/about-us/publications/australian-guidelines-reduce-health-risks-drinking-alcohol**
- Support for families & carers
  Access at: **https://www.icare.nsw.gov.au/injured-or-ill-people/motor-accident-injuries/families-and-carers/#gref**

Useful resources for consumers and medical professionals

- Management of the Neurogenic Bowel for Adults with Spinal Cord Injuries (18 pages)
  Access at: **https://www.aci.health.nsw.gov.au/__data/assets/pdf_file/0019/155215/Management-Neurogenic-Bowel.pdf**
- Neurogenic Bowel Management in Adults with Spinal Cord Injury (page 51)
  Access at: **https://pva-cdnendpoint.azureedge.net/prod/libraries/media/pva/library/publications/cpg_neurogenic-bowel.pdf**

Videos for consumers

- Bowel Management – Managing Medical Complications After Spinal Cord Injury (30 minutes)
  Access at: **https://youtu.be/uNfSJhZZZ34**
- Neurogenic Bowel (2 minutes)
  Access at: **https://youtu.be/AYQo1R-sFHk**
- Bowel Management: Diet and Nutrition (2 minutes)
  Access at: **https://player.vimeo.com/video/179212604**
- Bowel Maintenance (3 minutes)
  Access at: **https://youtu.be/_ZW1qWqtw4U**

Answers to knowledge test

1: a; 2: a; 3: b; 4: a; 5: b; 6: e;

Bowel diary

Keep this diary accurately each day, for at least 7 days. Use with Bristol Stool Chart.

Date and time/s of each bowel movement	Stool consistency (Refer to Bristol Stool Chart Type 1-7)	Did you feel the urge to go? (Yes/No)	Accident/soiling? Record time in left hand column and note description of leakage in this column	Fluid intake (record types of drinks and amount consumed over 24 hrs)	Notes Record any other relevant information, such as: • Use of medications (what taken and when) and its associated side effects • Pad usage • Urge or strong desire to urinate • Time when bowel emptied • Activities at the time when leakage occurred.

Notes

Notes

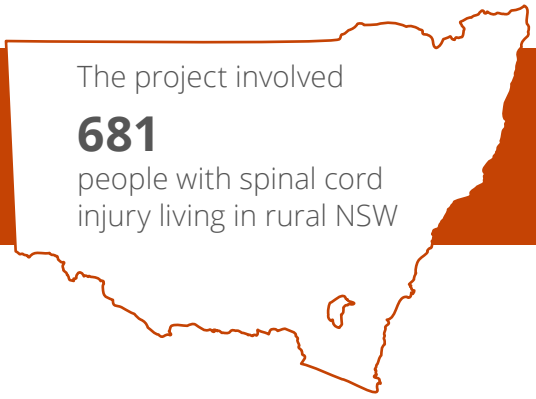
The skin

and its associated problems

Contents

Summary of findings

from the 2015 Rural Spinal Cord Injury Project



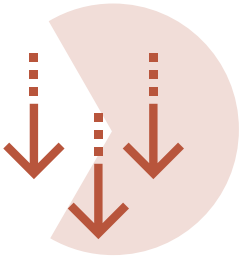
The project involved

681

people with spinal cord injury living in rural NSW

One third

of people with spinal cord injury had one or more current pressure injuries

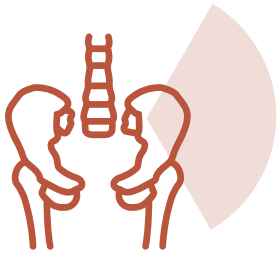


One quarter

of individuals reported having other skin-related problems, such as skin rashes and dermatitis, venous/arterial ulcers, infection (osteomyelitis and cellulitis), sinus and ingrown toenails

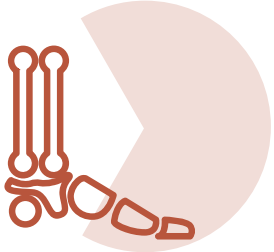
Two thirds

of pressure injuries were located over the ischial tuberosities (sitting bones), sacrum and greater trochanters (bone at side of hip)



One third

of individuals had pressure injuries over the region of the ankle or foot



Pressure injuries are most common between

21-30 years post-injury

How to navigate this module

KNOW Your skin and spinal cord injury (page 85)

CHECK Do you have a problem with your skin?
Refer to warning signs (page 88)

Yes

IDENTIFY PROBLEM
Look for important signs and symptoms:
Pressure injury (page 91)
Other problems (page 104 - 105)

CHECK SEVERITY
Based on the management index:
Severity scale (page 106)
Interference scale (page 107)

MANAGE
Based on problem severity and interference (page 106-107)

- Self-manage without support
- Self-manage with support from your GP or other healthcare professional
- Manage with specialist support

Is this problem resolved? Have your goals been met?

No

RE-ASSESS

Yes

OBSERVE/PREVENT

No

OBSERVE
Refer to questions in warning signs

PREVENT
Refer to:
Self-management tips (page 89)
Take home messages (page 109)

EDUCATE
Refer to skin management toolbox (page 91)

What will happen if you do not manage your problem 'just-in-time'? (page 108)

Know about your skin

How the skin normally works

Your skin is your body's largest organ. It serves as a protective barrier against most external agents like infection, dirt and harmful rays from the sun. It permits the senses of touch, pain, heat and cold to travel from the nerve endings in your skin to your brain through the spinal cord and helps regulate your body temperature.

Your skin regulates your body temperature through the dilation and constriction of blood vessels and the process of sweating.

When you're in cold weather, your skin signals your blood vessels to constrict and keep you as warm as possible.

When you're in hot and/or humid weather, your skin signals blood vessels to relax and triggers sweat glands under your skin to produce water and salt which in turn increases sweating. This process cools you down as the water evaporates from your skin.

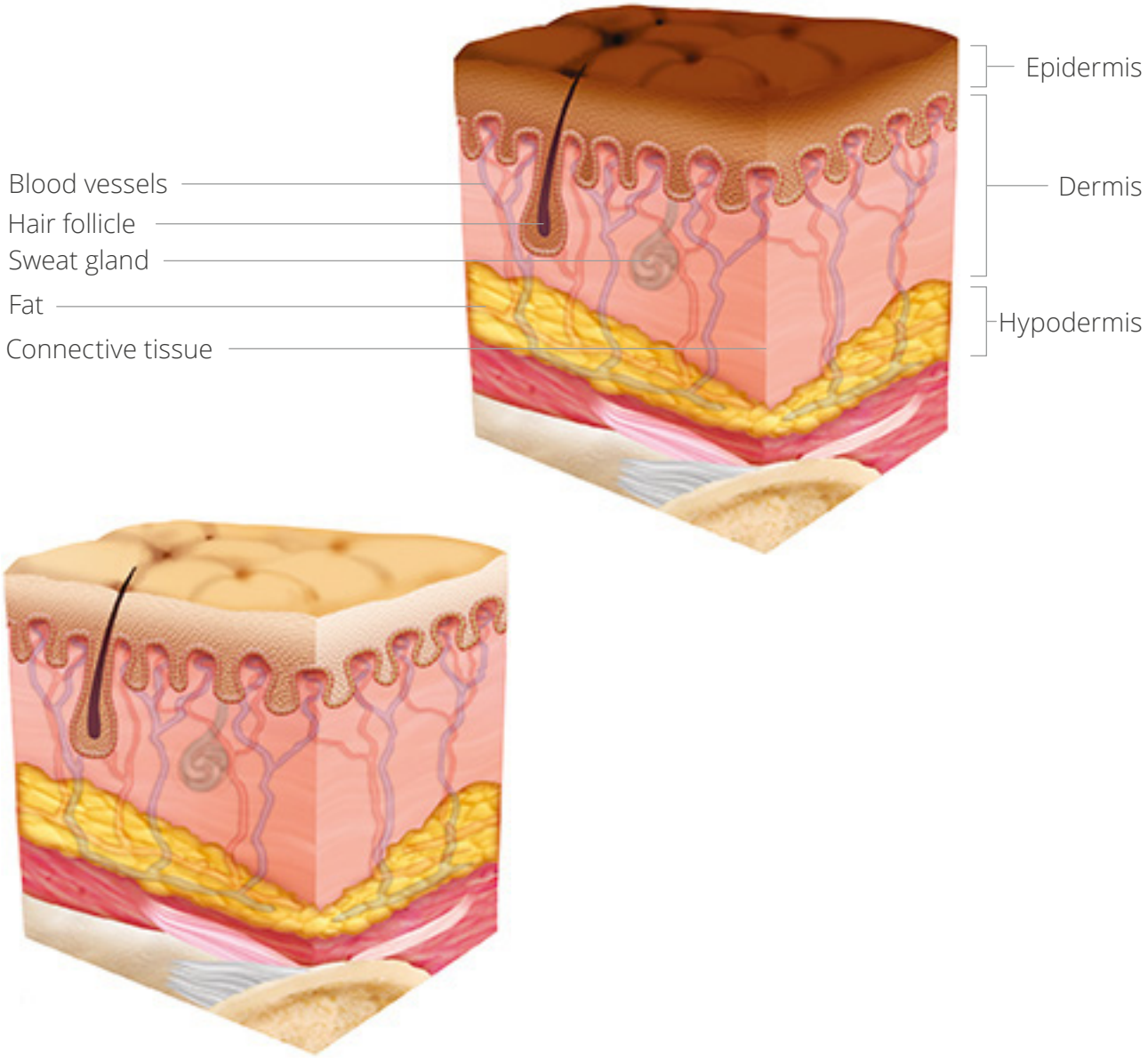


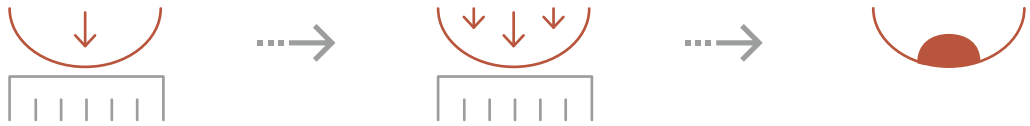
Image courtesy of The National Pressure Ulcer Advisory Panel 2016

Effects of a spinal cord injury on skin integrity

In people with a spinal cord injury, the **nerves** that carry messages back and forth between the skin below the level of your injury, spinal cord and brain don't work the way they should.

The following happens to the skin in people with a spinal cord injury:

- Decreased or absent sensations to register touch, pressure, pain, heat and cold below the level of a spinal cord injury.
- Reduced sweating to help cool body down below the level of the spinal cord injury.
- Excessive sweating may occur above the level of a spinal cord injury.
- Weakness or loss of muscle strength below the level of the spinal cord injury can produce swelling or oedema of the lower limbs due to pooling of the fluids.
- No change to the protective function of your skin below or above the level of a spinal cord injury allowing the skin to protect internal organs against heat, light, injury and infection.
- A pressure injury involves damage to the skin and the tissue underneath the skin due to prolonged or excessive pressure or pressure applied in combination with shear or sliding and friction.



Pressure is applied for too long or at a very high pressure over a bony prominence

Results in a compromised blood supply reducing oxygen to the affected area

The end result is skin breakdown or a pressure injury

Before your spinal cord injury, your body sent signals for you to move, squirm or change positions when you became uncomfortable. After your spinal cord injury, your early warning system doesn't work as well. You need to actively think about your body and regularly relieve pressure.

Skin problems

In addition to the loss of sensation and impaired regulation of your body temperature, there are many internal and external factors that affect your skin integrity and delay healing of your injured skin.

Internal factors include anaemia, poor nutrition, diabetes, lung disease, emotional and psychological problems, and issues with circulation. Anaemia is a lack of red blood cells carrying oxygen that help promote pressure injury healing.

External factors include drugs, old equipment, deflated or overinflated Roho cushion, alcohol use or smoking. The last two can have a negative effect on your ability to practice good skin care.

Common problems

- Pressure injuries, also called pressure ulcers, bedsores or pressure sores
- Skin rashes and dermatitis

Other problems

- Burns
- Cold injuries
- Ingrown toenails
- Sweating causing excess moisture
- More fragile skin over scar tissue
- Sunburn

Uncommon problems

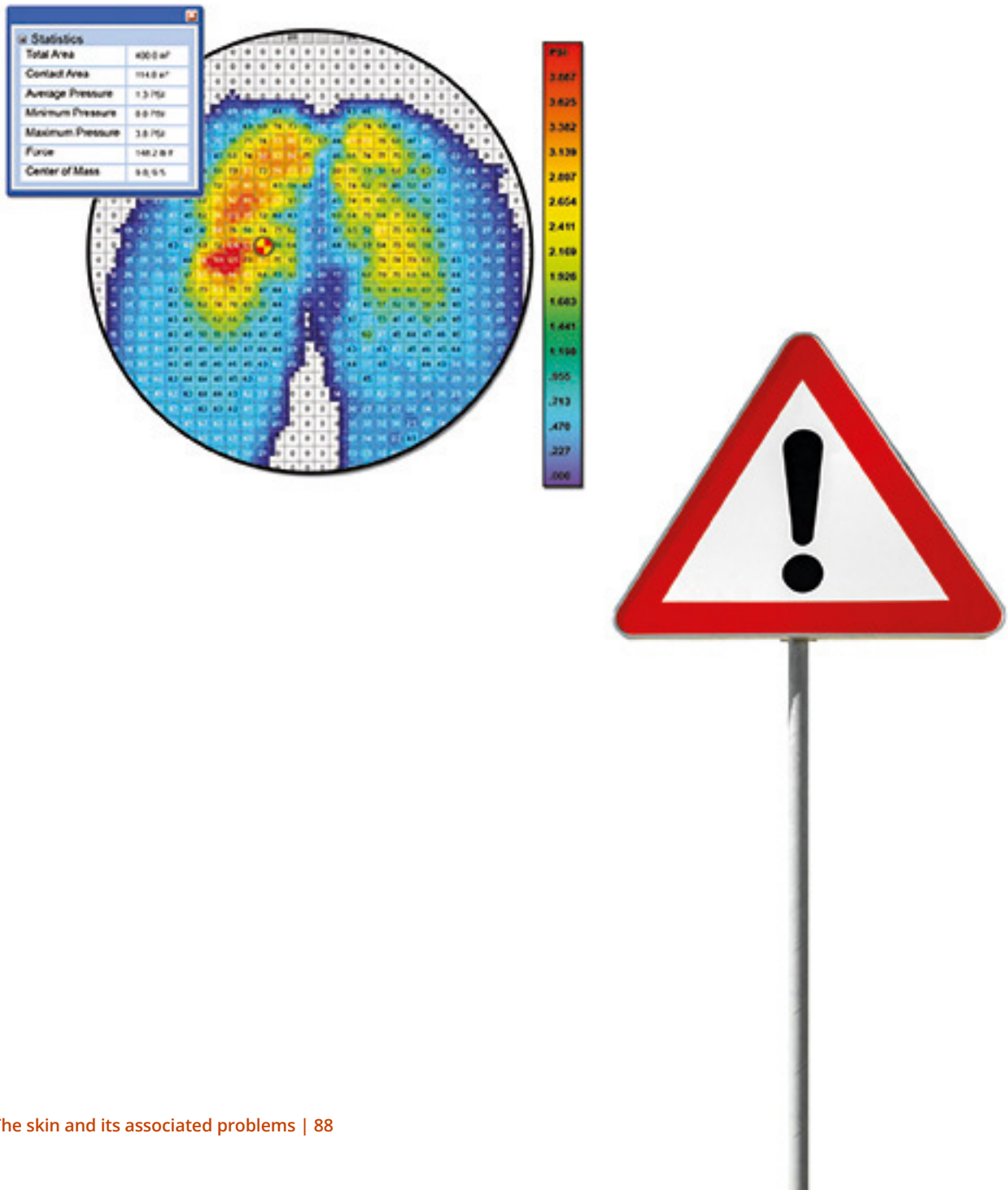
- Cellulitis, an infection of the skin
- Venous/arterial ulcers
- Sinus or tract in skin/underlying tissues
- Osteomyelitis, an infection of the bone under the skin, fat and muscle layers

Check if you have a problem

Warning signs

If you experience any of the following warning signs, you need to seek medical attention:

- Purple or discoloured skin or a blood-filled blister indicating a deep pressure injury that develops from the inside out
- Fevers, sweats, the shakes or you have been feeling unwell because of a pressure injury
- Your pressure injury is discharging a lot of pus and/or the surrounding skin is red
- Your pressure injury has not been improving, has increased in size and depth or has unhealthy tissue at its base.



Prevention

Self-management tips to prevent pressure injuries

Relieve pressure regularly

Action: Reposition yourself and/or lean forwards or from side-to-side in your wheelchair. Try to lean for 2 minutes, at least once every hour.

Check skin twice a day

Action: Use a mirror and/or touch to see or feel your skin, or instruct others to check your skin if you cannot check it yourself.

Use appropriate pressure-relieving devices

Ensure you have a mattress that meets your needs.

Action: If you are using an air mattress, ask your therapist for instructions then teach others how to use the equipment properly.

Use the right cushion and look after it

Learn how to look after and maintain your cushion, and always have a repair kit handy. Seating should be reviewed when replacing cushions, chairs or if problems develop. Avoid over-inflating your cushion, if you have the cushion shown in the picture.

Action: If unsure, see a seating specialist.

Know how to identify skin breakdown

Knowing how to identify skin damage can help you decide on the right course of action and recognise improvement or further breakdown.

Action: Understand the different stages of skin breakdown. Early detection reduces time to healing, improves outcomes and decreases cost.

Image courtesy of The National Pressure Ulcer Advisory Panel 2016

Maintain good skin hygiene

Action: Keep your skin clean and dry, especially after showering or swimming. Pay attention to the groin, between the buttocks and in between your toes.

Wear loose fitting clothes

Tight-fitting clothes and shoes can damage skin.

Action: Wear clothes that are appropriate for the weather. Wear properly fitting shoes to avoid too much pressure which can cause an ingrown toenail.

Maintain a healthy lifestyle

A healthy lifestyle will assist in keeping your skin healthy.

Do not use too many powders and creams

Powders can turn into tiny hard balls when moist, causing damage to the skin. Creams can make your skin 'soggy', making it more susceptible to breakdown.

Action: Avoid using powders and ensure creams are gently applied and completely absorbed.

Know your medications

Action: Understand the side effects of certain medications, such as sensitivity to sun if taking Baclofen (Lioresal) for spasms.

How to prevent heat injuries

When bathing

- Check yourself or ask someone to check the water temperature by dipping the hand (with normal sensation) into the water for 5 seconds. If you feel comfortable, then the water temperature is safe.
- Do not set your hot water system higher than 48 degrees Celsius.

Use of heat packs

- Avoid them, especially on body parts with little to no sensation.

Household amenities

- Do not sit too close to heat inside your house such as fireplaces, hot stove burners and radiators. When outdoors, don't sit too close to campfires.
- Do not use electric blankets.
- Do not carry hot fluids or foods in your lap without a tray. Have a cup holder and do not overfill the cup.

How to prevent cold injuries

Outside in cold weather

- Cover your head, nose, ears, chin and hands.
- Wear warm socks and sturdy shoes.
- Remove any wet clothing.

Please note: If you feel cold and tingling on your ears, then most likely your feet are cold too so move indoors.

Ice packs

- Always wrap them in a towel.
- Do not use them for more than 10 minutes.

Please note: Be careful with carrying frozen food on your lap in the supermarket.

Using a wheelchair

- Wear gloves to push your manual wheelchair.

Please note: Wheelchair parts and gel cushion can get cold and may cause your skin to dry out, causing cracks, splits and cold injuries that are hard to heal.

Pressure injuries toolbox

Management of a skin problem can be challenging because many factors play a role. A single strategy, for example, applying a wound dressing, may not be as effective when used in combination with other strategies. Your specialist nurse or doctor may need to try a combination of treatments and this may take some time.

Think about using the pressure injuries toolbox to treat your pressure injury. The toolbox is made up of 8 components as seen in the picture below.

Consider this 8-step toolbox when managing your skin care.

Important note

It is unlikely that changing just one component will fix a pressure injury.

1. Assessment

A proper assessment of a pressure injury considers all the possible factors that can impact healing and risk of recurrence.

These factors include:

- Spinal cord injury-specific factors
- Classification of stages of pressure injury
- Diet and nutrition
- Mechanical factors
- Pre-existing medical conditions
- Psychological and lifestyle factors.

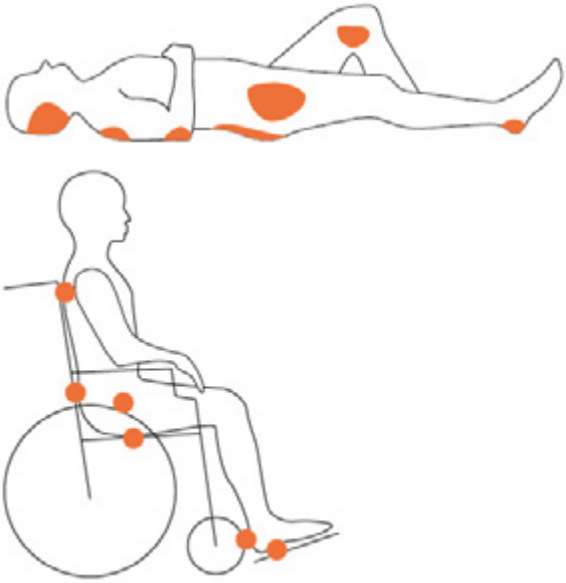
It is recommended to assess and address all of the above factors while monitoring them regularly to maximise pressure injury healing.

Spinal cord injury-specific factors

A variety of characteristics associated with a spinal cord injury affect your risk of getting a pressure injury and the time for healing. Factors include level and extent of injury, ageing, spasms, and bladder and bowel incontinence.

Remember that the greatest pressure is always on the deep tissues and overlying bony prominences.

Locations where pressure injuries commonly develop are shown in the picture below:



Do you know?

90% of pressure injuries are preventable.

Classification of stages of pressure injury

Pressure injury can be divided into 6 types. Duration of healing is directly related to the relevant pressure injury stage and applying the appropriate treatment. The 6 stages are:

Stage 1

Intact skin with a localised area of non-blanching redness with pressing, usually over a bony prominence. If treated early, stage I pressure injury can heal in about 3 days.

Stage 2

Partial thickness loss of dermis presenting as a shallow open wound with a red-pink wound base. Healing from this stage can last anywhere from 3 days to 3 weeks.

Stage 3

Wound extending through epidermis and dermis into the fatty subcutaneous layer. Healing usually needs at least 1 to 4 months.

Stage 4

Full thickness tissue loss extending into underlying tissues, such as muscle and possibly bone. Healing can take anywhere from 3 months to 2 years.

Deep tissue injury

Purple or maroon localised area, an area of discoloured intact skin, or a blood-filled blister.

Unstageable

Full thickness tissue loss in which the base of the pressure injury is covered by unhealthy skin.

Image courtesy of The National Pressure Ulcer Advisory Panel 2016

Diet and nutrition

Various strategies may be necessary to cater for an individual's nutritional requirements. Seeking advice from a qualified dietitian is recommended.

For more detailed information, refer to the Diet and nutrition section on page 101.

Pre-existing medical conditions

If your pressure injury is not healing after 4 weeks (it should be improving by at least 25% per month) or getting worse despite intervention, ask your GP to screen for common conditions, such as anaemia, infection, diabetes and nutritional deficiency, which are known to delay healing. Ensure that you receive appropriate treatment if any of these medical conditions are present.

The presence of infection in the pressure injury can be assessed using the below guide:

If 3 or more of the following signs are present, this means you have a high amount of bacteria in a superficial wound

- Your pressure injury is not healing
- Increasing ooze (exudate) from your pressure injury
- Red, friable tissue that tears and bleeds more easily
- Appearance of unhealthy tissue with debris or dead cells
- Your pressure injury is smelly.

If 3 or more of the following signs are present, this means you have a high amount of bacteria in a deep wound and surrounding skin

- Your pressure injury has increased in size
- You have a fever
- Exposed bone can be seen at the base of your pressure injury
- You have developed a new pressure injury in the surrounding area
- Redness and swelling (cellulitis) in the surrounding skin
- Increasing ooze (exudate) from your pressure injury
- Your pressure injury is smelly.

Increasing clinical problems

Contamination (being made impure)	Colonisation (establishing in an area)	Local infection	Spreading infection	Systemic infection (widespread infection)

Vigilance required — Medical treatment required

Source: Wound Care Made Incredibly Easy! 2nd ed., Lippincott Williams & Wilkins, 2007.

Ask your GP to perform the following tests to rule out certain health conditions:

Full blood count

Check for level of haemoglobin (cells carrying oxygen to tissues) and the number of white blood cells (that fight infection).

Inflammatory markers

C-reactive protein and ESR which are raised with infection.

Iron profile

Check for levels of ferritin, serum iron, percentage saturation, and total iron binding capacity which aids healing.

Biochemical screen

Check for fasting or random blood glucose, protein and prealbumin levels markers of adequate nutrition.

What does research tell you?

It is recommended to use antimicrobial dressings if signs of infection are present.

Mechanical factors

Various mechanical factors can influence healing of a pressure injury:

1. Impaired mobility
2. Altered sensory perception
3. Reduced tissue tolerance due to:
    a. Moisture
    b. Friction
    c. Shear.

Strategies:

- Avoid weight bearing on the pressure injury area
- Minimise weight bearing over bony prominences by:
  - Leaning forward or to side for 2 minutes for regular pressure relief
  - Frequently changing position while in bed.

Psychosocial and lifestyle factors

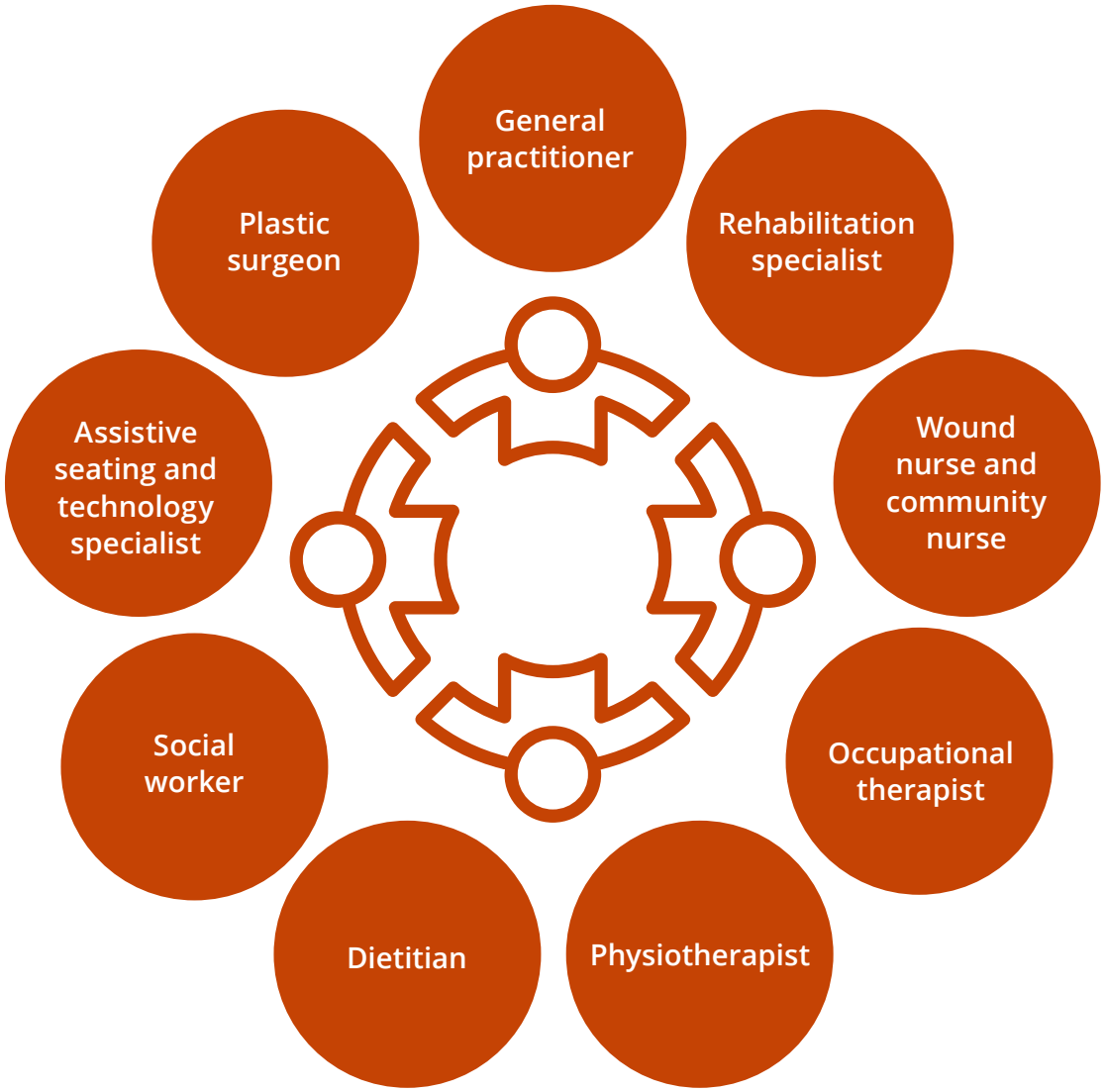
Psychosocial and lifestyle factors also contribute significantly to skin breakdown and impact on wound healing. Consider the following factors:

- Limited social support or living alone
- Inadequate personal care and/or domestic assistance
- Caregiver fatigue
- Financial concerns including access to quality equipment, repairs and provision of services
- Unsustainable work or family commitments
- Signs of mental health concerns, such as depression, depressed mood, social withdrawal or excess use of drugs or alcohol, drug and alcohol use or worsening of a pre-existing mental health condition
- Level of motivation
- Lifestyle priorities, competing interests, roles and responsibilities (trade-off between pressure management requirements and living life)
- Reduced ability to self-manage/direct care, problem solve and troubleshoot
- Smoking.

2. Interdisciplinary team approach

An effective way of treating a pressure injury is to have a comprehensive treatment plan developed with the support of an interdisciplinary team that may include doctors, community nurses, wound nurses, therapists, social workers, psychologists, engineers and dietitians. The plan should address the cause of the pressure injury, other contributing factors, methods for relieving pressure, specific wound care, adjunctive therapies to support healing as necessary, surgery for complex or deep pressure injuries (stage 3 and 4, if indicated), management of complications, and educational and nutritional interventions.

Interdisciplinary team members for pressure injury management



What does research tell you?

Expert opinion recommends a comprehensive assessment by an interdisciplinary team to identify pressure injury risk factors. This assessment includes level and completeness of your spinal cord injury, associated health conditions, level of functioning and mobility, nutritional status, continence, psychological and social factors, care and equipment.

3. Wound care

Good wound care is important and includes:

Cleansing

- Cleanse pressure injuries at each dressing change with a generous volume of sterile solution, e.g., saline water.
- Consider adding an antiseptic agent if there are signs of infections, e.g., Betadine Solution.

Dressings

- The selected dressing should:
  - Provide an optimal level of moisture to the wound base of a stage 2 or 3 pressure injury.
  - Meet your needs based on the location of the pressure injury or injuries and can be modified depending on your goals and/or change in wound status.
- Avoid daily dressing changes if possible, by using a dressing type (absorbent dressing) that manages fluid coming out from the wound bed (also known as exudate) and odour as well as remains in place for as long as possible.

In some instances, wound care may also include wound debridement

- Debridement is the removal of dead (necrotic) or infected skin tissue to help a wound heal.
- Ensure only a qualified doctor or a nurse debrides devitalised (dead) tissue from a pressure injury, using a method appropriate to the wound status.

Should you need to use any of these strategies you are advised to discuss this with your community nurse or general practitioner before applying.

Deciding on what type of wound care dressing is right for your situation

Selecting the right dressing will depend on:

- The size of your wound
- The amount of moisture in the wound
- The level of infection
- The condition of the surrounding skin.

Dressing moisture scale

Pressure injury is too moist

Management strategy

Absorb moisture by:

- Promoting debridement and cleaning the dead tissue from the wound, using an alginate dressing.
- Using an absorptive dressing that contains multiple layers of highly absorbent materials suitable for draining wounds.
- Using a hydrocolloid dressing that is adhesive, mouldable, impermeable to oxygen and water, and promotes debridement.
- Filling a deep wound with wound fillers to promote healing.
- Using foams to provide thermal insulation and create a moist wound environment.

Pressure injury neither too moist nor too dry

Management strategy

Maintain existing moisture level by:

- Using a collagen dressing to promote growth of tissue and blood vessels.
- Using dressings that are made from a woven or perforated material and to be placed directly over the wound then secured by a contact layer dressing.
- Using a transparent film dressing that adheres to the skin and helps maintain a moist wound environment. These types of dressings promote debridement and stimulate formation of granulation tissue.

Pressure injury is too dry

Management strategy

Add moisture by:

- Using a hydrogel dressing to promote hydration to the wound and soften dead tissue.

Other types of dressings

Composite

Combines two or more types of dressings into one depending on the stage of the wound.

Anti-microbial

Contains ingredients such as silver and iodine to protect your wound from bacteria.

What does research tell you?

Expert opinion recommends using a dressing that maintains an optimal level of moisture at the base of the pressure injury.

4. Offloading pressure

Strategies for managing pressure depend on:

- The location of your pressure injury
- Your circumstances and available resources.

Strategies to aid the healing process include:

- Full-time (24-hour) bed rest
- Limited time sitting with close monitoring
- A graduated sitting protocol for a healed pressure injury (see below for more details)
- Equipment monitoring
- A positioning aid such as a heel wedge.

Graduated sitting protocol for pressure injury management

Perform a skin check prior to – and after – sitting at all times.

Day 1	**Sit up for 15 minutes twice a day**	
	If skin condition does not deteriorate after the 1st day, increase sitting time as described on Day 2.	If a skin condition does deteriorate after the 1st day of sitting, return to bed rest until re-evaluated by medical staff.
Day 2	**Sit up for 30 minutes twice a day**	
	If a skin condition does not deteriorate after the 2nd day, increase sitting time as described on Day 3.	If a skin condition does deteriorate after the 2nd day of sitting, return to 15 minutes of sitting only.
Day 3	**Sit up for 1 hour twice a day**	
	If a skin condition does not deteriorate after the 3rd day, increase sitting time as described on Day 4.	If a skin condition does deteriorate after 3rd day of sitting, return to 30 minutes of sitting only.
Day 4	**Sit up for 2 hours twice a day**	
	If a skin condition does not deteriorate after the 4th day, increase sitting time as described below this section.	If a skin condition does deteriorate after 4th day of sitting, return to 1 hour of sitting only.

Sitting times can progress by doubling the overall length of time from the day before as long as skin checks demonstrate no new pressure-related problems.

Source: Adapted from Houghton PE, Campbell KE and CPG Panel (2013). Canadian Best Practice Guidelines for the Prevention and Management of Pressure Ulcers in People with Spinal Cord Injury. A resource handbook for Clinicians.

Talk with your community nurse or GP before starting a graduated sitting protocol.

5. Support surfaces and positioning

Ensure proper bed positioning by using devices and techniques that are suitable for the type of support surface and your health status.

- Use pillows, cushions and positioning aids to:
  - Bridge contacting tissues, including bony prominences
  - Unload bony prominences
  - Protect pressure injuries and other vulnerable areas of skin.
- Do not use closed cut outs in mattresses or donut type cushions, and avoid being positioned directly on your pressure injury.

Do you know?

Positioning in bed with the head of the bed elevated more than 30 degrees can cause destructive friction and shearing forces, especially over lower back/sacral region. Use the knee break to prevent sliding down the bed.

Important note

Do not place incontinence sheets over the top of your support surface as it negates the redistribution and relief of pressure.

Education is essential so you and your caregivers know how to:

- Carry out repositioning manoeuvres safely, including correct positioning of pillows and wedges, and aids to reduce friction such as slide sheets.
- Avoid pinching of catheter tubing and wrinkling of your clothing under weight-bearing parts of the body.

Talk with your community nurse or GP before using any of the above-mentioned methods.

What does research tell you?

Expert opinion recommends the reassessment of the pressure-relieving performance of sitting support surfaces at least every 2 years, or sooner, if there is:

- A change in your health status, including weight or functioning level
- Wear and tear of equipment
- Development of a pressure injury
- A change in your living circumstances, care and support needs.

Support surfaces are broadly classified in 2 categories: reactive or active types.

REACTIVE or STATIC

A reactive support surface is a powered or non-powered support surface with the capability to change its load distribution in response to the applied load.

Type	Performance characteristic	Application
Foam	• Standard support area • Some pressure redistribution • No shear or microclimate management • Routine transfers	Pressure injury prevention or treatment of uncomplicated pressure injury for high-specification foam or static flotation
High-specification foam	• Increased support area • Pressure redistribution • No reduction in shear • No microclimate management • Routine transfers	Pressure injury prevention or treatment of uncomplicated pressure injury for high-specification foam or static flotation
Static flotation air, gel or water	• Increased support area • Pressure redistribution and shear reduction • No microclimate management • May affect transfers • Gel and water heavy to move	Pressure injury prevention or treatment of uncomplicated pressure injury for high-specification foam or static flotation

ACTIVE or DYNAMIC

An active support surface is a powered support surface with the capability to change its load distribution properties, with or without the applied load.

Type	Performance characteristic	Application
Alternating air pressure	• Increased support area • Pressure and shear reduction • No microclimate management • Routine transfers	Pressure injury prevention or treatment: • Pressure injuries on multiple turning surfaces • Failure to heal on static support • Post-operative pressure injuries repair • Greater pressure reduction than static

Source: Modified from Houghton PE, Campbell KE and CPG Panel (2013). Canadian Best Practice Guidelines for the Prevention and Management of Pressure Ulcers in People with Spinal Cord Injury. A resource handbook for Clinicians.

Do you know?

The optimal period for a change in position is still unknown. However, changing position every 2 hours is widely recognised as an effective and clinically useful strategy.

Talk to your community nurse or GP before deciding on a suitable support surface.

6. Diet and nutrition

ONE SIZE DOES NOT FIT ALL

Consult a registered **DIETITIAN** for a comprehensive assessment to develop a personalised nutrition and diet plan, in consultation with your GP.

Your diet plan will tell you:

- How many **CALORIES** to consume each day
- How much **PROTEIN** to include daily
- Which **MINERALS** and **MULTIVITAMINS** you need to promote healing of your pressure injury
- Which **SUPPLEMENTS** to take or avoid.

Important notes

- Inadequate food intake, poor nutritional status, excessive nutrient and fluid losses, and unplanned weight loss impair wound healing.
- Low protein (albumin and prealbumin) values in your blood reflect the severity of illness or injury and the potential for the development or worsening of malnutrition, regardless of nutrition status.
- Inadequate fluid intake may result in dehydration, which plays a role in delayed wound healing.
- Effectively managing your bowel and bladder also impacts the healing of your pressure injury.

Do you smoke?
The most important thing you can do is quit.

What does research tell you?

Expert opinion recommends having an early assessment by a dietitian to provide optimal nutritional support for all people with a spinal cord injury who have a severe pressure injury, a pressure injury that is not healing at the expected rate, unintentionally lost weight or are at risk of malnutrition.

7. Adjunctive therapy

The two most common methods used to promote healing of a pressure injury are:

Electrical Stimulation

A small battery-like device sends an electrical current via two small rubber pads attached to the skin or surrounding a pressure injury.

This method is used for stage 2, 3 and 4 of pressure injuries.

Negative Pressure Wound Therapy

A suction is attached to a wound dressing that covers the pressure injury, which exerts carefully controlled suction or negative pressure. This action removes wound and tissue fluid from the treated area by draining it into a canister.

This drainage method is used for stage 3 and 4 pressure injuries.

The following interventions are less widely used for promoting healing of a pressure injury, and also have less evidence-based research:

- Maggot Therapy
- Electromagnetic Energy
- Ultraviolet Light
- Electrical Stimulation
- Topical Oxygen
- Laser
- Hyperbaric Oxygen.

Talk to your community nurse or GP before using any of the above-mentioned methods.

What does research tell you?

Electrical stimulation has been shown to increase the proportion of healed pressure injuries when compared with no stimulation. However, the research evidence to date supporting the positive effects of electrical stimulation is insufficient to support its widespread use.

Research evidence supporting the positive effects of negative pressure wound therapy is minimal. In comparison, a standard dressing has better outcomes and lower intervention costs.

8. Surgical treatment

Surgery can play an important part in the management of pressure injuries that are non-responsive to other strategies, e.g., in stage 3 or 4 pressure injuries.

There are a range of surgical interventions:

- Surgical debridement or removing dead tissue
- Direct wound closure
- Skin grafting
- Skin-muscle flap repairs.

Important notes

Consulting a Specialist Spinal Plastics or Skin Care Service for a comprehensive interdisciplinary evaluation is essential before deciding to undergo surgical intervention.

Advantages of surgical intervention:

- Definitive wound debridement with skin and soft tissue coverage
- Improved blood supply
- Improved healing with removal of underlying bony infection called osteomyelitis
- Improved function and independence.

Important notes

Surgery is a huge commitment requiring total bed rest in the prone position for months in hospital prior to and after surgery.

There is also a risk of further skin breakdown after the surgery.

Other skin problems

Ingrown toenails

- If the area around the nail is red and you see pus when you press on the edge of the nail, your nail may be cutting into the skin.
- Soak your foot in soapy water, wash it well, rinse and gently dry.
- Place a small piece of cotton under the nail to keep the edge of the nail away from the skin. Change the cotton daily.
- If it does not begin to heal in 2 or 3 days, see your doctor or healthcare provider.
- Make sure your socks and shoes leave plenty of room for your toes.
- Keep your feet clean and dry.
- Keep your toenails trimmed.

Heat injuries

Loss of skin sensation puts you at risk for a burn injury.

How to treat heat injuries

Apply cool water and administer first aid immediately. Do not use ice or an ice pack on a burn. Seek medical attention as soon as possible.

Cold injuries

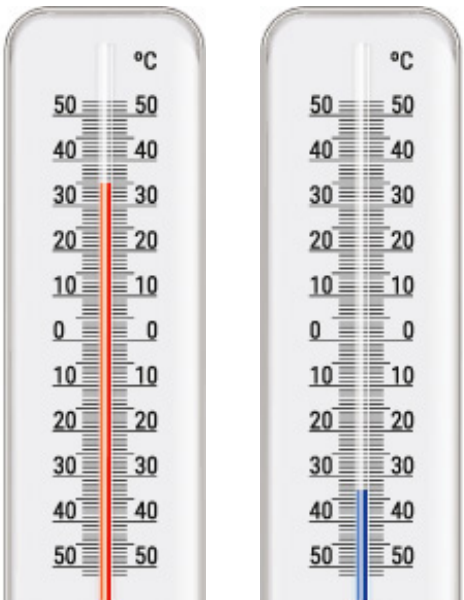
Loss of skin sensation increases your chances of getting a cold injury, also known as frostbite.

How to treat cold injuries

Since skin may be numb, people with frostbite can harm themselves further unintentionally. Seek medical attention as soon as possible.

Do you know?

Chilblains are patches of discoloured (red, blue, white) skin, along with swelling and blistering on your hands and feet. Chilblains are thought to be caused by a combination of cold weather and poor circulation. The toes are particularly vulnerable and tight shoes can contribute by further reducing circulation to the toes. Most chilblains don't cause any permanent damage to tissue, although sometimes they can cause skin ulceration.



Moist skin

Sweating, urine incontinence or diarrhoea make your skin wet increasing your chances of a skin infection.

Healthy tips

- Keep your skin clean and dry.
- Pay special attention to cleanliness in sweating areas.
- Clean and dry well under skinfolds.

Sunburn

Sunburn is a form of radiation burn affecting living tissue, e.g., skin, as a result of overexposure to ultraviolet or UV radiation, usually from the sun.

Healthy tips

- Check weather conditions on your weather app or check online and make sure you apply sunscreen with a recommended sun protection factor.
- Wear a hat and a long-sleeved shirt when you are out in the sun.
- Certain medications, such as antibiotics and local skin ointments, can make your skin more sensitive to sunburn. Check with your pharmacist.

Management index

The severity of your skin problems can vary depending on the underlying cause.

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

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

Severity scale

To check the severity of your problem, consider the intensity, duration and frequency of signs and symptoms using this table.

Problem	Mild	Moderate	Severe
Pressure injury	Stage 1 or 2 pressure injury, which heals rapidly	Stage 2 pressure injury (≥ 4 weeks), AND/OR infection (superficial) present Recurrent or multiple Stage 1 or 2 pressure injuries	Stage 3-4 pressure injury, deep tissue injury, prolonged healing (≥ 3 months) AND/OR infection (deep) present Recurrent pressure injuries/previous flap repair (Stage 3-4) Deteriorating or pressure injuries over multiple areas
Burn	Superficial burn (first-degree). Skin is red, painful, dry, without blisters. Mild sunburn	Partial thickness (second-degree) burn. Skin is red, blistered, and may be swollen and painful.	Full thickness (second-degree) burn. Skin looks white or blackened and charred.
Cellulitis	–	Red, swollen, tender, warm area of skin Occurs infrequently (once every 12 months or less often)	Red, swollen, tender, warm area of skin Occurs frequently (twice or more per year) AND/OR spreads to involve lymph nodes and/or enters bloodstream

Important note

Any skin-related symptoms of any severity associated with autonomic dysreflexia are considered **SEVERE** and require **URGENT MEDICAL ATTENTION**.

Interference scale

To determine to what extent your problem interferes with participating in everyday activities, use the scale below:

0	1	2	3
Not at all	A little of the time	Some of the time	A lot of the time

The following index provides a way to combine your self-assessment ratings on both severity and interference scales to help you decide what level of support you may need to most effectively manage your problem.

Severity rating	Interference rating	Management strategies
Mild problem	(0) Not at all	Self-manage
Mild problem	(1) A little of the time	Self-manage
Mild problem	(2) Some of the time	Self-manage with support from your GP or other healthcare professional
Mild problem	(3) A lot of the time	Self-manage with support from your GP or other healthcare professional
Moderate problem	(0) Not at all	Self-manage with support from your GP or other healthcare professional
Moderate problem	(1) A little of the time	Self-manage with support from your GP or other healthcare professional
Moderate problem	(2) Some of the time	Self-manage with support from your GP or other healthcare professional
Moderate problem	(3) A lot of the time	Manage with specialist support
Severe problem	(0) Not at all	Manage with specialist support
Severe problem	(1) A little of the time	Manage with specialist support
Severe problem	(2) Some of the time	Manage with specialist support
Severe problem	(3) A lot of the time	Manage with specialist support

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

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

Serious complications can arise if pressure injuries are not managed in a timely way. In the long term, these issues can lead to:

- **Worsening of the pressure injury:** The pressure injury may get larger and deeper, and result in tunneling which is a formation of track between layers of muscle, fat or bone that may be hard to heal.
- **Infection:** In a deep pressure injury, the bone can become infected, known as osteomyelitis. The infection can spread into your bloodstream making you extremely sick, in some cases leading to death.
- **Scarring:** Most superficial injuries heal by forming scar tissue. Scar tissue has poor blood supply, is less elastic and more susceptible to breakdown than normal skin, making reoccurrence of a pressure injury more likely. If you have scar tissue on a weight-bearing area, limit your time in that position to prevent recurrent breakdown.

'Just-in-time, or the right care at the right place at the right time, will reduce risk and prevent complications. 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 know how your spinal cord injury affects your skin and what the research tells us.
- Becoming a partner in decision-making with your doctor and health professionals.
- Developing an individual health management plan.
- Engaging in ongoing health and wellness activities for healthy skin by:
  - Relieving pressure regularly
  - Knowing how to identify a pressure problem
  - Maintaining a healthy diet and drinking plenty of water
  - Scheduling an annual check-up to rule out other causes of skin breakdown.

Take home messages

EAT

a balanced diet

MAINTAIN

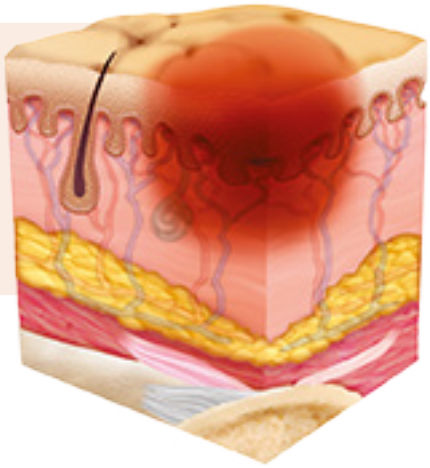
good hygiene with special attention to your groin and washing/drying between your toes

KNOW

how to identify signs of a pressure injury and skin breakdown

RELIEVE PRESSURE

regularly



TREAT

your pressure injury at an early stage

Knowledge test

1. When assessing your pressure injury risk, you need to consider:

   (a) Internal factors, such as immobility, lack of sensation and underlying medical conditions.

   (b) External factors, such as pressure, friction, moisture and force.

   (c) Mechanical factors.

   (d) All of the above.

2. List four treatment strategies from the pressure injuries toolbox:

   i. _____

   ii. _____

   iii. _____

   iv. _____

3. Effective bowel and bladder management lowers your risk of pressure injury and promote healing.

   (a) True (b) False

4. Other skin problems can occur after your spinal cord injury. Check the correct answers.

   (a) Burns.

   (b) Acne.

   (c) Frostbite.

   (d) Ingrown toenail.

5. When you have a pressure injury, what factors need to be considered by your healthcare professional to select the right wound dressing?

   (a) The size of your wound.

   (b) The amount of moisture in the wound.

   (c) Possible infection of the wound.

   (d) The condition of the surrounding skin.

   (e) All of the above.

For correct answers, please see page 112.

Glossary

Term	Definition
Cellulitis	A common, potentially serious bacterial skin infection. The affected skin appears swollen and red and is typically painful and warm to touch. Cellulitis usually affects the skin on the lower legs, but it can occur in the face, arms and other areas.
Debridement	The removal of damaged tissue or foreign objects from a wound.
Dermatitis	A common skin condition caused by inflammation of the skin. There are several different forms of dermatitis, but all are caused by the skin reacting to allergens or irritants. Dermatitis is usually characterized by red, itchy skin that can become blistered and weepy.
Osteomyelitis	An infection of the bone, a rare but serious condition. Bones can become infected in a number of ways, especially when the bone is exposed to an external environment due to your deep pressure injury.
Skin grafting	A surgical procedure that involves removing skin from one area of the body and moving or transplanting it to a different area.
Sinus	A tract leading from a skin to a deep tissue, resulting from acute or chronic pus.
Venous ulcers	Wounds that are thought to occur due to improper functioning of venous valves, usually in the legs. Often called leg ulcers.

Further resources

Reading resources for consumers

- Pressure Ulcers: What You Should Know - A Guide for People with Spinal Cord Injury (48 pages)
  Access at: **https://pva-cdnendpoint.azureedge.net/prod/libraries/media/pva/library/publications/consumer-guide_pressure-ulcers.pdf**

Useful resources for consumers and medical professionals

- Pressure Ulcer Prevention and Treatment Following Spinal Cord Injury: A Clinical Practice Guideline for Healthcare Professionals (104 pages)
  Access at: **https://pva-cdnendpoint.azureedge.net/prod/libraries/media/pva/library/publications/cpg_pressure-ulcer.pdf**

Videos for consumers

- Pressure sores (3 minutes)
  Access at: **https://youtu.be/C_UyC8l8-Vw**
- Understanding Pressure Injury Staging (4 minutes)
  Access at: **https://youtu.be/xNH8DDvjSME**
- Pressure Ulcer Prevention: A guide for patients and carers (18 minutes)
  Access at: **https://youtu.be/aMp7Dx7z3_w**

Answers to knowledge test

1: d; 2: i. Assessment, ii. Wound care, iii. Offloading pressure, iv. Diet and nutrition; 3: a; 4: a, c and d; 5: e;

Notes

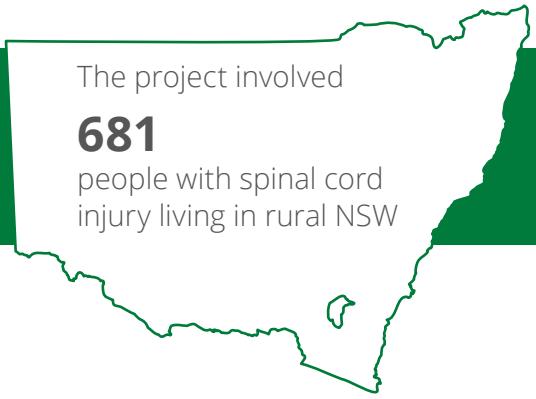
Notes

Pain

Contents

Summary of findings

from the 2015 Rural Spinal Cord Injury Project



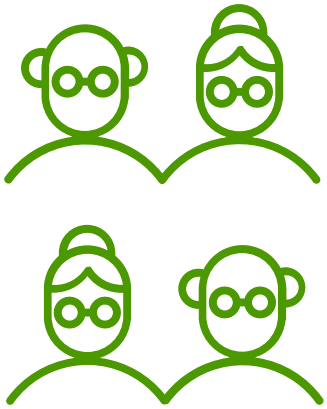
The project involved

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:

Painkillers

more than

50%

Other medications

Anticonvulsants

33%

Opioids

21%

Antidepressants

16%

How to navigate this module

KNOW Your pain and spinal cord injury (page 119)

CHECK Do you have pain?
Refer to checklist and warning signs (page 123)

Yes

IDENTIFY PROBLEM
Look for important signs and symptoms:
- Musculoskeletal pain (page 122)
- Neuropathic pain (page 122)
- Visceral pain (page 122)

CHECK SEVERITY
Based on the management index:
- Pain intensity scale (page 137)
- Pain interference scale (page 137)

MANAGE
Based on pain intensity and interference (page 137 - 138)

- Self-manage without support
- Self-manage with support from your GP or other healthcare professional
- Manage with specialist support

Is this problem resolved? Have your goals been met?

No

RE-ASSESS

Yes

OBSERVE/PREVENT

No

OBSERVE
Refer to questions in checklist and warning signs

PREVENT
Refer to:
- Self-management tips (page 125)
- Take home messages (page 140)

EDUCATE
Refer to pain management toolbox (page 126)

What will happen if you do not manage your problem 'just-in-time'? (139)

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.

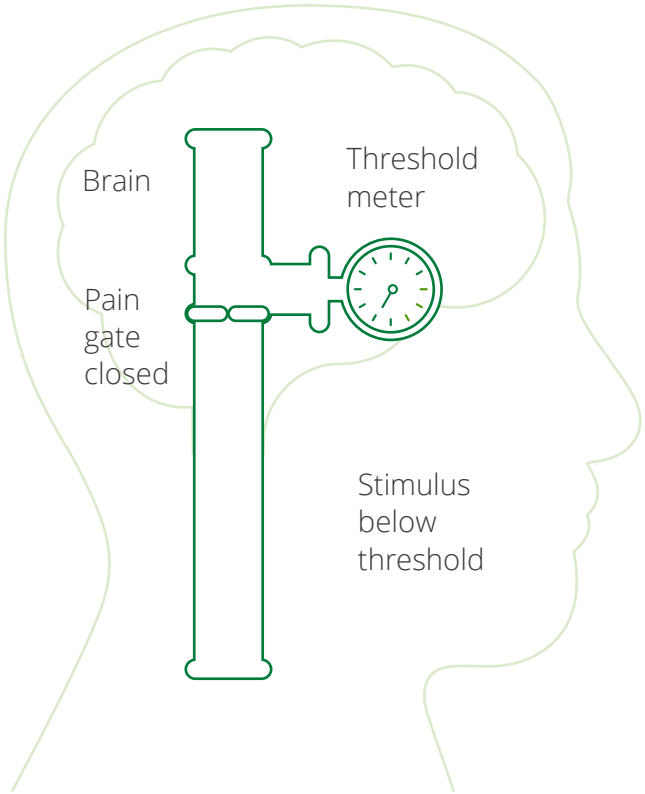
A strong stimulus triggers the nerve

A message reaches the spinal cord then travels to the brain

The messages are relayed to different parts of the brain

This is the point when you start experiencing PAIN

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.

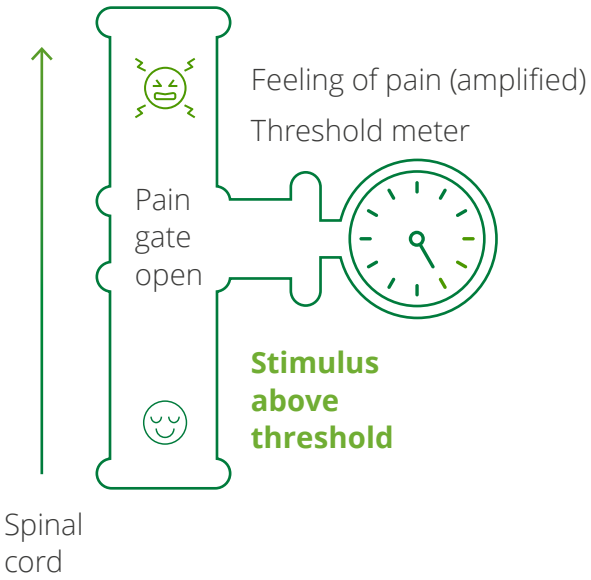
If these gates are not closed, your brain can become confused due to too much information.

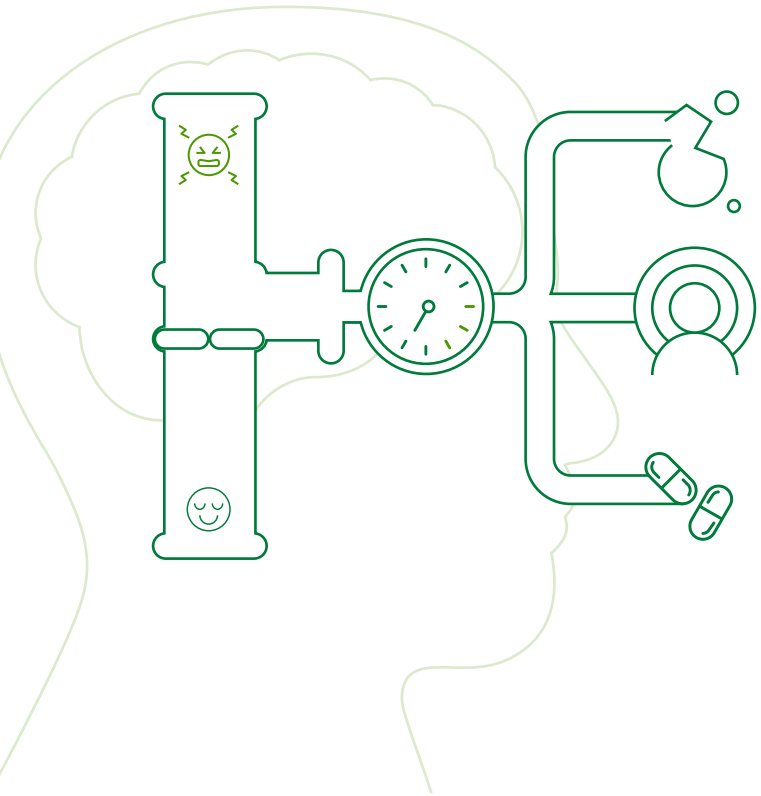
Effects of spinal cord injury on pain

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.





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.

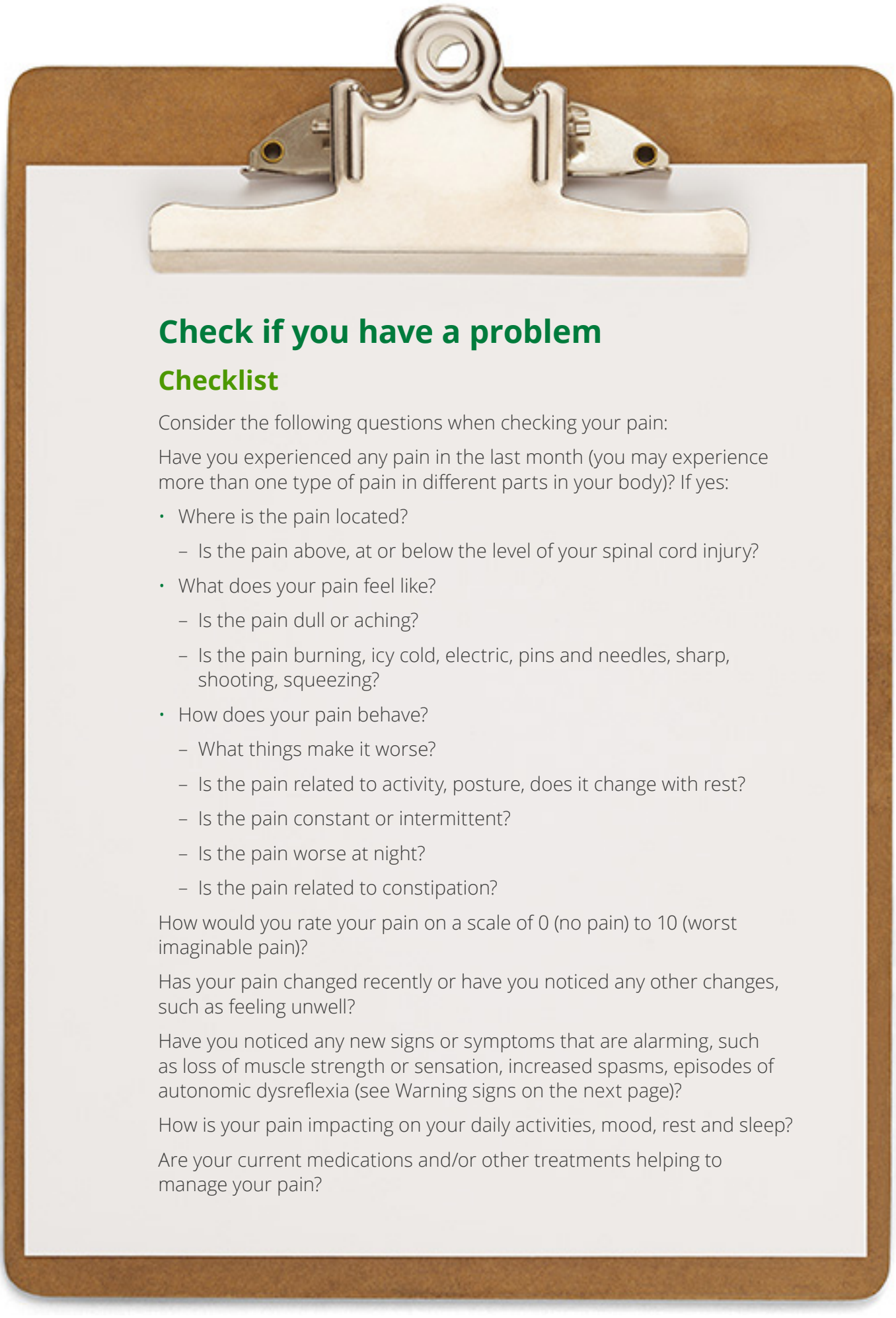
Pain description:
Hot, burning, shooting, stabbing, electric shocks, icy/cold, squeezing, constricting, crawling, tingling or pins and needles.

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

Checklist

Consider the following questions when checking your pain:

Have you experienced any pain in the last month (you may experience more than one type of pain in different parts in your body)? If yes:

- Where is the pain located?
  - Is the pain above, at or below the level of your spinal cord injury?
- What does your pain feel like?
  - Is the pain dull or aching?
  - Is the pain burning, icy cold, electric, pins and needles, sharp, shooting, squeezing?
- How does your pain behave?
  - What things make it worse?
  - Is the pain related to activity, posture, does it change with rest?
  - Is the pain constant or intermittent?
  - Is the pain worse at night?
  - Is the pain related to constipation?

How would you rate your pain on a scale of 0 (no pain) to 10 (worst imaginable pain)?

Has your pain changed recently or have you noticed any other changes, such as feeling unwell?

Have you noticed any new signs or symptoms that are alarming, such as loss of muscle strength or sensation, increased spasms, episodes of autonomic dysreflexia (see Warning signs on the next page)?

How is your pain impacting on your daily activities, mood, rest and sleep?

Are your current medications and/or other treatments helping to manage your pain?

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.

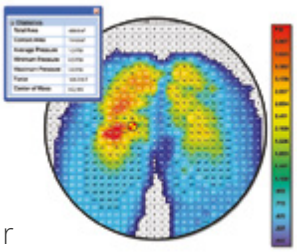
Action: Take part in enjoyable and meaningful activities to help you feel more in control of your life, especially when pain is at its worst.

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 144 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.

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.

Consider this 8-step toolbox when managing your pain.

Important note

It is unlikely that changing just one component will fix chronic pain.

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 143.

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.

Allied health professionals

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 144).
- 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

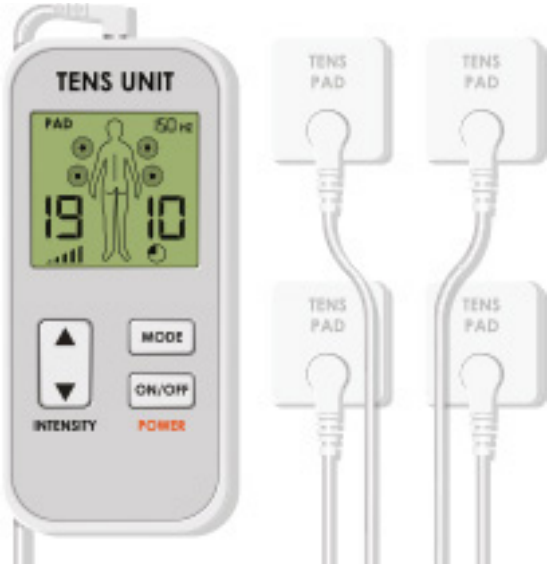
It is essential to have a healthy body and mind for ultimate pain control. Exercise can help reduce both neuropathic and musculoskeletal types of pain by releasing natural opioid-like chemicals called endorphins. By using the body's own pain-relieving chemicals, you can help reduce your pain and improve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

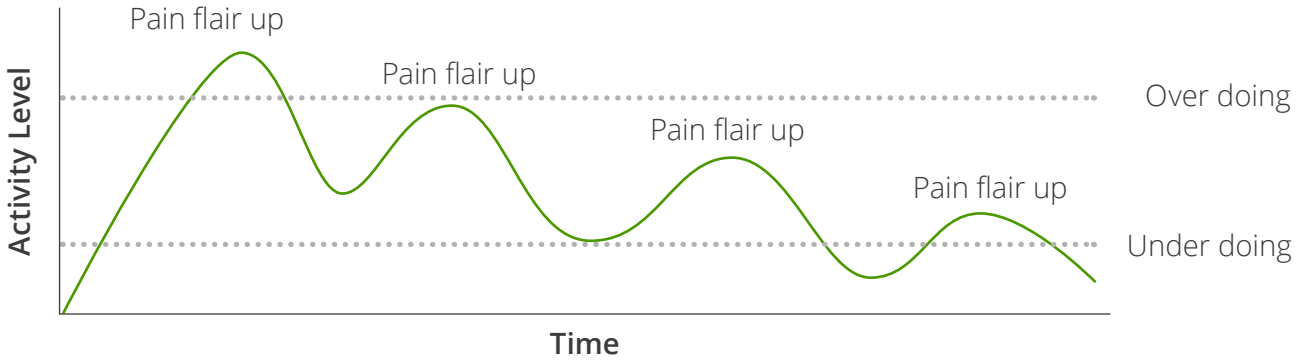
Exercising for as little as 3-10 minutes at moderate to high intensity produces significant amounts of endorphins.

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 under-doing 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.

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.
3. 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.

Desensitisation	Involves learning to focus on the pain but then letting it blend into the background and not focussing your attention on it.
Relaxation and meditation	Can assist in reducing muscle tension and stress that exacerbate pain by 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.

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

Slower mind reaction time

Reduced immune function

Lower mood

Poor memory and concentration

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.

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.

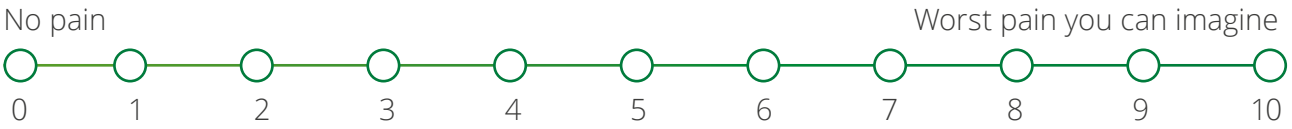
To decide on the most appropriate management strategy, it is important to assess the severity of your pain and how much it interferes with your participation in everyday activities.

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' means 'no pain' and '10' means 'worst pain you can imagine'



Pain interference scale

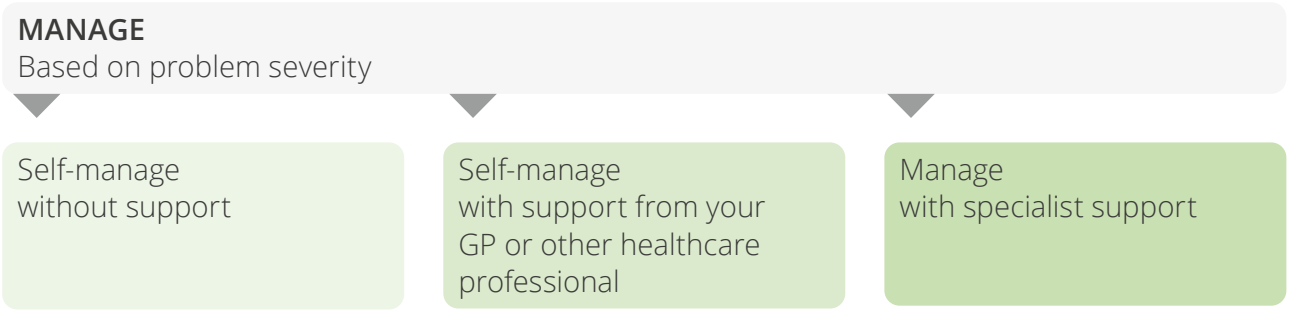
On a scale from zero (0) to ten (10), rate to what extent your pain is interfering with participation in your everyday activities.

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

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
Mild (1-3)	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 self-management 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

Work with your

HEALTHCARE TEAM

to improve your pain

Develop a pain

MANAGEMENT PLAN

that gets results

Light

EXERCISE

is recommended most days

Be aware of all possible

SIDE EFFECTS

of medications

MEDITATE

to train the brain to reduce pain

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.

5. List four treatment strategies from the pain toolbox:

i. _____

ii. _____

iii. _____

iv. _____

For correct answers, please see page 143.

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;

Pain diary

Keep this diary accurately each day, for at least 7 days.

Date and time when you experience pain	**Location and duration of your pain**	**Rate the intensity of your pain on a scale from 0 to 10** (10 means 'worst you can imagine').	**Rate how much your pain interferes with your daily life on a scale from 0 to 10** (10 means 'extreme interference').	**Fluid intake** (record types of drinks and amount consumed over 24 hrs)	**What helped you get through the day?** (medication and other strategies such as pacing, meditation, or exercise).	**Notes** Record other relevant information, such as: • Side effects of medications • Nature of pain, e.g., dull, sharp, burning or electric • How does the pain affect your daily life, including your mood, sleep, work or social life.

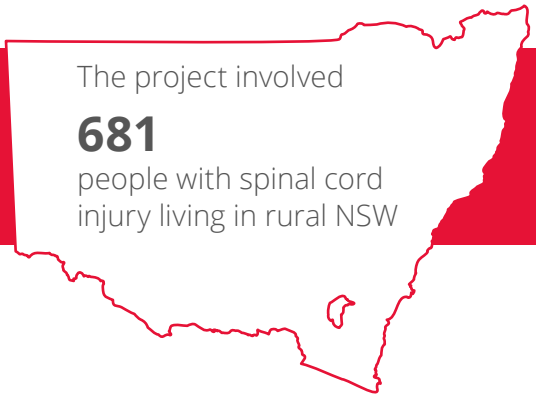
Notes

Notes

Autonomic dysreflexia

Contents

Summary of findings
from the 2015 Rural Spinal Cord Injury Project



The project involved

681

people with spinal cord injury living in rural NSW

Causes of autonomic dysreflexia

Bladder	Bowel	Sexual Activity	Skin	Other
70%	**16%**	**5%**	**2%**	**7%**

The most common cause of autonomic dysreflexia was distension of the bladder

53%

55%

of individuals were identified to be at risk of autonomic dysreflexia (AD)

The three most common recommendations related to autonomic dysreflexia management

Carry an AD emergency card	Renew medication script for AD	Education about AD
47%	**34%**	**35%**

How to navigate this module

KNOW How your autonomic nervous system works, what is normal blood pressure and why AD occurs (page 151)

CHECK Do you have current signs and symptoms of autonomic dysreflexia? (page 158)

Refer to warning signs (page 154)

Yes

IDENTIFY PROBLEM

Look for important signs and symptoms:

- An episode of autonomic dysreflexia (page 156)
- Recurrent autonomic dysreflexia (page 158)
- Frequent autonomic dysreflexia (page 158)

CHECK SEVERITY

Based on the management index: (page 159)

MANAGE

- Sit upright, lower legs and loosen any tight clothing.
- Remove compression stockings/abdominal binder.
- Identify and eliminate cause—first check for bladder distension, blocked catheter and constipation.

Is this problem resolved? Have your goals been met?

No

It is an EMERGENCY:

Call 000 for an ambulance

Yes

OBSERVE/PREVENT

Monitor for at least 4 hours due to risk of AD recurrence

No

OBSERVE

Refer to warning signs (page 154)

PREVENT

Refer to self-management tips (page 155)

What will happen if you do not manage your problem 'just-in-time'? (page 160)

Know about your autonomic nervous system

How the autonomic nervous system normally works

The autonomic nervous system is the part of the nervous system that supplies the internal organs, such as blood vessels, stomach, intestine, liver, kidneys, bladder and genitals.

The autonomic nervous system has two main divisions:

- Sympathetic
- Parasympathetic

After the autonomic nervous system receives information about the body and external environment, it responds by stimulating body processes, usually through the sympathetic division, or inhibiting them, commonly through the parasympathetic division.

The autonomic nervous system controls internal body processes:

- Blood pressure
- Heart and breathing rates
- Body temperature
- Digestion
- Metabolism which affects body weight
- The balance of water and electrolytes, e.g., sodium and calcium
- The production of body fluids, e.g., saliva, sweat and tears
- Urination
- Defecation
- Sexual response.

Many organs are controlled primarily by either the sympathetic or the parasympathetic division. Sometimes the two divisions have opposite effects on the same organ. For example, the sympathetic division increases blood pressure while the parasympathetic division decreases it. Overall, the two divisions work together to ensure the body responds appropriately to different situations.

What is normal blood pressure

Normal baseline blood pressure for most people is: $\frac{120}{80}$ mmHg

Blood pressure changes depending on what a person is doing and other factors, including:

- Smoking
- Being overweight or obese
- Lack of physical activity
- Too much salt in the diet
- Too much alcohol consumption (more than 1-2 drinks per day)
- Stress
- Older age
- Genetics.

Blood pressure (BP) category	Systolic BP (upper number)		Normal
Normal	Less than 120	and	Less than 80
Elevated	120-129	and	Less than 80
High blood pressure (Stage 1)	130-139	or	80-89
High blood pressure (Stage 2)	140 or higher	or	90 or higher
Blood pressure crisis	Higher than 180	and/ or	Higher than 120

What does research tell you?

People with a higher level (cervical and upper thoracic) spinal cord injury are more likely to experience a lower blood pressure (by around 20 mmHg) than those with lower level or incomplete spinal cord injury during the first month of rehabilitation, which may persist in the longer term.

Effects of a spinal cord injury on the autonomic nervous system

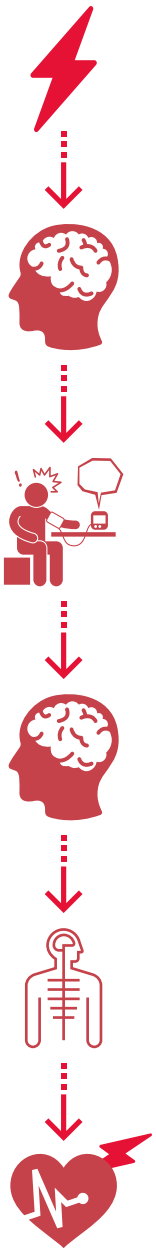
Autonomic dysreflexia (AD) is a medical condition that causes a rapid rise in blood pressure of people with a spinal cord injury, at or above the T6 spinal level. The condition is rare below the T6 spinal level.

AD occurs when there is a problem in your body below the level of your spinal cord injury causing irritation and overactivity in the part of the nervous system responsible for controlling blood pressure. In other words, it is a response by the body when pain and discomfort are experienced, although your spinal cord injury prevents that message from getting through to your brain.

AD is a **medical emergency** as the high blood pressure can lead to a stroke, fitting or death. It therefore calls for immediate action to find and treat the cause of the AD.

Do you know?

People with a complete spinal cord injury have a much higher incidence of autonomic dysreflexia: 91% with a complete injury versus 27% with an incomplete injury.



Irritation below the level of the spinal cord injury

Signal reaches the injured spinal cord resulting in massive constriction of the blood vessels below the level of injury

Leads to very high blood pressure

Brain detects a sudden rise in blood pressure and attempts to control the rise by sending signals via spinal cord to blood vessels, which are blocked

Signals from brain cannot get through below the level of injury, but a different nerve (called the vagus) tries to compensate

This results in a lowering of the heart rate down to 40-50 beats per minute

Causes of autonomic dysreflexia

Autonomic dysreflexia is most commonly triggered by a cause related to either **BLADDER** or **BOWEL**, but can be triggered by other stimuli.

Bladder causes

- Overfull bladder from kinked or blocked catheter or full leg bag
- Urinary tract infection
- Kidney stones
- Procedures such as catheter change or tests where the bladder is distended.

Bowel and abdominal

- Constipation
- Irritation from rectal examination or enema insertion
- Inflamed haemorrhoids
- Stomach ulcers, gallstones or appendicitis.

Other common causes include:

Skin causes

- Excess pressure from contact with hard or sharp objects
- Pressure injuries (sores)
- Ingrown toenails
- Burns
- Insect bites.

Sexual activity

In males

- Genital stimulation, especially with a vibrator
- Orgasm (ejaculation)
- Problems with the testicles (e.g., pressure on testicles).

In females

- Menstruation or labour
- Infections of vagina or uterus.

What does research tell you?

One of the most common causes of AD is bladder distension, which alone can account for up to 85% of episodes.

Check if you have a problem

Warning signs

The following warning signs are indicators that there may be a serious problem. Autonomic dysreflexia occurs when you experience a sudden rise in your blood pressure of 20 mmHg or more above your normal blood pressure.

Please note: Your normal blood pressure may be quite low at other times, so the early rise in blood pressure may still be within the range considered normal for a person without a spinal cord injury.

The signs and symptoms of autonomic dysreflexia include any of the following:

Pounding headache

Profuse sweating

Blotchiness or rash over skin

Goosebumps and chills

Stuffy nose

Blurred vision

Nausea or feeling unwell

Shortness of breath or feeling anxious

Prevention

Self-management tips for preventing autonomic dysreflexia

FIRST and FOREMOST things to do

Record your normal blood pressure

Always carry your personalised AD emergency card with you

Ask your doctor to prescribe medicine for AD to keep on hand, and check expiry dates regularly

HEALTHY TIPS to prevent AD

Bladder

- Ensure catheter tube is not kinked and flowing freely
- Drink plenty of water to prevent catheter blockage
- Perform regular intermittent catheterisation
- Regularly empty your leg bag.

Bowel

- Eat a well-balanced diet
- Take medications as prescribed
- Drink plenty of water to prevent constipation
- If constipated, perform evacuation gently
- Have a regular bowel routine.

Skin

- Perform regular pressure relief and inspect skin at least daily
- Check equipment (including cushion, wheelchair and other surfaces) regularly
- Do not wear tight clothes and shoes
- Avoid potential causes for burns, such as carrying hot liquids in your lap or sitting too close to a fire or heater
- Practice good foot care to prevent ingrown toenails.

Important note

Be aware of other stimuli such as a bone fracture, extreme temperatures or sexual activity.

"Don't be afraid to seek information for yourself."

- Consumer with a spinal cord injury

Management of autonomic dysreflexia

An episode of autonomic dysreflexia

Self-management tips

Immediate actions to be performed by yourself or a carer:

1. Sit up, if lying down
2. Loosen or remove any tight clothing
3. Search for a cause (check your Bladder first), eliminate cause if possible
4. Check blood pressure if possible
5. Call a relative or a friend for help.

Actions if warning signs do not subside and/or blood pressure remains high

1. Call the emergency number **Triple Zero: Dial 000**
2. Keep looking for the cause/s
3. Monitor your blood pressure every 5 minutes
4. Take your prescribed medication/s. See next page for details.

What to do when your AD subsides?

Monitor for any re-occurrence.

Please note: You may be at risk of another episode in next 24-48 hours.

What to do when problem still persists and blood pressure still remains high?

CALL an AMBULANCE.

Dial 000

REMEMBER

AD is most commonly triggered by a BLADDER or BOWEL cause. Check for kinks in catheter or blockage to flow or over-full leg bag.

TIGHT CLOTHING

This commonly include abdominal binders, shoes or leg braces, leg bag strap, external catheter tape, clothes or elastic hose or bandages.

MEDICATION

Check regularly for expiry dates.

Keep calm and call for help.

What does research tell you?

- An acute episode of autonomic dysreflexia can lead to an increased susceptibility to further episodes due to an excess of chemicals, called catecholamines, circulating in your blood. These chemicals make it more likely for AD to be triggered by stimuli like muscle stretches, bowel care or other activities that usually do not aggravate AD.
- Monitoring of your blood pressure for appropriately 48-72 hours after an episode of autonomic dysreflexia is recommended. During this time any medical procedures should be kept to a minimum.

Medications for treating autonomic dysreflexia

Before starting on any medication, always read the instructions and ensure this medication is safe to take with other medications. Check the dose and possible side effects, as well as the expiry date and contraindications.

Autonomic dysreflexia is commonly treated with two medications that can be self-administered:

- **Glyceryl Trinitrate (GTN)** is manufactured as a mouth spray, a chewable tablet and a skin patch. You need a prescription from your doctor.
- **Other blood pressure medications. Captopril** is manufactured as a chewable tablet. You need a prescription from your doctor.

How to take Glyceryl Trinitrate (GTN)

Spray
One spray under tongue
Dose: 400mcg per spray
Product name:
Nitrolingual pump spray

OR

Tablet
Half tablet under tongue
Dose: 300mcg per tablet
Product name: Anginine

OR

Patch
One patch on chest or arm
Dose: 5mg per 24 hours
Product name: GTN transdermal patch

Check blood pressure in 5 to 10 minutes

	No effect or little effect on your high blood pressure	**Low or normal** blood pressure
Spray	Second spray under tongue Dose: 400mcg per spray	Spit out residual spray
OR		
Tablet	Take other half tablet under tongue Dose: 300mcg per tablet	Spit out residual tablet
OR		
Patch	Do not remove the patch Dose: 5mg per 24 hours	Remove the patch

WARNING!

- **Be aware** that up to 3 doses of spray or tablet can be given in 30 minutes.
- **Do not take GTN** if you have used medications for erectile dysfunction, such as Sildenafil (Viagra), Vardenafil (Levitra) or Tadalafil (Cialis) in the last 3-4 days.
- **Do not take medications** for erectile dysfunction, such as Sildenafil (Viagra), Vardenafil (Levitra) or Tadalafil (Cialis), **within 24 hours after taking GTN**.

How to take Captopril

Captopril will sometimes be prescribed instead of GTN because:

- GTN spray, tablets or patch are unavailable.
- You have used Viagra, Vardenafil or Cialis for erectile dysfunction within the last 3-4 days so you are not allowed to take GTN due to the risk of it lowering your blood pressure too much.

Take one tablet under tongue
Dose: 25mg per tablet
Brand name: Capoten

Takes about 3 minutes to dissolve

↓

Check blood pressure in 15 minutes

↓ ↓

No effect or little effect on your high blood pressure

CALL an AMBULANCE

Dial 000

Low or normal blood pressure

Spit out the residual tablet

Recurrent autonomic dysreflexia

This refers to an episode of autonomic dysreflexia that recurs soon after an initial episode because the underlying cause has not been resolved, got worse or you may be more at risk. After a severe and prolonged episode, certain activities that do not usually cause autonomic dysreflexia, e.g., muscle stretching or bowel care, can lead to symptoms.

How to self-manage recurrent autonomic dysreflexia

- Monitor your symptoms and blood pressure for at least 4 hours after resolution of the autonomic dysreflexia episode to ensure a rise in blood pressure does not recur.
- Autonomic dysreflexia may resolve due to taking medication, not because the underlying cause has been resolved. Recurrence may be expected if the underlying cause has not been correctly identified and resolved.

Frequent autonomic dysreflexia

This refers to episodes of autonomic dysreflexia that occur on a regular basis.

- Regularly monitor your symptoms and know your baseline blood pressure.
- Autonomic dysreflexia may occur frequently because of an underlying cause.
- If you have frequent episodes of autonomic dysreflexia, consult with your doctor to investigate and rule out any underlying causes, which may include:
  - Recurrent urinary tract infections
  - Bladder and kidney stones
  - Bowel constipation
  - Other medical conditions.

What does research tell you?

Nifedipine bite-and-swallow capsules, previously used for treating autonomic dysreflexia in Australia, are no longer available due to risks associated with use in people treated for other conditions, such as chest pain (angina) or high blood pressure (hypertension).

Management index

Autonomic dysreflexia can vary in its duration and/or frequency as described in the table below.

Problem	AD resolves quickly	AD does not resolve This is an emergency
Autonomic dysreflexia	Cause identified, an episode of autonomic dysreflexia that resolves quickly (and does not recur)	An episode of autonomic dysreflexia that does not subside and/or blood pressure remains high Recurrent autonomic dysreflexia Frequent autonomic dysreflexia

Important notes

There is no such thing as mild, moderate or severe autonomic dysreflexia. Every case of autonomic dysreflexia is an emergency.

If warning signs do not subside and/or blood pressure remains high, call 000 for an ambulance.

What will happen if you do not manage your autonomic dysreflexia 'just-in-time'?

Serious complications can arise if autonomic dysreflexia is not managed in a timely way and/or occurs repeatedly. You could experience:

- Changes in the brain's electrical activity, which can cause fits or seizures.
- Bleeding in the retina, the light sensitive tissue of the eye, causing severe vision impairment (retinal haemorrhage).
- Excess fluid in the lungs called pulmonary oedema.
- Organ damage:
  - Heart attack, which can lead to heart failure.
  - Poor functioning of the kidneys (renal insufficiency), which can lead to kidney failure.
- A rupture or leak in a blood vessel in the brain, called cerebral haemorrhage.
- Death.

'Just-in-time', or the right care at the right place at the right time, will reduce risk and prevent complications. 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:

- Learning to understand why autonomic dysreflexia occurs, what causes it and how to deal with it.
- Becoming a partner in decision-making with your doctor and other health professionals.
- Carrying an AD emergency treatment card in your wallet at all times.
- Developing an individual autonomic dysreflexia management plan.
- Engaging in ongoing health and wellness activities for preventing autonomic dysreflexia:
  - Maintaining a healthy bladder function.
  - Maintaining a healthy bowel function.
  - Preventing other potential causes of autonomic dysreflexia.
  - Knowing what to do when you have autonomic dysreflexia.
  - Scheduling an annual check-up.

Take home messages

ASK

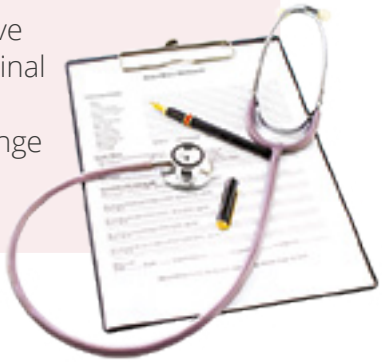
your GP to check your blood pressure at every visit so you know your normal blood pressure

If you are at risk of AD, consider having a blood pressure monitor at home.

ALWAYS REMEMBER

to carry your AD emergency card with you

If you do not have one, ask your spinal cord injury care provider to arrange one for you.



TREAT

AD as an emergency

Dial 000 for an ambulance if your autonomic dysreflexia does not resolve.

Knowledge test

Please tick one correct answer for each of the following questions:

1. What is the most common cause of autonomic dysreflexia?
   - (a) A blocked catheter.
   - (b) A skin infection.
   - (c) Wearing tight clothes.
   - (d) Constipation.

2. Which of the following is a symptom of autonomic dysreflexia?
   - (a) Sweating.
   - (b) Headache.
   - (c) Flushed face.
   - (d) All of the above.

3. If you have signs and symptoms related to autonomic dysreflexia, when is the right time to call the emergency number?
   - (a) Immediately without delay.
   - (b) After you have found and managed the cause of autonomic dysreflexia.
   - (c) If you are not able to manage to find the cause and control your blood pressure.
   - (d) None of the above.

4. GTN medication for treating autonomic dysreflexia should not be used, if you have used _____ within the last 3 to 4 days.
   - (a) Sildenafil (Viagra).
   - (b) Vardenafil (Levitra).
   - (c) Tadalafil (Cialis).
   - (d) All of the above.

5. For effective management of autonomic dysreflexia, you should:
   - (a) Know your normal blood pressure reading.
   - (b) Carry an AD Emergency Card with you.
   - (c) Treat autonomic dysreflexia as an emergency.
   - (d) Do all of the above.

For correct answers, please see page 164.

Glossary

Term	Definition
Autonomic dysreflexia	An abnormal response to a problem in the body below a spinal cord injury. It's most likely to happen if the spinal cord injury is at or above the 6th thoracic vertebra (T-6).
Autonomic nerves	Nerves in the spinal system that control involuntary action.
Barium enema	An examination of the inside of the body done with a substance called barium. This test is also known as a double-contrast examination.
Bradycardia	Slow heart rate, usually fewer than 60 beats per minute.
Cystoscopy	An examination of the inside of the bladder and ureter. It's done with an instrument called a cystoscope.
Deep vein thrombosis	Clots in the leg or pelvis veins. Also referred to as thromboembolism.
Epididymitis	Inflammation of the part of the testicle called the epididymis.
Gastritis	Inflammation of the stomach.
Impaction (of the bowel)	Occurs when hard stool is stuck in the rectum or somewhere else in the bowel.
Pelvic inflammatory disease (PID)	An infection anywhere in a woman's genital tract above the cervix.
Pulmonary emboli	Blood clots that travel to the lungs.

Further resources

Reading resources for consumers

- Medical emergency autonomic dysreflexia card (1 page)
  Access at: **https://www.aci.health.nsw.gov.au/__data/assets/pdf_file/0020/163442/Medical-Emergency-Card.pdf**
- Autonomic dysreflexia: What you should know (18 pages)
  Access at: **https://www.bronx.va.gov/docs/ADC.pdf**

Useful resources for consumers and medical professionals

- Treatment algorithm for autonomic dysreflexia (hypertensive crisis) in spinal cord injury (1 page)
  Access at: **https://www.aci.health.nsw.gov.au/__data/assets/pdf_file/0008/387998/08.-Autonomic-Dysreflexia-in-SCI-Treatment-Algorithm.pdf**
- Treatment of autonomic dysreflexia for adults and adolescents with spinal cord injuries (18 pages)
  Access at: **https://www.aci.health.nsw.gov.au/__data/assets/pdf_file/0007/155149/Autonomic-Dysreflexia-Treatment.pdf**
- Acute management of autonomic dysreflexia: individuals with spinal cord injury presenting to health-care facilities (40 pages)
  Access at: **https://pva-cdnendpoint.azureedge.net/prod/libraries/media/pva/library/publications/cpg_autonomic-dysreflexia.pdf**

Videos for consumers

- NSW Agency for Clinical Innovation Video Presentations on Autonomic Dysreflexia for Consumers
  - Part 1: What is AD (5 minutes)
    Access at: **https://vimeo.com/101253337**
  - Part 2: Causes of AD (2 minutes)
    Access at: **https://vimeo.com/101253338**
  - Part 3: Pathophysiology of AD (2 minutes)
    Access at: **https://vimeo.com/101253339**
  - Part 4: Signs and Symptoms of AD (1 minute)
    Access at: **https://vimeo.com/101253340**
  - Part 5: Management of AD (9 minutes)
    Access at: **https://vimeo.com/101253412**
  - Part 6: Prevention of AD (3 minutes)
    Access at: **https://vimeo.com/101253413**
- Understanding Autonomic Dysreflexia (2 minutes)
  Access at: **https://youtu.be/i8H7ABrhqVw**

Answers to knowledge test

1: a; 2: d; 3: c; 4: d; 5: d;

Notes

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