

SELF MANAGEMENT GUIDE FOR PEOPLE LIVING WITH SPINAL CORD INJURY

When you have a spinal cord injury (SCI), you have the same health concerns as the general population but also may have health issues related to your SCI. This guide can be used to help you understand and manage your health. The first two pages include routine tests and investigations for the general population.

Tests and investigations specific to your SCI are marked with an *.

PREVENTATIVE HEALTH

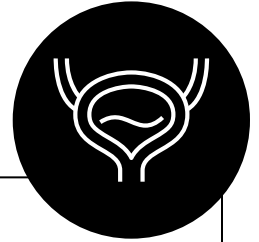
These tests are done to help maintain health and prevent problems. You may not need all of these depending on your SCI level, ask your healthcare provider.

DIAGNOSTIC TESTS	RECOMMENDED FREQUENCY
Blood Pressure	Every year
Weight	Every year
Cholesterol (Blood test)	Age 40 for men, age 50 for women (may be earlier if known cardiovascular/heart risk factors)
Blood sugar, glucose (Blood test)	Every 3 years after age 40 and until 65- then every year *May be earlier depending on individual risk factors
Bone-density (BMD)	Every 2 years if you use a wheelchair
Vitamin D and Calcium	Check Vitamin D levels every year Review calcium intake and avoid high oxalate foods for those prone to kidney stones
Urodynamics * (referral to urologist)	Consider every year during first 3 years post injury and every 2 years thereafter
Renal (kidney) Ultrasound *	Consider every year post injury
Colorectal cancer screening	Every 2 years after age of 50 *For those with history of colon cancer, talk to health care provider

DIAGNOSTIC TESTS		RECOMMENDED FREQUENCY	
MEN and people with a prostate including trans-women and non-binary			
Prostate Cancer Screening (PSA blood test)	Ask your health care provider * For men aged less than 55 years, we recommend not screening for prostate cancer with the prostate-specific antigen test. This blood test is not covered in Ontario and requires you to pay.		
WOMEN and people with breasts/cervix including trans-men and non-binary			
Breast Cancer Screening (Mammogram)	Every 2 years after age 50 *May be earlier or more frequent depending on individual risk factors		
Cervical Cancer Screening (Pap test)	Every 3 years after age 21 if sexually active, can be delayed until sexually active *May be earlier or more frequent depending on individual risk factors		
IMMUNIZATIONS		RECOMMENDED FREQUENCY	
Influenza (seasonal flu shot) and COVID	Every year		
Pneumonia	1 dose of Pneu-P-23 vaccine if not previously received (*some experts recommend Pneu-C-13 8 weeks before (not covered)) (*for those at highest risk, 1 dose of Pneu-P-23 at least 5 years after)		
Tetanus/ diphtheria (Td)	Every 10 years		
Pertussis (Tdap)	Administer 1 dose if not received since 18 years old		
EXERCISE		ENQUIRE DIRECTLY AT SCIGUIDELINES.UBC.CA	
Aerobic exercise: 20 minutes 2x per week build up to 30 min., 3x per week AND Strength training for each major muscle group 3 sets of 3 repetitions, 2x per week	Has been shown to decrease the progression of heart disease and other comorbidities in persons with SCI		

The following are additional details for precautionary healthcare measures.
For more information please speak with your health team.

BLADDER HEALTH



WHY IS IT IMPORTANT?

- ▶ Injury to the spinal cord can affect the way your bladder and kidneys function.
- ▶ Urinary tract infections (UTIs) can occur when there is an increased amount of bacteria present in the bladder, urethra or kidneys; when your bladder fails to empty completely; or if you use a catheter.

WHAT TO LOOK FOR

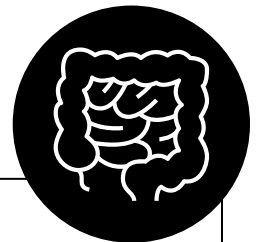
Symptoms of UTIs will vary and can include:

- Bloody, cloudy, or strong smelling urine
- Fever, pain, nausea, and vomiting
- Burning sensation when urinating
- Urge to urinate frequently, chills, shaking, or unusual sweating
- Autonomic Dysreflexia (see page 7)

WHAT TO DO

- Drink plenty of clear fluids
- Follow up with your health care provider about any of these symptoms or changes in function
- Abdominal ultrasound and blood tests may need to be done on a regular basis
- Special tests from a urologist (urodynamic studies, cystoscopy) may be recommended
- Repeat UTIs (> 3/year) may require specialist involvement

BOWEL HEALTH



WHY IS IT IMPORTANT?

- ▶ A spinal cord injury may affect the way your bowel functions
- ▶ These changes can be a source of considerable stress
- ▶ A bowel management program trains your body to achieve effective and predictable emptying
- ▶ This may include the use of stool softeners, laxatives, and suppositories.
- ▶ A proper diet and regular meals are very important

WHAT TO LOOK FOR

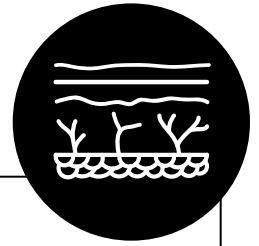
- Make note of any significant changes to your bowel movements/program
- Make note of symptoms of constipation, accidents, bleeding, abdominal discomfort, or bloating

WHAT TO DO

- If any of these symptoms are new or persistent, report to your health care provider
- Keep a regular bowel management routine
- Maintaining a regular diet with fibre and clear fluids is essential to keep your bowels moving effectively



SKIN



WHY IS IT IMPORTANT?

- ▶ Skin breakdown can be a common and serious issue in a person with SCI due to lack of feeling, decreased mobility, changes to circulation, and skin strength
- ▶ Continuous pressure, moisture, and friction may put pressure on your skin between a surface and a bone – such as hips, pelvis, heels, and ankles
- ▶ Once an injury to the skin occurs, it can take a long time to heal: Prevention is key
- ▶ Your risk of infection increases with open areas and infection can spread to the underlying bone
- ▶ Your risk of getting pressure sores increases with years post injury

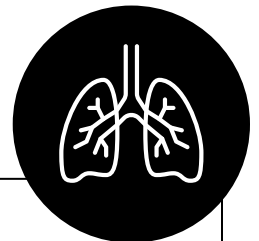
WHAT TO LOOK FOR

- Tears or breaks, redness, change in colour of the skin
- Pain
- Bleeding or discharge from the skin
- Fever
- Increase in spasms

WHAT TO DO

- Examine your skin **every day**
- Regular pressure relief is essential if you are not mobile (every 15 min)
- Keep clean, moisturized skin
- Have seating assessed periodically
- Wear wrinkle free clothing, no seams or buttons
- Proper nutrition and daily exercise is essential

RESPIRATORY



WHY IS IT IMPORTANT?

- ▶ A spinal cord injury, depending on your level, may cause you to be vulnerable or more susceptible to breathing problems by affecting the nerves and muscles that help you breath
- ▶ You could be at higher risk for chest infections and pneumonia
- ▶ Some individuals with high level injury may need a ventilator

WHAT TO LOOK FOR

- Cough, fever, shortness of breath, and production of phlegm
- Sleep apnea (gasp or stop breathing while sleeping), snoring, and feeling excessively tired during the day

WHAT TO DO

- Immunization for flu, pneumonia, and COVID
- Do not smoke
- Exercise
- Report symptoms to your health care provider
- Your team may follow up with a sleep study, breathing test (spirometry) or recommend regular breathing exercises



NEUROLOGICAL/ FUNCTIONAL ABILITIES

WHY IS IT IMPORTANT?

- ▶ Gradual change to your functional ability over time is anticipated
- ▶ Sudden or significant changes to your functional abilities could indicate something needs to be investigated

WHAT TO LOOK FOR

- Changes to your sensation, increased or new pain, or spasticity
- Changes in function such as increased difficulty turning in bed or transferring
- Decreased strength, even though you exercise
- Decreased stamina in walking or wheeling distances

WHAT TO DO

- Prevention is the best medicine with healthy eating, regular exercise, and healthy lifestyle choices
- Make note of any other changes in medication or lifestyle
- Speak to your health care provider

PAIN



WHY IS IT IMPORTANT?

- ▶ Many people with spinal cord injury experience chronic pain due to damage to nerves and muscles
- ▶ Neuropathic pain occurs when the nerve fibers themselves may be damaged. These damaged nerve fibers send incorrect signals to other pain centres
- ▶ Acute pain is a new pain that could be caused by overuse of muscles, joints, or may indicate bone fractures

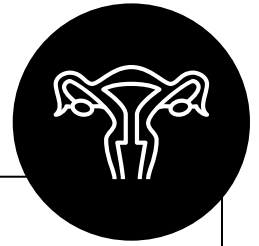
WHAT TO LOOK FOR

- Worsening or new pain
- Pain associated with other symptoms such as spasticity
- Pain due to overuse injuries in muscles and joints (shoulders and elbows are common)

WHAT TO DO

- Prevention is the best medicine with regular exercise
- Monitor new or worsening pain, if persists, see your healthcare provider

SEXUAL AND REPRODUCTIVE HEALTH



WHY IS IT IMPORTANT?

- ▶ Spinal cord injuries may cause damage to the nerves and muscles responsible for your sexual function and is unique to the individual.
- ▶ Sexual dysfunction has a major impact on quality of life and interpersonal relationships – having children may require medical assistance
- ▶ Lubrication, arousal, achieving and maintaining an erection and orgasm can all be affected by an SCI

WHAT TO LOOK FOR

MEN and people with a prostate:

- Difficulty maintaining an erection
- Loss of ejaculation or trickling emission
- Altered sensation (painful or diminished)

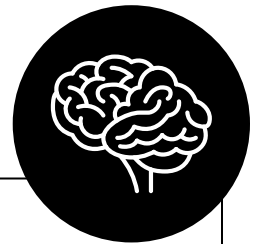
WOMEN and people with a cervix:

- Decreased lubrication
- Altered sensation (painful or diminished)

WHAT TO DO

- Consider the use of oral medications (eg. Viagra, Cialis)
- Consider the use of assistive devices (eg. vibrator, penile ring)
- Talk to your health care team if having trouble conceiving
- For women: have routine pap smears and pelvic exams and talk to your healthcare team about using over-the-counter lubricants or vaginal estrogen cream
- Talk to your health care provider about family planning or birth control options

MENTAL HEALTH



WHY IS IT IMPORTANT?

- ▶ There are many adjustments that may need to be made to accommodate how your body functions after your SCI
- ▶ Grief, sadness, and frustration may be common feelings after SCI

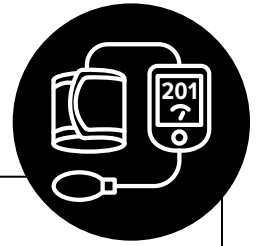
WHAT TO LOOK FOR

- Changes in mood (sad, depressed)
- Trouble concentrating, sleeping, changes in appetite
- Feelings of anxiety
- Feelings of wanting to hurt yourself
- Withdrawing (not wanting to participate in activities)
- Using alcohol or drugs to mask the feelings above

WHAT TO DO

- See your health care provider; counseling may also be helpful
- Communicate to family, friends and health care providers about struggles, challenges and hardships
- Regular exercise is helpful

AUTONOMIC DYSREFLEXIA (AD)



WHY IS IT IMPORTANT?

- ▶ AD is condition that may occur in people with SCI at or above T6
- ▶ AD occurs when there is stimulation below the level of injury that causes the nerves to respond in an uncontrolled way and raises blood pressure dramatically, which if sustained, can cause seizures, stroke, and can be life threatening
- ▶ You may have certain stressors that set off these symptoms that can be controlled or relieved easily

WHAT TO LOOK FOR

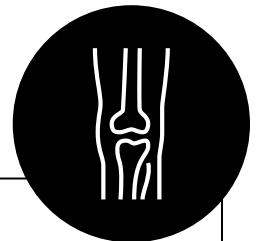
- A dramatic rise in blood pressure and sometimes a slowed pulse
- Pounding headache
- Flushed skin or sweating above the level of the injury
- Blotching of the skin or goosebumps
- Apprehension and anxiety
- Nasal congestion, vision changes, or nausea
- Tightness in the chest, fluttered heartbeat, or trouble breathing

*not all of these symptoms may occur

WHAT TO DO

- Identify triggers or stressors to lower risk of AD (daily journal)
- Common causes are: blocked catheter, constipation, or infection of any kind ie. skin, chest, bladder
- If the dramatic rise in blood pressure persists, consider it a medical emergency and seek medical treatment
- Talk to your doctor about ways to reduce or relieve AD symptoms

BONE HEALTH



WHY IS IT IMPORTANT?

- ▶ SCI causes osteoporosis which is a disease in which the bones become less dense and more likely to break (fracture)
- ▶ There is a greater risk of fractures in the hip and knee region for people with SCI
- ▶ Fractures can cause Autonomic Dysreflexia (AD), depression, blood clots, pressure injuries, infection, and limit physical mobility

WHAT TO LOOK FOR

- Swelling, bruising, redness, a deformity or bump
- AD- A dramatic rise in blood pressure and sometimes a slowed pulse
- Immediately see a doctor, get an X-ray, and see an orthopaedic surgeon

WHAT TO DO

- Prevention is the best medicine!:
- Eat foods rich in Calcium
 - Take a vitamin D supplement
 - Reduce your alcohol intake
 - Consider medications for bone health
 - Take your time to safely transfer
 - Include passive standing or electrical stimulation-based activity in your exercise routine
 - Every year have your healthcare provider assess your fracture risk, fall risk, and bone mineral density