



Adjusting to Spinal Cord Injury

A guide for patients

After a spinal cord injury, everyone copes differently with the journey toward psychological healing and adjustment. The topics below will explore common issues and concerns that can arise during that journey.

Key Points

Initial reactions to a spinal cord injury

- Coping with grief
- Who am I now?
- What can I do?
- Relationships
- Support
- **Contacts Initial reactions to a spinal cord injury**

There are many causes and factors leading to spinal cord injury. You may feel responsible for the events that led to your injury, or it may be the result of someone else's actions. Sometimes there is no one to 'point the finger at': it just happened.

Whatever the cause, the outcome is the same. You have lost some of the physical abilities that you once took for granted. Your body has sustained a major injury with very obvious physical effects. And your mind has also sustained an injury, although the wounds may not be as obvious – to the outside at least. In fact, it would be extremely unlikely if such a life changing experience did not affect your feelings or emotions.

Unlike the physical effects of spinal cord injury, the changes to your moods, feelings and emotion are not predictable. There is no one way that a person with a spinal cord injury is supposed to feel. Everyone copes with spinal cord injury differently.

The way you cope with it is unique to you. But one way or another you have to deal with it and only you can do that.

Just as there is no magic cure for your injured body, there is no easy way to heal your psychological hurt. The first step towards coming to terms with your changed abilities is to recognise what has happened, and how it affects both you and the people around you. It is also important to recognise that whatever your feelings are, they are not uncommon. Many people who have sustained a spinal cord injury experience similar feelings. It may help to express your feelings and share them with other people.

Coping with grief

For many people, learning to live with a spinal cord injury means coming to terms with their sense of loss. You may feel like you have lost part of your sense of self or the life you had before - a big gap has opened up and you may wonder how, or if, you can ever fill it. This experience is natural and called grief. The process of grieving is essential to us being able to move forward.

So what is grief?

Grief is one of the most intense and complex mix of emotions that we can ever feel as humans. The initial feeling may be one of great sadness, but there are many other feelings that may also play a part in your grieving process. Sometimes you may feel all of them at various times in a day.

Recognising what you are feeling, and accepting that it is a normal part of coming to terms with your spinal cord injury. Some of the emotions you may experience are:

Disbelief

During the early stages of your hospitalisation, you may feel a bit numb, like you are in a daze. You may feel like what has happened to you is not real, or that you will wake up at any moment. You may even believe that in time you will miraculously recover from your injury, and that everything will be as it was before.

Disbelief is not a surprising reaction to spinal cord injury. Many things may be different now from how they were not that long ago. You may have just had a major operation or be taking medication. You may even be having difficulties getting used to the hospital environment -waking up during the night, meeting new people, etc. All of these things may make it difficult for you to adjust to your current situation. And it may take some time for you to accept that your incident is likely to have permanent effects.

Anger

You may at times feel very angry that this happened to you. You may feel that life is very unfair to have allowed such a thing to happen. You may be angry at yourself, at the cause of your injury, at your God.

Anger is a common reaction to a spinal cord injury. It is a powerful emotion and the causes may not at first seem obvious. Usually, it is an attempt to fight back, or to regain control in situations of attack, threat and frustration. It may even be entirely justified. Losing your temper can be understandable, but aggressive retaliations often destroy your chance to solve the problems that led to your anger in the first place. It is important to fight for your rights, but possibly not to the extent of ruining relationships by belittling and abusing people. If you are angry - stop and think - try to find the cause of your anger and address it, rather than attack and continue the conflict.

Depression and sadness

As the realities of the changes that have occurred begin to sink in, you may be overwhelmed by negative thoughts. You may wonder what life will hold for you and find it difficult to see a positive future. You may even lose interest in the things that once brought you happiness - your friends, family or favourite foods and drinks. These thoughts can go round and round in your mind and leave you confused. They can also use up all of your energy, making you feel even more flat and tired than your physical injury does.

It is perfectly normal to experience depression or sadness as a result of a serious injury, and it is a part of the grieving process. Don't fight it too hard, but if you find that it does not pass, seek help. Clinical depression may occasionally be induced by a serious injury. Most importantly, find someone you can really talk to and confide in them. Get their ideas and opinions and share your ideas and opinions with them too. Usually there are alternatives that your depression prevents you from seeing. And talking to family, friends, other patients, and staff, will often lessen the isolation you may feel, give you hope, and maybe even solve your problems.

Anxiety

Many people become anxious or afraid following a spinal cord injury. The feeling of anxiety is sometimes difficult to describe. You may feel generally nervous or anxious about your disability, about your ability to cope, about the changes it will make in your life. High levels of anxiety can cause people to be stressed and affect their general health and sense of wellbeing. It may cause you to overestimate the severity of your circumstances and underestimate your ability to cope. And this anxiety and doubt may even make you feel exposed and vulnerable.

Being in a hospital may not help reduce these feelings as there are many people rushing about to do everything for you. This will change. You will soon learn that you have many abilities to control the pattern and quality of your life.

It is important to begin to use all the abilities you have as soon as you can. Don't fall into the trap of becoming dependent, letting other people do everything for you - especially the things you can do yourself.

Who am I now?

Modern society places a lot of emphasis on the physical make-up of a person. We are often judged by how we appear to others. Deep inside, all of us know that how people appear on the surface has very little to do with what they are actually like as people. You will still be you to those who know you.

Self-image

Physical disabilities can affect how we view ourselves and how others view us. You may have had a negative attitude towards people with disabilities prior to your impairment. You may have thought that people with disabilities were helpless, dependent, pathetic, objects of pity and charity, or possibly good material for jokes.

Now, like it or not, you are being forced to examine those negative ideas to see if they are true.

Disability is an experience. Humans learn and grow from experiences. Try and look at what your experience with disability is teaching you about yourself, about your perceived limitations, and about human nature.

Disabilities can have very positive effects on people. For some, a brush with death that results in a permanent disability can literally become a life saving experience. It enables some to come to terms with destructive forces in their lives. Sure, it's not all easy going - it can be down right tough, but toughness breeds strength of character. Just ask yourself, why is it that so many people with disabilities have much healthier views on life than the supposedly "able bodied" people of this world? Thousands of perfectly healthy people literally waste their talents, abilities and lives away.

Yet many people who cannot use parts of their bodies, enjoy great lives and achieve far more than their “able” fellow humans.

Whether a person is sick, healthy or disabled, has very little to do with what they achieve in life - it's their mind and attitude that defines this for them. A person with a broken body but a healthy mind and spirit, and strong relationships, can be healthier than a strong, fit person who is weak in other areas.

Take charge

Health care professionals are there to help. But when it comes to your mind and mental health, only you can start the process of healing. People can help to motivate you, support you, and talk to you, but only you can do the mental adjustment required to move forward.

Taking charge of the situation and deciding to “give it a go” is a very important step for a person to make following a spinal cord injury.

What can I do?

Some people think that life is basically over for a person with a disability. The more you sit back, not doing anything, the more likely it is that you will withdraw and never challenge this belief.

Finding the motivation to move forward with your life can be tough going. It can be easy to get into the “I used to be able to” mode. Changing the focus to what you are able to do now, may help you to get some momentum going. Focus on what you can do, not on what you can't do. You'll find that there are many things you can achieve from a wheelchair. They may be slightly, or totally different from what you are used to, but that does not mean that they are not as satisfying.

Set goals

Without realising it you have probably been setting goals and achieving them from the minute you arrived at the spinal unit. The first few weeks of your recovery involve achieving many small goals. Sitting up, getting around, going to the gym for the first time - these are all milestones in your rehabilitation.

All too often though, the goal setting slows down, or stops as people get stuck into rehabilitation. Everyone has one major goal; going home. But it shouldn't stop there.

As you learn to manage your disability better, you should be able to turn your attention to other goals. For some, the intense period of rehabilitation helps them to achieve new directions in life that they never would have risked before. Maybe you want to change your career or move to a better living environment, or take up a new sport?

Keep your options open. Life is for living. Have a dream and dare to be ambitious.

Motivation

If you find personal motivation hard, try using other people. Talk to “survivors” who have proved to the world that a rich and rewarding life is achievable. Read the stories of people with spinal cord injuries who go on to lead amazing lives is not an impossible dream. Most importantly, just get out there and start doing things. Just by getting started, you may find that motivation arrives on its own. The more active you get, the more you achieve. When it comes to the crunch, you just have to do it.

Relationships

When a spinal cord injury occurs, the people close to you will often be affected emotionally. They may feel many of the same emotions that you do including grief and anxiety. Their reactions may be quite different from your own, and you may have difficulty understanding their reaction.

We usually take our relationships for granted. However, it is important to stop and think about your relationships, how they work, and how you communicate with each other.

If you were having difficulties in your relationship prior to your injury, these issues will still have to be dealt with. However, a spinal cord injury can put pressure on even the best of relationships and effective communication is the most important skill to develop in your relationships at this time.

Here are a few tips that may help you communicate better-

- **Be open.** Clearly stating your own feelings and thoughts will help other people to understand you.
- **Be prepared to listen.** This will help you understand the other person's point of view.
- **Be willing to work together.** Often total agreement is impossible, but a working compromise may leave you both satisfied.
- **Be prepared to admit you are wrong.** We cannot always be right and saying sorry eases a multitude of hurt feelings.

The temptation is always there to avoid talking about problems because we are afraid of being rejected or hurt by the ones we love. Although this can be a very real anxiety, avoiding issues often only complicates them.

It is important to remember that relationships change in everybody's life, whether you have a spinal cord injury or not. Talking things through is no guarantee that our relationships will go the way we plan, but it is a helpful way of improving them.

Sexuality

Like your self-identity and relationships, your spinal cord injury can also challenge your sexuality in complex ways. Sexuality is a very important part of who we are. It is part of how we express ourselves, and it is also about how we communicate and relate with others.

As part of your recovery after a spinal cord injury, you may discover your sexuality is limited by your own personal ideas and beliefs. For example some people think that you have to have penile/vaginal intercourse to truly have sex. You may enjoy finding out that other forms of expression using different parts of your body, such as your mouth, or different positions, may provide more expression of your sexual creativity than before. This may involve trying new things, such as oral sex, or using sexual devices that you may not have felt comfortable with before. Talking to your partner can help you feel more comfortable about some of these issues.

Here are a few tips that may help you re-invent your sexuality:

- **Challenge the myths and beliefs you have about yourself** now that you are in a wheelchair, e.g., "no-one will find me attractive because I am in a wheelchair"
- **Be open.** Be prepared to experiment sensually and sexually. Read and learn more about sexuality and spinal cord injury and get new ideas about sexual positions.

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- **Try to maintain your self esteem, sexual identity and self respect.** Talk to a counsellor or to other people with spinal cord injuries about how to remain sexually confident.
 - **Remember to plan your intimate, sensual and sexual experiences and talk to your partner about using new and creative ideas.** It's difficult to do, but tell your partner if you don't have any sensations in your genitals. This is a good way to start the joy of exploring your sexuality and pleasure in new and creative ways.
 - **Take care and enjoy!**

If you are interested in finding out more about sexuality and Spinal Cord Injury, ask for the information guide provided by the hospital Sexual Health Team or ask to speak with the hospital Sexual Health Consultant.

Support

Learning to come to terms with your changed abilities may not be an easy task. It is likely that you will have “bad days” when everything seems hopeless. It takes courage to face your feelings and recognise the effects that emotions can have on your body. For example, it takes nearly as much energy to drive your brain as it does to drive the rest of your body.

If you find you are becoming “emotionally drained”, ask for help. Talk to a friend or family member. Talk to a trained Clinical Psychologist or Social Worker.

There are also many support groups out there set up to help you and your family learn how to cope with your changed abilities. They won't have all the answers, but they will all help in some way.

Contacts

If you would like more information, or wish to talk to someone about these issues whilst you are in hospital tell a team member you wish to speak with the Psychologist and you will be contacted. Once you are discharged, you may contact your GP who can refer you to a Clinical Psychologist in the community.

Contact

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www.fsh.health.wa.gov.au

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