



Government of **Western Australia**
Department of **Health**

Returning to the Community after Spinal Cord Injury

A Resource for Health Service Providers

WA State Spinal Injury Unit

Version 1 October 2013

Review Date November 2016

This document has been developed to provide health service providers with a basic knowledge of available community resources available to individuals with Spinal Cord Injury (SCI). Further information is available through other sources in the Spinal WA website.

Key points

Topics covered include

- Work and Study
- Leisure
- Equipment and Home Modifications
 - Equipment
 - Ongoing equipment repair and replacement
 - Wheelchairs and Pressure Relief Equipment
 - Home modifications
- Lifestyle
 - Transportation and driving
 - Domestic tasks
 - Parenting
 - Travel
- Community Supports
 - Assistance Dogs
 - Local Council Support

Introduction

One challenging experience for people with SCI is the transition from hospital services back to their community. People need to cope with the physical demands of their new bodies and possibly find new roles and directions for the future.

Prior to hospital discharge, information is provided to people with SCI regarding post hospital options such as return to work and return to leisure pursuits. Further support will be required from health professionals, carers and family on return home. People with SCI sometimes find thinking about the future challenging while still an inpatient and leave decisions about linking back into their community for later hoping everything will 'be fine once they are home'.

Although people with SCI may need to modify how they can become involved in an activity they should be encouraged and supported to review their interests and investigate alternatives if required. The d-ability website www.d-ability.com.au is a useful resource that demonstrates a range of possible activities that can be pursued by the motivated person with SCI.

Work and study

People with SCI are given written material about 'getting back out there' prior to discharge from the WA State Spinal Injury Unit. Topics include return to work, study and leisure. This information does not direct, but offers options with regard to services available to support the individual once they have decided which way to head.

As a health professional, carer or family member, you may find the person with SCI would benefit from support to think widely about their current abilities, interests and previous skills to determine their future activities. These may include a return to employment, with or without the support of a service such as the Commonwealth Rehabilitation Service (www.crsaustralia.gov.au) that can modify a work place or assist in alternate duties or retraining as required. Spinal specific services such as those provided by the Spine and Limb foundation www.slfw.org.au may also be of assistance to the person with SCI. This information may also assist in decisions about care support whilst at work and transportation options to support travel to and from work.

Leisure activities

General leisure inspiration and helpful travel ideas can be sourced through the d-ability website which has been developed and updated by the Spinal Unit at Royal North Shore in Sydney. This covers not only action and sport based interests, but also those which have a more artistic flavour (www.d-ability.com.au).

For customised modification of equipment to allow an individual to follow a dream or achieve a particular goal, organisations such as Dreamfit can assist (www.dreamfit.com.au).

Educational tools for service providers working with people with SCI have been developed to describe actual activities and set-up required for patients at different levels. These include:

- www.elearnSCI.org
 - OT section – instrumental ADL's – activity : leisure
- www.spinalhub.com.au
 - work and leisure

Equipment and Home Modifications

Equipment maintenance

People with SCI are provided with appropriate equipment to support their discharge from the WA State Spinal Injury Unit. Items such as hoist and sling, shower commode and wheelchair can be provided if needed. Funding is through WA Health or other sources if the person with SCI is eligible for them (such as Injury Council of WA (ICWA) and Worker's Compensation). If a person with SCI has a compensation claim then usually a private Occupational Therapist will be employed on your behalf to assist you with the process of equipment supply and home modifications.

On occasion stock items may be provided if a person's needs are likely to change over time, whilst they wait for equipment which has been ordered or if this equipment suits their needs.

Equipment needs identified within 3 months of discharge are dealt with by the prescribing Occupational Therapist from the WA State Spinal Injury Unit.

If the person has been discharged for longer than 3 months and requires assistance or maintenance of equipment the Community Aids and Equipment Programme (CAEP) is the first point of call. Details about this service, patient entitlements and referral processes are outlined through the following link:

[www.disability.wa.gov.au/services-support-and-eligibility/services-supports-and-eligibility-new/services/services-provided-by-the-commission/equipment-and-technology/community-aids-and-equipment-program-caep/#CAEP Brochure](http://www.disability.wa.gov.au/services-support-and-eligibility/services-supports-and-eligibility-new/services/services-provided-by-the-commission/equipment-and-technology/community-aids-and-equipment-program-caep/#CAEP%20Brochure).

For eligible patients referral through a GP or specialist is required and is submitted to their local hospital, health or disability service.

Routine maintenance of items such as a commode hoist and sling is encouraged. Details about the equipment should have been given to the person with SCI by the manufacturer and Occupational Therapy Department organising the equipment. Individuals are expected to contact their CAEP service provider (if eligible) or private contractors to arrange regular maintenance or repair of equipment.

Wheelchairs and Pressure Relief Equipment

The **Statewide Rehabilitation Engineering Clinic (REC)** supplies the majority of manual and power-drive wheelchairs and pressure relief equipment such as cushions and mattresses to people with SCI who have a clinical need for these items.

People are sometimes discharged from inpatient care with a temporary wheelchair. If there is an ongoing need for that equipment a request for permanent equipment will be processed through REC. Only one wheelchair will be provided by REC for your discharge. As wheelchairs are individually prescribed and manufactured to meet a patient's specifications, this process can take a number of months from assessment to supply.

Once the individual has been discharged for more than 3 months equipment maintenance should be done through the local CAEP provider (see details above).

Information sheets have been developed about the maintenance of wheelchairs and are available through www.rph.wa.gov.au/medphys/rehabclinic.html. Additional support can be purchased through private companies.

Future equipment needs

Other items such as an additional wheelchair, electric bed and communication devices may also be required to support the person with a SCI and their care staff. These items are not currently funded through WA Health. There are a range of grants available to support patients with costs towards these items. Some of these are outlined through www.ilc.com.au, and all have eligibility requirements. People with a SCI will require support from a Health Professional to verify their clinical need for the equipment when applying for these grants.

The Support, Equipment and Funding section of the website www.spinalhub.com.au includes relevant information and ideas. The NSW funding sources referred to on this site are **not** relevant to people in WA.

The range and availability of assistive technology is rapidly changing. Applications (Apps) for iPads, mobile phones and tablets may all assist the person with SCI to achieve optimal independence. Funding assistance to purchase items is limited but contact with the Independent Living Centre may provide ideas about suitable items and methods of access. Environmental Controls allow people to complete tasks such as changing channels on the TV or turning lights on and off independently and are available as a separate device, or through power-drive wheelchair controls or an iPhone application. Further advice about these items is available through:

- www.ilc.com.au
- WA State Spinal Injury Unit Occupational Therapy Department
- Local CAEP therapists
- www.elearnSCI.org has a section under the Occupational Therapists & Assistive Technologists in Instrumental ADLs - Activity: Communication that provides further information.

Home modifications

WA Health will assist in the funding of modifications that are deemed to be essential for discharge, usually including essential access requirements and those required to promote hygiene. The options available for these are discussed with the person with SCI by the Occupational Therapist prior to discharge. Funding is a contribution towards the cost of these modifications and approval must be sought *prior to work being undertaken*. Under no circumstances will modifications be paid for retrospectively nor will a person with SCI be approved for modification to more than one residence.

If a person has already been discharged from hospital for more than 3 months they may be entitled to modifications through CAEP which is funded through Disability Services. Details about this service are mentioned above.

Further ideas for home modifications can be accessed as follows:

- Visit the Independent Living Centre (ILC) to view equipment and a modified bathroom and kitchen. Visits can be organised directly via the ILC who can make an OT available to assist with viewing the range of equipment available. The ILC also has a website www.ilc.com.au containing above information.
- www.elearnSCI.org The OT and Assistive Technologies Module provides examples of home modifications to promote independence in the person with SCI
- www.spinalhub.com.au This site covers support, equipment and funding for modifying your home. It includes NSW funding sources which do not apply but ideas are appropriate.

People are also encouraged to do an internet search for “home modifications” and investigate You Tube clips on the same subject.

Lifestyle

Transportation and driving

Transport options are discussed with the individuals prior to discharge from hospital services. An Occupational Therapist will take patients on public transport prior to discharge, if appropriate, and assist with how to check for disabled accessible buses, trains and train stations. Further information can also be obtained from the Transperth website www.transperth.wa.gov.au.

In addition to public transport individuals may be eligible for a taxi user subsidy booklet which entitles them to discounts on taxi trips to a certain distance. For further information contact www.concessions.wa.gov.au or discuss with a Social worker. This support can be particularly useful for individuals using power-drive wheelchairs which can not be transported in a traditional vehicle. Subsidies are available to partially fund the purchase of a vehicle which is modified for access by people with a disability. Details about these grants can be obtained on the ILC website www.ilc.com.au.

People using a wheelchair may be eligible for a special licence to drive a modified van while sitting in their wheelchair. Specific criteria must be met to be eligible to apply. Further details can be obtained through the Department of Transport www.transport.wa.gov.au. The website discusses assessment requirements, prescription of suitable modifications and mechanisms to ensure modifications are done by approved suppliers.

All individuals post SCI must notify the Department of Transport of their injury and cannot return to driving unless cleared by a medical practitioner.

If a person with SCI has the capacity to transfer into the driver's seat of a vehicle and pull their wheelchair in with them, consideration can be given to return to driving. If the Specialist or GP agree to clear a person to drive in an unmodified vehicle, an on road assessment can be conducted by Department of Transport. If the Specialist or GP feels further assessment is required, referral to the driving Occupational Therapists at the ILC can be initiated by the consultant or Spinal Occupational Therapists.

If vehicle modifications and/or driving lessons are required, there is funding available through the ILC towards these costs.

Other items such as portable hand controls may be useful when travelling or if using an alternate vehicle for short periods of time.

If a person with a SCI is considering returning to driving, additional consideration needs to be given to having the right style of wheelchair to fold up in the car, or a hoist to place the wheelchair on the roof or in the boot. Further information about these ideas can be obtained from the ILC or the Spinal OT's. Driving responsibilities such as filling up the car can be slow and challenging, but some service stations can offer assistance.

Parenting

SCI can occur to anyone and this may of course include those who are parents, or might like to become one. Individuals have the opportunity to discuss issues of sexuality and fertility while receiving hospital services. Referral to the relevant specialist can be arranged through Outpatient Spinal Services at the WA State Spinal Injuries Unit.

The Rural Spinal Cord Injury project (NSW) has a well summarised information package for health professional 'Sexuality and Fertility following Spinal Cord Injury' for further information www.maa.nsw.gov.au

Advice about parenting is available via international resources, most of which are written by individuals who have had children themselves and felt more support was needed. General searching on the web will offer a range of resources, but some sites including those below, provide first hand experience of parenting in a wheelchair.

www.disabledparents.net

www.parentsinwheelchairs.com

Referral to the Spinal Occupational Therapy service at the WA State Spinal Injury Unit can assist with ideas about the selection of suitable equipment for baby or adaptation of equipment required.

Additional resources include:

www.spinalistips.se/?lang=en This site covers childcare, travel, leisure ideas from people living with different levels of SCI

www.ricability.org.uk/consumer_reports/parenting This site reviews equipment including pros and cons of different options

www.elearnSCI.org has a section in the OT module titled Instrumental ADLS - Activity: Parenting which gives ideas about how parents deal with issues depending on their level of function.

Domestic tasks

There are many ways of modifying domestic tasks to suit the level of function of a person with SCI. As a health professional, carer or family member you should encourage the person with SCI to participate in domestic tasks to the degree to which they are capable. Simple ideas such as planning meals and shopping together can assist with food preparation tasks, even if the person is unable to assist in the actual cooking task.

www.elearnSCI.org has a section under the Occupational Therapists & Assistive Technologists in Instrumental ADLS - Activity: Domestic Tasks.

The ILC has a range of equipment that can be purchased to make tasks easier. Some items such as a Thermomix cooking aide can be loaned to trial prior to purchase.

Travelling

People with SCI may be keen to travel and may require some care assistance or equipment to facilitate this. As with many aspects of living with a disability, substantial forward planning will assist this to run smoothly.

Many websites cover the basics of access to accommodation and facilities for people with disabilities in places away from home, but it is recommended that website contact be followed up with a phone call to the place itself to check details.

The eBility website covers topics such as adventure travel, hiring of vans, specific accessible locations and facilities, usually Australia wide www.ebility.com.au .

Airline travel advice for travellers with disabilities, including issues such as taking your wheelchair on the plane or how to address your bladder issues whilst flying is explained through the guide for airline operators in the Civil Aviation Authority website www.casa.gov.au/aoc/disabled or on individual airline websites.

Other individuals who have travelled will post blogs such as www.disabledTravelers.com which includes an Australian series covering each of the major centres in Australia, plus some outback travel experiences.

The National Information Communication Awareness Network (NICAN) provides information on recreation, tourism, sport and the arts for people with a disability. It is a national site with information on accessible venues and facilities for all States and Territories. It also has information on community groups, equipment hire and transport services. This is an excellent site for people wishing to travel interstate.

Tel: (02) 6241 1220 Website: www.nican.com.au.

Qantas Carer Concession cards

Qantas Carer Concession Card holders receive discount fares with Qantas travel within Australia and New Zealand. A person is eligible to apply for this concession if they need to have 'one on one' support once seated on the plane for assistance with meals, toilet access or communication with aircraft staff. A person is not eligible if they only require help in boarding and disembarking the plane. Applications can be made through NICAN.

To improve the travel experience, portable or folding equipment such as commodes, travel cushions, hoists, padded toilet seats and portable hand controls may be worth considering.

Community Supports

Local Council Support

Support and services are available to support people with SCI to manage as independently as possible within their own community environment. Approaches to local Council Disability Access or Support Officers can provide advice regarding available support.

Some local councils can assist with:

- Modifying pathways and kerbs to provide easy access
- Taking out or collecting rubbish
- Programmes and activities at the local community centre or library
- Access to recreation and social programs and services.

Using Assistance Dogs

Assistance Dogs Australia (ADA) is a non-profit organisation that trains Labradors and Golden Retrievers to help enhance the quality of life and improve the level of independence for people with physical disabilities. There is a dog training arm in Western Australia and the association is willing to talk to organisations about the benefits of such a service. The can be contacted via the website: www.waadinc.org.au/

Useful Resources

'*Getting Started Checklist*'—this checklist provide some prompts and ideas (See Appendix 1) This can be worked through by the person with SCI to assist in their planning and decision making for returning to community activities.

Complied by

Nicky Hunter A/Senior Occupational Therapist, State Spinal Unit Royal Perth Hospital – Shenton Park Campus

Contributors

- Kristy White A/Senior Occupational Therapist, Sir George Bedbrook Spinal Unit Royal Perth Hospital – Shenton Park Campus (2011)
- Carly Hartshorn, Clinical Nurse Consultant Spinal Urology, State Spinal Unit, Royal Perth Hospital
- Julie Brayshaw, Deputy Head of Department, Occupational Therapy Royal Perth Hospital
- Jane Sander, Clinical Nurse, Rehabilitation Engineering Clinic Royal Perth Hospital

The development of this document has been supported by the
TRACS WA Subacute Learning Fund project funding

Getting out There



Worksheet: How to make a decision and first step

Getting back into the community after a spinal cord injury can be a daunting but exciting step on your route to recovery with your changed abilities. Whether you want to get back into something you participated in prior to your injury or an entirely new interest, getting back into activity can lead to new and exciting changes in your daily life. It can increase your self-esteem, independence and social and support circles, while allowing you to test new abilities and boundaries.

Start by assessing your skills; physically what can you do independently and what do you require assistance with?

Independent

Assistance Required



Make a list of occupations you enjoyed prior to your injury. Include voluntary and paid work, hobbies, interests, clubs, committees and day to day tasks. Indicate which ones you are still interested in participating in. Your Occupational Therapist and Physiotherapist will be able to assist you in answering any questions you may have concerning how you can participate with your new abilities. Things to consider may include:

Self care skills- do I need assistance with self-care? Could this be arranged at work?

Mobility- Is the building/campus/area wheelchair accessible? Is there parking nearby? Is there an accessible bus?

Support networks- are my friends and family able to assist in my initial transition? Am I able to rely on other people involved?

Carer issues- Do I need to have a carer with me? Are they able to join me? Can I be ready in time?

Community access skills- distance required to push wheelchair. Locality to public transport. Accessibility to group transport.

Possible barriers- Is there anything stopping me from trying it out?

Getting out There

Worksheet: How to make a decision and first step

- _____
- _____
- _____
- _____
- _____
- _____
- _____

Try to choose one or two options to begin with. Remember that getting back into it may require some time and patience. Attempting an easier activity initially can help in identifying any areas you may not have previously considered. For example, enrolling in a short-term community education course prior to returning to full time study can assist you in building up stamina and give you time to problem-solve any issues that arise.

- _____
- _____

Now try to make contact with the appropriate group you want to get involved with, usually they are the best people to talk to regarding what they have to offer and what you can offer them. Your Occupational Therapist will be able to assist you both in answering questions regarding your abilities and find solutions to your limitations.

The outline below may help you plan the first phone call. Even if you decide not to join in straight away, it is useful to have the information for future reference.



Group/Institution/Workplace

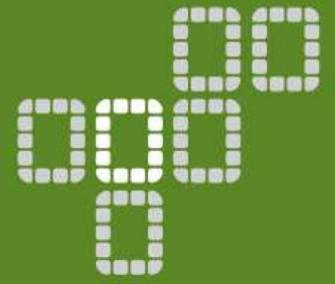
Contact Name

Contact Number

Questions to ask

Information to give them about you

Other notes



Delivering a **Healthy WA**