

Health Maintenance Tool Module 6: Autonomic dysreflexia

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

A product of the SCI Wellness Project

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DISCI AIMER

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 upto-date best-practice research and consumers' perceptions about their health. The tool is freely accessible to consumers with spinal cord injury, family members, carers and health professionals.

*The SCI Wellness Project consisted of two phases.

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

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

- Consumer with spinal cord injury

Autonomic dysreflexia

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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

Causes of autonomic dysreflexia



Bladder

70%



Bowel

16%



Sexual Activity

5%



Skin

2%



Other

7%

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

53%

55%

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

The three most common recommendations related to autonomic dysreflexia management



Carry an AD emergency card

47%



Renew medication script for AD

34%



Education about AD

35%

How to navigate this module

| KNOW | How your autonomic nervous system works, | |
|------|---|----------|
| | what is normal blood pressure and why AD occurs | (page 5) |

CHECK Do you have current signs and symptoms of autonomic dysreflexia? (page 12) Refer to warning signs (page 8)



No

IDENTIFY PROBLEM

Look for important signs and symptoms:

An episode of autonomic dysreflexia (page 10) Recurrent autonomic dysreflexia (page 12) Frequent autonomic dysreflexia (page 12)

OBSERVE

Refer to warning signs (page 8)

PREVENT

Refer to self-management tips (page 9)

CHECK SEVERITY

Based on the management index: (page 13)

MANAGE

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

Is this problem resolved? Have your goals been met?

 \times) No

Yes

What will happen if you do not manage your problem 'just-in-time'? (page 14)

It is an **EMERGENCY:**

Call 000 for an ambulance

OBSERVE/PREVENT

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

Know about your autonomic nervous system

How the autonomic nervous system normally works

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

The autonomic nervous system has two main divisions:

- Sympathetic
- Parasympathetic

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

The autonomic nervous system controls internal body processes:

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

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

What is normal blood pressure

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

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

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

| - | | |
|--------------------|---|---|
| Less than 120 | and | Less than 80 |
| 120-129 | and | Less than 80 |
| 130-139 | or | 80-89 |
| 140 or higher | or | 90 or higher |
| Higher than 180 | and/or | Higher than 120 |
| | Less than 120 120-129 130-139 140 or higher | 120 120-129 and 130-139 or 140 or higher or and/or |

Baseline blood pressure for some people with a spinal cord injury, may be lower:



What does research tell you?

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

Effects of a spinal cord injury on the autonomic nervous system

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

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

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

Do you know?

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



Irritation below the level of the spinal cord injury



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



Leads to very high blood pressure



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



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



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

Causes of autonomic dysreflexia

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

Bladder causes

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

Bowel and abdominal causes

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

Other common causes include:

Skin causes

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

Sexual activity

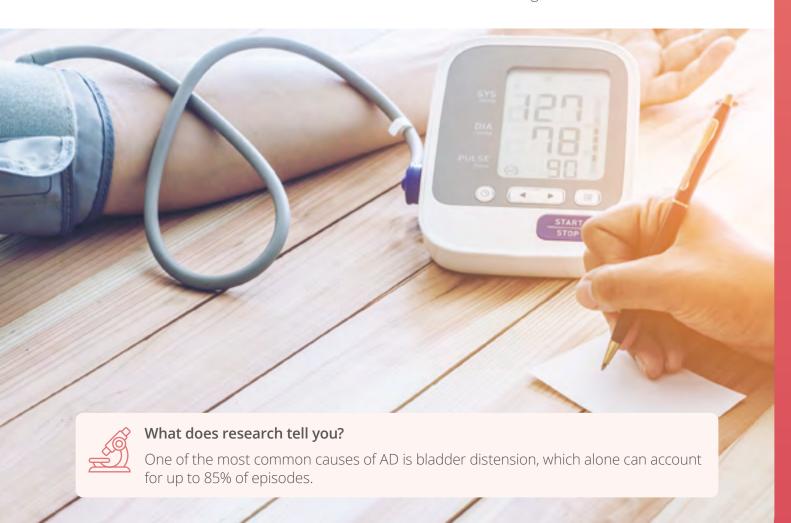
In males

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

In females

- Menstruation or labour
- Infections of vagina or uterus.

7 | Autonomic Dysreflexia



Check if you have a problem

Warning signs

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

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

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



Pounding headache



Blurred vision



Profuse sweating



Nausea or feeling unwell



Blotchiness or rash over skin



Shortness of breath or feeling anxious



Goosebumps and chills



Stuffy nose



Prevention

Self-management tips for preventing autonomic dysreflexia

FIRST and FOREMOST things to do



Record your normal blood pressure



Always carry your personalised AD emergency card with you



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

HEALTHY TIPS to prevent AD

Bladder

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

Bowel

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

Skin

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

Important note

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

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

- Consumer with a spinal cord injury

Management of autonomic dysreflexia

An episode of autonomic dysreflexia

Self-management tips

Immediate actions to be performed by yourself or a carer:

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



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

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



What to do when your AD subsides?



Monitor for any re-occurrence.

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

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

CALL an AMBULANCE.

Dial 000



REMEMBER

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

TIGHT CLOTHING

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

MEDICATION

Check regularly for expiry dates.

Keep calm and call for help.



What does research tell you?

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

Medications for treating autonomic dysreflexia

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

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

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

How to take Glyceryl Trinitrate (GTN)



Spray

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



OR **Tablet**

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



OR **Patch**

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



------ Check blood pressure in 5 to 10 minutes



No effect or little effect on your high

blood pressure

Spray Second spray under tongue

Dose: 400mcg per spray

Low or normal blood pressure

Spit out residual spray

OR

Tablet Take other half tablet under tongue

Dose: 300mcg per tablet

Spit out residual tablet

OR

Patch Do not remove the patch

Dose: 5mg per 24 hours

Remove the patch

WARNING!

- **Be aware** that up to 3 doses of spray or tablet can be given in 30 minutes.
- **Do not take GTN** if you have used medications for erectile dysfunction, such as Sildenafil (Viagra) or Vardenafil (Levitra) in the last 24 hours or Tadalafil (Cialis) in the last 2 to 4 days (up to 4 days for older men).
- **Do not take medications** for erectile dysfunction, such as Sildenafil (Viagra), Vardenafil (Levitra) or Tadalafil (Cialis), **within 24 hours after taking GTN**.

How to take Captopril

Captopril will sometimes be prescribed instead of GTN because:

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

Take one tablet under tongue

Dose: 25mg per tablet Brand name: Capoten

Takes about 3 minutes to dissolve





No effect or little effect on your high blood pressure

CALL an AMBULANCE Dial 000



Low or normal blood pressure Spit out the residual tablet

Recurrent autonomic dysreflexia

This refers to an episode of autonomic dysreflexia that recurs soon after an initial episode because the underlying cause has not been resolved, got worse or you may be more at risk. After a severe and prolonged episode, your body is more prone to further episodes of autonomic dysreflexia, which may occur with activities that are usually harmless and do not cause autonomic dysreflexia (e.g., muscle stretching or routine bowel care).

How to self-manage recurrent autonomic dysreflexia

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

Frequent autonomic dysreflexia

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

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



What does research tell you?

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

Management index

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

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

Important notes



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

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

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

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

'Just-in-time', or the right care at the right place at the right time, will reduce risk and prevent complications. As a result, you will maintain your quality of life, independence, health and wellbeing.

Be proactive and take responsibility for managing your own health risks.

This involves:

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



Take home messages



ASK

your GP to check your blood pressure at every visit so you know your normal blood pressure If you are at risk of AD, consider having a blood pressure monitor at home.





ALWAYS REMEMBER

to carry your AD emergency card with you If you do not have one, ask your spinal cord injury care provider to arrange one for you.





TREAT

AD as an emergency

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



Knowledge test

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

- 1. What is the most common cause of autonomic dysreflexia?
 - (a) A blocked catheter.
 - (b) A skin infection.
 - (c) Wearing tight clothes.
 - d Constipation.
- 2. Which of the following is a symptom of autonomic dysreflexia?
 - (a) Sweating.
 - (b) Headache.
 - (c) Flushed face.
 - (d) All of the above.
- 3. If you have signs and symptoms related to autonomic dysreflexia, when is the right time to call the emergency number?
 - (a) Immediately without delay.
 - (b) After you have found and managed the cause of autonomic dysreflexia.
 - © If you are not able to manage to find the cause and control your blood pressure.
 - d None of the above.

- 4. GTN medication for treating autonomic dysreflexia should not be used, if you have used _____ within the last 24 hours.
 - (a) Sildenafil (Viagra).
 - (b) Vardenafil (Levitra).
 - (c) Tadalafil (Cialis).
 - d All of the above.
- 5. For effective management of autonomic dysreflexia, you should:
 - (a) Know your normal blood pressure reading.
 - (b) Carry an AD Emergency Card with you.
 - © Treat autonomic dysreflexia as an emergency.
 - (d) Do all of the above.

For correct answers, please see page 18.

Glossary

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

Further resources

Reading resources for consumers

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

Useful resources for consumers and medical professionals

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

Videos for consumers

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



Answers to knowledge test

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

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) testFlu vaccination, especially for people with injuries at T8 and higherRenal/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 |

| Notes | | | |
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The Spinal Cord Injury Health Maintenance Tool

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

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

Booklets

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

OR

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



Website

The website has interactive elements that you can use anonymously.

Go to: www. healthmaintenance tool.com



Smartphone App

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

Or search
"SCI Health Toolkit"



Apple

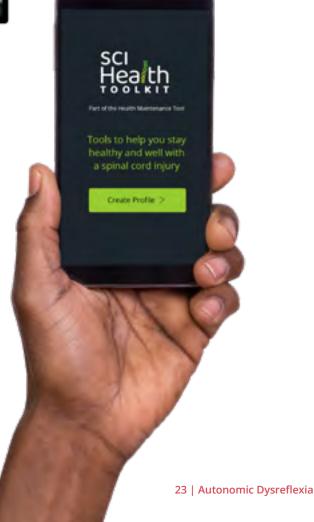


Google

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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