



ACI NSW Agency
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Health Maintenance for Adults with Spinal Cord Injuries



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All recommendations are for patients with spinal cord injury as a group. Individual therapeutic decisions must be based on clinical judgment with a detailed knowledge of the individual patient's unique risks and medical history, in conjunction with this resource.

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1. INTRODUCTION

Health outcomes and life expectancy following a spinal cord injury (SCI) improved dramatically after World War II with the introduction of comprehensive, multidisciplinary health management. Over recent years the acute mortality and complication rates during the first 12 months post-injury have fallen dramatically, yet a similar reduction in the rate of long-term medical complications for people with a spinal cord injury living in the community has not occurred.⁽¹⁾

Around 350 Australians suffer a traumatic SCI each year, with an age-adjusted incidence of 14.9 cases per million population.⁽²⁾ It is estimated that over 12,000 Australians live with SCI and more than one injury of this type occurs every day in Australia.⁽³⁾ A recent study on general practice visits by people with traumatic SCI in Queensland suggests that people with SCI, although few in number, are high users of general practice services, particularly young men with paraplegia.⁽⁴⁾ People with disabilities and chronic conditions generally are among the highest users of health care and yet they are often at a disadvantage when seeking to obtain primary care.^(5, 6) People with disabilities often do not have the same opportunities for health maintenance and preventive health behaviour as their non-disabled counterparts.⁽⁷⁾

For people with SCI, although physical inaccessibility of the office and equipment is often an issue, the most frequent impediment to accessible primary care is the need for some specialised knowledge and expertise in order to adequately serve as the first-line provider for patients with SCI. Cox and associates found that 81% of people with SCI living in the community reported limited local provider expertise in SCI as the greatest perceived barrier to needs being met.⁽⁸⁾

A number of approaches have been proposed for enhancing access to and quality of primary care for people with SCI. A pilot evaluation study in the setting of regional and remote areas of the state of New South Wales found that clinician confidence in managing people with SCI improved after education.⁽⁹⁾ Another study found that clinical guidelines with the use of targeted implementation plan improved outcomes for people with SCI.⁽¹⁰⁾

Most of the issues raised by people with SCI in primary care relate specifically to disability, such as common secondary complications associated with bowel and bladder dysfunction or pain. However, there is also evidence that many general health issues require attention

in this population such as bone density, depression, and sexual and reproductive health.⁽¹¹⁾ Data published in recent years also suggest that cardiovascular disease (CVD) has emerged as the leading cause of mortality in the chronic SCI population.⁽¹²⁾

Nearly all risk factors for CVD are more prevalent in persons with SCI compared to the general population. These risks include obesity, metabolic syndrome, lipid disorders and diabetes. Daily energy expenditure is significantly lower in people with SCI, not only because of a lack of motor function, but also because of a lack of accessibility and fewer opportunities to engage in physical activity. Autonomic dysfunction caused by SCI is also associated with several conditions that contribute to heightened cardiovascular risk, including abnormalities in blood pressure and a blunted cardiovascular response to exercise that can limit the capacity to perform physical activity. Thus, screening and treatment of cardiovascular disease should be an essential component of managing individuals with SCI.⁽¹³⁾

People with spinal cord injury also have a similar risk of skin, bowel, breast and cervical cancer to the general population and should be screened accordingly. Many general practices may not have height adjustable examination beds or hoists to facilitate transfers, making thorough physical examination and certain procedures difficult. Special arrangements (such as a home visit, assistance from practice nurses or carers) for pap tests and breast examinations and identification of wheelchair accessible facilities (e.g. for a mammogram) prior to referral may be necessary.

A recent review⁽¹¹⁾ of the empirical evidence regarding primary care for adults with SCI concluded that a robust system of primary care is the best assurance of good health outcomes and reasonable health service use for people with SCI and proposed that optimal primary care for patients with SCI include:

- routine annual comprehensive health evaluation
- multidisciplinary follow-up to address issues that accompany long-term disability
- accessible premises that permit full examination of presenting health complaints
- access to disability-specific expertise in the form of specialists regarding common secondary complications such as pain, bowel and bladder complications

- increased awareness of areas in which there are often unmet needs, such as psychological concerns, sexual and reproductive health, and lifestyle issues.

With good organisation and support of a practice team, as well as the utilisation of suitable tools, guidelines and specialised resources, general practitioners can deliver high quality care to people with complex disabilities and address health prevention activities. Judicious use of available Medicare items also ensures adequate remuneration for the time taken to co-ordinate the patients comprehensive care plan.⁽¹⁴⁾ This guide aims to support that role by providing a structure for comprehensive and systematic health surveillance for people living with SCI.

2. HEALTH MAINTENANCE RECOMMENDATIONS FOR ADULTS WITH A SPINAL CORD INJURY

Spinal Cord Injury Units encourage patients to consult their general practitioner shortly after discharge and on a regular basis to monitor and individualise their health maintenance plan. People with spinal cord injury should receive health promotion and maintenance as recommended for the general population in the 'Guidelines for preventive activities in general practice' developed by the Royal Australian College of General Practitioners.⁽¹⁵⁾ The following recommendations for people with SCI are based on this guideline and recent evidence and recommendations from systematic reviews and other national and international guidelines where appropriate.

2.1 Urinary Tract (kidney and bladder)

- Review bladder management. A history of recurrent urinary tract infections, haematuria or more frequent episodes of incontinence should prompt further investigation such as renal ultrasound looking for calculi.
- Image the urinary tract (renal ultrasound) annually for the first three years post-injury (then biannually). If there are abnormalities make a referral to a spinal cord injury clinic or urologist.
- Screening for prostate cancer is not recommended unless the patient specifically asks for it, and he is fully counselled about the potential benefits, risks and uncertainties of screening. There may be a stronger case where there is a higher risk in men with one or more first-degree relatives diagnosed under age of 65 years, since although rates of prostate cancer are lower in men with SCI they often present at a late stage.
- Patients with a long-standing SCI, smoking history or indwelling catheter usage for more than 10 years may be at a higher risk for bladder cancer. Although screening these patients is becoming more common practice, there is no evidence that the use of annual urinary markers or cystoscopy is effective, or that these investigations meet the principles of a screening test.⁽¹⁶⁾ The potential benefit of detecting an early malignancy

needs to be balanced with the inconvenience and potential risks associated with screening practices in this population.

2.2 Bowel

- Review bowel management. Assess regularity, stool consistency, use of aperients, time taken for bowel evacuation and presence of blood or mucus in the stool on an annual basis. Persons with SCI are at risk of long term neurogenic bowel complications such as faecal impaction, haemorrhoids and incontinence associated dermatitis.
- Organised screening by faecal occult blood testing is recommended for the asymptomatic average risk general population from age 50 years every 2 years until age 75 years. This should also occur for people with spinal cord injury. In the presence of complications of neurogenic bowel such as haemorrhoids, a high rectal specimen might help prevent a false positive result.⁽¹⁷⁾
- It is often challenging to prepare an individual with SCI for colonoscopy, however, a recent study has shown promise with newer preparations with higher polyp detection rates.⁽¹⁸⁾ The individual may require assistance at home or admission for bowel preparation, particularly those with higher level lesions.
- Digital rectal examination is not recommended as a screening tool, but is important in evaluating patients who present with symptoms such as rectal bleeding.

2.3 Skin

- Check integrity of skin on feet and high risk bony areas, such as the sacral, greater trochanter and ischial tuberosity regions. A review of seating and wheelchair equipment (and other surfaces such as toilet/commode seat if indicated) should be conducted by the local occupational therapist (OT) if the person with SCI develops recurrent pressure injuries, risk factors such as pain or spasticity related to seating, postural changes,

overuse syndromes impairing transfers or there are difficulties with wheelchair mobility. Specialist seating clinics are available for advice to support local OTs.

- If there is a pressure injury that is severe at presentation, recurrent, not healing or there is delayed healing, referral to state-wide speciality clinics should occur. Further information about clinical practice guidelines and referral pathways for pressure injury management are available on the State Spinal Cord Injury Service website (<http://www.aci.health.nsw.gov.au/networks/spinal-cord-injury/>) (Accessed January 2014).
- Routine screening for melanoma or non-melanoma skin cancer is not generally recommended in those without multiple atypical naevi and a history of melanoma themselves or in a first-degree relative, as the evidence to show this reduces death is not available. Providing education to the person with SCI and carer that raises awareness of early detection of skin cancer or its prevention is recommended, with encouragement to periodically check skin, including areas not normally exposed to sun, being alert for new or changing skin lesions.

2.4 Cardiovascular System

- Absolute cardiovascular risk assessment should be conducted at least every two years in all adults aged 45 years and older who are not known to have cardiovascular disease or to be at clinically determined high risk. This calculation requires information on the patient's age, sex, smoking status, total and high density lipoprotein (HDL) cholesterol, systolic blood pressure (SBP) and if the patient is known to have diabetes or left ventricular hypertrophy (LVH). See <http://www.cvdcheck.org.au/> (Accessed January 2014)
- However, there are limitations in the current evidence and the existing tools (such as the Framingham Risk Score) when estimating risk factors for CVD in the SCI population. To optimise CVD health outcomes in individuals with SCI it has been recommended that health care providers should obtain measurements of blood sugar and serum lipid levels following initial injury, and every year thereafter, and to provide treatment target driven management of dyslipidaemia in accordance with clinical practice recommendations for similarly high CVD event risk populations.⁽¹⁹⁾
- Blood pressure should be checked annually in positions of both supine lying and upright sitting in the relaxed, comfortable patient. Individuals with SCI can develop hypertension as distinct from autonomic dysreflexia. Even though blood pressure is often low early after

SCI, atherogenic processes and renal disease can cause hypertension with age. Elevated blood pressure may be masked during the day when the person is sitting due to peripheral pooling of blood. It is therefore important to check lying blood pressure. The presence of postural hypotension can complicate treatment. Patients may need a modified medication dose and may benefit from once daily, nightly dosing of a long acting agent.

- If an individual with SCI has an ischaemic cardiac event, it may pass unnoticed because of disruption of sensory nerve pathways. Thus, the identification of CVD risk or other macrovascular disease risk equivalents for CVD (such as peripheral vascular disease) may be grossly underestimated in those with SCI, requiring a more aggressive approach to determine the presence of atherosclerotic occlusive vascular disease.⁽²⁰⁾

2.5 Respiratory System

- The prevalence of sleep disordered breathing following SCI greatly exceeds rates in the general population and obstructive sleep apnoea (OSA) is the predominant form.^(21, 22) OSA may lead to life threatening problems if it is left undiagnosed. Polysomnography is the gold standard for OSA diagnosis. However, it is expensive and not widely available. The use of screening questionnaires such as STOP and STOP-Bang may facilitate early detection and further referral.⁽²³⁾ The discriminant validity of such generic scales for persons with cervical and high thoracic SCI lesions is, however, not particularly good. Selected questions about excessive daytime sleepiness (e.g. the first three questions from the Epworth Sleepiness Scale) and asking about witnessed apnoeas/snoring, in addition to BMI/neck circumference measures, may be just as helpful for screening. Useful guidance is available through the Sleep Health Foundation website (<http://www.sleephealthfoundation.org.au/>) (Accessed January 2014).
- Smoking status and interest in quitting should be assessed for every patient over age 10 years. All patients who smoke, regardless of the amount they smoke, should be offered smoking cessation advice.

2.6 Mental Health

- While there is evidence that depression screening instruments have reasonable sensitivity and specificity, the evidence for improved health outcomes and cost-effectiveness of screening for depression in primary care remains unclear.

- Depression and suicide rates are significantly higher among persons with SCI than in the general population.^(24, 25)
- There is evidence for routine screening in the context of staff-assisted support to the general practitioner in providing depression care, case management and coordination (e.g. via practice nurses). Clinicians should maintain a high level of awareness for depressive symptoms in patients at high risk for depression and screen for and consider the impact of other factors upon mental health, such as presence of persistent pain, substance use, social support, relationship issues or barriers to participation.

2.7 Musculoskeletal System

2.7.1 Osteoporosis

- Individuals with SCI are at increased risk for developing many inactivity-related health problems during the chronic stages of injury, such as bone loss (osteoporosis).⁽²⁶⁾ As many as 40% of the individuals with chronic SCI experience fractures.⁽²⁷⁾ Fractures are discovered after minimal trauma and are most commonly treated with prolonged bed-rest and bracing in many cases. However, the combination of the injury and extended bracing results in prolonged immobility, worsening disability, and serious medical complications, such as pressure injury formation, increased pain and spasticity, and lower extremity amputation.⁽²⁶⁾
- To date there is no consensus regarding the effectiveness, harms and intervals for bone density screening after SCI, whether performed by dual-energy X-ray absorptiometry (DEXA) or by estimating absolute fracture risk.
- Fracture risk reductions with optimal therapy and treatment according to current guidelines are recommended unless absolutely contraindicated.^(26, 28) Optimal treatment includes ensuring adequate calcium intake and correcting vitamin D deficiency.

2.7.2 Physical Activity / Exercise

- Physical inactivity is a major risk factor for CVD, and this risk factor is particularly high in SCI. Physical activity in SCI is limited not only by physical capacity, but also by availability of facilities, expertise in exercise prescription for people with SCI, psychosocial barriers and co-morbidities.

- It has been recommended by an expert panel that for important fitness benefits, adults with a SCI should engage in (i) at least 20 minutes of moderate to vigorous intensity aerobic activity 2 to 3 times per week and (ii) strength training exercises two times per week, consisting of three sets of 8 to 10 repetitions of each exercise for each major muscle group.⁽²⁹⁾

2.7.3 Overuse Syndromes

- People with SCI face unique physical stresses and experience overuse syndromes. Wheelchair users experience increased upper extremity pain with the most frequent complaint being shoulder discomfort. Wrist pain and carpal tunnel syndrome is also common. Overuse syndromes result from repetitive stresses in daily living related to wheelchair propulsion, transfer activities and pressure relief manoeuvres.
- Most overuse syndromes can be managed conservatively by activity modification, addressing muscular imbalance through strengthening exercises, correcting ergonomic factors, improving sub-optimal posture and seating adjustments. Advice from an experienced SCI physiotherapist and occupational therapist can be very helpful.

2.8 Nervous System

- A recent large case control study found that persons with SCI are at a higher risk of stroke, particularly the ischaemic type, and higher vigilance and intervention strategies may be needed for prevention in this population.⁽³⁰⁾
- In the SCI population, neurological deterioration such as the onset of new weakness or sensory loss should also raise suspicion of development of post-traumatic syringomyelia. This is characterised by progressive enlargement of a cystic cavity originating at the site of injury and extending in either a cephalad or caudal direction within the spinal cord. This can occur from months to decades after the SCI, most often between 4 to 8 years after injury. Magnetic resonance imaging is required to confirm the diagnosis.
- Individuals with SCI may also experience cognitive decline due to the recurrent orthostatic hypotension and possibly concomitant traumatic brain injury that may require early intervention and treatment strategies.⁽²⁰⁾

2.9 Carer and Environment Issues

- Carer arrangements and environmental factors must be considered, particularly if the individual with SCI is ill or there are changes in functional capacity (including ageing of carer).
- Where possible, it is useful to have a multi-disciplinary review to:
 - o Determine adequacy of equipment and home modifications, function and independence.
 - o Assess changes in life situation, including social supports, attendant care, coping and adjustment, community access and participation.
 - o Perform a comprehensive physical and neurological examination and review pain, spasm, spasticity, skin integrity, sexual and reproductive health.

3. GENERAL RECOMMENDATIONS FOR HEALTH PROMOTION

- Immunisation according to the Australian Standard Vaccination Schedule, if not already immunised.
- Pneumococcal pneumonia vaccination and influenza inoculation at earliest opportunity – particularly recommended for SCI at T8 level or higher.
- Screening for falls and initiating falls prevention activities, especially in people with SCI who are ambulant.
- Visual acuity should be assessed from age 65 years using the Snellen chart in those with symptoms or who request it. There is no evidence that screening of asymptomatic older people results in improved vision.
- Hearing loss is a common problem among older individuals and is associated with significant physical, functional and mental health consequences. Annual questioning about hearing impairment is recommended with people aged 65 years and over.
- Calorie requirements are reduced in people with SCI and dietary advice may be required. Brief dietary advice should be given to reduce saturated fat and sodium and increase fruit and vegetable portions (2 + 5 portions) as these are associated with a lower risk of CVD and diabetes.
- All patients should be asked about the quantity and frequency of alcohol intake from age 15 years. Those with at-risk patterns of alcohol consumption should be offered brief advice to reduce their intake.
- Pap test screening is recommended every 2 years for women who have ever had sex and who have not had a hysterectomy, commencing from age 18 to 20 years (or up to two years after first having sexual intercourse, whichever is later).
- It is recommended that women aged 50 to 69 years attend the BreastScreen Australia Program every two years for screening mammograms, unless there is a higher risk due to familial or other factors that indicate a need for surveillance from an earlier age.
- Barriers to accessing dental care for individuals with SCI might delay visits and hinder appropriate dental care, and may require oral health education and advice regarding importance of regular check-ups and assistance with identification of wheelchair accessible facilities.

4. RED FLAGS

The following symptoms and signs may indicate the possible onset of health complications in a person with spinal cord injury, requiring further investigation:

- altered bladder drainage, urinary incontinence, frequent urinary tract infections, “gravel” or calcified material in urine, blood in urine
- changes in bowel function (e.g. constipation, faecal incontinence), increased laxative requirements, abdominal pain or bloating, heartburn, weight loss
- skin breakdown/delayed healing or recurrent pressure injuries
- autonomic dysreflexia (pounding headache, sweating, rash, raised blood pressure).
- coughing, fever, shortness of breath and/or chest pain
- unexplained increase in muscle spasms/tightness
- development of new or worsening pain
- increasing muscle weakness, loss of coordination, altered balance, falls or changes in sitting posture, fatigue not associated with activity
- signs of depression
- excessive daytime sleepiness, memory disturbance, snoring at night – symptoms may indicate presence of obstructive sleep apnoea, especially in persons with tetraplegia and should have a sleep evaluation
- problems with wheelchair, mobility or pain related to functional activities, seating or postural changes in wheelchair requiring review of seating and wheelchair set-up by a suitably experienced occupational therapist or physiotherapist.

5. QUIZ

- Q1. Which statement below is FALSE regarding health care and people with disabilities?**
- a) People with disabilities (PWDs) generally are among the highest users of health care;
 - b) PWDs are at a disadvantage when seeking to obtain primary care;
 - c) PWDs often do not have the same opportunities for preventive health behaviour as their non disabled counterparts;
 - d) Physical accessibility of the office is often the most frequent impediment to primary health care for PWDs;
 - e) Most of the issues raised by PWDs in primary care are related to disability.
- Q2. Choose the INCORRECT statement: Individuals with higher levels of spinal cord impairment may:**
- a) not perceive cardiac related pain;
 - b) require admission for bowel preparation for endoscopic bowel examination;
 - c) be at a lower risk of developing ischaemic stroke;
 - d) have blood pressure reading within normal clinical range despite being hypertensive;
 - e) experience cognitive decline due to the recurrent orthostatic hypotension episodes.
- Q3. Cardiovascular disease (CVD) has emerged as the leading cause of mortality in the chronic population with spinal cord injury (SCI), possibly due to all the following EXCEPT:**
- a) a significantly higher daily energy expenditure among people with SCI;
 - b) nearly all risk factors for CVD being more prevalent in persons with SCI;
 - c) identification of CVD risk may be grossly underestimated in those with SCI;
 - d) lack of accessibility and fewer opportunities for persons with SCI to engage in physical activity;
 - e) abnormalities in blood pressure and a blunted cardiovascular response to exercise.
- Q4. All the following are reasonable health promotion activities for people with spinal cord injury EXCEPT:**
- a) screening for falls and initiating falls prevention activities;
 - b) screening for depression in the context of staff-assisted support in providing depression care;
 - c) screening for obstructive sleep apnoea;
 - d) obtaining measurements of blood sugar and serum lipid levels yearly;
 - e) screening for bowel cancer by annual colonoscopy.
- Q5. All the following are appropriate health recommendations for people with spinal cord injury EXCEPT:**
- a) reduce saturated fat and sodium and increase fruit and vegetable (2 + 5) portions;
 - b) obtain yearly serum creatinine and electrolytes to monitor renal function;
 - c) get pneumococcal pneumonia vaccination and influenza inoculation at earliest opportunity;
 - d) attend BreastScreen Australia Program every two years for screening mammograms;
 - e) engage in at least 20 minutes of moderate to vigorous intensity aerobic activity 2-3 times per week.

Q1. D - The most frequent impediment to accessible primary care for patients with SCI is the need for some specialised knowledge and expertise in order to adequately serve as the first-line provider. **Q2. C** - Persons with SCI are at a HIGHER risk of developing ischaemic stroke. **Q3. A** - Individuals with SCI have significantly LOWER daily energy expenditure. **Q4. E** - Neurogenic bowel due to SCI has not been found to be a risk factor for bowel cancer requiring an annual colonoscopy. **Q5. B** - Serum creatinine is not sensitive for detecting early renal function deterioration in patients with SCI.

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7. ADDITIONAL RESOURCES

- NSW State Spinal Cord Injury Service: <http://www.aci.health.nsw.gov.au/networks/spinal-cord-injury/> (Accessed January 2014).

The ACI State Spinal Cord Injury Service website has many resources and tools, including the Spinal Outreach Service Health Questionnaire (SOS-HQ), which can be used to help identify new problems, alert to red flags and prompt preventive care activities.

- Spinal Cord Injury, Australia: <http://scia.org.au/> (Accessed January 2014).

A website with information and resources for persons living with SCI in Australia, and services that include accommodation, advocacy, employment and peer support.

- Paraplegic and Quadriplegic Association of NSW: <http://paraquad.org.au/resources/> (Accessed January 2014).

A website providing information, links and access to a number of areas that can assist people with a physical disability, and services that include community consultancy (specialist nurses, OTs and a social worker), personal care services, accommodation and training for personal care attendants and community health providers.

- Physiotherapy exercises for people with spinal cord injury: <http://www.physiotherapyexercises.com/> (Accessed January 2014).

A website that enables clinicians to search for exercises appropriate for people with spinal cord injuries and other neurological conditions, with selected exercises being compiled into booklets for use by clients.

- Paralyzed Veterans of America, Consortium for Spinal Cord Medicine: http://www.pva.org/site/c.ajlRK9NJLcJ2E/b.6431479/k.3D9E/Consortium_for_Spinal_Cord_Medicine.htm (Accessed January 2014).

A range of clinical practice guidelines for health care professionals and companion consumer guides helping people living with SCI put this information to use in their daily lives.

- Spinal Cord Injury Action, Canada: <http://www.sciactioncanada.ca/> (Accessed January 2014).

SCI Action Canada has useful information about increasing levels of physical activity and participation for individuals with SCI.

