

Getting ready for home

Following a spinal cord injury you are likely to spend many weeks in rehabilitation away from all things familiar. While most people look forward to being able to return home, it can also be a very stressful and anxious time for you, your family and friends. The process of planning for your hospital discharge home starts from Day One and it is important that you are involved from the beginning. This fact sheet aims to provide you and your family with some information about your hospital stay and getting ready to go home.

While in hospital

- **Getting active again:** Once your acute medical needs are taken care of, the focus will move to getting you as strong as you can, active and able to maximise your independence.
- **Learning:** The process of rehabilitation is as much about learning and education as it is about hitting the gym. Make the most of the opportunities to learn. This is also a good time to develop your skills in directing and managing your care. This can help your transition back home feel a little less daunting and nerve wracking.
- **Putting yourself out there:** You will be encouraged to make regular outings into the hospital's local area and then into your own local community. This is a very important stage of your rehabilitation and may be easier to face when supported by people who are in a similar situation to yourself or who have the skills and expertise to answer your questions. The more you experience life outside the spinal unit, the easier it will be to make the transition home, and the more prepared you may be to deal with any issues that may arise.
- **Setting up home:** You will be supported by your rehabilitation team to obtain essential equipment and to find suitable accommodation after your

discharge from hospital. If you need help with your personal care or domestic activities at home, you will be supported in getting the services you need, and choosing a care provider or model that best meets your needs.

- **Thinking about work:** Part of your rehabilitation will include planning for your return to work or considering opportunities for future education or employment. Refer to the "Employment, Education and Training" fact sheet in this series for further information.

Your rehabilitation team in hospital

The different staff you come to know during your time in hospital are all valuable sources of knowledge. You will meet a large number of specialists who work together to serve your needs and work with you to achieve your goals.

- **Spinal Consultant:** Your spinal consultant specialises in spinal medicine and rehabilitation and will co-ordinate your medical care and rehabilitation program.
- **Registrar:** Registrars are doctors who are available routinely to see to your day-to-day medical needs. They liaise closely with your spinal consultant to monitor your medical care.
- **Nursing Team:** This is usually made up of a nurse unit manager (NUM), registered nurse (RN), enrolled nurse (EN), and assistants in nursing (AIN). It is their job to help with many aspects of your day-to-day care and help you and your family learn about your care. If you have any concerns about the care you are receiving in hospital or rehab, talking with the registered nurse is a good place to start.
- **Occupational Therapist:** Your occupational therapist (OT) will work with you to help you become more independent with activities that you will be involved in – personal care tasks, work, leisure, driving and household tasks. Your OT will work with you

to ensure your home, work and community are accessible to you when you are discharged and that you have the necessary equipment for your independence. See the “Equipment” fact sheet in this series for more details.

- **Physiotherapist:** Your physiotherapist (physio) will work with you to maximise your physical potential, addressing your strength, balance, fitness and motor control needs and aiming to achieve the highest level of independence with the impairment you have. Activities you do with your physio lead towards building your confidence and increasing your independence.
- **Psychologist:** Clinical psychologists will generally meet with everyone during their admission to talk about adjusting to life with a spinal cord injury, as well as other concerns such as pain or mental health issues. You may also meet a neuropsychologist who can help with problems with attention or memory.
- **Social Worker:** Your social worker will offer assistance with social, emotional and psychological concerns that arise for you, your family and friends. Your social worker can provide counselling services for you and your family, and can assist with a number of practical tasks such as income support, accommodation, access to personal care services and liaison with government and community services.
- **Support Services:** During your rehabilitation you may also meet one, none or all of the following health care professionals: a dietitian, a speech therapist, a psychiatrist, a urologist, a medical specialist, a vocational rehabilitation consultant and a recreation officer. They are available to meet your needs and goals as required. Information on what services are available to you can be accessed by asking any member of your rehabilitation team.

The process from hospital to home

Acute

- You may be medically “unstable” which just means you are awaiting further tests, surgery to stabilise your spine or you may be having difficulty breathing independently.
- You may be located on an “acute” ward or in an Intensive Care Unit.
- Initially you will be seeing a lot of different doctors and nurses. Soon you will see less of them and more of your rehabilitation team.
- The focus will be on keeping you healthy and stabilising your spine. You will likely require full



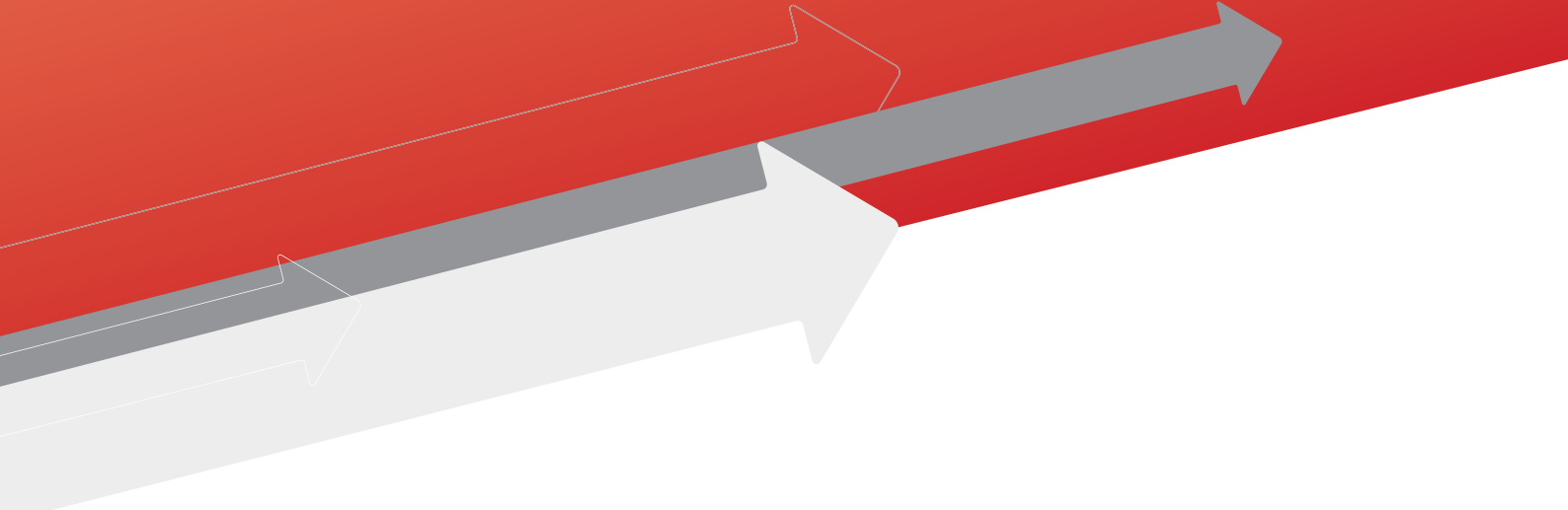
assistance from the team to help turn you in bed, look after your skin, bladder and bowel care needs.

Rehabilitation

- You will likely move onto a different ward or to a different unit to begin the more “active” stage of your rehabilitation.
- You will start mobilising (either standing with assistance or into a wheelchair) and begin learning about what having a spinal cord injury means to you.
- You will have a timetable or diary outlining the appointments you have around the rehabilitation unit (gym, swimming pool, sports centre).
- You will be encouraged to participate in group sessions, sport sessions, trips out of the hospital and peer group sessions.
- The focus is on you learning and maximising your independence.

Discharge

- You will work closely with your rehabilitation team to plan for your return home. If you are a Lifetime Care and Support participant, your coordinator and/or case manager will also be involved in supporting your discharge from hospital.
- Depending on where you live, you will be referred to the team at the State-wide Spinal Outreach Service (SOS) before your discharge. The team at SOS is there to help you achieve any goals you may have once you are home.
- If you live in the Hunter/New England area, you will be referred to the Hunter Spinal Cord Injury Service (HSCIS). You may also have input from your local



health professionals for further rehabilitation at home, especially if you live in a more rural location.

- You will have access to ongoing follow up by your spinal consultant, who will liaise with your general practitioner (GP) for local management of your health needs.
- You will also have access to reviews (as you need them) by the seating clinic assigned to your spinal unit.
- If you live in a regional, rural or remote area you may be able to get financial support through the Isolated Patients Transport and Accommodation Assistance Scheme (IPTAAS) to access the specialist spinal outpatient services of your spinal unit.
- You will be encouraged to meet with your GP as soon as possible after your discharge so that he or she can be aware of your needs once you are home.

Tips to maximise learning in the lead up to your discharge

- Collect all the information that has been given to you about your spinal cord injury and keep it all in a safe place ready to take home with you.
- Don't be afraid to ask questions, or ask again, if you do not understand something your treating team has said to you.
- Make sure you know the details of the equipment, care and support services that will be available to you for discharge.
- If you have trouble remembering questions and taking in everything that has been said, write down your questions ahead of time and/or take a friend, relative or advocate with you to take notes.

It is very common for people to feel anxious or distressed in the lead up to going home and as you settle into life outside the rehabilitation unit. It is not inevitable to feel this way and usually this will settle within a few weeks. If feelings of anxiousness persist after returning home, it is a good idea to speak to your health professional about effective ways to manage these feelings.

At Home

Once you have returned home from hospital, you may require support from some or all of the various types

of health professionals you worked with during your hospital stay.

Your GP will play a key role in helping you manage your health and wellbeing in the community. Your GP will become your first point of call for issues relating to your health, including prevention and health promotion. It is an important aspect of health prevention to schedule regular checkups with your GP, much like servicing your car to avoid mechanical problems.

Having a positive professional relationship with your GP and investing the time in prioritising your health are vital to living well with a spinal cord injury.

References and Further Resources

NSW Health is committed to ensuring that people with a spinal cord injury receive the highest quality of service. The State Spinal Cord Injury Service aims to ensure all individuals with a spinal cord injury receive care that is well co-ordinated, equitable and of high quality. A number of research projects are constantly being undertaken. The State Spinal Cord Injury Service website is a good place to access resources on SCI, NSW Health spinal services and research. www.aci.health.nsw.gov.au/networks/spinal-cord-injury

NSW State Spinal Cord Injury Service Directory of Information and Support Services
www.aci.health.nsw.gov.au/__data/assets/pdf_file/0004/155227/sci_directoryweb.pdf

Queensland Health Handbook of Spinal Cord Injuries
www.health.qld.gov.au/qscis/info_handbook.asp

Canterbury District Health Board (NZ), Burwood Spinal Unit Orientation Information
www.cdhb.govt.nz

Community spinal services in NSW:

- i. Spinal Outreach Service (02) 9808 9666
- ii. Rural Spinal Cord Injury Service (02) 9808 9666
- iii. Hunter Spinal Cord Injury Service (02) 4925 7888
- iv. ParaQuad NSW (02) 8741 5600
- v. SCIA (02) 9661 8855

Planning your discharge from hospital, a guide from the Commonwealth Department of Veterans' Affairs for the veteran community.