



Health Maintenance Tool

Module 2: The bladder and its associated problems

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

A product of the SCI Wellness Project

A collaborative project between

Funded by



THE UNIVERSITY OF
SYDNEY



Royal Rehab
Empowering Independence



NSW
GOVERNMENT

icare[™]
Insurance and Care NSW

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DISCLAIMER

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

Foreword

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

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

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

– Tanya Fitch, Consumer with spinal cord injury

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

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

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

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

Background

The Spinal Cord Injury Health Maintenance Tool

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

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

Behind the Spinal Cord Injury Health Maintenance Tool

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

*The SCI Wellness Project consisted of two phases.

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

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

– Consumer with spinal cord injury

The bladder

and its associated problems

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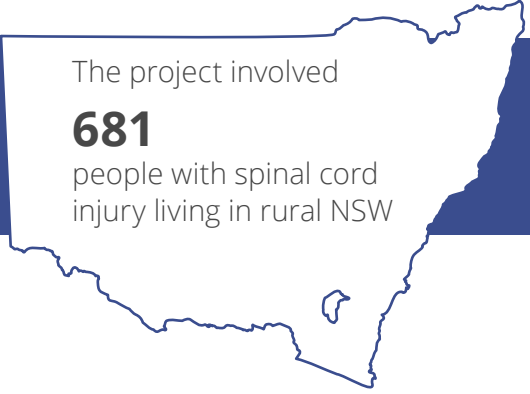
Summary of findings

from the 2015 Rural Spinal Cord Injury Project

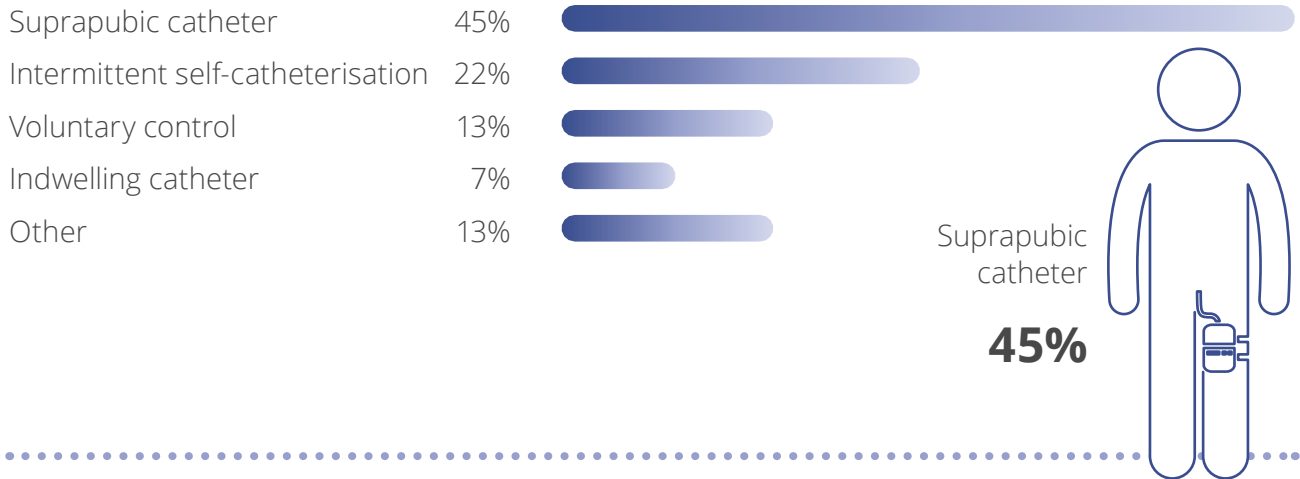
The project involved

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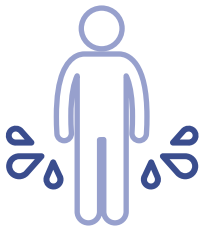
people with spinal cord injury living in rural NSW



Ways people manage their bladder



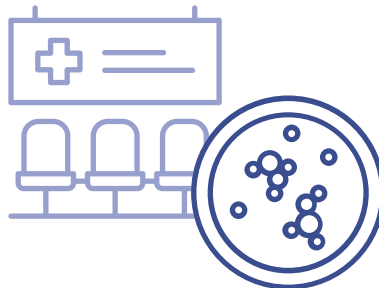
The three most common problems related to the bladder



33%

of individuals performing intermittent self-catheterisation reported

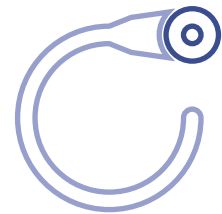
Urine leakage



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 20)

✓ Yes

✗ No

IDENTIFY PROBLEM

Look for important signs and symptoms:

- Urinary tract infection (page 19)
- Urine leakage (page 20)
- Catheter blockage (page 21)
- Difficulty inserting catheter (page 22)
- Female specific problems (page 23)
- Male specific problems (page 24)
- Bladder and kidney stones (page 25)
- Blood in urine (page 26)
- Urinary retention (page 27)
- High urine output (page 28)
- Other problems (pages 29- 30)

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)

CHECK SEVERITY

Based on the management index:

- Severity scale (page 20)
- Interference scale (page 32)

EDUCATE

Refer to bladder management sections (pages 19-30)

MANAGE

Based on problem severity and interference (pages 20-32)

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?

What will happen if you do not manage your problem 'just-in-time'? (page 33)

✗ No

✓ Yes

RE-ASSESS

OBSERVE/PREVENT

Know about your bladder and kidneys

How the bladder normally works

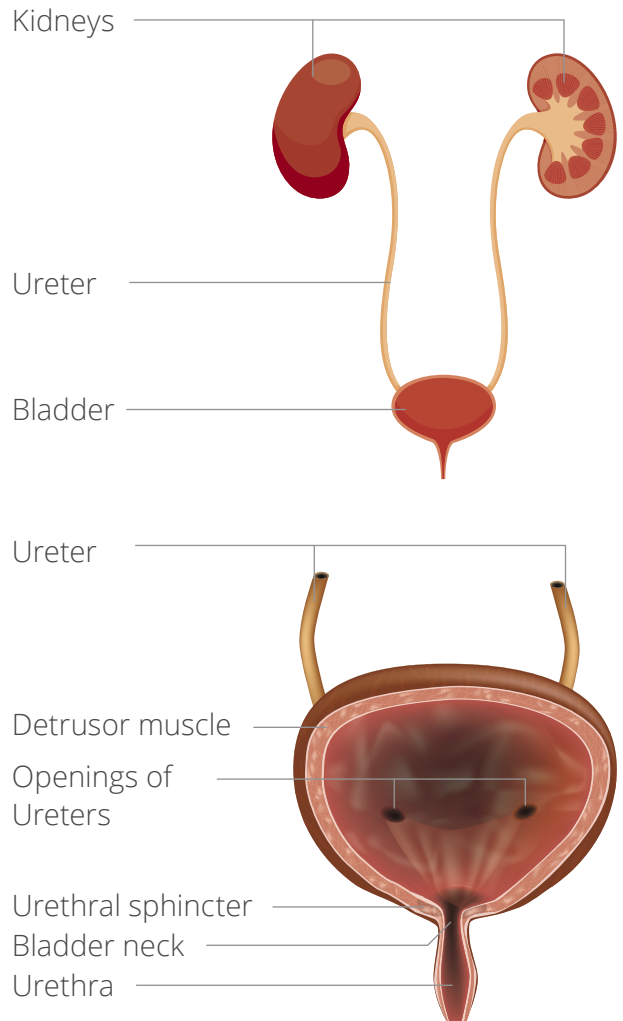
Urine forms as the blood filters through the kidneys. The urine drains down through tubes called ureters for storage in the bladder.

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.

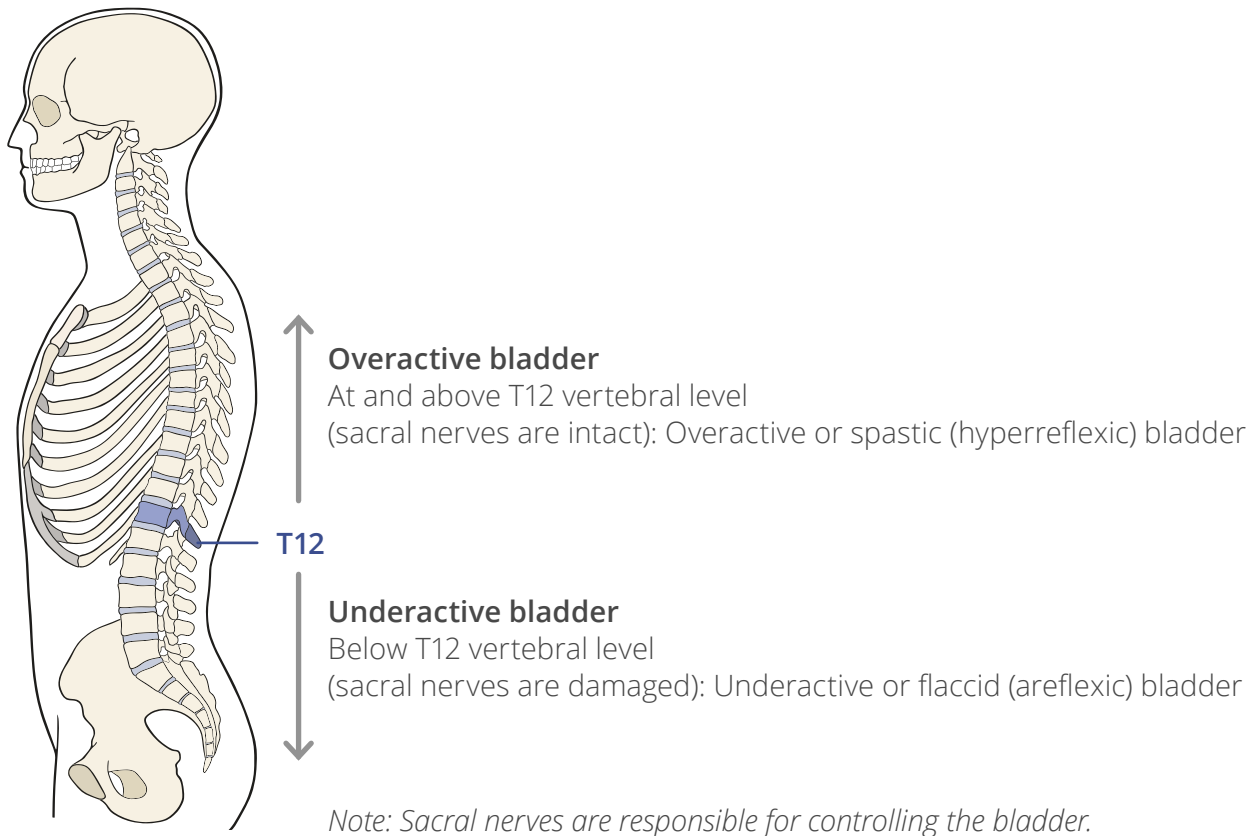


Effects of a spinal cord injury on bladder and kidney function

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.

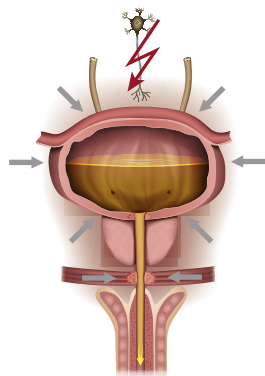
There are two main types of neurogenic bladder depending on where your injury is:



The two main types of neurogenic bladder are:

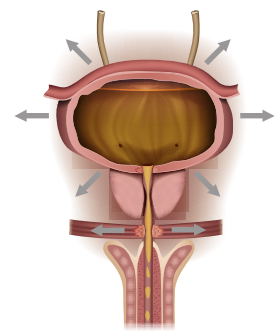
Overactive or spastic (hyperreflexic) bladder

- 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').

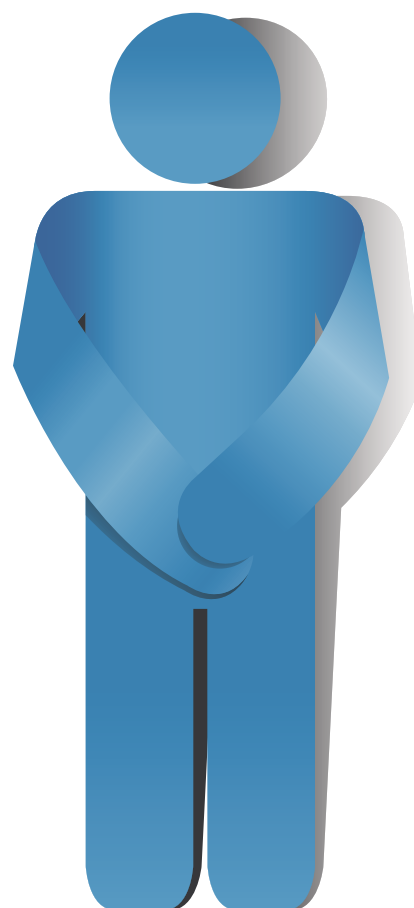
Your doctor may recommend taking an oral tablet to relax your bladder. The most common anticholinergic medication is Oxybutynin (sold as Ditropan). If tablets do not work, a procedure for Botulinum toxin injections into the bladder wall may help. This aims to increase the urine storing capacity of an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

Female specific problems

- Problems related to pregnancy, menstruation, menopause and sexual activity

Male specific problems

- Infection and swelling of the testicles (known as epididymo-orchitis)
- Inflammation of the prostate glands (prostatitis)
- Narrowing (or stricture) of the urethra

Other problems

- Autonomic dysreflexia in person with spinal cord injury at/or above T6 level (please refer to Autonomic dysreflexia module for further information)
- Bladder and kidney stones
- Blood in the urine
- Urinary retention
- High urine output
- 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)
- 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:

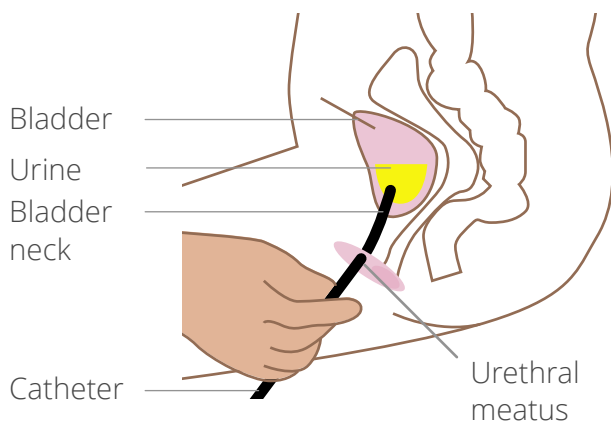
- Intermittent catheterisation
- Permanent catheterisation
- Reflex voiding.

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 prostate 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?

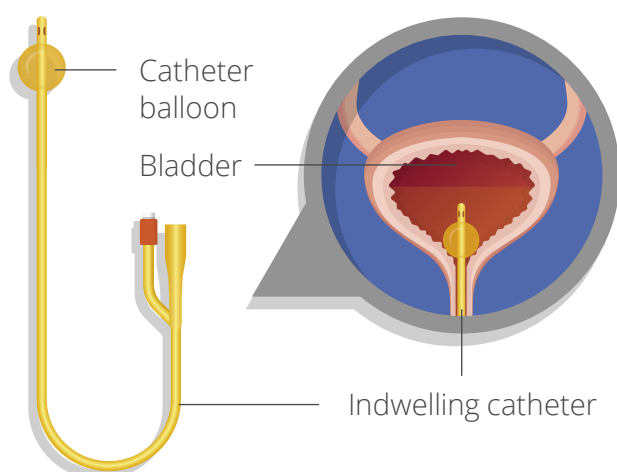
- Clean intermittent self-catheterisation is the preferred method of bladder management for people with spinal cord injury who have enough hand function.
- The use of single-use hydrophilic catheters lowers the risk of a urinary tract infection.

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 1 May 2023

Check if you have a problem



Checklist

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

How do you empty your bladder?

- Clean intermittent self-catheterisation
- Indwelling urethral or suprapubic catheter
- Reflex voiding
- Other methods

Have you been experiencing any recent problems or changes in bladder emptying/ drainage:

- Difficulty passing catheters into your bladder or bleeding afterwards?
- Frequent catheter blockages requiring catheter changes. Is this getting worse?
- Difficulties passing urine (taking longer or needing to strain more)?
- Have you been experiencing any problems with leakage of urine (incontinence) or less warning before leaking (an increased sense of urgency)?

Have you been experiencing signs or symptoms, including:

- General – fever, chills, nausea, vomiting, feeling unwell, cloudy or smelly urine, discomfort/burning when urinating or blood in urine, along with
- Specific to SCI – leakage of urine (incontinence), increased spasms, lower abdominal pain or autonomic dysreflexia?
- Have you been experiencing a dull aching pain and tenderness in one or both flanks (lower back below ribcage at side) where your kidneys are located?
- Have you been noticing an increase in sediment, sand, grit or hard calcified matter in your urine?
- Have you seen any blood in your urine recently?
- Are you experiencing high urine volumes (more than 600ml), increased frequency of bladder voiding or passing more catheters overnight?
- Have you been experiencing frequent episodes of pounding headache, profuse sweating, blotchy skin/rashes or blurred vision related to your bladder (e.g., distended bladder, blocked catheter), which may indicate autonomic dysreflexia?

What to do next

If you answer "yes" to any of the questions above, please refer to the Severity Scale (page 31) to see whether your problem is mild, moderate or severe, and Interference Scale (page 32) to decide on what management strategy to take.

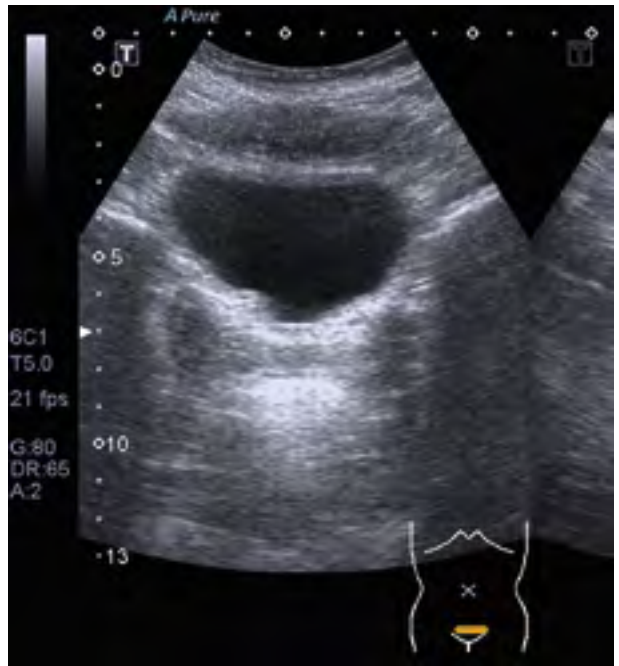
Warning signs

If you experience any of the following issues, these are warning signs indicating that 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
- Signs of infection associated with pain in one or both flanks (lower back at sides below ribcage) over kidneys.
- 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 unhealthy liquids such as alcohol, caffeine and sugar drinks

- Reduce intake of liquids

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.

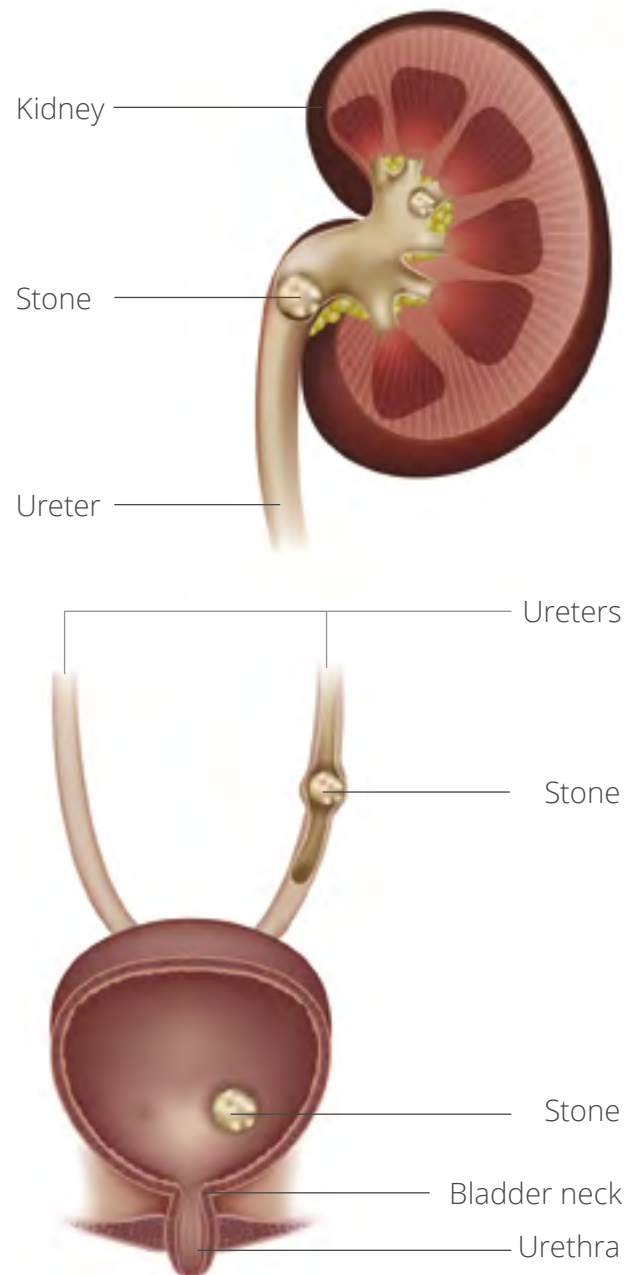


What does research tell you?

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.
- 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?

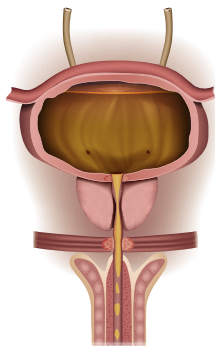
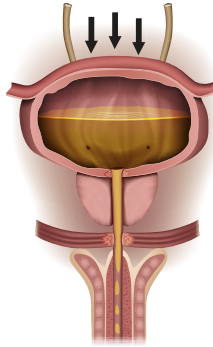
Long-term use of antibiotics is not encouraged as it results in reduced effectiveness of that antibiotic.

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 38).

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.

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

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



What does research tell you?

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

Difficulty inserting 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 that catheter is 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 or your carer 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.



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 flesh), 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.

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.

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:

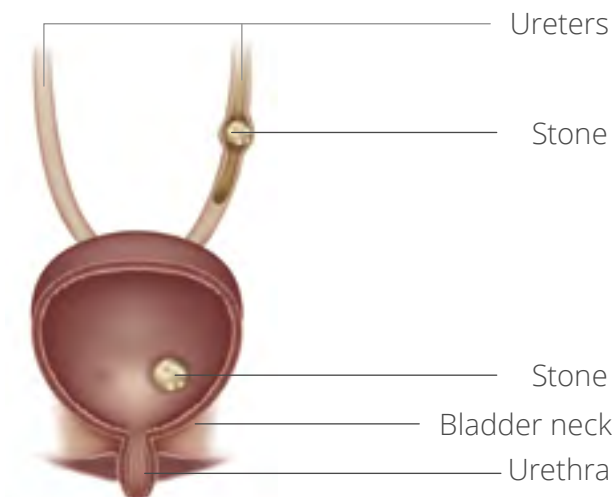
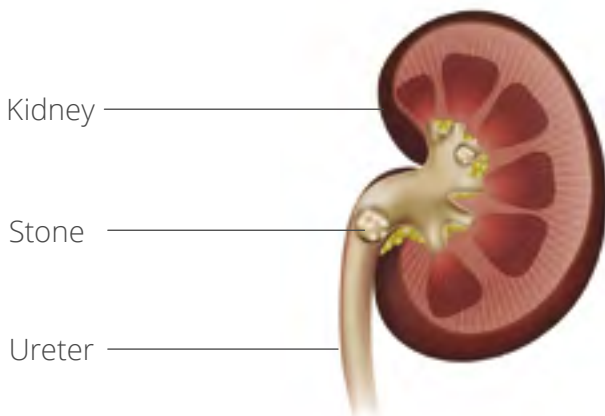
- Incision of the stricture in an operation called urethrotomy or
- Sometimes a repair of a defect within the urethral wall by urethroplasty surgery.

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.

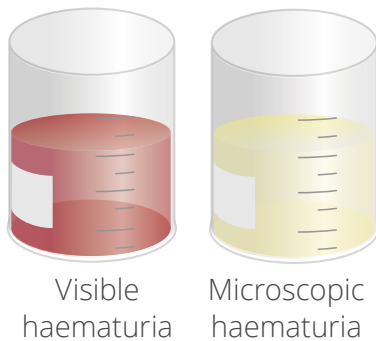


What does research tell you?

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 on urine analysis during a routine health check.



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.

Urinary retention

Urinary retention refers to the **inability to completely empty your bladder** of urine. Urinary retention can be sudden (acute) or more gradual and long-term (chronic). Acute retention is a serious problem that requires urgent medical review and treatment.

Signs and symptoms of urinary retention may include:

- not completely emptying your bladder after urinating and leaving high residual urine volumes in the bladder (this increases the risk of urinary tract infections)
- feeling an urgent need to pass urine (called urgency) but without good emptying
- having difficulty starting the flow of urine (called hesitancy)
- needing to use greater amounts of percussion (tapping over bladder) or straining to start voiding
- needing to go to the toilet often or soon again after passing urine (called frequency)
- passing small amounts of urine with a slow stream or weak flow.

Common causes of urinary retention:

- An overactive bladder with spasming of the bladder outlet or sphincter muscles
- An underactive or weakened (overstretched) bladder
- In men, problems occur with emptying of your bladder when:
 - the prostate gland gets so big that it presses on the urethra (tube draining the bladder)
 - scar tissue from damage inserting a catheter cause narrowing (stricture) of the urethra.

- In women, problems may occur with emptying of your bladder due to weakness of pelvic floor muscles related to spinal cord injury and overstretching (after childbirth), changes in hormone levels (with menopause) or increased abdominal pressure and straining from constipation with:
 - bladder becoming lower and pushing against the vagina causing obstruction (cystocele)
 - uterus sagging/dropping down from its normal position into the vagina (called a uterine prolapse).
- Certain medications (antidepressants or alpha blockers) can cause urinary retention.

How to treat urinary retention

- Some medications (alpha blockers) can help to relax muscles at the bladder outlet and prostate.
- You may need to change the way you empty your bladder (e.g., learn self-catheterisation).
- See your doctor for an assessment and physical examination (including rectal exam to check prostate if male), and to arrange appropriate blood tests and an ultrasound of your kidneys and bladder.
- You may need to see a urologist, who may undertake further special investigations:
 - Video-urodynamic test (assessing how much your bladder holds, pressures inside bladder with filling and how well it empties) or
 - Cystoscopy (looking inside the urethra and bladder with a thin telescope). This test may show a stricture (scarring) of the urethra, an enlarged prostate, blockage caused by a stone, or unusual causes, such as a tumour.
- You may need surgery to remove excess prostate tissue, divide a urethral stricture (scar tissue), inject Botulinum toxin into an overactive sphincter muscle, insert a tube (stent) in urethra or perform a repair of a uterine prolapse.

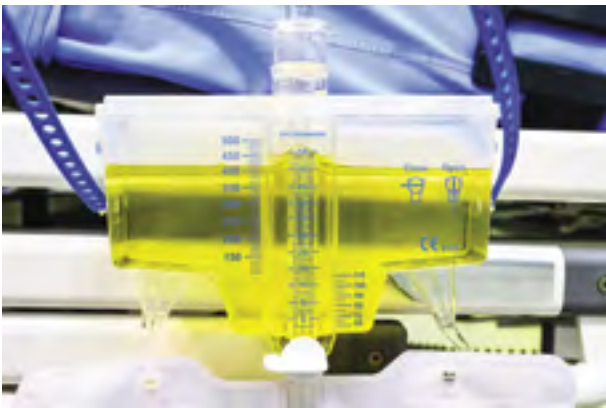
High urine output

High urine volume, called polyuria, occurs when you urinate more than normal (greater than 3 litres per day in an adult). Urine volume depends on how much you drink, your age and gender. A urine output of 2 litres or less per day is usually considered normal, passing 250-400mls each time.

Causes of high urine output

High urine output can be due to use of certain medications (such as diuretics, which increase urine volume) or due to health problems, including:

- urinary tract infection
- urinary incontinence
- diabetes
- kidney problems, such as inflammation of the kidney, kidney stones or kidney failure
- blood disorder, such as sickle cell anaemia
- enlarged prostate (benign prostatic hyperplasia), most common in men over 50 years old
- certain kinds of cancer.



Signs and symptoms of high urine output

High urine output or frequent urination can be due to many different problems from kidney disease to simply drinking too much fluid. Certain symptoms should prompt you to see your doctor right away, including:

- fever
- an urgent need to urinate
- back pain or discomfort in the abdomen
- leg weakness
- sudden onset of polyuria
- night sweats
- weight loss

How to treat high urine output

High urine output not caused by underlying health issues can be addressed at home.

You can likely relieve your symptoms by changing actions that contribute to making excessive urine volumes, such as following:

- watch your fluid intake
- limit fluids before bedtime
- limit the amount of caffeinated and alcoholic beverages you drink
- understand the side effects of medications.

High urine output caused by health issues can be managed by treating the underlying issue. For example, treatment for diabetes through making changes in diet and medication will often relieve the side effect of high urine output.

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:

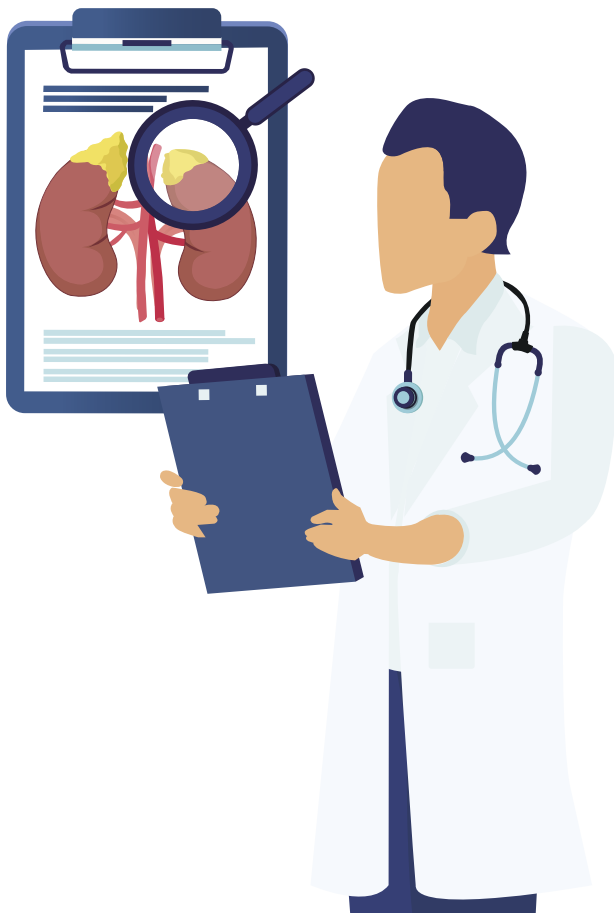
- Fever and chills
- Pain in your back, side or groin
- Nausea and vomiting
- Cloudy, dark, bloody or foul-smelling urine.

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.

Important note

Infection of a kidney is a severe type of urinary tract infection that often begins in your bladder and moves upstream to one or both of your kidneys.



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:

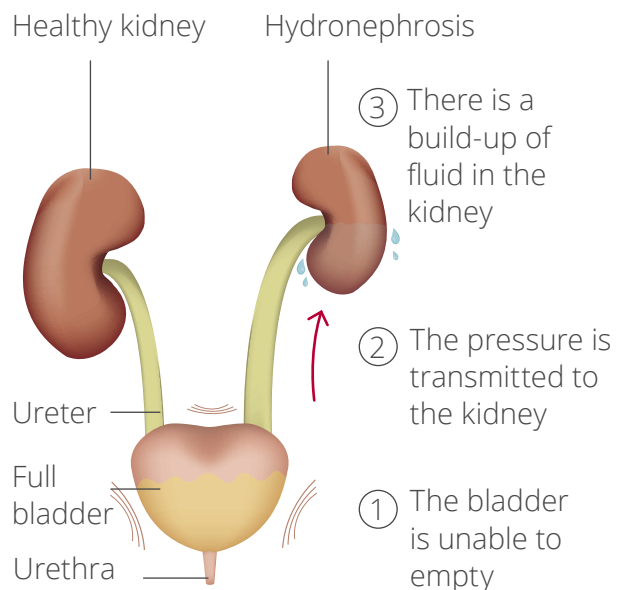
- A kidney stone blocking the ureter
- High pressure in an overactive bladder
- An enlarged prostate.

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

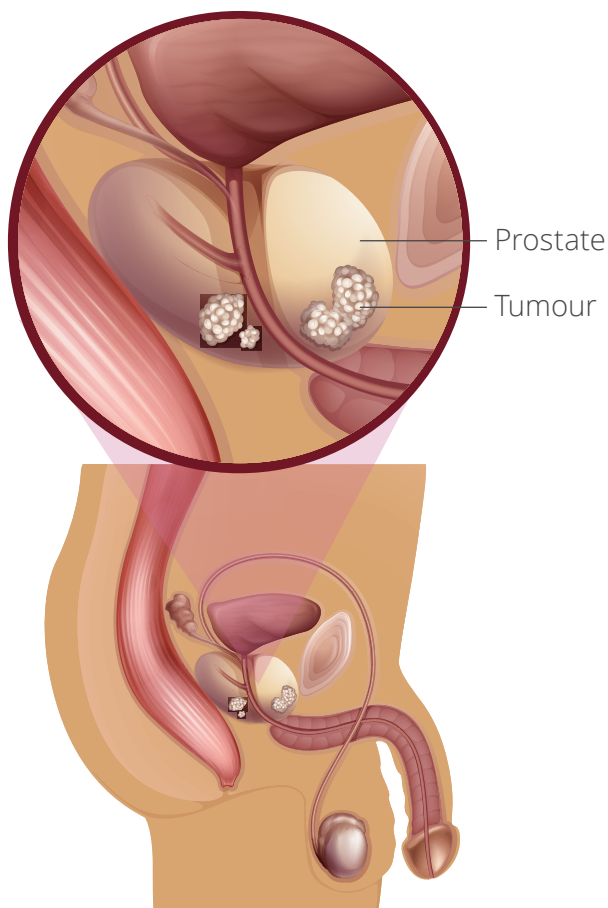
Treatment involves addressing the cause, e.g. removing a stone from the ureter.

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.



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.



Prostate cancer

Prostate cancer occurs when abnormal cells grow in an uncontrolled way in the prostate gland, creating a malignant tumour. Men with spinal cord injury generally have a lower incidence of prostate cancer. However, prostate cancer when present may be detected at a later stage because of accessibility problems limiting prostate examination, as well as common symptoms (such as frequent urination, pain while urinating and pain in the back or pelvis) being masked by your spinal cord injury. More widespread disease can spread to the bones causing pain, unexplained weight loss and fatigue.

From the age of 50 years, all men should discuss prostate screening with their doctor, including individual level of prostate cancer risk, and potential benefits, harms and uncertainties of screening using a prostate-specific antigen (PSA) blood test. There is a higher risk in men with one or more first-degree relatives diagnosed under age of 65 years. Treatment will depend on the extent of the cancer.

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.

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 how severe your problem is, use the Severity Scale to assess the intensity, duration and frequency of your signs and symptoms using this table.

Problems	Mild	Moderate	Severe
Urinary tract infections (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
Urinary retention	Residual volume = 100 to 150mls	Residual volume = 150 to 300mls	Residual volume = >300mls on 2 or more occasions

Important note

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

Interference scale

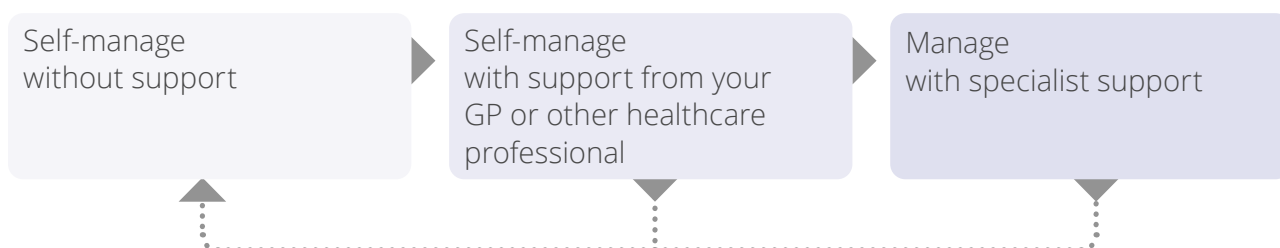
To determine to what extent your problem interferes with participating in everyday activities, use the scale below:



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.

A photograph of a person in a wheelchair sitting on a paved path in a park. The person is wearing a blue denim jacket and jeans, and has their arms raised in the air, pointing upwards. They are looking up at the sky. The background is filled with lush green trees and foliage, suggesting a sunny day in a park.

Prevention is better than cure

Take home messages



EMPTY

your bladder fully every 4 to 6 hours

COMPLETE

full course of antibiotics, as prescribed



SCHEDULE

an annual check-up of bladder & kidneys with your doctor

QUIT

smoking



MAINTAIN

good hand hygiene when catheterising

AVOID

straining to empty your bowel as this can weaken the bladder neck muscles and cause urine to leak



DRINK

plenty of water



Knowledge test

- The main job of your bladder is to:
 - Store urine.
 - Get rid of urine.
 - Both.
- How frequently should clean intermittent self-catheterisation normally be done?
 - Every 2 hours.
 - Every 4-6 hours, depending on fluid intake.
 - Three times a day.
 - Twice a day.
- If you are experiencing signs and symptoms of a urinary tract infection, what should you do?
 - Start antibiotics straight away and send a urine sample if you feel better in a few days.
 - Collect a clean sample of urine and send to lab for testing – if results are positive, indicating an infection, start antibiotics as prescribed.
 - Start antibiotics straight away and stop taking them when you are feeling better.
- Reflex voiding is no longer recommended because it can cause too much pressure in the bladder and damage the kidneys.
 - True
 - False
- Signs and symptoms for bladder or kidney stones can include:
 - Grit in the catheter.
 - Blood in urine.
 - Recurrent urinary tract infections.
 - All of the above.
- Urine leakage may be due to:
 - Stress when you laugh or sneeze.
 - An overactive bladder.
 - Overflow from a full bladder.
 - All of the above.

For correct answers, please see page 32.

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 symptom, including 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 homeostasis. 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. 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/cpgbladdermanage_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;



Keep this diary to record each time you pass urine for up to 7 days.

<p>Date</p> <input type="text"/>	<p>Date</p> <input type="text"/>	<p>Date</p> <input type="text"/>	<p>Date</p> <input type="text"/>
<p>Time</p> <input type="text"/>	<p>Time</p> <input type="text"/>	<p>Time</p> <input type="text"/>	<p>Time</p> <input type="text"/>
<p>Amount of urine (half a glass = 125 ml)</p> <input type="text"/> ml	<p>Amount of urine (half a glass = 125 ml)</p> <input type="text"/> ml	<p>Amount of urine (half a glass = 125 ml)</p> <input type="text"/> ml	<p>Amount of urine (half a glass = 125 ml)</p> <input type="text"/> ml
<p>Did you feel an urge to go? (0 is no urgency and 10 is severe urgency)</p> <input type="text"/>	<p>Did you feel an urge to go? (0 is no urgency and 10 is severe urgency)</p> <input type="text"/>	<p>Did you feel an urge to go? (0 is no urgency and 10 is severe urgency)</p> <input type="text"/>	<p>Did you feel an urge to go? (0 is no urgency and 10 is severe urgency)</p> <input type="text"/>
<p>Have you had leakage since last voiding?</p> <input type="text"/>	<p>Have you had leakage since last voiding?</p> <input type="text"/>	<p>Have you had leakage since last voiding?</p> <input type="text"/>	<p>Have you had leakage since last voiding?</p> <input type="text"/>
<p>Amount of leakage</p> <input type="text"/>	<p>Amount of leakage</p> <input type="text"/>	<p>Amount of leakage</p> <input type="text"/>	<p>Amount of leakage</p> <input type="text"/>
<p>Activities when leakage occurred</p> <input type="text"/>	<p>Activities when leakage occurred</p> <input type="text"/>	<p>Activities when leakage occurred</p> <input type="text"/>	<p>Activities when leakage occurred</p> <input type="text"/>
<p>Notes Record any other relevant information, such as use of medications (what taken and when) and its associated side effects, pad usage, time when bowel emptied, etc.</p> <input type="text"/>	<p>Notes Record any other relevant information, such as use of medications (what taken and when) and its associated side effects, pad usage, time when bowel emptied, etc.</p> <input type="text"/>	<p>Notes Record any other relevant information, such as use of medications (what taken and when) and its associated side effects, pad usage, time when bowel emptied, etc.</p> <input type="text"/>	<p>Notes Record any other relevant information, such as use of medications (what taken and when) and its associated side effects, pad usage, time when bowel emptied, etc.</p> <input type="text"/>



Fluid Diary

Keep this diary to record each time you intake fluid for a **up to 14 days**.
 Note: If completing the bladder and bowel diary, you only need to collect information on fluid intake once.

<p>Date <input type="text"/></p> <p>Time <input type="text"/></p> <p>Amount drunk since last entry (1 glass equals 250 ml)</p> <table border="1"> <tr> <td> Less than 100ml</td> <td> 100ml - 250ml</td> <td> 250ml - 500ml</td> </tr> <tr> <td> 500ml - 750ml</td> <td> 750ml - 1000ml</td> <td></td> </tr> </table> <p>Type of drink</p> <table border="1"> <tr> <td> Water</td> <td> Coffee / Tea</td> <td> Soft drink</td> </tr> <tr> <td> Fruit drink</td> <td> Alcohol</td> <td> Other</td> </tr> </table> <p>Notes</p> <div style="border: 1px solid black; height: 100px;"></div>	Less than 100ml	100ml - 250ml	250ml - 500ml	500ml - 750ml	750ml - 1000ml		Water	Coffee / Tea	Soft drink	Fruit drink	Alcohol	Other	<p>Date <input type="text"/></p> <p>Time <input type="text"/></p> <p>Amount drunk since last entry (1 glass equals 250 ml)</p> <table border="1"> <tr> <td> Less than 100ml</td> <td> 100ml - 250ml</td> <td> 250ml - 500ml</td> </tr> <tr> <td> 500ml - 750ml</td> <td> 750ml - 1000ml</td> <td></td> </tr> </table> <p>Type of drink</p> <table border="1"> <tr> <td> Water</td> <td> Coffee / Tea</td> <td> Soft drink</td> </tr> <tr> <td> Fruit drink</td> <td> Alcohol</td> <td> Other</td> </tr> </table> <p>Notes</p> <div style="border: 1px solid black; height: 100px;"></div>	Less than 100ml	100ml - 250ml	250ml - 500ml	500ml - 750ml	750ml - 1000ml		Water	Coffee / Tea	Soft drink	Fruit drink	Alcohol	Other	<p>Date <input type="text"/></p> <p>Time <input type="text"/></p> <p>Amount drunk since last entry (1 glass equals 250 ml)</p> <table border="1"> <tr> <td> Less than 100ml</td> <td> 100ml - 250ml</td> <td> 250ml - 500ml</td> </tr> <tr> <td> 500ml - 750ml</td> <td> 750ml - 1000ml</td> <td></td> </tr> </table> <p>Type of drink</p> <table border="1"> <tr> <td> Water</td> <td> Coffee / Tea</td> <td> Soft drink</td> </tr> <tr> <td> Fruit drink</td> <td> Alcohol</td> <td> Other</td> </tr> </table> <p>Notes</p> <div style="border: 1px solid black; height: 100px;"></div>	Less than 100ml	100ml - 250ml	250ml - 500ml	500ml - 750ml	750ml - 1000ml		Water	Coffee / Tea	Soft drink	Fruit drink	Alcohol	Other	<p>Date <input type="text"/></p> <p>Time <input type="text"/></p> <p>Amount drunk since last entry (1 glass equals 250 ml)</p> <table border="1"> <tr> <td> Less than 100ml</td> <td> 100ml - 250ml</td> <td> 250ml - 500ml</td> </tr> <tr> <td> 500ml - 750ml</td> <td> 750ml - 1000ml</td> <td></td> </tr> </table> <p>Type of drink</p> <table border="1"> <tr> <td> Water</td> <td> Coffee / Tea</td> <td> Soft drink</td> </tr> <tr> <td> Fruit drink</td> <td> Alcohol</td> <td> Other</td> </tr> </table> <p>Notes</p> <div style="border: 1px solid black; height: 100px;"></div>	Less than 100ml	100ml - 250ml	250ml - 500ml	500ml - 750ml	750ml - 1000ml		Water	Coffee / Tea	Soft drink	Fruit drink	Alcohol	Other
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Ageing with your spinal cord injury

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

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

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



What does research tell you?

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



Issues with ageing with spinal cord injury

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

Recommendations for ageing with spinal cord injury

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

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

The Spinal Cord Injury Health Maintenance Tool

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

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

Booklets

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

OR

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



Website

The website has interactive elements that you can use anonymously.

Go to: www.healthmaintenance.com



Smartphone App

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

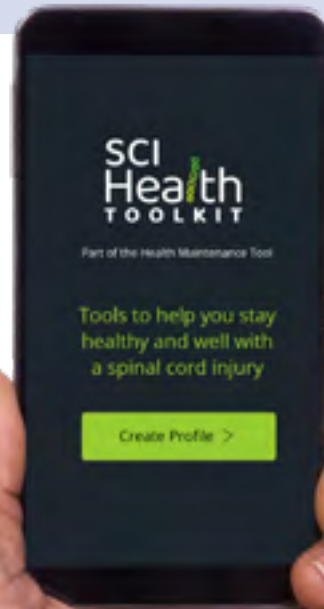
Or search "SCI Health Toolkit"



Apple



Google



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

The website includes below elements:

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

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

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