

Adjusting to your injury

A spinal cord injury is a major and challenging life event for you and also the people around you. This fact sheet is designed to answer some basic questions you may have about managing the changes that can come with a spinal cord injury.

Generally, adjustment is defined as adapting to an altered condition or situation. With a spinal cord injury, not only are there changes to your body, but you can also expect to experience emotional effects, too. That is, the way that you think and feel about yourself, others and the world can change after a spinal cord injury.

The process of adjusting to a spinal cord injury is a unique one. The way you adjust to your injury can depend on a number of things, for example, your life experiences prior to your injury, how you respond to stress and change, where you come from, your background and culture. Your individual circumstances not only shape who you are, but also influence the process of adjustment to life with a spinal cord injury. Your injury is an individual experience.

Imagining Life After Injury

It is not uncommon for individuals with a new injury to find it difficult to imagine how life will be after a spinal cord injury and what there is to look forward to. In the early stages, it's hard to know where you will now fit across relationships, work and play.

Your injury means there will be a number of changes in your life. Depending on how your spinal cord injury affects you, and the level of your injury, your needs will vary. Some of the physical changes you may expect may include:

- Differences in physical functioning and mobility
- Adapting the way you manage your bladder and bowel functions
- More time being devoted to your health and well-being

- Changes in your sexual function
- Requiring assistance with everyday tasks
- New approaches to hobbies, interests and work

Some of the practical considerations may be:

- A difference in your household income
- Modifications to your home environment
- Changes to your previous level of independence
- Modifications to your workplace, or consideration of a new vocation
- Managing a range of services that may be involved with you, including personal care services

Reactions to Stress

There are some common reactions to stress that you may experience as the reality of having a spinal cord injury sinks in. Some of the psychological or emotional effects that you may experience - particularly during the early stages - include:

- Feeling irritable or even angry
- Feelings of grief and/or prolonged sadness
- Loss of pleasure, feeling hopeless and/or having thoughts of suicide
- Feeling anxious, worrying or finding it hard to wind down
- Recurring memories or mental pictures of how you sustained your injury
- Changes in your levels of concentration
- Changes in your day-to-day memory
- Changes in your sleeping habits
- An increased use of substances
- Difficulty managing pain
- Reduced self esteem
- Change in your body image

Initially you may experience grief for the losses associated with your spinal cord injury. Grief is a

normal response to experiencing some type of loss or major change in life. There is no right or wrong way of accepting the changes that come with a major life event such as a spinal cord injury.

After your spinal cord injury, you may experience some of the following common thoughts or feelings:

Denial or disbelief: “This can’t be happening to me” or “I’ll be fine, I’ll walk out of here”. You may feel that your injury is temporary, or feel that you can recover from your injury like an illness.

Anger: “Why is this happening to me?” or “What did I do to deserve this?” You may feel like blaming others, feel angry with those who have not been injured, feel angry with your family or friends, or maybe even be angry at yourself.

Bargaining: “I’ll give anything to be able to walk again”. You may start to acknowledge your injury, but try to bargain for a cure.

Sadness: “What’s the point trying, it’s no use” or “I’ll never walk again, why bother?” Sadness after a spinal cord injury is common. You have experienced a major life event and experienced some level of loss.

Acceptance: “It will be okay” or “We can get through this”. Accepting your injury, your new circumstances and looking toward creating a meaningful life for yourself generally begins the end to the initial grieving process. This is the beginning of an understanding that there is life after spinal cord injury, and it can be a great one.

It is perfectly normal to, at first, feel angry, sad, cheated or frustrated about what you have lost as a result of your spinal cord injury. Try to focus on your strengths as an individual, your remaining physical function and your capabilities, and what you can improve on. Working at letting go of what you cannot control or change will help you move towards re-establishing a meaningful and fulfilling life.

If you are having difficulty managing the changes brought on by a spinal cord injury, you may find it useful to talk to someone about this and find some additional support that will work for you. Some people find it helpful to talk to health professionals or other patients on the ward, to attend patient education sessions, sports and recreation activities, and to access peer support workers to find out more about their own injury and what to expect. Understanding your injury, and knowing what to expect, can help you to plan for the future and regain a sense of control in your life.

During your hospital stay, it may feel as though real life is on hold. While you are in hospital, you will have some opportunities to head out into the community



before going home for good. Use these opportunities to engage with family or friends, attend your children’s sports matches or get involved again with everyday activities and interests that bring you joy. This will help give you an idea of life after hospital, and whether there is any additional support or equipment you may need to assist you with everyday activities.

Investing time in keeping well means you can focus on relationships, family, work, study, seeing friends or anything else that brings you happiness. There may be days when you are unwell, and it could mean missing out on certain events for the sake of your long-term wellbeing. Informing family, friends and colleagues of the importance of maintaining your health can be helpful in maintaining your social and professional relationships.

This communication with your family and friends can start while you are still in hospital. Some people have found it helpful to start a blog. A blog (short for a web log) is an online journal that is usually maintained by one person who makes regular entries online. This person could be you, a close family member or friend who has regular access to the internet and is able to maintain journal entries for you. Blogs can be useful tools to keep family and friends in the loop with your progress. This way you have control over the information you share, and the people who care about you still feel involved in your progress.

Adjusting to your spinal cord injury is not only a process for you, but for family and friends, and those who care about you. There is a fact sheet in this series for your family and friends to consider some changes that may affect them.



For parents with a spinal cord injury

Children of a parent with a spinal cord injury are also significantly affected by this life event. It is important to give children information about what has happened to you, using language they can understand and information that is appropriate to their age. If you need help or support to talk to your children about your injury, you may find it helpful to have a member of your treating team present.

Some parents can worry that they won't be able to have the same relationship with their children as they had before their injury. Just because you have experienced changes in your physical function doesn't mean you can't give your child what they need. The relationship you have with your children can be just how you want it to be after injury.

If you notice any unusual changes in your child's behaviour, then you should discuss this with your health professional. Speaking to the school teacher, school counsellor, or another involved adult (such as their sports coach) can be helpful so that your child can be supported. You know your child and family better than any health professional and understand what is normal for your family.

References and Further Resources

Contact the social worker or psychologist on the ward to discuss how you are coping.

Speak to your health worker or a spinal social worker in the community:

- Spinal Outreach Service: (02) 9808 9666
- ParaQuad NSW: (02) 8741 5674
- Hunter Spinal Cord Injury Service: (02) 4925 7888

Contact your GP and discuss your needs and circumstances. Your GP may be able to recommend a psychologist in your local area. Currently, Medicare is supporting people to better access these services.

Peer support workers are regularly on the wards and there is peer support available in the community at SCIA Peer Support Program (02) 9661 8855 or Spinal Talk (02) 9808 9628.

Lifeline 13 11 14

Spinal Cord Injury Information Network: Adjustment to SCI Fact Sheet 20, University of Alabama
www.spinalcord.uab.edu/show.asp?durki=45584&site=1021&return=21479

Dezarnaulds A & Ilchef R (2002). *Psychological Adjustment after Spinal Cord Injury*

Queensland Spinal Injuries Services (2002). *Handbook of Spinal Cord Injuries*, 2nd Edition

Dr Elisabeth Kübler-Ross (1969). *On Death & Dying - five stages of grief model*

Mental Health First Aid
www.mhfa.com.au

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