

# What to expect following spinal cord injury



## Information for patients

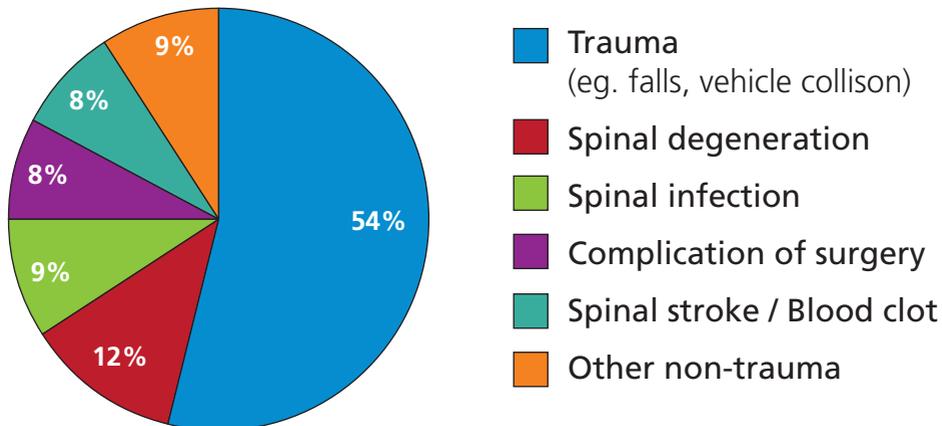
Therapy Services



## Introduction

This leaflet aims to explain what spinal cord injury is and what to expect over the next few months.

## What is spinal cord injury (SCI) and what causes it?

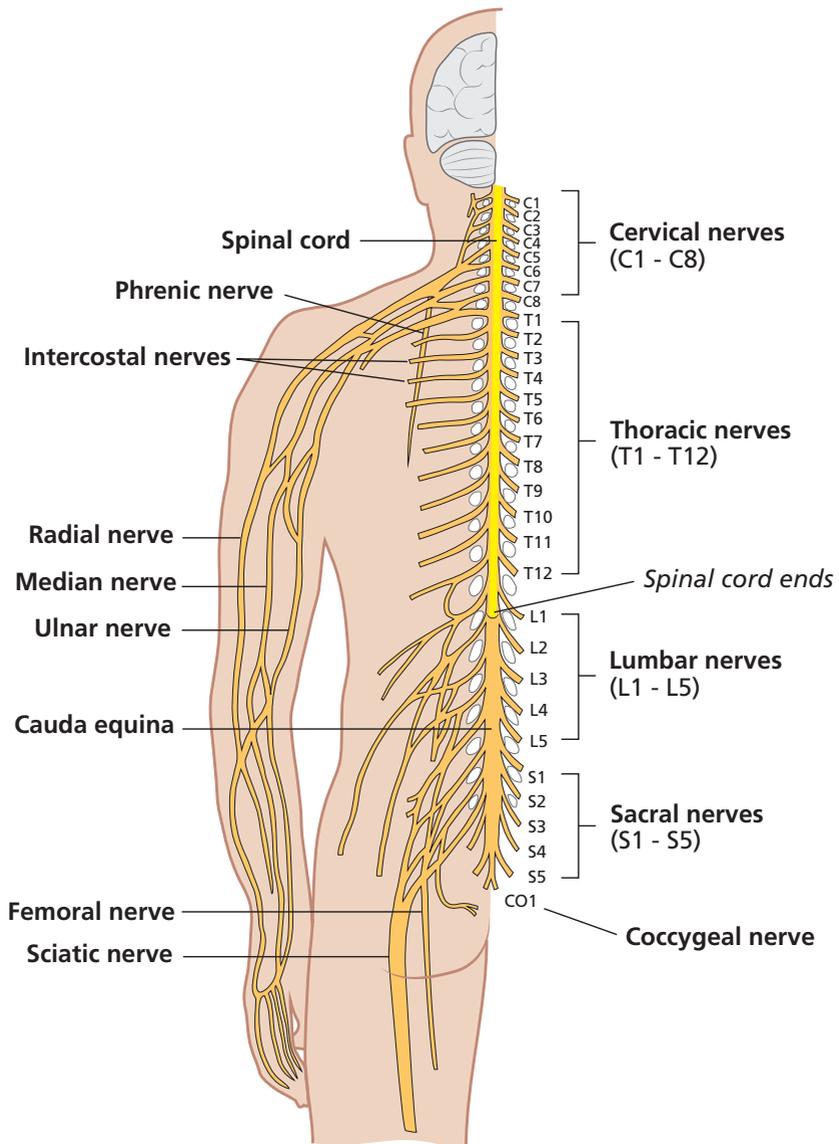


**Causes of spinal cord injury to Princess Royal Spinal Injury Unit 2016/2017**

The spinal cord is a collection of nerves, about the thickness of your little finger, which runs from your brain and down into your body within your spine (back bone). Normally there is plenty of room for this, but if the space inside your spine becomes narrowed, or the cord is damaged in an accident or its blood supply is interrupted, the cord becomes damaged.

The spinal cord is a very complicated information superhighway carrying messages back and forth between the brain and the body. These messages enable us to move our body, feel pressure and control vital functions like our breathing, blood pressure, bladder and bowels.

When the spinal cord is damaged the messages between our brain and the rest of our body can't get through, resulting in a loss of movement and sensation from below the level of injury.



**Diagram showing spinal cord and nerves**

## **How will spinal cord injury affect my body?**

The higher up you damage the spinal cord, the more movement and sensation will be affected.

- Damage to your spinal cord in your back can result in paraplegia. Paraplegia affects the movement and sensation in your legs and possibly some stomach muscles.
- Damage to the spinal cord in your neck can result in tetraplegia. Tetraplegia affects movement and sensation in both your arms and legs, as well as stomach and some chest muscles.

Your bladder control is likely to be affected and most often is initially managed by a catheter (a tube which is used to drain pee from your bladder), whilst your bowel may need daily support from the nursing staff until you establish a regular management program. It is important to be aware that the loss of movement and sensation will vary from person to person, even with those who have damaged their spinal cord in the same place.

## **What are the letters and numbers healthcare professionals keep mentioning?**

The use of letters and numbers refers to the level of your injury.

If you have injured the spinal cord in your neck, you will have injured one of your cervical nerves (1-8). An injury like this would be referred to as C1, C2 etc.

If you have injured the spinal cord in your back, you will have injured either thoracic nerves (1-12) or lumbar nerves (1-5). A back injury would be referred to as T6, L1 etc. (See the first diagram)

## **What does complete/incomplete mean?**

Complete or incomplete injury refers to the type of injury you have sustained.

If both sides of your body are affected and there is no voluntary movement or feeling from the injury level and below, then your injury is complete.

If you have some feeling in your bladder or bowels and still have some voluntary movement below your injury, such as being able to move one limb (e.g. an arm), then your injury is incomplete.

## **Will I recover?**

When the cord is damaged, the degree of recovery can vary tremendously from person to person. Some people fully recover whilst others are left with a permanent loss.

Whilst most recovery takes place in the first 6 months, it may take up to two years for you to reach your full potential following your injury. As the spinal cord recovers from the shock of the injury, you may make some progress with movement and/or sensation. Although progress and adaptation is possible, it is important to remember that there is not yet any effective repair available for spinal cord injury, but research into this continues. Your doctors may be able to give you some idea of your potential to improve but for the most part it's a waiting game.

## **What happens next?**

At first you may be initially cared for on an orthopaedic or general ward. How your cord injury is managed will vary from person to person depending on the cause. If you've had a traumatic injury, you may need an operation to stabilise your spine, whilst others will need an operation to remove anything which is pressing on the cord. Infections may need to be cleaned out and courses of antibiotics given.

Most people need to spend a period of time on bed rest and the length of this can vary from a few days to months. Whilst this can be hard to deal with, this period of immobility is allowing the cord to heal as much as it can and will optimise your long term recovery.

## **What can I do whilst I'm on bed rest?**

Whilst you are on bed rest, your physiotherapist will come and help you keep your body moving. If you are completely paralysed, your physio will perform passive movements to keep your joints loose and maintain muscle length. If you are able to contract any of your muscles, you will be encouraged to do this as much as possible. After a spinal cord injury you are much more likely to develop pressure sores as your sensation is reduced and you are less able to move. This is why it is important to move regularly, known as pressure relief. The nursing staff will also ensure you are turned regularly, usually every 4-6 hours

Your physiotherapist will also help you if your breathing has been affected. They will encourage you to take deep breaths to keep your chest clear and may use equipment such as a cough assist machine to help you cough to clear any phlegm.

Your occupational therapist will assess you to see if you need any splints. These help to ensure your limbs are held in a good position if you are unable to do this yourself.

## **Can my relatives and friends help?**

Yes they can. Your physiotherapist and occupational therapist can teach your relatives and friends many of the exercises to help keep you moving and increase your strength.

## **What happens when I'm allowed out of bed?**

Once the doctors are happy your condition is stable, your spine is stabilised or your infection treatment well under way, you will be able

to start getting out of bed. In most cases where there is significant weakness in your legs, you will need to use a wheelchair, at least initially. Sitting out of bed can be more challenging than you might imagine as your postural muscles will have become weak whilst on bed rest and you will take time to adjust to being upright. After being fully supported on the bed, a wheelchair can seem very uncomfortable at first. It is important to see getting out of bed and gradually increasing your tolerance to sitting, as an exercise in itself. It is important that you gradually increase the time sat out and don't overdo things. At first you are likely to be hoisted out of bed, but where possible, you will be taught to do this more independently using other equipment where appropriate.

## **Where will I go next?**

- Everyone, except those diagnosed with progressive metastatic cancer, is referred to the geographical SCI Centre linked to the hospital to which they were admitted
- You may be referred to the SCI with the correct catchment for your GP's postcode

The SCI Centre will allocate a consultant in spinal cord injuries to review your referral and make a decision on the best way to manage your rehabilitation, in collaboration with the local hospital team.

They may recommend one of the following:

- Transfer to a specialist SCI Centre for inpatient rehabilitation and discharge back to the community
- Transfer to a local neurology rehabilitation centre or community hospital for inpatient rehabilitation, and then discharge home with outpatient follow up at the SCI centre
- Completing your rehabilitation in your current ward/hospital and then discharge to either an off-site rehabilitation facility or home.

Either way you will be followed up as an outpatient at the SCI Centre

In order to make this decision a member of the SCI Centre Outreach Team may come and visit, collect more information for the SCI Team or to help you make an informed decision regarding your rehabilitation options.

## **The multidisciplinary team: We're here to help**

Whilst you are in hospital there are a number of different people to help you.

### **Doctors**

The doctors will explain to you about your specific injury, treatment options (including medication) and your likely long term outcome. If you are transferred to the spinal cord injury centre it is important that you arrange to meet with your consultant, preferably with your family, to discuss your progress and any concerns that you may have. Your ward manager can give you the contact details of your consultant's secretary so you can arrange this meeting.

### **Physio (PT) and occupational therapy (OT)**

SCI affects the communication between the brain and the body, PT and OT in the early stages are aimed at the following:

- You may receive chest care and support with your breathing if required.
- Maximising the strength of the muscles still communicating with the brain.
- Maintaining range of movement in the joints and muscle length.
- Teaching you the best ways to be as independent as possible with what movement you have, including bed mobility and getting dressed.

- Working on your sitting balance and learning to move around is one of the main challenges for most patients initially. Learning how to transfer into and use your wheelchair will also be covered, as well as how best to pressure relieve to avoid pressure sores.
- After an initial assessment, therapy staff will assist you in identifying realistic goals which we will work towards. It is important to realise that some of these goals may not be achievable whilst you are at the spinal injuries centre but may be achieved after discharge.

## **Nursing support**

The nursing team consists of registered nurses, support workers, specialist nurses, sisters/charge nurses and the Discharge Liaison Team.

If you move onto a specialist spinal cord injury ward, the nursing staff there will have more specialist knowledge about spinal cord injury to support you throughout your stay. They will work with you to manage your injury. This may include managing your medication, skin and hygiene support, bladder and bowel management and supporting you to get out of bed.

## **Psychology service**

As individuals we cope with situations in different ways and the same is true following a spinal cord injury. It is common for people to experience a wide range of emotions and everyone's experience is unique and individual. It is natural and understandable to experience some psychological difficulties following a spinal cord injury. These difficulties may include:

- Management of pain and spasms
- Coping with different emotions
- Concerns about relationships and the future
- Distress and trauma following an accident

Often support from friends and family, as well as going through the rehabilitation process, is enough to help manage these difficulties, but some people need further support.

There is a psychology service available for inpatients at the spinal injuries centre. A member of the psychology team will meet with you during your first few weeks on the ward to talk about how you are doing. This is an opportunity to speak about any concerns you may have. Following this you may be asked whether you accept or decline psychology input, and offered further psychology sessions during your stay. You have a choice.

### **Other emotional support**

Many people find it very helpful to access support from other people who have experienced an SCI and who are now living positive lives several years later. This support can be arranged through charity organisations and volunteers – please ask a member of staff if you would like this arranged.

### **Benefits and financial advice**

If you have had a spinal cord injury you may be entitled to benefits. You could be entitled to disability benefits such as Personal Independence Payment or, if your income has dropped, you may be entitled to income related benefits such as Housing Benefit.

For more information contact your local Citizens Advice

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

If you are transferred to a spinal injury centre the OT's will be able to help you with this.

## **Additional Information:**

In addition to the above support, there are other opportunities at the spinal injury centre:

- Weekly education sessions are organised in the centre covering important information about your condition
- A number of activities and classes are also available such as sport, art, gardening (seasonal) and bingo
- An assessment flat can be made available to patients and family (when appropriate), to help prepare you for life outside the centre as you approach your discharge

## **What support is out there?**

It is to be expected that you will have lots of questions beyond the scope of this booklet. If you are on an orthopaedic or general ward, the staff there may have the knowledge to answer some of these, whilst others may be best answered by the specialist staff which may come and visit you.

There are also a number of organisations available to support you through this difficult time of adjustment. We can arrange for a volunteer who has had a spinal cord injury to come and visit you if you would like.

There are also a number of websites with lots of information:

**<http://www.sth.nhs.uk/services/a-z-of-services?id=277>**

Spinal Injuries Association: **[www.spinal.co.uk](http://www.spinal.co.uk)**

Aspire: **[www.aspire.org.uk](http://www.aspire.org.uk)**

Back Up: **[www.backuptrust.org.uk](http://www.backuptrust.org.uk)**



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