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spinal injuries association
for life after spinal cord injury

EMOTIONAL IMPACT OF SCI

FACTSHEET



This factsheet explains:

- Initial emotional impact on family and friends
- Normality of varied emotional reactions
- How relationships may change
- The ups and downs of rehabilitation
- Practical challenges for families
- The emotional toll on close family members
- Recognising and understanding stress
- Common emotional reactions
- Strategies for managing stress
- Importance of accessing support
- Impact on children and teenagers
- Where to find additional support

This factsheet is designed to support individuals living with a spinal cord injury (SCI), along with their families and friends. It offers clear guidance to help individuals understand the clinical, psychological and social aspects of spinal cord injury, and to feel more confident navigating daily life, healthcare decisions and long-term wellbeing.



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Feeling sad and worried

When someone sustains a spinal cord injury, it's a big shock for their family and friends. You might feel sad, worried, and not know what to do. This is normal - nothing can prepare you for something like this.

Feeling sad can happen at any time - right after it happens, while they're getting better in hospital, or even after they come home. Everyone feels different things, and there's no right or wrong way to feel.

"I can't believe this has happened to my husband. He used to be so active and did everything at home, and I just don't know how I am going to manage now. I am so desperate for a hug from him, but he can't put his arms around me anymore – I really miss that form of contact because we are a very tactile couple.

"My partner often used to say he was unhappy in his job, and I always nagged him to move jobs. About 15 months after his injury, we both realised that this was a wonderful opportunity for him to change direction. He now writes about his experiences and has surprisingly found a confidence that was never there before.

It can feel like everything has changed. But with time and help from doctors, nurses, family and friends, life can get better. Sometimes families become closer because of what happened. The injured person might spend more time at home, try a new job, or discover they're really good at something new.

How families are affected

When someone in your family sustains a spinal cord injury, it affects everyone. Families have to get used to lots of changes. The person might be in hospital for a long time. You might miss doing things together that you used to do. You might feel upset about changes to hugging and being close, plans for holidays, jobs, and other things you did together.

Family members often stay by the hospital bed and remember how scary things looked at first. Thinking about these scary times is normal but very hard.

Some days you might feel happy about how they're getting better. Other days it might feel like things have got worse. The best thing you can do is support them and think about what you'll still be able to do together, instead of only thinking about what they can't do anymore.

Many things have to be done differently when someone in your family has a spinal cord injury. Finding new ways to do things will help make life easier and happier for everyone.

Spinal cord injury can also make you worry about money. If you are worried about money, talk to SIA who can help you find the right people to help.

"She was so energetic and always had loads of projects on the go. She never sat still, and I was worried she wouldn't cope with this injury. We received some compensation as a result of her injury and were able to make changes to one of the rooms on the ground floor of our house. My partner now runs a business from home. All her energies go into creating new ideas for her work and she is just as busy as before the accident.

As the person gets better in hospital, they'll start coming home for visits or days out. This helps them learn how to manage with their injury and helps you work out what they'll need at home. When you can start planning for the future, time goes by more quickly and you'll feel more in control again.



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Knowing when you're stressed

Everyone gets stressed sometimes, and we all deal with it differently. Stress affects your body and mind by making more adrenaline, which gets your body ready for action.
Signs your body is stressed:

- Can't sleep well
- Feeling tired
- Dry mouth
- Tight muscles
- Headaches
- Tummy problems

Signs your feelings are stressed:

- Feeling worried
- Feeling nervous
- Feeling like it's all too much
- Changes in mood or how much you eat

When friends ask how you're doing, it might be hard to say you're feeling sad. Some people like to deal with problems on their own. We're all different, and there's no right or wrong way to handle stress. Books and websites can help you learn how others have coped. Try reading: 'The Very Alternative Guide to Spinal Cord Injury' by Anthony Papathomas and Joe Robinson.

How to cope with stress

We can't always control what makes us stressed, but we can control how we think, feel and act. Here are some things that can help:

- Write down what worries you. Put them into two lists - things you can change and things you can't change. This helps break big problems into smaller ones. You can also write your worries in a diary
- Make sure you exercise, rest and relax. Try having a bath, reading or listening to music
- Eating well is really important to stay healthy and have energy
- Don't drink coffee or energy drinks late at night. Try a warm milky drink if you can't sleep. Talk to your doctor if you can't sleep for a long time

Difficult feelings you might have

Feeling numb

This can last for hours or days and is normal when you're stressed. You might find it hard to remember what doctors have told you, so ask as many questions as you need. Everyone reacts to shocking news differently.

"I went into a state of shock for days after his accident. I was so worried about his injuries that I shut everything else out of my mind."

"I couldn't eat when I heard the news. I just felt sick and sort of numb."



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Not believing it's real

It's normal not to believe it when someone in your family gets a spinal cord injury. You might not know much about being disabled, or you might have wrong ideas about it. This can make you feel worried or scared about how your family will manage.

"It's so unfair. Why did it have to happen to us? We were just getting everything straight in our life."

"She will never be able to work again."

"We won't be able to go away on holiday together anymore."

"He is going to be stuck at home."

The things we think might happen are often not true. What seems really bad at first might not be as bad as you think. There's lots of help available to help disabled people live happy, full lives. Breaking your worries down into smaller pieces and asking others what they think can help you solve problems and make things feel easier to manage.

Feeling sad

Feeling sad is normal when something upsetting happens. You might even feel angry at the injured person, which can make you feel guilty. These feelings will probably get better over time as you learn more about the injury. It helps if you can talk about these feelings with friends, family, a counsellor, or someone else who has been through the same thing.

Sometimes sadness can turn into depression. Signs of depression include:

- Feeling down and overwhelmed most of the time
- Not being interested in things you used to enjoy
- Feeling worthless and hopeless
- Feeling tired, not sleeping or eating normally

Help is available for depression. You can talk to your doctor if your feelings don't get better. Most spinal cord injury centres also have psychologists or counsellors who can help.

It's normal and often the right thing to ask for help during difficult times, or to take time away from the hospital to find ways of coping.

Feeling helpless

When someone you love sustains a spinal cord injury, it might take time to understand what's happened. Learning lots of new information and making decisions about changes can be overwhelming, and you might feel helpless.
The injured person will probably be in hospital for a while, so this gives you time to learn about spinal cord injuries and where to get help. The doctors and nurses at spinal cord injury hospitals know a lot and can answer questions to help you understand the injury.
Once you feel more in control, you'll be better able to cope with challenges and help the person with the spinal cord injury.



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Feeling anxious

Feeling anxious is common, especially when something scary happens. These feelings are normal and helpful - they tell us we need to take action.

Signs you're feeling anxious include feeling scared, worried and panicked. You might have tight muscles, headaches, sweating or feel sick.

When someone is anxious, they might think about situations differently than if they felt calm. They might think their skills won't work or be scared of the future. The more anxious you feel, the more anxious thoughts you have. This becomes a cycle that can make you lose confidence and avoid things that might make you more anxious.
Recognising what's making you feel anxious and finding ways to deal with it will help you feel more in control. Some anxiety might be about changes in your family, having to move house, change jobs, or being in a difficult situation. You might also worry about medical problems like Autonomic Dysreflexia.
Talking to someone you trust or finding ways to relax can help. This could be reading, going for a walk, playing sport, meeting friends, or doing breathing exercises. You can find relaxation recordings online, and some doctors and nurses can give them to you.



I was incredibly worried about carrying on with my job. I didn't feel I could discuss it with my employers, and I was constantly tense and snappy with my family. Eventually, I decided to talk to my boss, and he was very understanding and sympathetic. He allowed me some time off and I was able to change my work hours during the period my husband was in hospital. I was so relieved, and I now feel I can talk to him when I have problems.

Children and spinal cord injury in the family

Like everyone else in the family, children can be affected when a parent or relative hurts their spinal cord. Most children cope well, and it's unlikely to cause them long-term problems. Having information that's right for their age and staying in touch with the injured person can help.

Young children are less likely to think about how the injury will affect their life in the long term, but they may still feel sad when the family member doesn't come home and then can't take them out, play with them, or look after them in the same way.

Older children and teenagers will understand spinal cord injury more like adults do. They can see the physical changes and might understand how their parents are feeling. They may also want to read books or research online.

Helping a child cope with a parent's spinal cord injury isn't always easy. Children, like adults, are all different. How well they cope might depend on their age, how much they understand about what happened, and whether they have other problems at home or school.

Listening to their worries and letting them visit the hospital regularly will comfort both them and the person with the spinal cord injury. Older children and teenagers might also find it helpful to talk to other young people who have had similar experiences.

A doctor, school, or specialist children's service can give more support for children whose relatives have spinal cord injuries. Spinal cord injury centres will also have their own ways of helping children and can give you advice.



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Where you can get help

SIA Support Line

The SIA helpline offers specialist advice on things like housing, benefits and care packages.
Freephone, open Monday - Friday 10.00am - 4.00pm.

T: 0800 980 0501

SIA Specialist counselling service

SIA offers a free counselling service to people with SCI and their loved ones, after discharge from hospital. The service is open five days a week, offering up to 10 free sessions with a therapist who has SCI themselves. Please call the support line (above) to arrange a call from a counsellor.

The following organisations can also help you find a counsellor in your area:

British Association of Counselling and Psychotherapy (BACP)

Contact directly, or view their online directory of therapists.
BACP House, 15 St John's Business Park, Lutterworth, Leicestershire, LE17 4HB

bacp.co.uk
E: bacp@bacp.co.uk
T: 0870 443 5252

British Psychological Society (BPS)

Contact directly, or view their online directory of psychologists.
St Andrew's House, 58 Princess Road East, Leicester, LE1 7DR

bps.org.uk
E: enquiries@bps.org.uk
T: 0116 254 9568

National Council of Integrative Psychotherapists (NCIP)

Contact directly, or view their online directory of therapists.
PO Box 7219, Heanor, DE75 9AG

the-ncip.org
E: info@the-ncip.org
T: 0300 365 3635

United Kingdom Council for Psychotherapy (UKCP)

Contact directly, or view their online directory of psychotherapists.
2 America Square, London, EC3N 2LU

psychotherapy.org.uk
T: 020 7014 9955



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Charities offering counselling and support

Mind

Mind offers advice and support to anyone with mental health problems without needing a GP referral. The charity also campaigns to improve service and raise awareness. Contact them directly, or find your local group on their website.
2 Redman Place, London, E20 1JQ

mind.org.uk
E: supporterrelations@mind.org.uk
T: 020 8519 2122

Relate

Relate is the UK's largest provider of relationship and family counselling and sex therapy. Contact them directly, or visit their website for advice and resources.
Premier House, Carolina Court Lakeside, Doncaster, DN4 5RA

relate.org.uk
T: 0300 100 1234

RoadPeace

RoadPeace provides a national helpline, offering information and support for people who have been bereaved or injured following road traffic accidents (and their carers). Contact them directly, or visit their website for advice and resources. Their helpline is freephone, and open Monday - Friday, 10.00am - 4.00pm.
PO Box 2579, London, NW10 3PW

roadpeace.org
E: helpline@roadpeace.org
T: 020 8838 5102
Helpline: 0845 4500 355

Samaritans

Samaritans is a national charity providing confidential, mental health support, 24 hours a day for people experiencing feelings of distress or despair, including those that could lead to suicide. A Samaritan is also there to talk to you if you are worried about something, feel upset or confused, or just want to talk. Contact them directly by telephone, email and letter.

samaritans.org
E: jo@samaritans.org
T: 116 123

For more information, contact us at:
Spinal Injuries Association, SIA House, 2 Trueman Place,
Milton Keynes, MK6 2HH
0800 980 0501 *(freephone support line open Mon-Fri 10.00am-4.00pm)*
support@spinal.co.uk

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About SIA

Spinal Injuries Association (SIA) is the UK's leading charity for everyone affected by spinal cord injury. We provide free, specialist support to help you navigate the mental and physical challenges you may face now and throughout your life.

Our nationwide team can connect you with our trusted network of experts and partners, offering guidance on legal matters, care, housing, finance, mental health and more. You can reach our support line on **0800 980 0501**.

We are the voice of people with spinal cord injury. Through our expertise we can connect you to the services and organisations you need through our network for all. Join the SIA community for free at **www.spinal.co.uk**

Tell us what you think
If you have any comments about our publications, you can email **academy@spinal.co.uk**

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This publication has been reviewed for accuracy and updated by:
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- **our Health & Care Advisory Group**

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