

**LIVING WITH SCI**

**FACTSHEETS**

**sia** spinal  
injuries  
association  
FOR LIFE AFTER SPINAL CORD INJURY



**EMOTIONAL IMPACT  
OF SPINAL CORD INJURY  
ON THE FAMILY**

### The emotional impact of spinal cord injury on the family

#### Sadness and reaction to stress

When a family member sustains a spinal cord injury (SCI), the news can feel shocking to the whole family, bringing feelings such as distress, helplessness and a general sense of sadness. Suddenly having a family member who has sustained an SCI can cause a wide range of emotions for many people, including anxiety about the future, the extent of the relative's disability and how the family are going to manage. There is nothing that can prepare us for the impact of spinal cord injury.

Feeling very sad during this period is a perfectly natural emotion and may be experienced at any time, perhaps shortly after the accident, during the rehabilitation process or after the relative has left the hospital. Not everyone experiences the same emotions and there is no right or wrong way to feel.

***“I can't believe that 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 round me any more - I really miss that form of contact because we are a very tactile couple”.***

At the time of the injury it may feel that nothing will be the same again. Given time, encouragement and support from hospital staff and family, life can once again become fulfilling and sometimes relationships become stronger and closer because of what has happened. This may be because the SCI person spends more time at home and develops a deeper relationship with their partner or child or may even start a different career or find a talent for something that they hadn't envisaged before the injury.

***“My partner often used to say that 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 excuse for him to change direction. He now writes about his experiences and has surprisingly found a confidence that was never there before”.***

#### **The challenges of spinal cord injury on the family**

After an SCI, and depending on the level of the injury, you and your family may have to adapt to some changes.

Your relationship with the person who has an SCI may feel different. It is possible that they will be in hospital for a long period and some days you may long to do the things that you previously took for granted. These emotions could be around the longing for physical intimacy and closeness, plans and aspirations for the future, holidays, jobs, retirement and all the other things that were part of your life together prior to the injury.

Some days you may feel really positive and perceive that the rehabilitation process is going well for your relative and you can see “light at the end of the tunnel”. Other days it might feel as if things have taken a “step back” and this might feel frustrating for both of you. You may find it difficult to sound encouraging on the days that you feel down and sad. This doesn’t mean that you can’t make plans together and pursue goals and objectives, rather than only focussing on perceived difficulties and problems for the future. An important goal during rehabilitation is positive encouragement and realistic thinking about the possibility of things that can be done both by you and the person who has the spinal cord injury.

The challenges of a person having an SCI may mean that some everyday activities have to be approached in a different way. Finding ways of readapting and learning how to approach those different aspects of everyday life will help all of the family to make life more manageable and to find future happiness and fulfilment.

***“She was so energetic and always had loads of projects on the go. She never sat still and I was worried that she wouldn’t cope with this injury (T6/7 incomplete). 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. Although she can’t walk, all her energies go into creating new ideas for her work and she is just as busy as before the accident”.***

As the person with an SCI goes through their rehabilitation, they will begin to come home for visits or have days out of hospital. Not only does this give the person encouragement to manage their disability in different situations, but also enables him/her to make the transition from hospital to home. During these periods it will really help you to assess (with the help and support of healthcare professionals) the realistic needs of the SCI individual and their family when they come home.

When you are able to start planning for the future, you will probably find that time goes by faster and you will start to feel more optimistic and more in control of your life together again.

### **Recognising stress**

Everyone feels stressed at some stage in their life and we all deal with it in different ways. Stress can affect you either physically or mentally by the increase in adrenaline levels that prepare us for “action”.

The physical symptoms of stress may be loss of sleep, a dry mouth, muscle tension, headaches, gastrointestinal disturbance or fatigue. The emotional symptoms may include anxiety, feeling nervous, changing eating habits, feeling overwhelmed and mood changes.

Friends may tell you “how well you are coping” but you may find it difficult to say that you are actually feeling quite vulnerable. Others are more resilient during difficult periods in their life and prefer to deal with setbacks on their own. We are all different and there are no right or wrongs about how we deal with the psychological and physical symptoms that we experience due to stress.

There are books and websites which may help you to learn how others have coped, and may make it easier to start conversations about difficult topics, such as the following:

Dr Anthony Papathomas and Joe Robinson. *The Very Alternative Guide To Spinal Cord Injury*. Easy On The Eye Books; 1st edition, 2015.

### **Managing Stress**

Although we are not always able to control the external sources of stress, the way that we think, feel and act during these periods will affect how we cope and respond to the difficulties that come our way.

There are several things that you can do to help yourself cope. Perhaps it might help to think about a specific situation that may be causing you to feel stressed and imagine how you can change this situation so that you feel more in control. It might also help to list all the things that are concerning you and prioritise what is the most important. Stress can also be managed by taking regular exercise, having rest or finding ways of relaxing by temporarily putting issues on one side. Encouraging yourself to eat is also important to try and stay healthy and to boost energy and your immune system. If you cannot change the cause of stress, you can work on increasing your fitness to deal with it.

Ways of helping you to relax may be to try not to drink alcohol or caffeine late in the evening, but instead have a warm milky drink. Other ways of helping to clear the mind may be to have a bath, read a relaxing book or listen to music. Some people find that writing their worries in a diary is also helpful. Very occasionally persistent sleeplessness has other underlying causes and if you are worried, it might help to go and see your GP.

### **Emotional reaction to a stressful situation**

Some of the following emotions may be experienced in response to a stressful situation. This is not a definitive list, as there are many other emotions that people can experience at different times and these will be written about on separate fact sheets.

### **Numbness**

This may last just for a few hours or even for a few days and is a natural reaction to a stressful situation. You may find it hard to remember what has been said by the medical staff about the extent of your relative's injury. When the initial shock has passed it may help to ask further questions to clarify any misunderstandings or information that you are unsure about. Everyone reacts to bad news in different ways and there is never a right or wrong way to handle one's emotions.

*“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”*

### **Disbelief**

Having learned that a member of your family has a spinal cord injury, it is quite understandable that one reaction may be a sense of disbelief. You may have negative views about disability arising from information that you have read or from social attitudes. You may also have had little previous experience of disability. This could leave you feeling apprehensive and anxious about how you and your family are going to manage in the future.

*“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 work again”*

*“We won't be able to go away on holiday together anymore”*

*“He is going to be stuck at home”*

Often our beliefs and assumptions about things are not the reality and what may feel quite bleak at the time, may in fact not be the case. There is extensive help and support for people with disabilities to facilitate living a fulfilling life both at home and within the community.

Identifying and acknowledging your fears and breaking these down into concerns which can be problem-solved or expressed to others to gain an alternative perspective, can help make the seemingly unmanageable more “manageable”.

### **Sadness**

When an upsetting event happens in your life involving a trauma, feeling sad can be a very normal reaction. It is probable that your feelings will be transient and will diminish over time as you gradually learn more about the injury and its management. It helps if these feelings are recognised and acknowledged either by yourself, friends and family or by talking to a counsellor. Peer support can also be extremely helpful.

Letting go of some of these emotions and being able to move forward can be hard for some people. Occasionally sadness can turn into depression. Common symptoms of depression include feeling down and overwhelmed much of the time. Other symptoms include a general loss of interest in life, a sense of worthlessness, helplessness and/or hopelessness, fatigue and changes to sleep and appetite. You might also no longer enjoy things you would normally enjoy.

There is help and support available for depression and it is therefore important for that person to feel able to talk to their doctor if these feelings persist. Alternatively, most spinal units should have a clinical psychology service or a counsellor who will be able to offer professional and confidential support. It is best to enquire at the individual centres to check their referral policy.

There is nothing wrong in asking for support during a difficult period in your life or wanting to take time out from the hospital in order to have space and to find ways of coping and feeling stronger.

### **Helplessness**

When a relative sustains an SCI, it may take you some time to process everything, for example taking in lots of new and detailed information and having to make decisions regarding changes to lifestyle and routine. This may possibly leave you feeling overwhelmed or helpless and not knowing where to begin.

The injured person is likely to be in hospital for quite a while, so this will give you a chance to learn what there is to know, and where and how to access informed help or advice for any questions or concerns that you may have. There will be a range of healthcare professionals within the Spinal Injuries Centre who will have specialist knowledge and experience to answer any questions that might help you in your understanding of spinal cord injury. Once you feel more in control of the situation, you are likely to feel better able to cope with any difficulties that come your way and this will lead you into feeling more actively involved in helping the spinal cord injured person.

### **Anxiety**

We all suffer from anxiety from time to time, especially in response to traumatic and challenging events in our life. These feelings are perfectly normal and are a natural and helpful response in times of stress, alerting us to the fact that we need to take action and respond to a particular situation.

Emotional symptoms of anxiety may include feeling fearful, apprehensive and panicky, whereas physical symptoms might include muscle tension, headaches, sweating, feeling nauseous and 'jittery'.

When someone is anxious, they may think about situations in a different way from how they would view them if they were feeling calm. They may feel that their skills have become ineffective or they might be frightened of the future. The more anxious you feel, the more anxious thoughts come into your head and it then becomes a self-perpetuating cycle, which may lead to loss of confidence and an avoidance of things that may lead to more anxiety.

Recognising what is actually causing you to feel anxious and finding ways of dealing with these underlying issues will help you to feel more in control and less worried and stressed. Perhaps some of this anxiety is around a change of roles within the family unit after an SCI, having to move house, change jobs or finding yourself in a difficult situation?

A way of helping control your anxiety is either by talking to someone whom you can trust (as mentioned previously) or finding ways of helping you to relax. This could be reading a book, going for a walk, playing a sport, meeting friends or finding a simple breathing exercise to reduce your tension. Relaxation recordings are available online, or can be provided by your healthcare professional.

*“I was incredibly worried about carrying on with my job. I didn’t feel that 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 hours of work during the period my husband was in hospital. I was so relieved and I now feel that I can talk to him when I have problems”.*

### **How do children cope with spinal cord injury within the family?**

Children, just like others in the family, are affected by a parent or relative’s SCI. Most children cope well with the situation and it is unlikely to cause them problems in the long term. Most children are helped by receiving age appropriate information and being able to maintain contact with the person who is injured.

Very young children are unable to make assumptions about how the injury will affect their life in the long-term, but they may still feel a sense of loss when the family member doesn’t come home, can’t take them to school, play with them, care for them or take them out.

Older children and teenagers’ understanding of an SCI may be similar to an adult, having awareness of visible physical changes and perhaps some insight into how their parent might be feeling. They may also ask to read books or look up information on spinal cord injury on the internet.

Helping your child cope with their reactions to a parent’s spinal cord injury may not always be easy, especially if you are feeling very stressed. Children are all very different and their ability to cope may depend on their age, their understanding of what has happened and whether they are also experiencing other problems at home or at school.

Allowing them to maintain regular contact through frequent visits to the hospital or by telephone and helping them to feel listened to and helped will undoubtedly be a source of comfort to them and also for the person in hospital. Older children and teenagers may also find support by talking to other young people who have had a similar experience and are much the same age.

If required, additional support for child relatives can be sought via your GP, school or a specialist children’s service. Spinal units will also have their own referral policy for children and it might be helpful to seek their advice.



### **Additional information**

If there is something that you don't understand or if you need some help in dealing with a particular issue on spinal cord injury, there are plenty of sources of help both within hospital and as listed at the bottom of this Fact Sheet.

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## **Sources of Help**

### **SIA Advice line**

T: (Freephone) 0800 980 0501

The advice line provides specialist advice on subjects such as housing, benefits and care packages etc.

### **Telephone Counselling**

After your relative has been discharged from hospital, SIA also offer continuing support with a telephone counselling service which is available for any relative of a person with SCI and for people with SCI in the United Kingdom. This service is available on two Fridays each month. Just ring the Advice Line to arrange for the Counsellor to contact you.

The following organisations will also enable you to find a counsellor in your area:

## **Professional Bodies**

### **British Association of Counselling and Psychotherapy (BACP)**

BACP House  
15 St John's Business Park  
Lutterworth  
Leicestershire LE17 4HB

T: 0870 443 5252

@: [bacp@bacp.co.uk](mailto:bacp@bacp.co.uk)

W: <http://www.bacp.co.uk/>

BACP can provide advice on a range of services to help meet the needs of anyone seeking information about counselling and psychotherapy. It is the largest and broadest governing body within the counselling sector.

**United Kingdom Council for Psychotherapy (UKCP)**

UKCP

2<sup>ND</sup> Floor, Edward House

2 Wakley Street

London EC1V 7LT

T: 020 7014 9955

@: [info@psychotherapy.org.uk](mailto:info@psychotherapy.org.uk)

W: <http://www.psychotherapy.org.uk/>

UKCP regards the regulation of psychotherapists and the public accountability of their practice as paramount importance and promotes and maintains the profession of psychotherapy to the highest of standards. This is in order to safeguard the interests of patients and clients and the reputation of registered practitioners.

The National Register of Psychotherapists is published annually. You can find a UKCP approved psychotherapist in your area by either going into their website or contacting UKCP directly.

**British Psychological Society (BPS)**

BPS

St Andrew's House

58 Princess Road East

Leicester LE1 7DR

T: 0116 254 9568

@: [enquiries@bps.org.uk](mailto:enquiries@bps.org.uk)

W: <http://www.bps.org.uk/>

The British Psychological Society is the representative body for psychologists and psychology in the UK. The Society has national responsibility for the development, promotion and application of psychology for the national good and aims to raise standards of training and practice in the application of psychology. You can contact them direct or use their website to find a psychologist in your area.

**National Council of Psychotherapists**

PO Box 7219

Heanor DE75 9AG

T: 0845 230 6072

W: <http://thencp.org/>

The NCP is a national association of therapists, mainly in private practice, to whom the public may confidently refer. Most schools of psychological thought are represented and a wide variety of therapeutic approaches are offered.

Therapists in your area can be viewed online via website [www.ncphq.co.uk](http://www.ncphq.co.uk) and click on “members”.

### **Charities offering Counselling and Support**

#### **Mind**

15-19 Broadway

Stratford

London

E15 4BQ

**T:** 020 8519 2122

**E:** [supporterservices@mind.org.uk](mailto:supporterservices@mind.org.uk)

**W:** [www.mind.org.uk](http://www.mind.org.uk)

Mind provides advice and support to empower anyone experiencing a mental health problem. The charity campaigns to improve services, raise awareness and promote understanding. It won't give up until everyone experiencing a mental health problem gets support and respect. It has a network of more than 140 local Minds, offering specialised support and care based on the needs of the communities they support.

#### **Relate**

Premier House

Carolina Court

Lakeside

Doncaster DN4 5RA

**T:** 0300 100 1234

**W:** [www.relate.org](http://www.relate.org)

Relate is the UK's largest provider of relationship, family counselling and sex therapy. They also offer a whole range of other relationship support services, including useful books covering relationship issues about staying together and recommitting to your relationship. A wide variety of people go to Relate and have found that it has helped them gain more insight by improving and strengthening bonds with their family and partner.

In order to find out your nearest Relate, telephone the above contact number or visit their website as listed above.

#### **Counselling Ltd**

Counselling Ltd

5 Pear Tree Walk

Wakefield  
West Yorkshire WF2 0HW  
@: [secretary@counselling.ltd.uk](mailto:secretary@counselling.ltd.uk)  
W: [www.counselling.ltd.uk](http://www.counselling.ltd.uk)

This is a registered charity with a membership organisation for counsellors and psychotherapists in the British Isles. All their Counsellors and Psychotherapists reside within the British Isles and have some recognised level of counselling qualification.

They play a key role in helping to link those on low incomes to local counsellors in their area who have opted to provide occasional cost-free, face-to-face counselling.

To apply you MUST be in receipt of either: Income Support, Pension Credit, income-based Jobseekers Allowance OR Incapacity Benefit. Send your name, home address, email details, telephone number, NI number and the benefits you receive and you will then be contacted.

**RoadPeace**  
PO Box 2579  
London NW10 3PW  
T: 020 8838 5102  
Helpline: 0845 4500 355  
@: [helpline@roadpeace.org](mailto:helpline@roadpeace.org)  
W: [www.roadpeace.org](http://www.roadpeace.org)

RoadPeace provides a national helpline for bereaved, the injured and their carers, following road traffic accidents. Their helpline offers vital information, advice and support 7 days a week from 9am to 9pm. This service is backed up by publications written from the victims' perspective and practical experience of hundreds of cases on investigations, prosecutions and civil claims.

**The Samaritans**  
T: 08457 909090  
@: [jo@samaritans.org](mailto:jo@samaritans.org)  
W: [www.samaritans.org](http://www.samaritans.org)

The Samaritans is a national charity providing confidential, non-judgemental and emotional support 24 hours a day for people who are experiencing feelings of distress or despair, including those that could lead to suicide. They are also there to talk to you even if you a bit worried about something, feel upset or confused, or just want to talk. The Samaritans offer their service by telephone, email, letter and face to face in most of their branches.

**Disclaimer**

This factsheet has been prepared by SIA and contains general advice only which we hope will be of use to you. Nothing in this factsheet should be construed as the giving of specific advice and it should not be relied on as a basis for any decision or action. SIA does not accept any liability arising from its use. We aim to ensure the information is as up-to-date and accurate as possible, but please be warned that certain areas are subject to change from time to time. Please note that the inclusion of named agencies, companies, products, services or publications in this factsheet does not constitute a recommendation or endorsement by SIA.

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## ABOUT SIA



The Spinal Injuries Association (SIA) is the leading national user-led charity for spinal cord injured (SCI) people. Being user led, we are well placed to understand the everyday needs of living with spinal cord injury and are here to meet those needs by providing key services to share information and experiences, and to campaign for change ensuring each person can lead a full and active life. We are here to support you from the moment your spinal cord injury happens, and for the rest of your life.

For more information contact us via the following:

Spinal Injuries Association  
SIA House  
2 Trueman Place  
Oldbrook  
Milton Keynes  
MK6 2HH

**T:** 01908 604 191 (Mon – Fri 9am – 5pm)

**T:** 0800 980 0501 (Freephone Advice Line, Mon – Fri, 11am – 1pm/2pm – 4.30pm)

**W:** [www.spinal.co.uk](http://www.spinal.co.uk)

**E:** [sia@spinal.co.uk](mailto:sia@spinal.co.uk)

Charity No: 1054097

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