

## Emotional Health after Spinal Cord Injury (SCI)

### Introduction

The following information has been put together by the clinical psychology team at the NSIC. It is based on many years' experience working alongside people with spinal cord injuries and their families. It is also drawn from research aiming to better understand what it is like to live with spinal cord injury, as well as general evidence about enhancing emotional health and wellbeing.

Everyone's experience of spinal cord injury is different, and not everything in this leaflet will be meaningful or relevant to you. You may find you need different things at different times. Please feel free to explore each section at your own pace and make a note of anything you find helpful.

### Emotional responses to SCI

People who sustain spinal cord injuries describe feeling a wide range of emotions. These include:

- Feeling stressed & overwhelmed, as if the demands on you are more than you can handle
- Feeling anxious & fearful
- Feeling low in mood, consistently sad, unmotivated or even hopeless
- Feeling a sense of grief or loss
- Feeling anger or disbelief at what has happened
- Feeling regretful or even guilty, perhaps blaming yourself for your spinal cord injury

For some people, arrival at the NSIC can underline the impact of their spinal cord injury. Moving between different hospitals can also be difficult, with the need to learn new 'rules' and routines and often being further away from family and friends.

Although these reactions are common and normal, not everyone will experience them. Some people report a new sense of strength or feeling more 'robust' than they expected to. Some people notice a new clarity or perspective about their lives and what's important to them. Some people struggle to know how they are feeling and may feel numb or emotionally detached for a while.



“The involvement of my family in this process has been very helpful, as they, along with the team, have encouraged me to stay motivated.” Elaine

It may help to know that after the acute phase and with the right support in place, quality of life does not diminish for most people compared with before their injury. This may surprise you, but we consistently see evidence for it in research studies and in our clinical work. Life may not be the same as before your injury. However, the values underlying the way you used to live your life – such as connection with others, challenging yourself or making a meaningful contribution – can still underpin the things you do.

**If you only remember one thing from this guidance, it should be that there is no ‘correct’ way to respond to a spinal cord injury, and that whatever you are feeling is likely to be a normal and natural part of the adjustment process.**

## Beliefs & assumptions

“As my level of injury means I have very limited hand and arm movement, I believed I could not be involved with very much. How wrong I was.” Sandra

One of the biggest challenges in adjusting to life with a spinal cord injury is managing your own and other people’s beliefs and assumptions about what has happened. You may find you have thoughts like:

- I have no control over this situation
- I’ll never be able to do that
- I’m not the same person as before the injury

Such thoughts and doubts are entirely normal and natural, particularly in the first weeks and months after your injury.

People around you may also make assumptions about what life is like for you and how they should act around you. Those around you may try to do things for you (even when you don’t actually need help) or to protect you from certain information or experiences. On the other hand, you may feel as if others are putting pressure on you to do more than you feel able to. This is a period of adjustment and new learning for everyone.

**The goal of rehabilitation is to provide a safe environment where beliefs and assumptions can be tested out. Over time, you will work out which are helpful and which are not.**

**You will also end up with a realistic sense of what you can do independently and what you need support with.**

## What helps

The following list provides practical advice and guidance for looking after your emotional health while at the NSIC.

### Checking in with yourself

The first step is to identify the things that you find most challenging about your situation, as this will vary from person to person. You might do this by talking things through with a close family member or friend or a trusted member of staff. It can also help to find space to be alone, away from the busy rehabilitation environment, to give yourself a chance to notice how you are feeling. **You do not need to “fix” how you are feeling, especially while you are managing the multiple demands of being in hospital.** The idea is simply to acknowledge the impact your SCI has had and the changes you’ve had to make – some temporary and to do with being in hospital, some longer term – and think about what support you might need.

### Resources at the NSIC

“The community here is really important, as we all support each other, sharing information, problems and solutions.” Marius

- Perhaps most importantly, the goal-planning process and patient education sessions are designed to reduce stress and anxiety by putting you at the centre of the rehabilitation process. This helps you to feel informed and able to take an active role in managing your SCI.
- You should have a named nurse or nursing team who can help with any questions or issues.
- The NSIC has a dedicated clinical psychology team to provide confidential support to patients. You can ask a member of staff to refer you, or your team might refer you with your consent if they feel you would benefit from talking things through. A member of the clinical psychology team will then meet with you to discuss your



situation and think about how best to help. This might involve a single problem-solving session, signposting to specific organisations or multiple sessions to explore issues in more depth.

- The NSIC has a dedicated family counsellor who offers confidential support to patients' families – please ask a member of staff to pass on your details if you would like to use this service.
- We also hold a Relatives' Day regularly during which families can learn about SCI and speak to other people in similar situations.
- Our patient education and peer support team help patients to learn about their injuries and how to manage them effectively. They include members of staff and volunteers with lived experience of SCI.
- We are lucky to have a beautiful outdoor space within the centre, thanks to the Horatio's Garden charity. This is designed to be a peaceful sanctuary away from the wards.
- NSIC-Online (<http://main.nsic-online.org.uk/>) is our centre's website, providing detailed information and practical guidance about living with a spinal cord injury.
- We have other information and self-help leaflets available:
  - coping with low mood and depression
  - coping with anxiety
  - coping with pain
  - coping with head injury and memory loss
  - managing stress and anxiety within the family after SCI
  - rehabilitation and goal-planning
  - supporting children when their parent has an SCI



## SCI charities

Several charities exist to offer information and support relating to spinal cord injury, as well as services such as peer mentoring, training courses and vocational support. Representatives from these charities visit the centre regularly. These include:



01908 604191; <https://www.spinal.co.uk/>



020 8875 1805; <https://www.backuptrust.org.uk/>



020 8954 5759; <https://www.aspire.org.uk/>

**NSIC Department of Clinical Psychology  
National Spinal Injuries Centre  
Buckinghamshire Healthcare NHS Trust  
Stoke Mandeville Hospital  
Aylesbury  
HP21 8AL**

**Telephone: 01296 315823 / [bht.nsicpsychology@nhs.net](mailto:bht.nsicpsychology@nhs.net)**

## **How can I help reduce healthcare associated infections?**

Infection prevention & control is important to the well-being of our patients and for that reason we have infection prevention & control procedures in place. Keeping your hands clean is an effective way of preventing the spread of infections. We ask that you, and anyone visiting you, use the hand sanitiser available at the entrance to every ward before coming in to and after leaving the ward. In some situations hands may need to be washed at the sink using soap and water rather than using the hand sanitiser as hand sanitisers are not suitable for use when dealing with patients who have symptoms of diarrhoea.

**If you need advice or further assistance, please contact our patient advice and liaison service (PALS):**

**call 01296 316042 or email [bht.pals@nhs.net](mailto:bht.pals@nhs.net)**

Please remember that this leaflet is intended as general information only. We aim to make the information as up to date and accurate as possible, but please note that it is subject to change. Please therefore always check specific advice on any concerns you may have with your doctor.