Health
MAINTENANCE TOOL

Health Maintenance Tool

Module 3:
The bowel 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

THE UNIVERSITY OF SYDNEY

Royal Rehab
Empowering Independence

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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 bowel

and its associated problems

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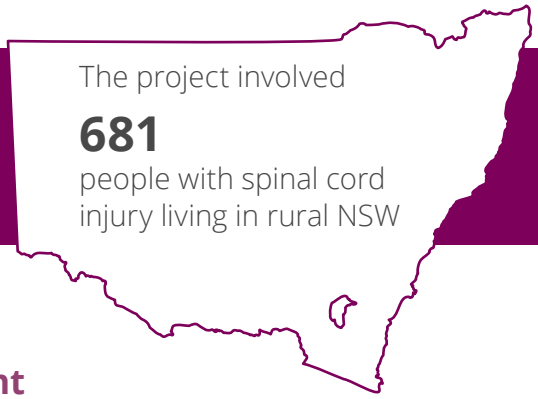
Summary of findings
from the 2015 Rural Spinal Cord Injury Project



The project involved

681

people with spinal cord injury living in rural NSW

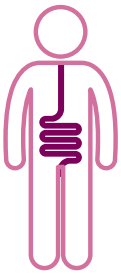
The main techniques used for bowel management

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.

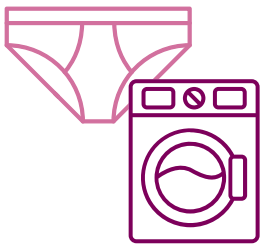
The three most common problems related to the bowel



19%

Constipation

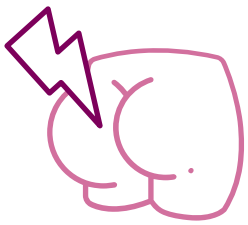
The occurrence of CONSTIPATION was 21-28% from 6 to 20 years post-injury



16%

Faecal incontinence

The presence of faecal incontinence did not vary across different age groups or duration 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 5)

CHECK Do you have a problem with your bowel?
Refer to checklist and warning signs (page 8)

Yes

IDENTIFY PROBLEM
Look for important signs and symptoms:

Constipation	(page 28)
Diarrhoea	(page 29)
Alternating constipation and diarrhoea	(page 30)
Haemorrhoids	(page 31)
Abdominal bloating and discomfort	(page 32)
Other problems	(pages 33-34)

CHECK SEVERITY
Based on the management index:

Severity scale	(page 35)
Interference scale	(page 36)

MANAGE
Based on problem severity and interference (pages 35-36)

- 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 10)
How to prevent constipation	(page 11)
How to prevent haemorrhoids	(page 11)
Routine follow-up and tests	(page 12)

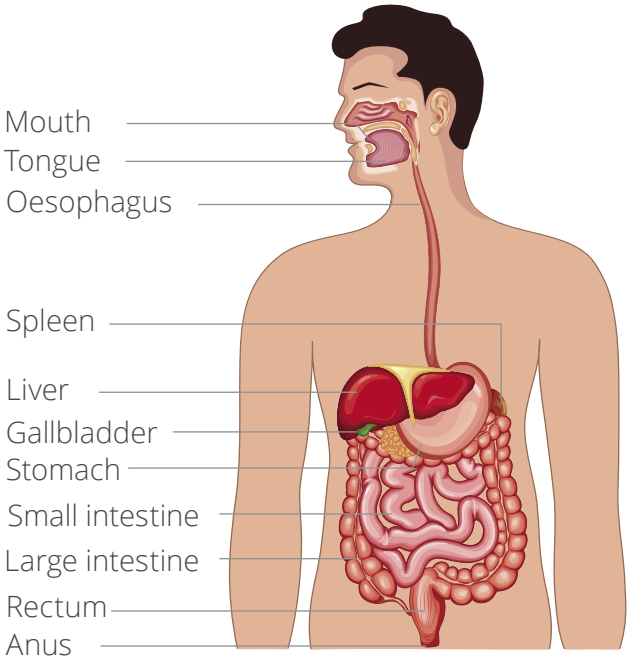
EDUCATE
Refer to bowel management toolbox (page 15)

What will happen if you do not manage your problem 'just-in-time'? (page 37)

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 that 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.

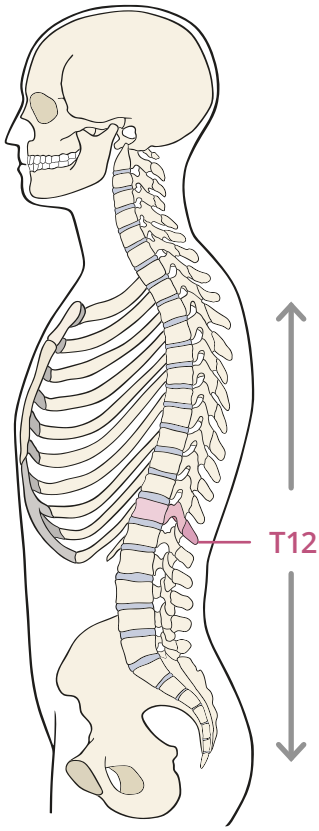
If you decide to empty your bowel, a message is sent back down your spinal cord to the sphincter muscle, telling it to relax and pass the stool.

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) • 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:

How do you manage your bowel?

Bowel care methods and procedures:

- Voluntary control to empty your bowel
- Straining/bearing down to empty your bowel
- Digital stimulation
- Enema or suppositories
- Laxatives
- Dietary supplements
- Assistive techniques
- Anal irrigation
- Colostomy
- Other

Frequency of bowel emptying:

- >2 motions/day
- Once daily
- Second daily
- <3 times/week

Consistency of stool:

- Type 1
- Type 2
- Type 3
- Type 4
- Type 5
- Type 6
- Type 7

Quantity of stools passed:

- Small quantify
- Regular quantity
- Varying amount
- Large quantity

Time taken to empty bowel (time from transferring to the toilet/commode until transferring back to the wheelchair or moving from the toilet):

- <30 mins
- 31-60 mins
- >60 mins

Have you been experiencing any recent problems or changes in bowel emptying/routine:

- Having episodes of alternating constipation and diarrhoea (note: this can result from severe constipation with episodes of bowel impaction and overflow? It may sometimes indicate another problem, such as irritable bowel syndrome)
- Having frequent bowel accidents, occurring once a fortnight or more often?
- Having either very loose, watery stools (diarrhoea) or opening your bowels more often than usual?
- Having harder stools that are difficult to remove, emptying your bowel less often than usual, feeling your lower bowel has not been fully emptied or needed to take more laxatives?

Have you been experiencing bleeding during or after bowel care?

Have you been experiencing any problems with abdominal discomfort, pain or bloating? Is it relieved by emptying your bowel?

Have you been experiencing any difficulty swallowing, or having a burning sensation in your chest or acid taste in the mouth after meals or when lying down, occurring more than once a week?

Do you have a family history of bowel cancer or inflammatory bowel disease?

Have you been experiencing any unplanned weight loss?

Have you been experiencing episodes of sweating, headache, blotchy skin/ rashes or blurred vision during your bowel care, 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 35) to see whether your problem is mild, moderate or severe, and Interference Scale (page 36) to decide on what management strategy to take.

Warning signs

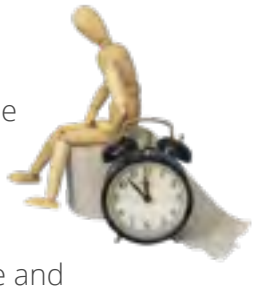
The following symptoms are warning signs indicating there may be a serious problem that requires further investigation and/or treatment:

- 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.

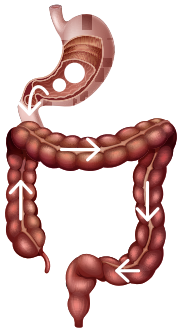
Some foods may increase the risk of bowel problems

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 17) to establish regular and predictable bowel emptying.

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 42).

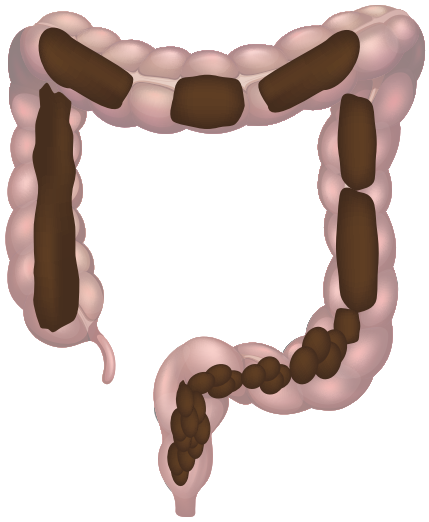
What does research tell you?

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.

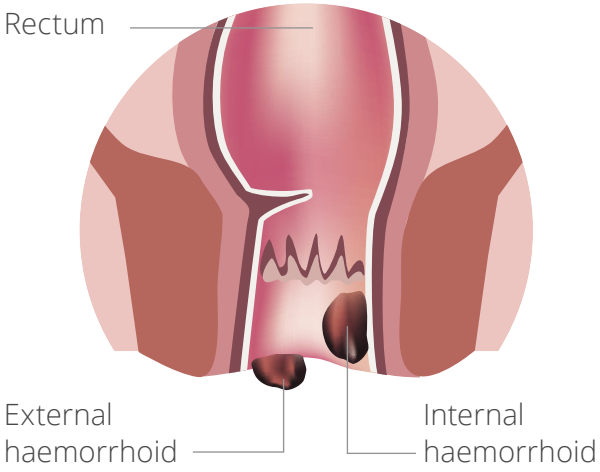


How to prevent haemorrhoids

Haemorrhoids 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.

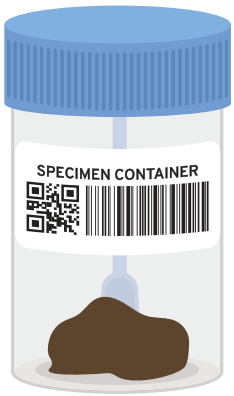
As part of a yearly review of your bowel function, particularly when experiencing problems or your bowel pattern has changed, you may require further tests. The different tests available are outlined below:

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).



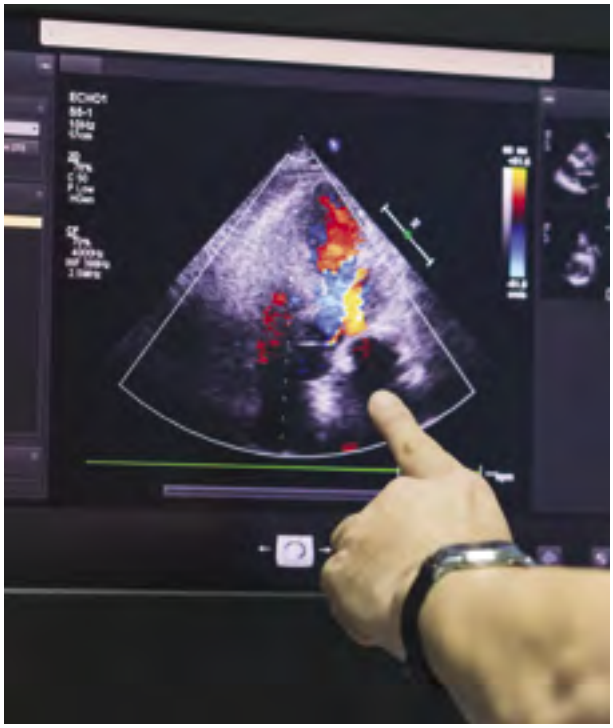
Blood tests

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 (MRI) 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. **Australian National guidelines recommend that people 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).

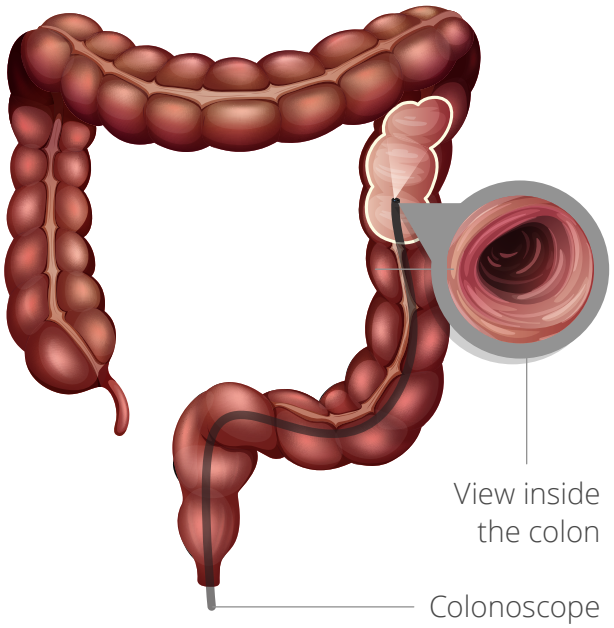
Endoscopy

A long flexible 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.

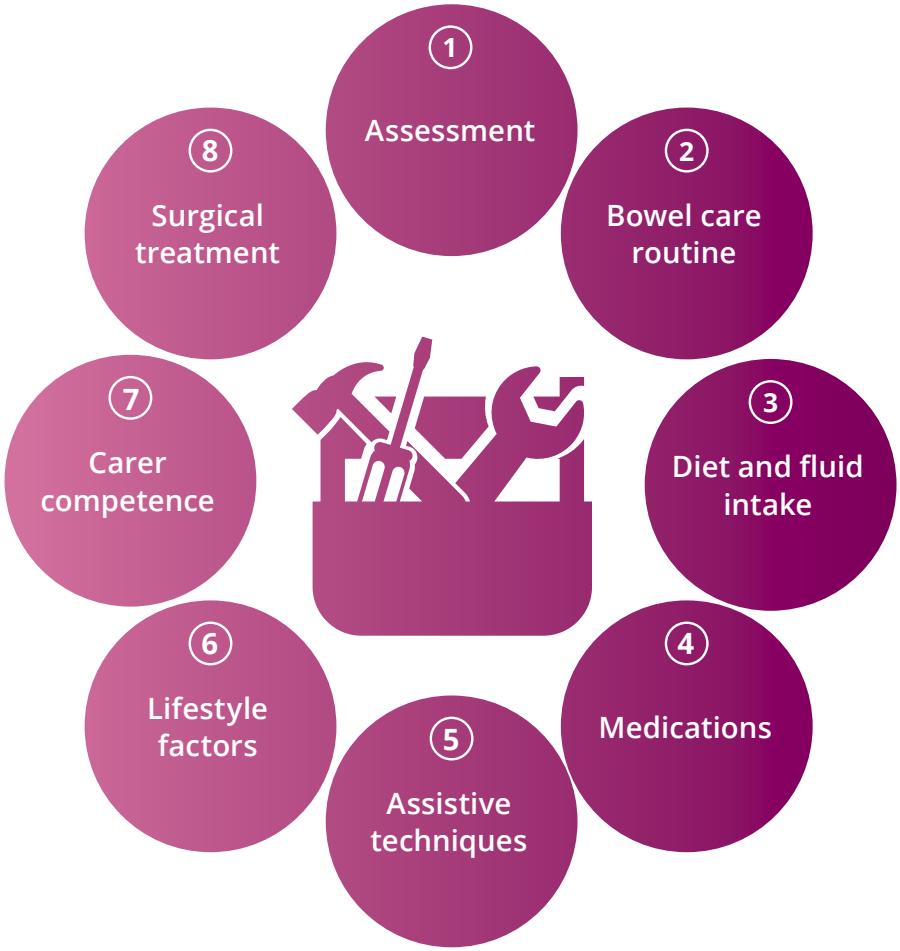
The bowel management toolbox provide you with eight strategies to manage your bowel care and to help solve your bowel problems. An individualised approach to bowel management is needed and includes:

- 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 using just one strategy will fix a bowel problem, you need to use a combination of strategies.



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 20.

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 20.

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?

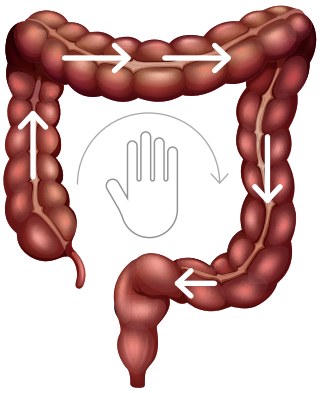
Expert opinion strongly suggests avoiding the long-term use of Senna, although robust evidence is lacking to support this concern.

5. Assistive techniques

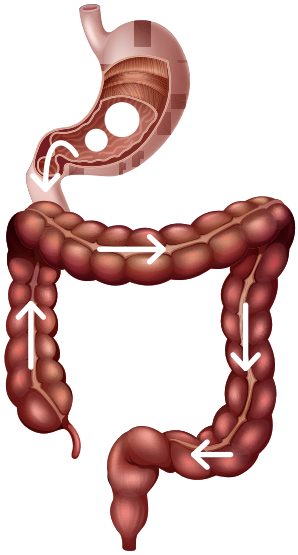
Assistive techniques can increase the speed of bowel care routines by promoting wave-like movements of your bowel, called peristalsis, which help to improve your bowel management.

The commonly used techniques are:

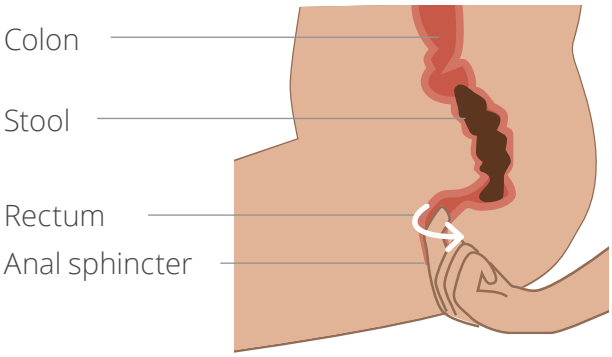
Abdominal massage uses a firm, slow and rhythmic action in a clockwise motion from the lower right side of the abdomen, across the top to the left and continuing down the left side of abdomen to assist the stool move along the large bowel towards the rectum and anus.



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.

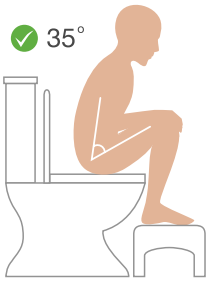


Digital stimulation involves gently inserting a gloved and well-lubricated finger into the rectum, up to the second finger joint. Rotate the finger in a gentle sweeping motion against the rectal wall. While digital stimulation can be repeated every 5-10 minutes until the bowel has evacuated, each stimulation 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.

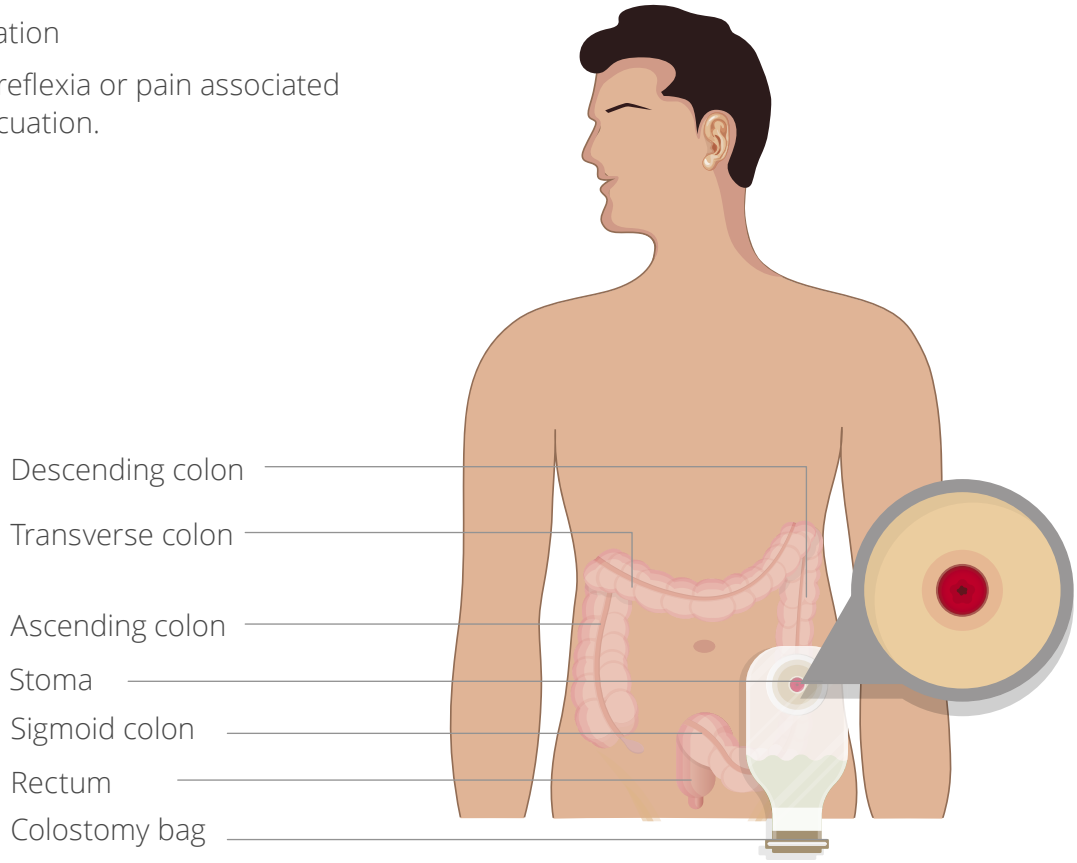
Common reasons for a person with spinal cord injury to consider a colostomy include:

- 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.

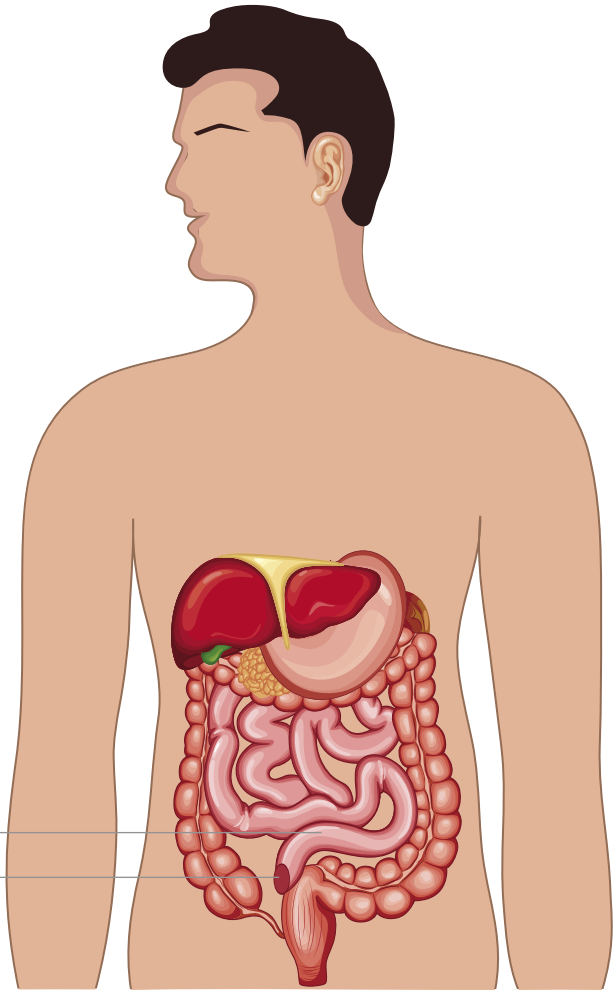
There is no agreement about when to have a colostomy. It is often only considered as a last resort when all other methods have failed. Yet, in most cases after having a colostomy, people report wishing they had had the procedure much earlier. It can be very helpful to talk to a peer who has already had 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 42).

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 41.

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:

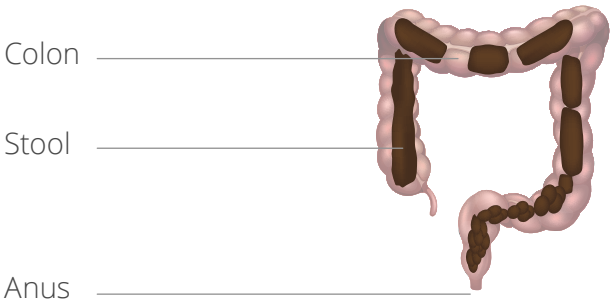
- Less frequent bowel movements
- Hard stools
- Difficulty opening your bowels.

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 the 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 sometimes may 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."

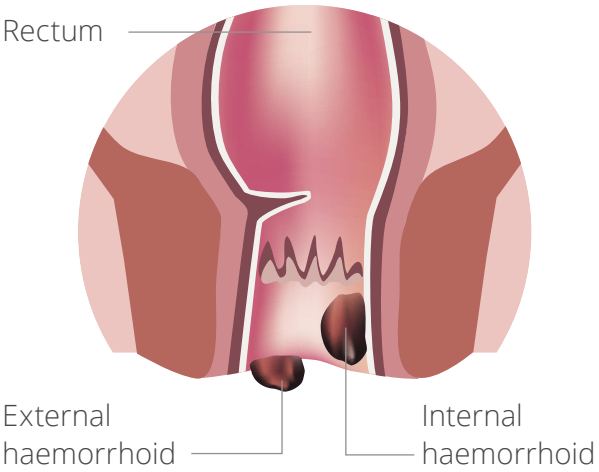
– Consumer with spinal cord injury

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:

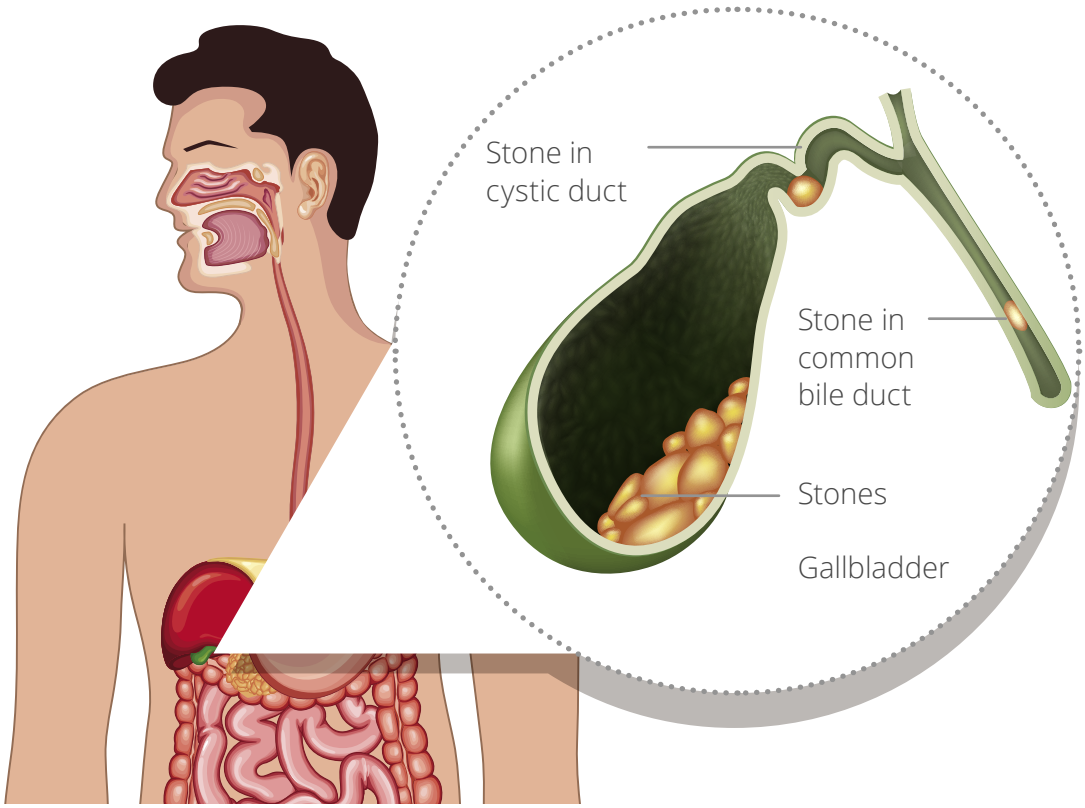
- Sudden severe pain or discomfort in your upper right abdomen – just below the rib cage – or right shoulder.

  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	Less than 3 bowel movements per week; firm to hard stools (BSC* type 2-3) Less than 25% of time	Less than 3 bowel movements per week; hard stools (BSC* type 2) 25-50% of time	Less than 3 bowel movements per week; prolonged (>1 hour) or incomplete evacuation, very hard stools (BSC* type 1-2) More than 50% of time
Bowel accidents and/or diarrhoea	Occasional – once or twice a year	1 to 3 times a month	Once or more a week
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	1 to 3 times a month	One or more a week
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

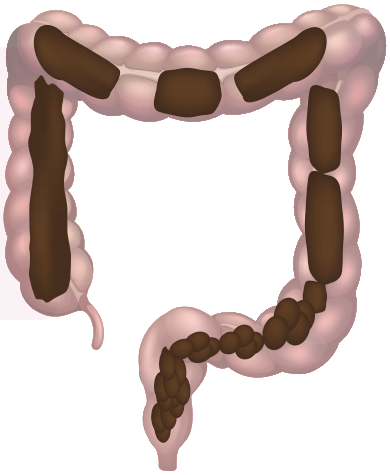
smoking

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 41.

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;

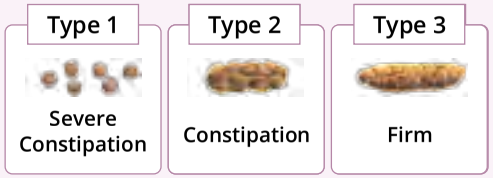
Health MAINTENANCE TOOL

Bowel Diary

Keep this diary to record each time you have a bowel movement for a **minimum of 14 days**.

Date | Time

Stool consistency:



Did you feel an urge to go?

Accident or soiling since last bowel motion?

Activities when leakage occured

Notes

Record any other relevant information, such as: Use of medications (what taken and when) and its associated side effects, pad usage, etc.

Date | Time

Stool consistency:

Did you feel an urge to go?

Accident or soiling since last bowel motion?

Activities when leakage occured

Notes

Record any other relevant information, such as: Use of medications (what taken and when) and its associated side effects, pad usage, etc.

Date | Time

Stool consistency:

Did you feel an urge to go?

Accident or soiling since last bowel motion?

Activities when leakage occured

Notes

Record any other relevant information, such as: Use of medications (what taken and when) and its associated side effects, pad usage, etc.

Date | Time

Stool consistency:

Did you feel an urge to go?

Accident or soiling since last bowel motion?

Activities when leakage occured

Notes

Record any other relevant information, such as: Use of medications (what taken and when) and its associated side effects, pad usage, etc.

Health MAINTENANCE TOOL

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.

Date Time

Amount drunk since last entry
(1 glass equals 250 ml)

Less than 100ml | 100ml - 250ml | 250ml - 500ml | 500ml -750ml | 750ml -1000ml

Type of drink

Water | Coffee / Tea | Soft drink | Fruit drink | Alcohol | Other

Notes

Date Time

Amount drunk since last entry
(1 glass equals 250 ml)

Less than 100ml | 100ml - 250ml | 250ml - 500ml | 500ml -750ml | 750ml -1000ml

Type of drink

Water | Coffee / Tea | Soft drink | Fruit drink | Alcohol | Other

Notes

Date Time

Amount drunk since last entry
(1 glass equals 250 ml)

Less than 100ml | 100ml - 250ml | 250ml - 500ml | 500ml -750ml | 750ml -1000ml

Type of drink

Water | Coffee / Tea | Soft drink | Fruit drink | Alcohol | Other

Notes

Date Time

Amount drunk since last entry
(1 glass equals 250 ml)

Less than 100ml | 100ml - 250ml | 250ml - 500ml | 500ml -750ml | 750ml -1000ml

Type of drink

Water | Coffee / Tea | Soft drink | Fruit drink | Alcohol | Other

Notes

Ageing with your spinal cord injury

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

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

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

What does research tell you?

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

Issues with ageing with spinal cord injury

Body System	Issues with ageing with SCI
Bladder and kidneys	Age-related changes are intensified by the type of bladder problem, how you manage your bladder and length of time after injury. Potential backflow of urine with kidney damage can result from an overactive bladder and poor emptying.
Bowel and digestive system	The function of your digestive system naturally declines with age and spinal cord injury makes slowing of the gut worse.
Endocrine (glands)	The secretion of hormones is vital for metabolism, growth, sleep and tissue healing and repair. People with a spinal cord injury have lower levels of certain hormones that decrease with age, including growth hormone and testosterone leading to changes in body composition, obesity and metabolic disorders, with impaired glucose tolerance and higher rates of diabetes.
Heart	Heart disease may occur as the metabolism slows down, with weight gain over time (may eventually become obesity), reduced exercise tolerance, changes in lipid profile (increase in "bad" cholesterol or LDL with decrease in "good" cholesterol or HDL), and diabetes.
Lungs	Worsening lung function due to respiratory or abdominal muscle weakness, spinal curvature or spasms with increased risk respiratory tract infections and clots. Risk of obstructive sleep apnoea increases with age, more so in people with tetraplegia.
Mental health	People usually live fulfilling and pleasurable lives without experiencing major emotional problems as they age. In fact, most older adults, with and without a spinal injury, are resilient and adjust well to changes in their physical abilities. They also note improved relationships with loved ones, increased appreciation for life, and changes in priorities.
Muscles, joints and bones	Overuse ('wear and tear') of muscles, tendons and joints occurs particularly in the upper limbs (shoulders, arms, and hands) due to the demands of everyday living, leading to injuries (e.g., shoulder rotator cuff tears), inflammation (e.g., tendonitis), arthritis and pain. These changes impact on level of functioning and independence in performing daily activities (such as transfers and wheelchair mobility).
Skin	People with spinal cord injury are already susceptible to pressure injuries due to altered sensation and mobility. In addition, with progressive tissue thinning due to ageing, becomes even more prone to breakdown and harder to heal once a pressure injury has developed.
Spinal cord and nerves	Late onset weakness or sensory loss, increasing muscle weakness, pain or spasticity can occur with ageing due to normal nerve drop out or problems from: • over- or misuse of muscles and bones leading to nerve damage. • changes within the spinal cord itself (such as a cyst).

Recommendations for ageing with spinal cord injury

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

Frequency	Checks
Daily	• Self-skin check • Stay active • Eat and drink responsibly
Monthly	• Women: Breast self-exam • Men: Testicular self-exam
Yearly	• Vital signs / measures including pulse, blood pressure (in sitting and supine lying positions), vital capacity, weight/waist circumference • Blood tests including full blood count, biochemistry (electrolytes, Liver function, renal function, blood sugar level), HbA1c, Cholesterol, Vitamin D level. • Women (40 years and older): mammography • Men (50-69 years): may have digital rectal exam and prostate specific antigen (PSA) test • Flu vaccination, especially for people with injuries at T8 and higher • Renal/Bladder ultrasound
1- to 2-yearly	• Comprehensive Health Evaluation reviewing all body systems • Faecal occult blood test (50-74 years) • 55 years and older: comprehensive eye exam • Cystoscopy (in those with long-term indwelling urethral or suprapubic catheters > 10 years)
3- to 5-yearly	• Women: breast cancer exam by a doctor • Women: gynaecological exam and Pap smear • Assess adaptive equipment and posture • Assess range of motion, contractures, and function • Bladder exam; also do this each year for the first 3 years after any major change in urologic management (including Videourodynamics) • Bone Health - DEXA scan, performed in first year post-injury (baseline reading) then repeat every 3-5 years)
5-yearly	• Motor and sensory testing • Multidisciplinary clinic review (of function, participation, ADL, community mobility and lifestyle demands, equipment and care assistance requirements) • Pulmonary (Lung) function test
10-yearly	• Tetanus booster • Colonoscopy, which allows your doctor to examine your colon, beginning at 50 years of age (unless at high risk)
When required	• Recognise and treat adverse health conditions early

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.healthmaintenancetool.com*

Website

The website has interactive elements that you can use anonymously.

Go to: *www.healthmaintenancetool.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 "

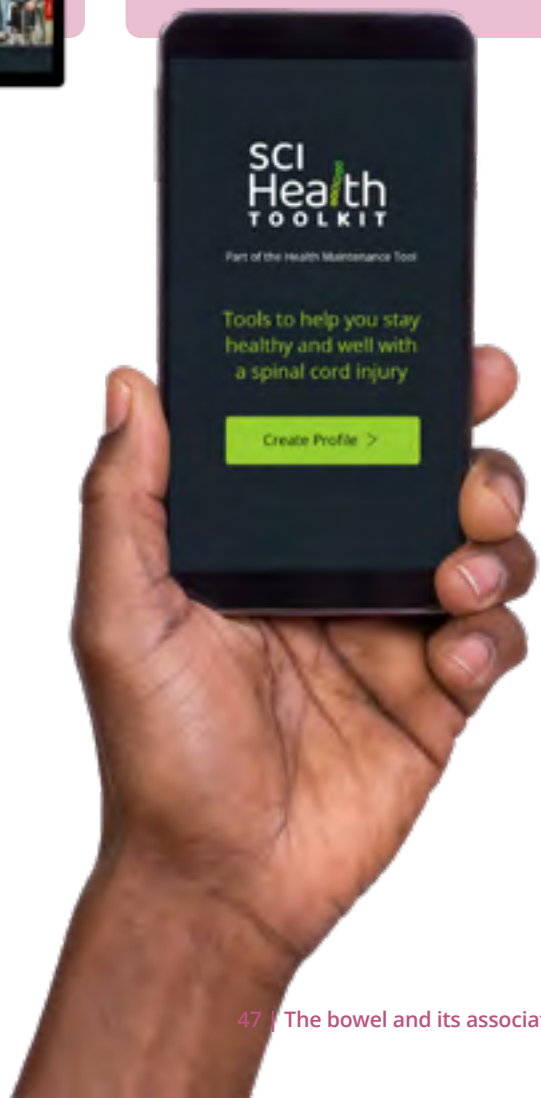
Apple

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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Health
MAINTENANCE TOOL

www.healthmaintenancetool.com