



MIND MATTERS

sia spinal
injuries
association
for life after spinal cord injury

EMOTIONAL SUPPORT

FACTSHEET





Emotional impact of SCI on the family

Our mental health

No two people respond the same emotionally following a spinal cord injury (SCI). Some can pick up the pieces and get on with life immediately, while others find this difficult. Some view the injury as yet another of life's challenges to be overcome, and others feel overwhelmed by the impact.

If you feel you're in the latter category (and many people are), it's important to remember that, just as there is no magic cure for a SCI, there is no instantaneous way of healing emotional pain. It may help to:

Know that your feelings are a natural and understandable response to what has happened to you

Realise that you are not alone and that these feelings are also experienced by other SCI people and those with serious illnesses

Express your feelings, share them with others where appropriate and, if necessary, consider talking to a professional counsellor or therapist for support (further information on this is covered later in this factsheet).



The emotional impact of SCI

Few life events can prepare you for such a sudden and often devastating change. At first, you may find it hard to take in all that has happened and difficult to understand what you are being told. You may be confused and surprised by the power and overwhelming nature of the feelings you're experiencing. Whatever they may be, try to set yourself simple and achievable goals broken down into steps. This will help rebuild confidence and self-esteem.

We are unique creatures, and there are no set responses to injury. However, some people experience:



Disbelief and low self-esteem

At the onset of SCI, people often go through periods of shock, numbness and disbelief about how this could happen to them. This can be made worse by the difficulty of knowing the full extent of the injury, particularly if the injury is incomplete. At this stage, you may tend to deny or minimise the severity of what has happened to you or have unrealistic expectations of recovery or a cure.

Gradually, as the reality of the condition becomes clearer, you may experience a sense of loss and find yourself becoming tearful and depressed. Feelings of helplessness and apathy may mean that you will want to withdraw from activities. A sense of depression is a normal reaction to SCI for many.

“When I first arrived at the spinal unit, 150 miles from home, one week after the accident, my husband was able to stay with me for the first three days. After he left, I felt very low and deserted.

I have never forgotten the kindness of a staff nurse who came just to talk and soften the blow. One thing in particular she said has stayed with me: “Remember not to mind anything that is done to your body while you’re here or what your body does to you.” I had always been so independent, and it had never occurred to me that I could lose control of my bodily functions”.

Anne Spooner, C6/7 incomplete

Anger and guilt

Feelings of anger are not unusual. This anger may be turned towards yourself, perhaps because you feel guilty that you should have done more to prevent your injury or that you might now be a burden to your family. The anger could be turned towards the doctors and nurses for telling you bad news or against fate or your God, feeling that it is unfair and unjust that this should have happened to you.

Whatever the nature of your anger, it is neither right nor wrong; it simply is. It is something you feel and entirely valid.

“I felt terrific resentment and a powerful determination to get my own back on life and anyone who was negative towards me. I was furious with everybody who would not cooperate, but everything became normal and settled down as the years went by”.

Ken Roberts, T9/10

“I was suicidal for months in the early stages, but my wife called my bluff and asked me to put an end to the misery/threats/nastiness. I found I didn’t really want to die – I just wanted the pain and suffering to stop”.

Jon Bamforth, T5/6

Fear

Most people become anxious or afraid about the injury itself or its potential effects on their lives, their families and others around them. Anxiety can be a major emotional problem for SCI people because of the uncertainty and lack of control.



Grief and vulnerability

Grieving for what you have lost is natural, and loss makes us more aware of our vulnerability.

“Six weeks after my injury, I had a really black day, when I cried and cried. I can’t remember what had triggered it, perhaps just the dawn of realisation. I was left alone. I felt so conspicuous, laid in my bed with no privacy. It was awful. You do get your soul laid bare in that situation. Outwardly, I managed really well. Inwardly, I was a wreck. I did everything I had to do: get on my feet, built up my strength, learned to take over my bodily functions. I was a grade-A student – with a timebomb ticking away inside me”.

Alison Lyon, T10

Dealing with other people’s reactions is not always easy. Some people don’t know how to respond to someone in a wheelchair. Sometimes people are well-intentioned and helpful, while others can appear patronising. It’s important to remember that those who seem patronising may do so because of a lack of understanding. They don’t mean harm, even though it’s irritating, and it may not be intentional.

“Many people have to meet me several times before they meet me, not the wheelchair”.

Jon Bamforth, T5/6

The family

SCI inevitably affects family relationships. Partners, family and friends may experience their own emotional stress and anxiety when adjusting to new roles and responsibilities. You may be at home a large part of the time and in need of a care package with support from personal assistants, for which they may feel ill-prepared.

“My family were brilliant. Still are. Considering we were all bruised and new to this trauma, we all did so well. Dad was great with the practicalities, overseeing the living and driving arrangements; mum had a day off work during the week when we shopped or visited friends whose houses I could get into, but none of us was very good at talking about the way the trauma affected us, so it was rarely mentioned. If it did slip into the conversation, it was like someone had picked at a scab and made it bleed”.

Alison Lyon, T10

Relationships can be particularly stressful early on when there may be a lot of uncertainty about what you want, how you are feeling and how much you want or do not want to talk about your injury. It can be difficult to talk when you are unwell or feel low. Frustration can build up, both your own and that of others, if there is no safe outlet for your frustration.

“When my husband was first injured, I thought he was coping quite well. He seemed cheerful enough and downplayed what had happened to him. Now he criticises everything and everyone and is impossible to please. Sometimes his outbursts are quite violent”.

Anon

“My sons [age six and five at the time] were very upset to begin with. They kept hoping I would walk again, but after a few months of being at home, we settled into a routine of what I could and couldn’t do, and they were very helpful. They showed more depth of understanding than their father and took everything in their stride, accepting that mum’s bladder and bowels did not work like before without any problem and without broadcasting the fact to the world as young children can do. They were a great comfort”.

Mrs D Esse



“My eldest has seemed to pretty much take the wheelchair in his stride, but I know he still prays at night – bless his heart – not always for a miracle, sometimes just to ask God to make my pain go away. My second son has had a much harder time, regularly asking me to “just try to walk”. He sees the legs there and can’t really take in why they don’t work. When the accident occurred, my husband made a puppet for them and then cut the string that made the legs work – we think it may have helped them understand a bit better. He has also been teased a bit at school, and he intensely dislikes the time it takes to do anything or go anywhere and then having to enter at a different time or entrance to everyone else. C’est la vie”.

Jean Ginder, T11

Books can help friends and relatives of SCI people to understand the injury better. These include *The Very Alternative Guide To Spinal Cord Injury* by Anthony Papathomas and Joe Robinson (Easy on the Eye Books).

Other relationships

You may find friends and colleagues feeling unsure about how to respond to you post-injury. Some friends and people you meet may irritate you by being overprotective or come across with false jollity. Others may become distant rather than risk saying the wrong thing. Remember that these initial reactions may have much more to do with their own emotions than with you.

Setting boundaries is a good idea. Show people what it is you want at a particular time – when you want to talk or be left alone – and they should respond accordingly.

“In the early period after injury, I felt upset, naturally, but I also felt life had given me a challenge. I knew from [when the accident occurred] that I was paralysed, but I had to ask the doctors what the situation was, as far as how permanent it all was. When told the position, I decided not to think about what I couldn’t do any more, but to concentrate on what I could”.

Lezlee Coupe, C5/6

Professionals

The professionals you meet, whether doctors, nurses, physiotherapists, social workers or district nurses, are human beings too, with the usual virtues and failings. Some can be a great source of help and support, but others may seem insensitive because they deal with people with similar problems to your own daily. For them, your experience is not unique.

“We did not receive any counselling other than little chats with a very unsympathetic consultant. He took great pains to tell my husband that our life would be totally changed, and it would be very difficult to look after me. In fact, I found his attitude very negative. He even went so far as to say I would not be able to look after myself, let alone my sons. I was so incensed I hardly spoke to him again. I was determined to prove the b*****d wrong and moved heaven and earth to do things my way. We found chatting to ward sisters and nurses, OTs and physios more helpful”.

Mrs D Esse



Strangers

Some people find the presence of a disabled person embarrassing, challenging, disturbing or upsetting. They can make a series of assumptions about what the disabled person is like and what they can or cannot, should or should not do. Because they are too frightened to ask and too unsettled to wait and see, they often behave in ways that range from evasiveness (refusal to make eye contact) to being patronising (assuming that you are incapable of doing this or that).

Challenge this behaviour, which is based on a lack of understanding. Do your best to be relaxed with people, and your attitude will likely rub off on them. Humour can sometimes work its magic in these situations too. Practise being assertive, not aggressive.

Sharing and support

However independent you are, there are times when it can help to talk to someone outside the family about your experiences if you have a specific problem. This may be about everyday difficulties and challenges that you face in adapting to your SCI, or it could be about relationship difficulties, loss of self-esteem, financial worries or other issues.

You do not have to be alone. There are people at SIA who may be able to offer you support and give you some time and space to talk. The following SIA services are there to help:

Peer support

We all need good role models when going through life changes. A SCI person can offer a unique type of support and recommend practical advice. Contact SIA on 01908 604 191 for more information about our peer support service.

Peer-led counselling

This free service allows you to talk in complete confidence to a professional counsellor who is also an SCI person. Up to 10 sessions are available either by video call or telephone. Call SIA to arrange for someone from the counselling service to get in touch with you.

Freephone support line

Telephone 0800 980 0501 Monday to Friday 10.00am-4.30pm. Email the support line at support@spinal.co.uk.

Getting outside help

A session with a trained therapist will allow you to work through your feelings. A therapist (and in this factsheet, we use the term “therapist” to cover counsellors, psychotherapists and psychologists) will listen in an unbiased, uncritical way and reflect your feelings and thoughts back to you, giving you a chance to see a new perspective. This approach can help you see things more clearly. It may also be helpful to explore parts of your past during a therapy session to help you better understand why you feel the way you do.

A good therapist will never tell you what to do – they will work with you on the basis that you have the answers to your own problems, although you may need some help to find them. Therapy is not just having a good moan (although it may be helpful to do that as well), nor is it simply going over and over the problems.

Successful therapy will see you working together with your therapist to get a sense of understanding, power and purpose, helping you move towards a more relaxed, positive and happy way of life. The ultimate aim is for you to make your own choices and put them into action. This way, you gain control of your own life.



Therapy at spinal injury centres

Make enquiries at your spinal injury centre if you would like to consult a specialist where you are or have been treated. Many centres have clinical psychologists and counselling psychologists working on their specialist teams or employ peer counsellors.

How do you know when you should seek help?

Most people will experience difficulties at some point in their life. However, there are occasions when the help of a qualified therapist can be beneficial, and the onset of disability can be one such time.

Even those who are years post-injury can suddenly find themselves feeling in need of help and support. The most common signs of distress include:

- Persistent feelings of dissatisfaction
- Unexplainable fatigue or difficulty in sleeping
- Difficulties in talking with partner, family, friends
- Feelings of loneliness, moodiness, depression, stress or anxiety
- Problems with alcohol or drugs
- Challenges in dealing with anger, hostility or life's frustrations

If you experience any of these symptoms, you may wish to consider consulting a qualified therapist to discuss the issues troubling you and explore the background to any feelings you have.

What's the difference between a therapist and a counsellor?

These terms are often used interchangeably, as are "therapy" and "counselling". However, counsellors deal with immediate presenting and apparent issues, while therapists, such as psychotherapists, carry out more in-depth work with you, often lasting months or even years.

Counsellors and psychotherapists have different qualifications and levels of experience. At the very least, a counsellor should have undertaken two years of training and a diploma. Psychotherapists should have two degrees, the second being in clinical or counselling psychology. Many do not have experience in SCI but have skills in listening and treatment for depression, anxiety and stress. Whatever the qualifications, it is essential that the person you consult is registered with an appropriate professional body (see below).

Clinical and counselling psychotherapists have two degrees – academic and applied (clinical training in various settings). For antidepressants or other medications, you will need to see a GP and possibly a psychiatrist.

What do therapists do?

Therapists are typically interested in strengths, patterns, roles, rules, goals and relationships. Depending on their qualifications and training, therapists may use interviews, psychological tests, rating scales, hypnosis, reading assignments, discussions, relaxation exercises, reward systems and other techniques as appropriate. They all have in common the listening skills and knowledge of topics that have proved to be helpful in research studies, i.e. using either one-to-one situations or group sessions to talk about and explore the issues troubling you.



Counselling, psychotherapy, psychoanalysis, psychology: what's the difference?

Counselling tends to be shorter-term than other forms of therapy, and the therapist may concentrate on helping you clarify your feelings by reflecting things back to you for a better perspective. They also tend to deal more with the here and now.

In psychotherapy, there may be more childhood, upbringing and relationship exploration. Psychotherapy usually takes longer than counselling, and psychoanalysis is even more in-depth, sometimes involving three or more sessions a week, working with the unconscious mind. This is rarely available on the NHS.

Psychology is the study of human behaviour, thinking and feeling. Most therapists, whether they are called counsellors or psychotherapists, tend to use a mixture of counselling and psychotherapeutic techniques.

Who are qualified therapists?

If you are considering therapy, it is essential to consult a suitably approved and registered therapist. There are no regulations covering counselling, so you need to ensure the counsellor you are thinking of consulting has a suitable qualification. Most qualified counsellors will be registered with a professional body. A counsellor should have a diploma and have undergone a recognised training course of at least two years, which should have included skills practice, and personal therapy themselves. Shorter or correspondence courses do not offer the necessary level of training.

Registration with a relevant professional body requires an individual to have received the appropriate training and qualifications, the necessary experience and subscribe to a professional code of ethics. Ensure any counsellors or psychotherapists you consult are members of professional bodies such as the British Association for Counselling and Psychotherapy (BACP), the United Kingdom Council for Psychotherapy (UKCP) or the National Association of Counsellors, Hypnotherapists and Psychotherapists (NACHP). Contact details for these organisations are given at the end of this factsheet.

Find a counsellor or psychotherapist in your area using the BACP's register and therapist directory. Visit bacp.co.uk/about-therapy/how-to-find-a-therapist to search online.

If you want to see a specific psychologist, you can check whether they are suitably qualified (ie chartered) by searching for them on the British Psychological Society (BPS) website. If you don't have a particular person in mind but are looking for a qualified psychologist in your area, you can search the directory of chartered psychologists, also published by the BPS. The searches are available online at Bps.org.uk. Psychologists are also registered with the Health and Care Professions Council (HCPC), which can be found at Hcpc-uk.org.

Remember: always enquire about a therapist's training and experience.

How often are sessions scheduled?

One session a week is typical, but they can be scheduled more frequently in some situations (and for some therapies, such as classical Freudian analysis). Help with adjusting to a SCI may need sessions spaced at longer intervals over an extended period.



How long do sessions last?

Introductory sessions tend to be longer than regular sessions, particularly if this is an assessment by a therapist who has been asked to see you by your GP. After that, most therapy sessions last about 50 minutes. The sessions might include measuring progress, questionnaires or planning goals and review dates.

How can I be sure that what I talk about will remain private?

A suitably qualified therapist will subscribe to the relevant professional bodies' ethical framework. This requires absolute confidentiality for clients, except in rare circumstances. Your therapist will explain this at your first meeting and keep you informed of their actions should they need to break confidentiality.

Do I need a referral from my GP?

You will only need a referral from your GP if you wish to be seen by an NHS therapist. Access to this type of treatment through the health service is severely restricted. Even if you are referred, you may find the therapist can only see you over a brief period and has limited knowledge of SCI matters. Some GPs surgeries have a therapist attached to the practice, but again their time is highly restricted.

What if I don't feel comfortable with my therapist?

Good therapists are aware of the importance of a good fit and will invite you to use the first session to decide if you feel comfortable working with them. If, at any time, you don't feel things are working for you, let your therapist know. They can likely direct you to a more suitable therapist.

Should I only see a SCI therapist?

There are a limited number of people who are both SCI and suitably professionally qualified. There are obvious advantages to seeing a therapist who is SCI, but a good therapist will not just see your disability. They will consider the whole you, including your background, childhood, family, relationships and work with various perspectives. Never assume that only a SCI therapist can help you; a non-disabled therapist will also have invaluable skills and expertise.

What does therapy cost, and who pays for it?

If you are lucky enough to have had therapy through the NHS following a referral from your GP, the treatment is free.

For private consultations, therapists' fees vary considerably depending on their professional qualifications, expertise and where in the country you live. Prices can range from £20 an hour to anything up to and over £100 an hour. Fees for long-term therapy can also be on a sliding scale, which usually means that your income determines part of the total fee you pay.

Establishing fees from the outset is essential. Fee guidelines are available for both counsellors and psychotherapist from their respective professional associations, and there is no reason why you should pay more than these guidelines state. Most private therapists will invoice you with their fees monthly. Again, it is important to be clear about how you will be charged before committing yourself.



How long does therapy last?

This depends on you and the issues you take to the therapy sessions. From the outset, the therapist should be able to give you some idea and should certainly do so if they see the therapy as long term. For some people, especially those undertaking what's known as cognitive therapy, the sessions can last from six to eight weeks. For more in-depth analytical therapy, the time could span months or years.

What if I want to stop?

You are always in charge of the process and can stop at any stage. You will also have opportunities at various points to review with your therapist. There's no reason why you should feel compelled to continue.

However, be aware that uncomfortable feelings are often signs that things are moving in your unconscious mind – paradoxically, you may feel worse before you feel better. Discuss this with your therapist rather than simply deciding not to go to your next session. It will be more helpful to understand what is happening than to evade it.

It's usual for you and your therapist to agree on a date to finish, typically about six weeks in advance. This allows time for a slowing down of the therapeutic process, review of the progress made and closure.

What is e-counselling?

Online or e-counselling is where a therapist talks with you over the internet. It could be by email, chat or video call.

Video calls using Zoom, Skype or Teams enable you to speak with a therapist with the advantage of not having to travel for a session. This therapy method is popular and successful, although it is wise to consider face-to-face sessions first.

Computerised CBT

This form of therapy usually entails working through exercises rather than being led by a person. It is an effective way to learn coping strategies, and if you decide afterwards to contact a therapist, you might progress more quickly, having learned the model and techniques online.



Sources of help

Professional bodies

The following organisations are good starting points for finding a therapist and course of treatment.

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.



Voluntary organisations offering counselling or support

The Outsiders Trust

WestEnd
Redwood Farm Barrow Gurney, Avon
BS48 3RE

Helpline: 07872 681 982/01997 421 019
e: members@outsiders.org.uk
w: outsiders.org.uk

The Outsiders Trust is a social, peer support and dating club, run by and for socially and physically disabled people. Our members have a wide range of impairments, including visual and hearing impairment. They tell us only other disabled people really understand them, so make the best partners.

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. Callers will be put in touch with trained volunteers who have themselves experienced bereavement or injury through road accidents.

Samaritans

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

Samaritans provides confidential emotional support 24 hours a day for people experiencing feelings of distress or despair, including those that may lead to suicide. Callers needn't be suicidal to call Samaritans; it is there to help if someone is worried about something, feels upset or confused, or just wants to talk.

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.

Updated - June 2022

Registered Charity Number: 1054097

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