



# Adjusting to Spinal Cord Injury ...you are not alone

Spinal cord injury (SCI) affects people in many and different ways. During your hospitalisation you will be assisted to manage your recovery by a number of highly skilled people.

In an attempt to cope with hospitalisation many people choose to tune out to their environment however it is important that you try to maximise your time in hospital.

You can do this by interacting with as many people as you can and trying to find out as much as you can about managing the physical, social, emotional, psychological, financial, and vocational consequences of your injury.

Knowledge will facilitate your discharge back into the community and potentially assist you to adjust to your injury.

## Tips to maximise learning whilst you are in hospital:

- ➔ To avoid conflicting information always ask to talk to the most qualified health professional on duty
- ➔ Ask if written information is available about how your injury has affected you
- ➔ Ask your medical specialist if you can have copies of written reports or letters concerning your treatment
- ➔ If you have trouble remembering questions and taking in everything that is said, write down your questions ahead of time and/or take a friend, relative or advocate with you to scribe
- ➔ Keep asking your treating team questions until you understand their answers
- ➔ Make repeat appointments with your treating team if you are unclear about your management
- ➔ Make sure you know where you will be able to get your equipment before you leave, what support services are available to you and where to get health support in the community
- ➔ You have a RIGHT to information about what is happening to you; be proactive and confident in collecting this information
- ➔ You have a right to see all records about your management.

## To facilitate discharge into the community:

- ➔ Ensure that you have a copy of the medical, nursing and allied health discharge reports
- ➔ Ensure that your treating team refer you on to the appropriate community health services. These are listed overleaf.



# Community health services can help you once you have been discharged:

## General practitioner (GP)

Your GP will be of enormous support to you in the community. Your GP is available to provide general medical advice and support and can refer you on to services or specialists as required.

If you already have your own GP and you are moving back to the same area then you should keep the same GP as they would already have an intimate knowledge of your health care needs. However if you do not have a GP in the area ask around to find one that has some knowledge of SCI management or some other SCI clients on their books.

## Medical specialist

Your medical specialist can offer comprehensive individualised assessment of your health needs as they relate to your SCI. They can explain why things are happening, what problems may potentially arise, offer health management strategies to improve your health outcomes and refer you on to other support services in the community.

## Spinal Outreach Service

The Spinal Outreach Service (SOS) is an initiative of the NSW Department of Health. SOS offers a health maintenance and promotion service to all people newly discharged from spinal units, their family and carers for an 18 month period following discharge. After this 18 month period regular reviews will be provided by ParaQuad Clinical Services. Upon referral, both teams will see people with a SCI who have been readmitted to Spinal Units for a variety of health reasons.

The SOS team is staffed by a rehabilitation medical specialist, social worker, occupational therapist, physiotherapist and nursing staff.

The service will review your management of the following: skin care, continence, equipment, exercise programs, finances, relationships and anything else that concerns you following discharge.

## ParaQuad NSW

ParaQuad NSW provides a support system that aims to meet the needs of people with SCI, their families and carers at every stage of life.

ParaQuad has designed its services to assist members to have the same opportunities as

non-spinal injured people in the community to participate in life.

ParaQuad strives to empower people with a spinal cord injury to reach their potential.

## ParaQuad's Community Services

This unit comprises the following:

- Clinical Services Team (specialist nursing and occupational therapy services)
- Personal care support for clients with funded care packages
- Transitional respite and long-term accommodation
- Education and training in personal care and SCI
- Medico-legal assessments.

ParaQuad NSW's nursing and occupational therapy services can provide specialist health assessments and management advice about the following specialist issues:

- Continence management: bladder and bowel
- Autonomic nervous system management:
  - Autonomic dysreflexia/orthostatic
  - Hypotension and poikilothermia
- Skin management
- Management of functional decline (i.e. Syringomyelia /aging with SCI/overuse syndrome)
- Maximising independence; personal care tasks and community participation
- Management of hand function
- Consultation about housing needs
- Equipment assessment.

These services are provided free to members of ParaQuad with SCI.

➔ **Contact ParaQuad NSW Clinical Services Intake/Information Officer**  
Tel: 02 8741 5674 or Fax: 02 8741 5650  
Email: [paraquad@paraquad.nsw.asn.au](mailto:paraquad@paraquad.nsw.asn.au)

The SOS and ParaQuad Clinical Services both have a health promotion philosophy which aims to reduce the incidence of health breakdown. As well as health promotion these services offer a consultancy service to community health staff where continued management is required.

## **Spinal Cord Injuries Australia (SCI Australia)**

Spinal Cord Injuries Australia offers services that enable people with SCI to be full participating members of their community. SCI Australia offers accommodation, advocacy, information, public education, rehabilitation and peer support and an employment service.

### **Physiotherapist**

A physiotherapist can help you optimise your physical functioning following SCI. They can assess and treat your posture, mobility, muscle strength, co-ordination and fitness. They can also give you advice on aids and splints.

The SOS provides a consultancy service for the initial 18 month period.

### **Occupational therapist**

An occupational therapist (OT) looks at how you are functioning in everyday life following SCI at home and/or work and can assist you to make the most of your functional ability. They are able to assist you by showing you alternate ways to do things or review and recommend equipment to assist you. They may also assist with your return to employment, driving, leisure activities etc.

The SOS provides a consultancy service for the initial 18 month period.

ParaQuad NSW's OT can also work in consultation with your local OT to provide specialised spinal expertise.

### **Nurse**

A registered nursing service can assist you to maintain and promote your physiological health. They can review how you manage all your body systems and recommend strategies to optimise your health and independence.

The spinal nursing consultants from Prince of Wales (POW) and Royal North Shore Hospital (RNS) are able to assist with issues related to your sexual health and fertility. You can refer yourself to these services by contacting either hospitals and asking to speak to the spinal nursing consultant. The SOS provides a consultancy service for the initial 18 month period.

ParaQuad NSW Clinical Services Team can work in consultation with your community nurse to provide specialist spinal expertise.

Registered nurses work closely with the clients' treating team and in particular the client's GP and medical specialist.

### **Social worker**

A social worker can assist you to deal with the emotional and social repercussions of your SCI. This can include assisting you and your family to adjust to the changes in lifestyle, relationships, vocation and avocational activities. This assistance can be in the form of counselling, support and advice, and information on other services and agencies, including care. The SOS provides a consultancy service for the initial 18 month period.

You can get assistance from a social worker by contacting SCI Australia or by contacting your local hospital and requesting contact information about services available in the community. Hospitals will often provide an outpatient social work service.

### **Psychiatrist/psychologist**

These specialists can assess your mental and emotional health and recommend strategies to assist you with adjustment to your new life style.

### **Regional support**

This is available through Rural Networkers (funded under the Rural Spinal Cord Injury Program), ParaQuad NSW's regional network and SCI Australia's regional officers.

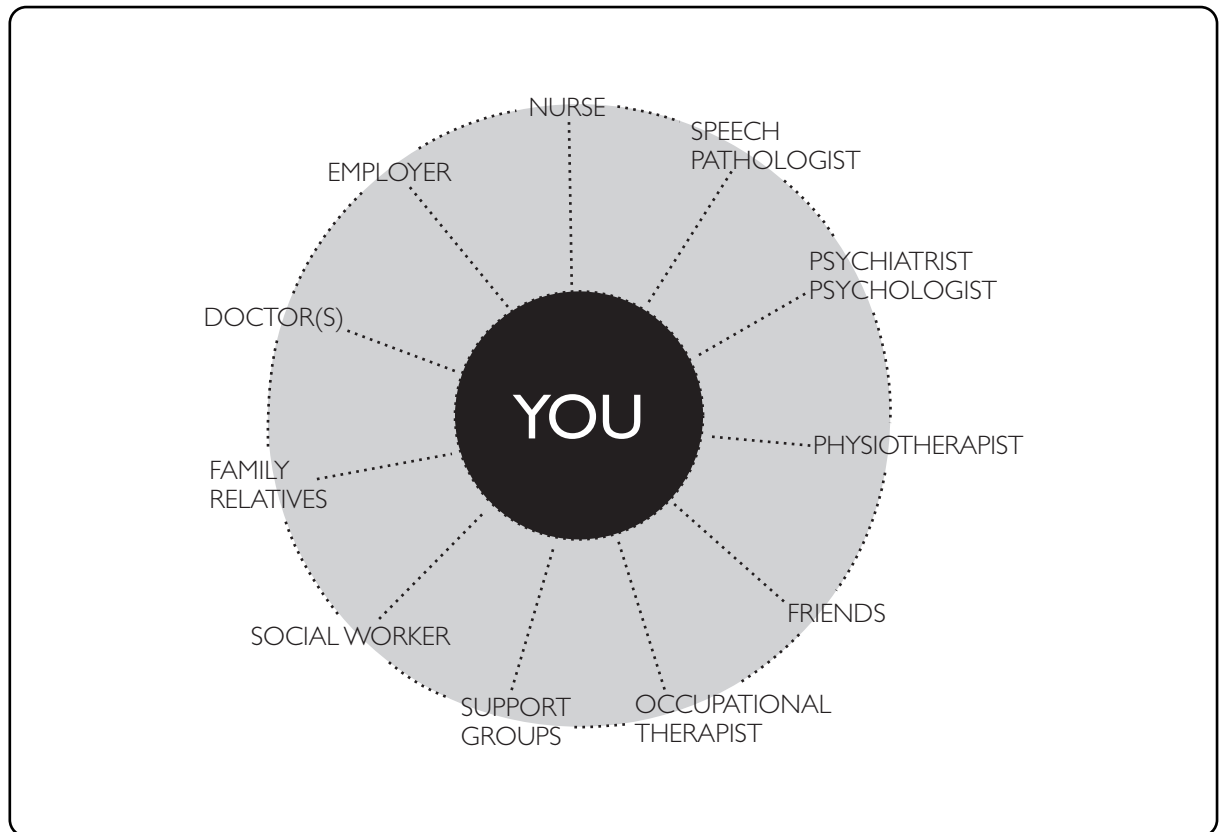
In some regional areas other disability organisations such as the Northcott Society and the Spastic Centre can provide support and information.

### **Peer Support Officer**

A peer support officer is a person with SCI who has been through many of the situations you are experiencing yourself. They provide support to you, your family and to carers. This service is available through SCI Australia.



## Finding support



## Further information

Most of the above services can be provided privately if you are able to pay. However if you are not able to pay then you might be able to access a service through your local hospital's outpatients department. Try your local hospital for availability and recommendations on the same.

### ParaQuad NSW — Sydney Office

Address: 6 Holker Street, Newington NSW 2127  
Postal: PO Box 6347, Silverwater DC NSW 1811  
Freecall: **1800 424 096** (outside metropolitan Sydney)

- Contact any of the professionals mentioned for advice about your particular situation, the local hospital is a good place to start.
- For further details see the specialised Fact Sheet for your particular inquiry or look up 'Returning to the Community' at the end of this kit.

Tel: **+61 2 8741 5600**  
Fax: **+61 2 8741 5650**  
Email: [paraquad@paraquad.nsw.asn.au](mailto:paraquad@paraquad.nsw.asn.au)

Internet: [www.paraquad.nsw.asn.au](http://www.paraquad.nsw.asn.au)

### Newcastle Office

Address: 65 The Avenue, Wickham NSW 2293  
Postal: PO Box 395, Hamilton NSW 2303  
Tel: **+61 2 4969 6388**  
Freecall: **1800 636 388** (outside metropolitan Newcastle)  
Fax: **+61 2 4961 6101**  
Email: [newcastle@paraquad.nsw.asn.au](mailto:newcastle@paraquad.nsw.asn.au)  
For ParaQuad NSW regional network coordinators contact **02 4969 6388**

### Spinal Cord Injuries Australia

PO Box 397, Matraville NSW 2036  
Tel: **+61 2 9661 8855**  
Freecall: **1800 819 775** (outside metropolitan Sydney)  
Fax: **+61 2 9661 9598**

Internet: [www.spinalcordinjuries.com.au](http://www.spinalcordinjuries.com.au)

For SCI Australia regional offices please contact **02 9661 8855**