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EMOTIONAL IMPACT OF SCI ON THE FAMILY

FACTSHEET





Emotional impact of SCI on the family

Sadness and reaction to stress

When a family member sustains a spinal cord injury (SCI), the news can shock their loved ones, bringing feelings of distress, helplessness and a general sense of sadness. Suddenly having a family member who has sustained a SCI can cause a wide range of emotions, including anxiety about the future, the extent of the relative's disability and how the family will manage. There is nothing that can prepare us for the impact of SCI.

Feeling sad during this period is a natural emotion and can be experienced at any time, including shortly after the accident, during the rehabilitation process and after the relative has left hospital. Not everyone shares the same emotions, and there is 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."

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 they hadn't envisaged before injury.

"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."



The challenges of SCI on families

Following a SCI, and depending on the level of injury, families may have to adapt to changes.

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

Some days you may feel positive and optimistic about the person's rehabilitation process, seeing a light at the end of the tunnel. On other days it might feel as if things have taken a step back, which can be frustrating for all involved. You may find it difficult to sound encouraging on the days you feel down and sad. This doesn't mean you can't make plans together and pursue goals, which is always more favourable than focusing on perceived difficulties and problems. 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 SCI person.

SCI's challenges may mean that some everyday activities have to be approached differently. Finding ways to readapt and learning how to approach those aspects of daily life will help all the family make life more manageable and find future happiness and fulfilment.

As the SCI person goes through rehabilitation, they will begin to come home for visits or have days out of hospital. This gives the person encouragement to manage their disability in different situations and enables them to transition from hospital to home.

This time will help you assess (with the help and support of healthcare professionals) the practical needs of the SCI person in the home.

When you can start planning for the future, you will likely find that time goes by quickly, and you will begin to feel more optimistic and in control of your life together again.

The impact on those closest to the SCI person can be significant. This can cause feelings of sadness and resentment towards the injured person, leading to feelings of guilt.



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.



Recognising stress

Everyone feels stressed at some stage in life, and we all deal with it differently. Stress can affect you physically and mentally by increasing the adrenaline levels that prepare us for “action”.

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

Friends may ask how you are coping, but you may find it difficult to say that you are feeling vulnerable – some people prefer to deal with life’s setbacks on their own. We are all different, and there are no rights or wrongs when dealing with the psychological and physical symptoms that we experience due to stress.

Books and websites can help you learn how others have coped and may make it easier to start conversations about complex topics. One such book is *The Very Alternative Guide to Spinal Cord Injury* by Anthony Papathomas and Joe Robinson (Easy on the Eye Books).

Managing Stress

Although we are not always able to control the external sources of stress, the way 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 you can do to help yourself cope. 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 to give you a sense of greater control. Listing the things that concern you can help you prioritise what is most important. Stress can also be managed by taking regular exercise, resting and finding ways to relax by temporarily putting issues aside. Encouraging yourself to eat is also essential to staying healthy and boosting your energy and immune system. Sometimes you cannot change the causes of stress, but you can work on increasing your fitness to deal with it.

Avoiding alcohol or caffeine late in the evening and instead having a warm milky drink can help. So too can clearing the mind by having a bath, reading a relaxing book or listening to music. Some people find writing their worries in a diary helpful. Occasionally, persistent sleeplessness has other underlying causes. If you are worried, seeing your GP might help.

Emotional reaction to a stressful situation

The following emotions may be experienced in response to a stressful situation. This is not a definitive list, and people can experience many other emotions.

Numbness

This can last for a few hours or days, and it is a natural reaction to a stressful situation. You may find it hard to remember what medical staff have said about the extent of your relative’s injury. It may help to ask further questions to clarify any misunderstandings or information you are unsure about when the initial shock has passed. Everyone reacts to shocking news differently, 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

A sense of disbelief is a normal and understandable reaction to learning that a family member has a SCI. You may have negative views about disability arising from information you have read or from social attitudes. You may also have little previous experience of disability. This could leave you feeling apprehensive and anxious about how you and your family will 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 to work again”.

“We won’t be able to go away on holiday together anymore”.

“He is going to be stuck at home”.

Our beliefs and assumptions are often not the reality, and what may feel quite bleak at the time may not be the case. There is extensive help and support available for disabled people to help them lead a fulfilling life both at home and within their 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

Feeling sad is a normal reaction to an upsetting life event or trauma. Your feelings will likely be transient and diminish over time as you gradually learn more about the injury and its management. It helps if you can recognise these feelings and they are acknowledged by 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 challenging 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 hopelessness, fatigue and changes in sleep and appetite. You may also no longer find enjoyment in the things you would typically look forward to.

Help and support are available for depression, and it is important to feel able to talk to a doctor if the 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. Ask your centre about their referral policy.

Asking for support during a difficult period in your life or wanting to take time away from hospital to have space to find ways of coping and feeling stronger is normal and often the right thing to do.



Helplessness

When a relative sustains a SCI, it may take you some time to process everything. Taking in lots of new and detailed information and making decisions about lifestyle and routine changes can leave you feeling overwhelmed, helpless and unsure about where to begin.

A newly injured person is likely to be in hospital for some time, 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 you may have. Various healthcare professionals at spinal injury centres have specialist knowledge and experience to answer questions that might help you understand the 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. This will help you feel more actively involved in helping the SCI person.

Anxiety

Anxiety is common from time to time, especially in response to traumatic and challenging life events. These feelings are perfectly normal and are a natural and helpful response in times of stress, alerting us that we need to take action and respond to a particular situation.

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

When someone is anxious, they may think about situations differently from how they would view them if they felt calm. They might believe that their skills have become ineffective or be frightened of the future. The more anxious you feel, the more anxious thoughts come into your head. It becomes a self-perpetuating cycle, which can lead to the loss of confidence and avoidance of activities that are perceived to bring more anxiety.

Recognising what is causing the anxious feelings and finding ways of dealing with these underlying issues will help you feel more in control and less worried and stressed. Some of this anxiety could be around a shifting of roles within the family unit after a SCI, having to move house, a job change or finding yourself in a difficult situation.

Talking to someone you trust or finding ways that help you relax can help. 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 and some healthcare professionals can supply them too.

"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 SCI in the family

Like others in the family, children can be affected by a parent or relative's SCI. Most children cope well with the situation, and it is unlikely to cause them long-term problems. Age-appropriate information can help children, as can staying in contact with the injured person.

Young children are often 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 SCI may be similar to an adult's because they are aware of visible physical changes and perhaps have some insight into how their parent might be feeling. They may also ask to read books or look up information on the internet.

Helping your child cope with their reactions to a parent's SCI may not always be easy, especially if you feel stressed. Children, like adults, are all different, and their ability to cope may depend on their age, understanding of what has happened and whether they are experiencing other problems at home or school.

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

A GP, school or specialist children's service can provide further support for child relatives of a SCI person. Spinal units also have their own referral policies for children, and it might be helpful to ask for their advice.

Additional information

If there is something you don't understand or you need help in dealing with a particular SCI-related issue, other sources of help are listed below in this fact sheet, or available at hospitals.

Sources of Help

SIA support line

t: 0800 980 0501 (freephone, open Mon-Fri 10.00am-4.30pm)

The helpline offers specialist advice on matters such as housing, benefits and care packages.

SIA's peer-led counselling service

Once a relative has been discharged from hospital, SIA offers continuing support with a counselling service available for SCI people and their relatives in the United Kingdom. The service is open five days a week, offering up to 10 free sessions with a therapist who is SCI themselves. Please call the support line to arrange a call from the counsellor.



Professional bodies

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

British Association of Counselling and Psychotherapy

(BACP) BACP House
15 St John's Business Park Lutterworth
Leicestershire LE17 4HB
t: 0870 443 5252
e: bacp@bacp.co.uk
w: bacp.co.uk

The 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)

2 America Square
London
EC3N 2LU
t: 020 7014 9955
w: psychotherapy.org.uk

The UKCP regards the regulation of psychotherapists and the public accountability of their practice as of paramount importance and promotes and maintains the profession of psychotherapy to the highest standards. This is 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 visiting the website or contacting the UKCP directly.

British Psychological Society (BPS)

St Andrew's House
58 Princess Road East Leicester
LE1 7DR
t: 0116 254 9568
e: enquiries@bps.org.uk
w: bps.org.uk

The BPS 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 the BPS directly or use the website to find a psychologist in your area.

National Council of Integrative Psychotherapists (NCIP)

PO Box 7219
Heanor
DE75 9AG
t: 0300 365 3635
e: info@the-ncip.org
w: the-ncip.org

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

Find therapists in your area using the search form on the website's homepage.



Charities offering counselling and support

Mind

2 Redman Place
London E20 1JQ
t: 020 8519 2122
e: supporterrelations@mind.org.uk
w: mind.org.uk

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

Relate

Premier House
Carolina Court Lakeside
Doncaster
DN4 5RA
e: 0300 100 1234
w: relate.org.uk

Relate is the UK's largest provider of relationship and family counselling and sex therapy. It also offers other relationship support services, including books about staying together and recommitting to the people in your life. People who have used Relate services have found that it has helped them gain more insight by improving and strengthening bonds with their family and partner.

Find your nearest Relate by calling the above contact number or visiting the website.

Counselling Ltd

5 Pear Tree Walk
Wakefield
West Yorkshire
WF2 0HW
w: counselling.ltd.uk

Counselling Ltd is a registered charity with a membership organisation for counsellors and psychotherapists in Britain. Members have recognised counselling qualifications.

The organisation helps link those on low incomes to local counsellors in their area who have offered to provide occasional cost-free, face-to-face counselling.

RoadPeace

PO Box 2579
London NW10 3PW
t: 020 8838 5102
Helpline: 0845 4500 355
e: helpline@roadpeace.org
w: roadpeace.org

RoadPeace provides a national helpline for bereaved or injured people and their carers following road traffic accidents. The helpline offers vital information, advice and support on Mondays to Fridays between 10am and 1pm. The service is backed up by publications written from victims' perspectives and practical experience of hundreds of cases on investigations, prosecutions and civil claims.

Samaritans

t: 08457 909090
Helpline: 116 123
e: jo@samaritans.org
w: samaritans.org

Samaritans is a national charity providing confidential, non-judgemental and emotional 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. Samaritans offers its service by telephone, email and letter.

For more information, contact us at:

Spinal Injuries Association, SIA House,
2 Trueman Place, Milton Keynes, MK19 6HY

0800 980 0501 (freephone support line open Mon-Fri 10.00am-4.30pm)

sia@spinal.co.uk



About SIA

Spinal Injuries Association (SIA) is the leading national charity for anyone affected by spinal cord injury. We have specialist support available, for free, to support you through the mental and physical challenges you may face, both now and for the rest of your life.

Our support network is coordinated by a team of people, across the UK, who can put you in touch with our network of experts and trusted partners, covering all aspects of mind, body and life, to help you move forward with life. Our partners specialise in services such as legal, care, housing, finance, mental health and much more.

We are the voice of spinal cord injured people, through our expertise and we can connect you to the services and organisations you need through our network for all.

You can join the SIA community by signing up for free online at www.spinal.co.uk.

Disclaimer

This factsheet has been prepared by SIA and contains general advice that we hope will be useful. Nothing in this factsheet should be construed as giving 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.

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