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forward >>

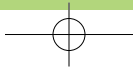
the guide to living with  
spinal cord injury



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## Spinal Cord Injury – in the early days





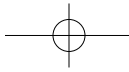
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the guide to living with spinal cord injury



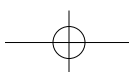
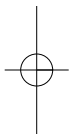
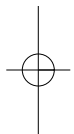
## Spinal Cord Injury - in the early days

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## Moving Forward with SCI in the early days

"Saturday 16 July 1994 is a day that is now firmly etched in my mind. It was a hot summer day and a day off from my work as a London Police Officer. I was a fit and healthy 31-year-old who enjoyed running, cycling and water sports. It was the perfect afternoon for a long, hard ride on my mountain bike. Some thirty minutes into my journey I fell from my bike and took the full impact on my head.

"I still don't know what caused my accident but now I was fighting for my life having broken my neck at the C2, C3 & C4 vertebrae. I was completely paralysed from the neck down and struggling to breathe. I was airlifted to the Royal London hospital by helicopter and the next few days were a blur. I was ventilated, in skull traction and on all sorts of medication. The doctors broke the awful news that my spinal cord was severely damaged and it was unlikely for me to have any recovery.

"I was then moved to the Spinal Cord Injury Centre at the Royal National Orthopaedic Hospital, Stanmore; 'home' for the next year. I had to learn a new way of life and was totally reliant on others for all my needs. I had some recovery and was discharged being able to stand using a frame, with my arms being considerably weaker than my legs. I went through some very emotional times coming to terms with what had happened to me, these were heightened when I was back in the 'real' world after leaving the security of the hospital and its staff.

"A decade on and I honestly believe I have accepted my injury and am a better person for the experience. Although my condition hasn't improve much since leaving hospital, I realised I had two choices – either feel sorry for myself and wallow in self pity or get on with life to the best of my abilities. The latter is what I decided to do and I have channelled my energies into helping others with injuries similar to myself."



# 1 A brief history of the treatment of spinal cord injury (SCI)

**Acknowledgement:** SIA is grateful for the help of Anne Seaman, Lead Nurse at the Duke of Cornwall Spinal Treatment Centre in Salisbury for writing sections 1-16 of this *Moving Forward*.

Until the early years of the last century, a spinal cord injury was regarded as fatal. In the First World War, 90% of people who experienced SCI died within one year of wounding and only about one per cent survived more than 20 years. By 1937, 80% of SCI people died within three years of their injury. During the Second World War several specialist spinal units were established to cope with war wounded, and in 1944 a National Spinal Injuries Centre was founded at Stoke Mandeville Hospital by Dr (later Sir) Ludwig Guttmann to cater for the anticipated wave of injuries following the Second Front invasion of Europe.

By 1951, when it was taken over by the new National Health Service, the Centre at Stoke Mandeville had expanded from one small ward to a vast 200-bed complex. Guttmann and other pioneers revolutionised the treatment of the injury and vastly improved the survival chances of the injured. Even so, by the 1960s there was still a 35% mortality (death) rate among those with tetraplegia. Since 1950, a regional network of Spinal Cord Injury Centres (SCI Centres) has been established, with eight in England, and one each in Wales, Scotland, Northern Ireland and the Irish Republic. The map opposite shows the location of these 12 centres. For contact details, see Appendix 2.

## UK and Irish Spinal Cord Injury Centres



Illustration: Simon Roulstone/SIA

Improvements in the treatment of spinal cord injury (SCI) have come about. Not by dramatic advances in surgical techniques or the development of new drugs, but by developing the care provided by paramedics at the scene of the accident, followed by an integrated multidisciplinary team approach where doctors, nurses and therapists work together to *manage* the care required to enable an injured person to become as independent as possible. Central to the team is the spinal cord injured person and their family. Some of the greatest improvements have been in empowering and training the spinal cord injured individual and their family to be as independent as possible in their care. This includes having the knowledge and skills to avoid potential complications such as pressure sores and chest infections and to minimise bladder and kidney infections, which in the past were a major cause of early death after discharge from hospital.

## 2 Causes of spinal cord injury

There are thought to be between 30,000 and 40,000 people in Britain today who are spinal cord injured. All sorts of people break their necks or backs, or develop an illness that leads to damage to the spinal cord. Amongst the SCI community, you will find people of all ages ranging from very young children, to the elderly. However, most are fit and active adults under the age of 40 years, who have a range of roles and responsibilities. There is an increasing trend for people to become spinal cord injured later in life, mostly through falls. Many of these people will have years of life as an SCI person ahead of them.

It is estimated that each year, between 750 and 1,000 people experience a new spinal cord injury. Unfortunately, it is impossible to be exact because SCI is not a 'notifiable' condition. Hospitals are not required to notify cases to the Department of Health, and no national central database is kept. It is estimated nationally that nearly 80% of all spinal cord injuries are due to an accident, or trauma. The largest causes of injury are road traffic accidents and falls.

The Spinal Injuries Association and staff at SCI Centres recognise that some people with SCI are not admitted to the specialist centres, particularly those whose paralysis is caused by illness or disease, known as non-traumatic injuries. This can be because the individual has never been referred to an SCI Centre. It may also be because some centres concentrate on those people with traumatic SCI. Although hospitals are encouraged to refer all patients with an SCI to a specialist centre, it is thought that many people with lower level injuries, and those with non-traumatic injuries, are often not referred and are treated in general hospitals.

### Causes of Spinal Cord Injury

130 new patient admissions to the Duke of Cornwall Spinal Treatment Centre, Salisbury 2005-2006

|  |              |
|--|--------------|
| <b>Road Traffic Accidents</b>                          | <b>35.3%</b> |
| Motorcycle   | 6.9%         |
| Car, van, coach, lorry                                 | 22.3%        |
| Pedestrian   | 1.6%         |
| Cyclist  | 4.6%         |
| <b>Domestic &amp; Industrial Accidents</b>             | <b>22.3%</b> |
| Domestic falls- stairs, ladders                        | 18.5%        |
| Accident at work                                       | 3.8%         |
| <b>Sporting Accidents</b>                              | <b>13.1%</b> |
| Water Sport Injuries                                   | 5.4%         |
| Horse riding   | 3.1%         |
| Other sporting injuries  (Skiing, gym, motocross etc.) | 4.6%         |
| <b>Self-harm &amp; Criminal Assault</b>                | <b>0.8%</b>  |
| Self harm  | 0.0%         |
| Criminal assault                                       | 0.8%         |
| <b>Non Traumatic</b>                                   | <b>26.9%</b> |

It appears a growing proportion of new admissions to spinal cord injury centres are people who have broken their necks, resulting in tetraplegia. These people are at a higher risk of developing complications. This is due to a number of factors: better treatment at the scene of accident means that more people are surviving and reaching hospital and SCI Centres; improvements in motor vehicles and crash helmet design result in fewer fatal skull and chest injuries; wider knowledge of the techniques of managing SCI may mean that more people who break their backs, paraplegics, are being treated in general hospitals.

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# 3

## The spinal cord

In order to function normally a person must be able to use their nervous system to sense and respond to both external and internal changes, or stimulus, affecting the body. For example, stepping on a pin is an external stimulus that causes pain, the response is to move the foot out of the way. If you have a high temperature, due to an infection, an internal stimulus, the body will need to use the nervous system to lower your temperature and keep it within the normal range.

The brain and spinal cord are essential and the major parts of the nervous system. Together they form the central nervous system. The spinal cord is an extension of the brain and made up of a thick bundle of nerves which branch off to connect all areas of the body. The spinal cord works much like a group of telephone wires, carrying messages in both directions from the brain to individual muscles and tells them to move, known as motor function. It also connects the skin and other organs to the brain, therefore communicating sensations of touch, pain, pressure or heat and cold, known as sensory functions.

Picture the brain as a vast intelligent telephone exchange, dealing with all these messages; the spinal cord is the first section of thick cable taking the nerve impulse messages to all areas of the body.

The centre of the spinal column carries the spinal cord in a hollow channel, known as the spinal canal. The spine is a stack of 33 bony rings called vertebrae. All the vertebrae have a similar structure but change in size, with the smallest in your neck and the largest in the lower back. The structure allows the column to support body weight and connects head, shoulders, chest and pelvis, which are in turn linked to arms and legs. The spine has to be immensely strong to lift weights, it also needs to be supple to withstand a lifetime of shocks caused by walking, running and jumping; and flexible enough to allow the trunk and neck to bend and rotate. Each vertebra is separated from its neighbour by a flat pad of gristle called an intervertebral disc.

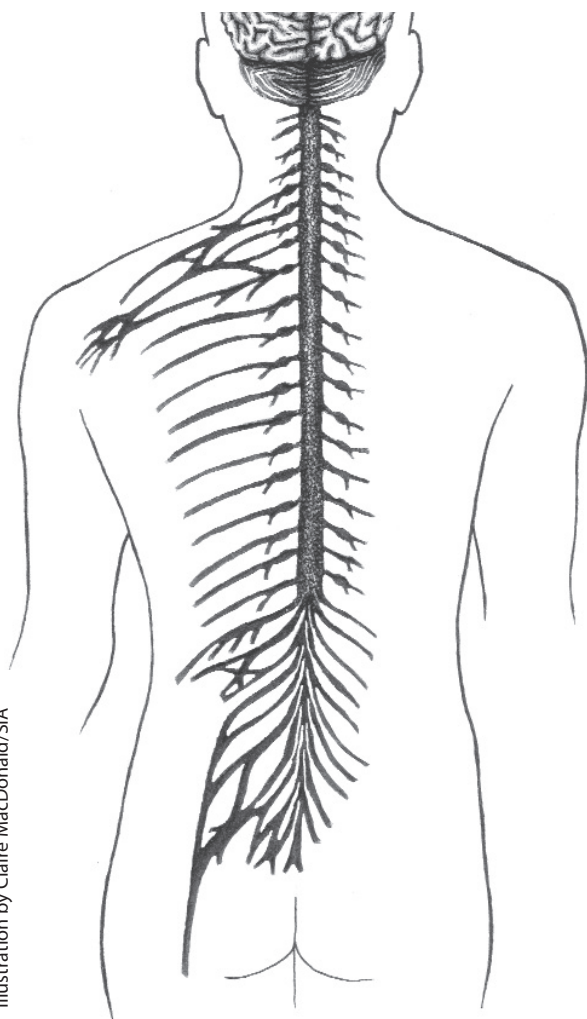
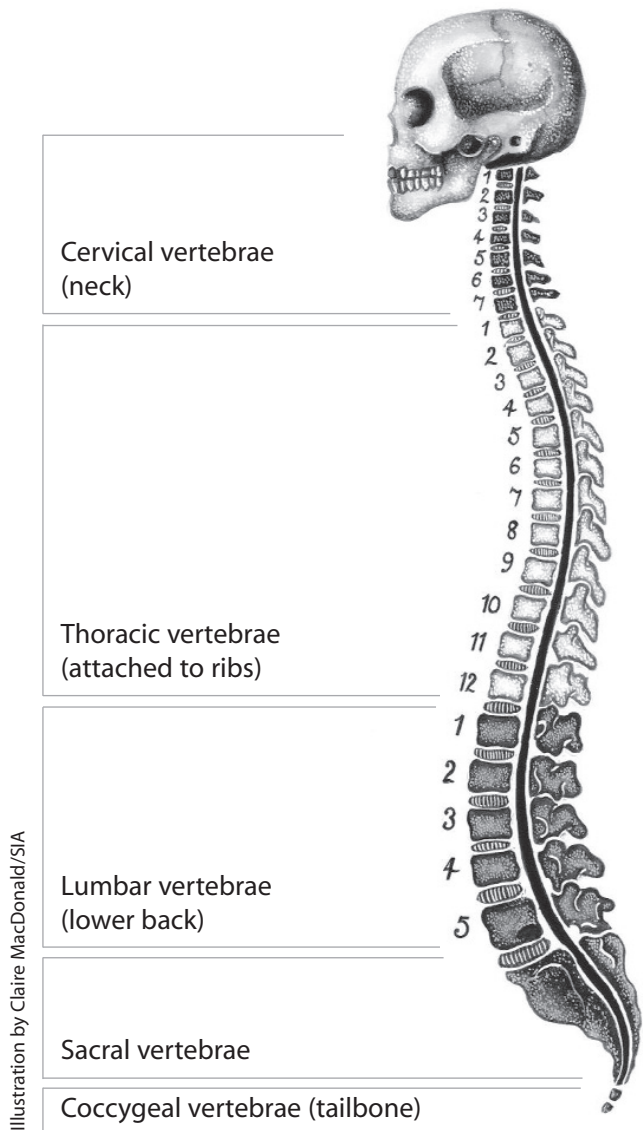
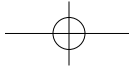


Illustration by Claire MacDonald/SIA

**Diagram showing how the spinal nerves lead to different parts of the body**





There are four major divisions of the spinal column:

**Cervical (C)** or neck region containing the first 7 vertebrae and the first 8 pairs of spinal nerves. These are labelled as C1, C2 etc.

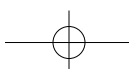
**Thoracic (T)** or chest region (also sometimes called Dorsal) containing the next 12 vertebrae and 12 pairs of spinal nerves. These are labelled as T1-T12.

**Lumbar (L)** or lower back region containing the next 5 vertebrae and 5 pairs of spinal nerves. These are labelled as L1-L5.

**Sacral (S)** or pelvic region containing the last 9 vertebrae fused together into two sections, the **sacrum** and the **coccyx**, containing 6 pairs of spinal nerves. These are labelled as S1-5 and C1 (This C1 is rarely referred to).

The spinal canal, described earlier, provides protection for the spinal cord, which is approximately 18 inches long and about the width of an adult's little finger. A series of layers, known as the meninges, also protect the spinal cord. Between one of the layers is the cerebrospinal fluid, which provides nutrition and further cushioning for the spinal cord. The spinal cord starts at the base of the brain, and ends in the small of the back, level with the first lumbar vertebrae (L1). At this point a bundle of spinal nerve roots emerge, known as the *cauda equina* because it looks like a horse's tail.

The spinal cord is divided into segments, which are consistent with the vertebrae and are also given the same names as the vertebrae. From the spinal cord, 31 paired spinal nerves, one left and one right, branch out to different parts of the body. From the upper part of the cord, these roots connect to the nerves of the upper torso, arms and hands; from the lower cord they lead to the abdomen, thighs, calves and feet. These nerves carry the sensory messages to the brain. The brain interprets and responds by sending a motor message down the spinal cord to the muscles and organs of the body.



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## 4 What happens when the spinal cord is damaged?

Most spinal cord damage is caused by trauma, a physical injury that normally results in an immediate paralysis. However, those caused by viral infections, cysts or tumours on or near the spinal cord, generally result in a paralysis that progresses over a varying time span.

Traumatic injury to the spinal cord is an extremely severe blow to the body's central nervous system. The body responds by going into *spinal shock* for a period, which can last anything from a couple of hours to six weeks. During this period, loss of sensation and movement will be almost complete, depending on the actual extent of the damage, and an injured person may not show any signs of improvement. While the doctors will know the approximate location and extent of the injury from X-rays, testing reflexes, muscles and the changes in sensation, they won't know for sure how serious the effects will be in the long term for several weeks.

## 5 Paralysis

Remembering the comparison of the brain to a telephone exchange, if the spinal cord, the main entry and exit cable, is damaged, then any spinal nerves, the branch lines, which join the cable *below* the point of damage, may be partially or completely cut off from the brain, the exchange. Lines joining *above* the point of damage should be intact and will continue to operate normally. Nerves below the damage point will continue to conduct messages, but the messages won't get through to the brain (the exchange) and messages from the brain will not reach their destination.

Injury to the human spinal cord causes paralysis, the inability to purposefully move or feel particular parts of the body. In general, the higher the level of the injury, the more limbs will be paralysed and the more the disruption to normal bodily functions. It is important to remember that damage to the spinal cord for each person is unique and the consequent effects therefore vary from one person to another.

Cervical (neck) injuries usually result in **tetraplegia**, also known as *quadriplegia*. People with injuries above the C4 level may require a ventilator to breathe. Tetraplegia means that the body, including arms, will be partially or fully paralysed – all four limbs are affected. The chest muscles will also be affected, and the individual may have difficulty with breathing, coughing and clearing the chest.

If the spinal cord is injured below the level of the neck, T1 and below, then a person is said to be a **paraplegic** and will be paralysed to some degree in the chest, abdomen and legs. Movement in the trunk and chest will depend on how high the level of lesion is (see diagrams on pages opposite).

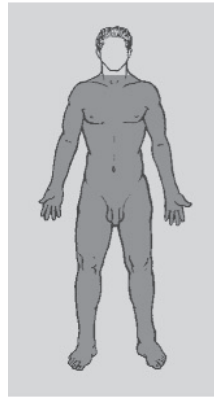
As well as the parts of the nervous system that control movement and transmit sensation, there is also a part that controls the involuntary or automatic functions of internal organs and glands. This is known as the **autonomic** nervous system. Although it is outside the spinal cord it is connected to it. It is responsible for maintaining the body's functions within the normal range such as the heart rate and blood pressure. With all parts of the nervous system working together normally it is possible to control the bowel, bladder and sexual function. Damage to the spinal cord will usually affect the ability of the autonomic nervous system to function normally.

The **level of lesion** (injury) is the exact point (segment) along the spinal cord where the injury occurred, measured by counting the nerves in the four regions of the spinal cord. The level of lesion determines which of a person's limbs and functions are affected. This is because the nerves, which control the muscles and bodily functions and provide sensation, each connect to the spinal cord at designated points.

**Upper motor neurone** paralysis is such that there is direct injury to the spinal cord above L1 where the cord itself ends. The nerves below the level of lesion no longer pass messages to the brain, but are capable of reflex action, leaving some muscle tone, reflex movement and spasm below the level of lesion.

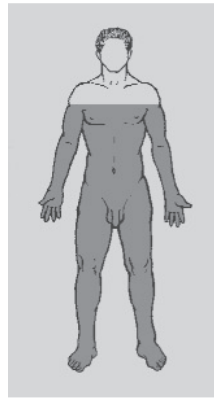
**Lower motor neurone** paralysis occurs below the spinal cord, below L1, which is where the cord ends. The damage occurs to the spinal nerves which have already left the spinal cord. This typically happens with lesions at the first lumbar level (L1) or below and results in flaccid/floppy muscles (no tone) and no reflex activity.

The extent of paralysis and the degree to which specific bodily functions are affected depends on how much of the spinal cord is damaged at the level of injury. When the whole segment of the spinal cord is damaged, it is described as being a complete injury. The result is that there is no movement or sensation below the level of the lesion.



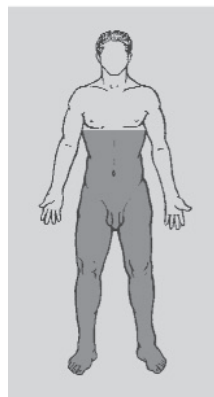
**C4**  
**INJURY : TETRAPLEGIA**

Results in partial or complete paralysis from the neck and below



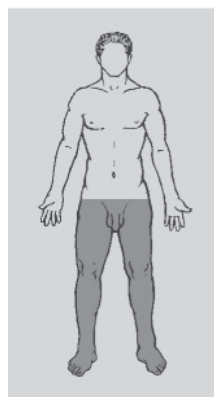
**C6**  
**INJURY : TETRAPLEGIA**

Results in partial or complete paralysis below the neck with some preservation of arm and hand function



**T4**  
**INJURY : PARAPLEGIA**

Results in partial or complete paralysis below the chest



**L1**  
**INJURY : PARAPLEGIA**

Results in partial or complete paralysis below the waist

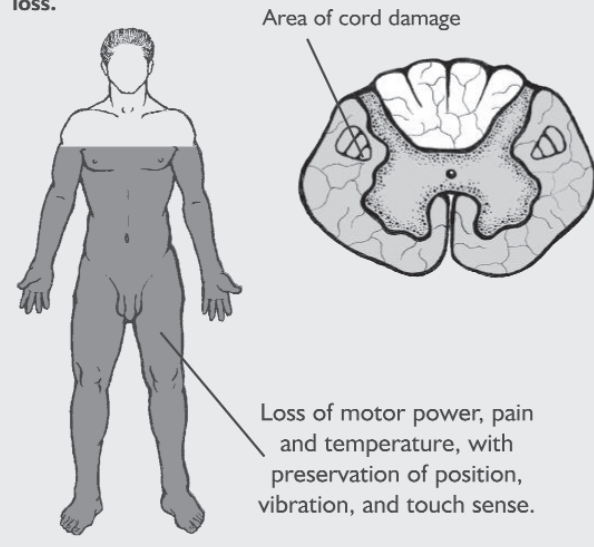
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However, many people sustain only partial damage to the cord, which is described as being **incomplete**. This results in some messages continuing to pass between the brain and your muscles and organs. This explains why some spinal cord injured people retain some sensation and or arm and leg movement, and a few are able to walk to some degree. This incompleteness makes each person's spinal cord injury unique.

Spinal cord injured people are often described by the level and completeness of their lesion. For example, someone who broke their neck may be described as having a complete C4 tetraplegia or tetraplegic, meaning their spinal cord was damaged at the level of the fourth cervical nerve, and the damage was complete. Someone who broke their back may be described as having an incomplete T12 paraplegia or paraplegic, meaning their cord was injured at the level of the 12th thoracic nerve, but they retain some function either motor and/or sensation in nerves lower than T12.

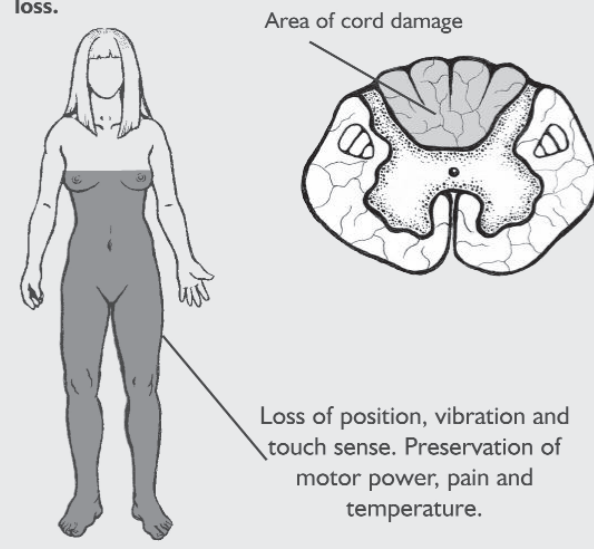
There are a number of different types of incomplete syndromes in spinal cord injury, all of which have the potential for some recovery.

**Anterior cord syndrome:**  
A cross section of the spinal cord showing area damaged and associated motor and sensory loss.

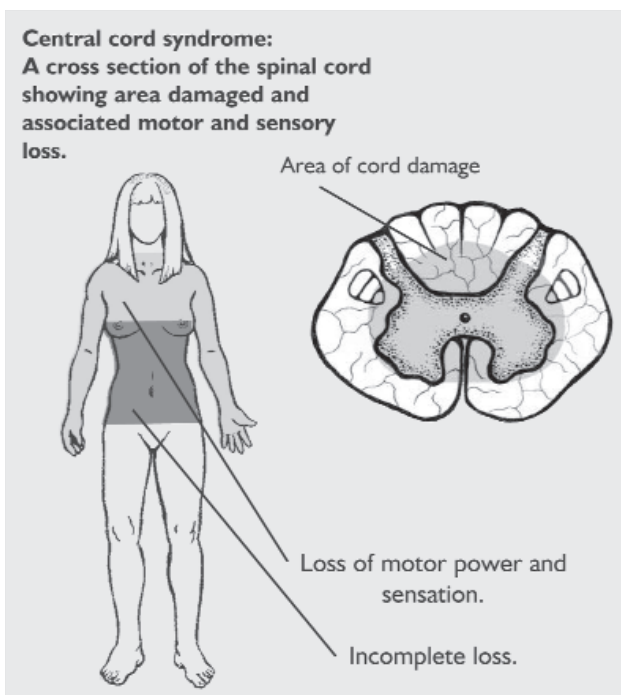


**Anterior cord syndrome:** damage is only to the front of the cord, usually leading to complete loss of movement, but with partial or complete loss of pain, temperature and light touch sensations below the level of lesion. The sensations of pressure, vibration and joint position remain intact.

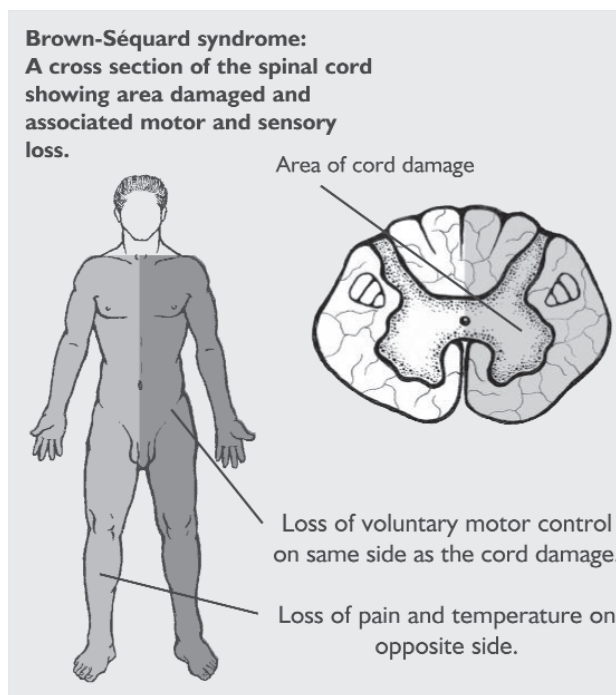
**Posterior cord syndrome:**  
A cross section of the spinal cord showing area damaged and associated motor and sensory loss.



**Posterior cord syndrome:** damage to the rear area of the cord, which preserves movement and sensations of pain and temperature, but the injured person may have great difficulty co-ordinating walking.



**Central cord syndrome:** damage is to the central area of the cord. There is usually complete loss of arm movement, but some leg function and sensation remains. Bladder and bowel function are often partially spared. Initially, people with this injury are unable to move their arms and legs but they recover slowly, regaining the ability to move and feel their legs and some sensation in their trunk. The arms and hands remain completely or partially paralysed.



**Brown-Séquard syndrome:** damage to one side of the cord, often as a result of stab injuries. Motor power is reduced or absent on the injured side, but pain and temperature sensation are relatively normal. The opposite is true on the non-injured side: power is normal, but pain and temperature sensation are reduced or absent. Therefore, people often present with one or both limbs having movement but no sensation, while the opposite limb(s) have sensation but no movement. Having a leg that you are able to control can be very helpful with dressing and other tasks.

Illustrations by Claire MacDonald/SIA



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**Cauda equina lesion:** the cauda equina is the mass of nerves fanning out from the base of the spinal cord at L1 down. Injury here can also be complete or incomplete. If the nerve roots are not completely crushed, there is some potential for functional recovery. As the spinal reflexes will not function, the bladder, bowel and sexual functioning is affected. An active support group can be found at [www.caudaequina.org](http://www.caudaequina.org)

**Sacral sparing:** Here there is damage to most of the cord segment with the outside edges being spared. This results in the sensation of the sacral area being intact. Therefore the person will have the ability to feel their bladder and bowel working but they are unlikely to have any control over them.

The precise nature and effect of paralysis will vary in each individual, and depend on age, weight, general state of health, life-style before injury, and what other injuries have been sustained. It will also be influenced by a person's psychological state and the extent to which a person is able to adapt to life with SCI. It is important to remember that every person's injury is unique and that people with the same level of lesion will nevertheless have differing levels of ability.

## 6 The effects of spinal cord injury on you

- > It is important to remember, while it is easier to think of the things you are unable to do, in time you will begin to focus on your abilities rather than your disability. Thinking in this way will enable you to have a more positive outlook and develop the new skills you need to regain control of your life.
- > You will be aware you are unable to move and unable to feel. A doctor will examine you and will be able to tell you the level of your lesion. However, this may change slightly in the first few weeks whilst you are in hospital or in an SCI Centre.
- > Initially you will be on bed rest for a period of time and dependent on the help of the nurses to meet all or most of your needs. If you do not understand anything you must ask.
- > In the paralysed parts of your body you cannot feel pressure or discomfort, and you cannot move your body to relieve the pressure or discomfort. The supply of blood to your skin is diminished and as a result you will be at risk of developing pressure sores or ulcers. Therefore you will be turned and repositioned every two or three hours to relieve pressure from your skin, preventing pressure ulcers from developing.
- > You will be unable to feel when your bladder is full and will be unable to empty it. Your nurse will explain how your bladder will be emptied, initially this may be achieved using an indwelling catheter, a rubber tube, inserted into your bladder and attached to a drainage bag. Alternatively, nurses may insert a different type of catheter, allow the bladder to empty and then remove it. This will be done several times a day and is known as intermittent catheterisation. Later you will learn more and with training you will learn how to do one or both of these for yourself.

- > You will also need help at first to empty your bowels. You will be taught how control of your bowels can be achieved.
- > As you will not be able to move paralysed parts of your body, a physiotherapist will move them for you to prevent the joints from becoming stiff or deformed.
- > You may feel 'phantom' pain in the paralysed limb(s), or 'root pain' at or just below the site of your spinal injury.
- > You may also experience spasm, uncontrolled movement caused by reflexes in the muscles of your paralysed limbs.
- > Women may find that their periods stop for a time, but they usually return to normal within a few months.
- > Men may find that they cannot get an erection. Again, this ability can return, to some extent during the first few months, but normally only if the injury is at T12 or above.
- > You may suffer from unusually low blood pressure, especially if you have a high lesion and tetraplegia. It is common to feel dizzy when you start getting up out of bed into your wheelchair.
- > If you have tetraplegia, your body's system for regulating temperature is likely to be disrupted. Often this results in your body temperature adopting that of your environment. You may find that when the room or the weather is cold so are you and you are unable to shiver to keep warm. If it is hot your temperature will rise, sometimes too much, either because you are unable to sweat or you may find yourself sweating profusely.
- > Initially you won't be able to sit up unaided, and to begin with you will be raised from lying flat only very gradually and for short periods. If you are raised too quickly you may faint, especially if yours is a high lesion.
- > When you do sit up, you may find you cannot balance without support. Your physiotherapist will help you learn how to balance your body with your limited movement and sensation.
- > You may feel very low or depressed, and perhaps angry and guilty at times. This is a perfectly natural reaction to your injury, the shock to your body, the boredom of lying flat on your back in hospital, the indignity of having everything done for you, your uncertainty about the future and your concern for family and friends. Remember that everyone reacts differently to their situation and most people find that talking to someone about their worries can be very helpful.
- > Prior to your injury, there were many things that you probably took for granted, which initially are out of reach, such as going home, to work, shopping, studying, making love, caring for children or older relatives, cooking meals, playing sport, and going out to the pub to name a few. After a while, you will be able to do all or most of these things. Although experiences will be different and often more difficult than before your injury, you should find them just as rewarding, and perhaps even more so.
- > With an individualised rehabilitation programme, and if there are no other complications, a person with paraplegia can expect to return to full or nearly full independence in anything from four to twelve months, the average time being about six months. For someone with tetraplegia it may take a year or even longer to achieve this, the average being six to nine months. When you have achieved a level of independence, it is likely that you will have the opportunity to leave hospital for a few days, often at the weekend.

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## 7 Hospital Care – an introduction

In the first few weeks following your spinal cord injury, whether it is due to an accident or disease, you are likely to find it difficult to take in much information at one time, and you are unlikely to read this chapter until later. However, during this time, the doctors, nurses and others will begin to explain, a little at a time, what having a spinal cord injury means and about the care you need. What follows is a general outline of what is likely to happen during the period after your injury, especially if you are in an SCI Centre. If you are in an hospital orthopaedic, trauma, or neurological surgical unit, treatment and facilities will be different. Whatever your situation, each hospital and SCI Centre has its own way of working and will adapt medical and rehabilitation treatment to suit each individual patient.

The treatment and care you will receive can generally be divided into four phases of care that may overlap slightly: immediate, acute, rehabilitation and continuing care. Each phase of care has a different time span, which will be dependent on your individual needs.

## 8 Access to hospital treatment

Although it is a serious condition, spinal cord injury is not a notifiable one – the Department of Health does not have to be informed. The Government published the National Service Framework (NSF) for Long Term Conditions in 2005; this long-term plan aims to improve the lives of the many people who live with neurological and other long term conditions, including those with spinal cord injury, by providing them with better health and social care services. An NSF is a set of national standards and key interventions, putting into place strategies to support the changes and developments. Key themes are: independent living; care planned around the needs and choices of the individual; easier, timely access to services and joint working across all agencies and disciplines involved.

What happens to you when you are injured will vary to some extent depending on your individual circumstances and the services in your local area. Your hospital experience and treatment will be influenced greatly by the cause of your spinal cord damage and subsequent paralysis. There are many causes, which can be divided into two general categories; approximately 80% are traumatic, the result of an accident and approximately 20% are non-traumatic, resulting from illness or disease. Therefore, it is likely that if you have sustained a traumatic injury you will have been admitted to hospital via paramedic or ambulance service and if you have an illness or disease you may have seen your GP who will have referred you to a hospital for treatment. Most people are admitted to their local hospital rather than being admitted directly to an SCI Centre and will be transferred later.

## 9 The immediate phase of care

### At the scene of accident

The treatment you receive at the scene of the accident is crucial. Today the ambulance service has highly-trained paramedics who work with recognised national standards, to assess a person's injuries and condition.

While maintenance of a free airway and breathing, control of serious external bleeding and removal from imminent danger are the priorities, paramedic staff are trained to suspect an injury to the spine and spinal cord injury in anyone who has suffered substantial trauma, whether or not they are conscious. Therefore, they will also take action to support the neck and spine when moving an injured person. This involves applying a ridged neck collar and a spinal board to prevent further movement of fractured bones that may cause more damage to the spinal cord.

Most injured people are taken to hospital by standard ambulance, but an air ambulance helicopter may be used if available, especially if the accident site is remote or hard to access by road.

### Accident and Emergency Department

Casualties are initially treated at the Accident and Emergency (A&E) Department of the nearest general hospital, also known as the Emergency Department (ED), though a few may be taken directly to an SCI Centre. It is during this time that casualties have a physical examination, X-rays and sometimes a computerised tomography (CT) scan or an MRI scan is performed to enable a diagnosis to be made. The full extent and effects of the spinal cord injury will not be known at this stage. Approximately 40% of people have additional injuries, which may be life-threatening; often to the head, chest, abdomen or limbs requiring immediate treatment and in some cases, surgery.

### General Hospital Ward or SCI Centre?

Once a clear diagnosis of spinal cord injury is made, the A&E team will make an initial decision as to whether you remain in the same hospital in an orthopaedic, trauma, neurology or intensive care ward, to arrange transfer to a neuro-surgery unit in another hospital, usually for surgery, or to an SCI Centre. This will depend on your condition, the availability of beds and the relationship between the A&E hospital and the nearest SCI Centre.

Some hospitals will seek advice from a spinal cord injury consultant at an SCI Centre on the initial management of the injured person and the timing of the transfer to the centre. Transfer to an SCI Centre is dependant on the doctors in the admitting hospital contacting them, this can be either hours or weeks following injury. Some people are treated in general hospitals without referral to a centre. However, an SCI Centre team would support SIA's view that a specialist centre should treat everyone with an SCI.

***"The Spinal Injuries Association believes it is in the interest of all spinal cord injured people to be treated as soon as possible in a specialist spinal cord injury centre, where the concentration of expertise, staff resources and equipment provides the best medical treatment, nursing care and rehabilitation work. Treatment to stabilise the condition is more likely to be successful first time and free of complications if performed in an SCI Centre."***

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# 10

## The acute care phase of care

At this point that you would ideally be referred and transferred to an SCI Centre. However, some patients may be too ill to travel. If you are referred, you may have to wait for a suitable bed to become available in a centre as not all are equipped to care for patients who need a ventilator for breathing. Therefore, some patients undergo the acute phase of care in a general hospital ward prior to transfer to an SCI Centre.

### **Surgical treatment of the unstable spine**

Approximately 40% of injured people need surgery to fix the damaged bones of the spinal column, however, no surgery can repair the spinal cord itself. Operations to stabilise the spine will involve moving the vertebrae back into alignment, reducing the dislocation, followed by inserting a device to hold vertebrae in the best position. Usually this is achieved using metal plates and screws, wires or bracing rods.

In addition, bone is sometimes removed from the back part of the pelvis and placed into the fracture site. This is known as a bone graft and ensures that over time the stabilisation becomes stronger. The hospital may perform this surgery prior to transfer, or at the SCI Centre once you have been admitted.

### **Stabilisation of the spine without surgery**

If your spine does not require an operation, you may be 'managed conservatively' which is the alternative to surgery. This involves spending several weeks lying flat in bed to maintain the correct position for the vertebrae and ligaments of the spine to heal without the need for an operation, just as a plaster cast immobilises an arm or leg, enabling it to heal.

If you have tetraplegia resulting from a cervical fracture, and are treated conservatively, you may have skull traction applied to help maintain a good position of your neck to aid healing and stability. Skull traction involves the insertion of a semicircular shaped metal calliper or circular 'halo' with pins into the skull.

### **Effects of SCI on the nervous system – including spinal shock**

Immediately after a traumatic spinal cord injury, it is usual for a patient to experience a period of 'spinal shock' lasting from a few hours to several weeks. During this time, the paralysis may appear to be complete, and the spinal reflexes, which control many body functions below the level of the lesion, disappear.

As spinal shock recedes, and any bruising or swelling of the spinal cord subsides, it becomes possible for your doctors to determine with more certainty the severity of your spinal cord injury. However, if the injury is incomplete it may be many months before it is clear whether you will recover some sensation or controlled movement in the paralysed parts of your body. Recovery can range from very slight to very significant, where there is a meaningful improvement in your physical ability.

Spinal shock also slows your heart rate, lowers your blood pressure and effects your ability to maintain normal body temperature, particularly if you have a high level of injury. Monitoring and treatment will keep them within acceptable limits. Therefore, you are likely to have special monitoring equipment and an intravenous infusion of fluids.

People with a high cervical lesion, especially C4 or above, may well have trouble breathing effectively and need the help of a ventilator for a period of time. This usually involves transfer to an Intensive Therapy Unit. Depending on the level and completeness of your SCI, you may recover the ability to breathe unassisted after a period of days or weeks. During this time the team caring for you will explain the treatment you are receiving.

Other complications which may affect a newly spinal cord injured person include deep vein thrombosis (DVT), pressure sores or ulcers, stomach ulcers, bladder and bowel problems – see *Medical Complications*. Careful management of the injured person can avoid a lot of these complications. Drug treatment will help prevent DVT and stomach ulcers.



Skilled specialist nursing will play a vital role in preventing other complications. Nurses will explain the care they provide. For example, regular turning to change your position in bed to relieve pressure and avoid the development of sores, usually every two or three hours. This will also assist your blood circulation and breathing and avoid congestion of the lungs.

#### **What you will be told**

Today doctors and other staff are more open with their patients. It is more widely accepted that people who are ill or injured not only have a right to know what is wrong with them, but also have a need to know, if they are to adjust to their situation and be active participants in their own recovery and rehabilitation. However, when you have suffered a spinal cord injury, you are likely to be extremely ill in the first days or weeks. You may have no recollection of your accident, and be unable to take on board what has happened to you. You will almost certainly be aware of your paralysis as soon as you recover consciousness. Initially a doctor will explain with care what has happened to you and what the effects of paralysis might be.

It is important to note that doctors who are not working in an SCI Centre, for example those working in A&E, are unlikely to have any specialist knowledge and as a result their diagnosis of recovery may well be inaccurate. Doctors vary widely in their communication skills, some are much better at explaining than others. Often, a nurse will talk through with you what the doctor has said and will give you the opportunity to ask more questions.

“The evening before I left the hospital to transfer to a spinal centre, a junior doctor told me I would never walk again. I hated him for it, but it was probably the kindest thing.”

In an SCI Centre, the spinal injuries consultant will be able to use their specialist knowledge and skills to explain to you that it may be weeks, and more likely months, before they can be sure of the long-lasting effects of your spinal cord injury.

“I was in a general hospital initially, then moved to a Spinal Cord Injuries Centre after one month. The doctors in the general hospital left me totally unaware of the gloomy prognosis, and it was only when I was transferred to the spinal unit that I realised the permanency of the paralysis.”

“I knew that I was paralysed, and when told that this was permanent I was determined to make the best of it.”

“The morning after the accident a neurologist came to see me. He began with: ‘It’s quite astonishing under the circumstances, but you should regain 95% of your former ability,’ but he did not explain to me exactly what had happened to my spine or the possible consequences.

“I have since thought that, had I been given fuller details at the time I might have found it easier to accept the situation in the long-term. However, it is also possible that, had I known it might all be pointless, I might not have tried as hard to get up and walk again.”

You may have some burning questions such as “Will I get better?” or “Will I recover the use of my legs, and arms, if tetraplegic?”. Your doctors will try to answer these questions as directly as possible; they may not know for certain for some time, especially if your lesion is incomplete.

Later you will also want to know what will happen to you in the future: “Will I ever walk again?”, “Will I be able to drive?”, “Will I be able to control my bladder?”, “Will I ever have sex?”, “Can I have a child?”. Again, hospital staff will try to be honest, but the answers to these questions can be unknown at the time, and so they will say that their answer is a tentative prediction, rather than a certainty. Hospital staff, including doctors and nurses, appreciate that too much information too soon can be overwhelming. They will slowly introduce more information over time. Listen to what they tell you and ask questions when you are ready.

## 11

## The Spinal Cord Injury Centres

There are eight regional Spinal Injury Centres in England and one each in Wales, Scotland, Northern Ireland and the Irish Republic – see map in Appendix 2

Each one is part of a larger hospital, usually a District General hospital, with which it shares key facilities such as operating theatres, X-ray, catering, laundry and specialist medical facilities such as orthopaedics, plastic surgery, obstetrics and gynaecology units and more. However, many centres are purpose-built and self-contained, with their own consultants, highly trained nurses, and a host of other staff such as physiotherapists, occupational therapists, and social workers who work together as a multidisciplinary team. As well as their own wards, they tend to have their own physiotherapy, occupational therapy and outpatient departments, all of which will have special equipment designed to facilitate your progress.

Due to the special needs of those with SCI, especially those with tetraplegia who are highly dependant on nursing care, the staffing levels are higher than on the general wards in a hospital. As the average length of stay in hospital for someone with a spinal cord injury is many weeks or months, rather than days, the atmosphere in the centres is quite friendly and informal as people have time to get to know one another whilst still respecting the patient-staff relationship.

#### The wards

All the SCI Centres use their wards differently, some have separate wards for acute patients and those undergoing rehabilitation. Some have integrated wards that are, where there are both acute and rehabilitating patients.

Newly injured people will be cared for in either an acute ward or an acute area of a ward. In some centres, these areas will have levels of staffing and equipment equal to that of an intensive care unit.

In general, SCI Centres have wards that tend to be divided into small rooms or bays with four to eight beds at most, and there are usually several single rooms. Individual bed areas tend to be larger than in the average hospital ward, allowing room for lifting and other special equipment. As you progress through the stages of care, you may find you are moved to a different area of an integrated ward or to a rehabilitation ward.

#### Facilities within SCI Centres

You will find that the toilets, showers, sinks and other equipment around the centre are designed or adapted for wheelchair use. For example, the toilets are likely to be different in that some will be near to the wall on the left or right, this allows you to use a toilet similar to that in your home. The showers have drain-away floors often called 'wet rooms', rather than shower cubicles, which would be inaccessible for a wheelchair user. Sinks may be at different heights and will have room underneath to allow you to sit close to them. They may also have thermostats that ensure that water is not too hot to prevent scalding.

Some Centres have accessible laundry and cooking facilities, so that when you are ready you can start to care for yourself. They may have a dining room and sitting rooms with televisions, often with digital TV channels. There may be games rooms and there are usually quiet rooms where you can spend time with family or friends. There is usually some overnight accommodation for relatives of recently-injured people who would like to stay.

Some units have their own gymnasium and hydrotherapy pool, others share these with the District Hospital. The physiotherapy department may resemble a high-tech gym, with lots of equipment for muscle development, standing and walking. The occupational therapy department is more like a workshop, with wheelchairs and numerous pieces of equipment for you to try out, and the tools for staff to modify them to suit your specific needs. Often there is an IT suite, with a range of computers to enable you to learn new skills and technology to help you keep in touch with friends and family while you are in hospital. Some SCI Centres also have sports gyms, which may be used for basketball, archery and other wheelchair sports.

### Infection control

It is unfortunate but true that some people develop infections when in hospital, known as 'hospital acquired infections' they are worrying to everyone. In hospital, it is likely that you will come into contact with many types of bacteria to which you would not normally be exposed. While those known 'superbugs', such as MRSA, have been known for many years, there are others. However, there is much that staff, patients and their visitors can do to reduce the risk of infection, the most effective is good hand washing.

### Hand washing

Hand washing is the single most important way of reducing the bacteria and viruses carried on an individual's hands passing from one person to another or from things to people and causing infection. It is important that everyone cleans their hands regularly. It is especially important:

- > after using the toilet or bathroom
- > before eating snacks and meals
- > between contact with other patients
- > on entering and leaving any ward or department.

Soap and water are very effective, but it is also acceptable to use alcohol gel instead. You will find the alcohol gel at the entrances to all wards and departments and by patients' beds. Please encourage all your visitors to wash their hands and remember to wash your own or ask for assistance if required.

You will find that your SCI Centre has their own information for patients and their visitors, to help everyone to understand how they can contribute to preventing the spread of infection in hospital and at home.

### MRSA

Methicillin-Resistant Staphylococcus Aureus (MRSA) is a bacteria that has become resistant to most of the antibiotics available and is a world-wide problem. You may develop MRSA and it will have an effect on your hospital experience.

It is important to understand that most patients are carriers of the bacteria rather than infected with it. MRSA lives on skin, and it is skin that helps it to spread, usually on the hands of health-care workers and possibly relatives and friends. MRSA is not only found in hospitals, it also lives freely outside hospitals; most people carrying it do not feel unwell, so it may go undetected.

In order to prevent the spread of this bacteria and others, hospitals attempt to contain it and the approaches used vary from hospital to hospital. As SCI Centres have patients that are from a wide geographical area, most will care for a newly transferred patient in an individual room, so that potential MRSA can be isolated and contained. Therefore, it is possible that if you are in a different hospital you may have to wait for a individual room to become available before you can be admitted. It may also affect you if you are re-admitted following your initial rehabilitation. See the continuing care phase on page 28.

Once in the SCI Centre, a set of swabs to detect MRSA are taken in order to establish your MRSA status. If any of the swabs are positive to MRSA you will be treated and re-swabbed; it may take 2-3 days for the results to be known. It is usual to obtain several clear sets before you can be moved out of isolation into the main area of the ward. This may take some time, therefore most centres have specific procedures for enabling the SCI patient to progress onto the rehabilitation phase of care when they have MRSA.

## 12 Rehabilitation phase of care

Essentially, rehabilitation focuses on enabling you to regain control over your body and your life. The aim is that by the time you are ready to leave hospital you should be able to live independently, making your own decisions. You may need assistance to do some things, but the decisions about what to do, when and how to do them, should be yours. SCI Centres probably place more emphasis on this, than any other kind of special hospital unit.

Once your condition has stabilised and your spine, including your neck, has been fixed surgically or you have completed conservative bed rest, you will begin to be mobilised. Initially this will allow you to sit up slightly in bed for a while to allow your blood pressure to adjust. Then you will be transferred to a hospital wheelchair for an increasing amount of time each day, usually using a mechanical hoist. until you are spending most of your waking hours in your chair rather than in bed. Hospital wheelchairs tend to be heavy, strong and stable, making them the most suitable for your rehabilitation needs.

Although your rehabilitation began when you were first injured, this is when your rehabilitation programme begins to become more active, when you begin to leave the ward to attend physiotherapy and occupational therapy. It is also the time when some of your personal care will change, for example being able to have a shower rather than a bed bath; often perceived as one of the great pleasures of starting rehabilitation. As the aim of your rehabilitation is that you become as independent as possible, one of the most important aspects is your education programme (see below).

"I was on skull traction for nearly seven weeks and when my traction was taken off, I was sat upright in bed for two days, and then on the third day I went into my chair and was in the chair every day after that. I don't think I was ready for my move from bed to chair quite so soon, as it took me a long time to acclimatise from a prone position to sitting up. I found I was passing out all the time and therefore attempting to do anything, like physio, was very hard."

Rehabilitation generally covers gaining knowledge about:

- > breathing
- > balance
- > mobility, including transfers, wheelchair skills, choosing a wheelchair, vehicles and walking aids
- > bladder and bowel management
- > skin care and prevention of pressure sores/ulcers
- > avoiding other medical problems (especially autonomic dysreflexia)
- > healthy eating
- > coping with the emotional and psychological effects
- > sexuality and fertility
- > adapting your home so that you can live in it (or finding a new home)
- > aids and equipment
- > benefits and money matters
- > preparing for discharge
- > access to education, employment, hobbies, travel and holidays to name a few
- > arranging your 'care package' when you leave hospital.

### Goal planning and education

If you are to regain your independence, you need a good deal of information about the nature of your injury, how to look after your body, and how to take your place in a society, which will label you as 'disabled'. Therefore, part of the rehabilitation process involves planning goals for yourself, in conjunction with your care team, who will advise and support you all the way through the rehabilitation phase of your care.

Most SCI Centres have a well-structured method of goal planning which you take part in. Its purpose is to ensure you have the opportunity to gain the knowledge and skills you need for your independence to progress and provides a step-by-step plan for each individual with an SCI. This plan will include progressing to going home, if accessible, for weekend leave with the support you need, which will continue until you are ready to be discharged.

Together with goal-planning, there will be a patient-education programme of some kind. Many SCI Centres use a combination of one-to-one teaching with you and a member of staff, together with a formal programme of classes or training sessions that you and sometimes your family can attend. These classes or training sessions are generally in addition to your one-to-one teaching, where you have the opportunity to learn with other patients in the centre at the time.

The topics are likely to include:

- > what the spinal cord is
- > the effects of SCI, be it: skin care and prevention of pressure sores/ulcers; managing spasm and pain; bladder and bowel management
- > diet
- > sexuality and relationships
- > the emotional effects of SCI and building confidence
- > looking after your wheelchair and cushions
- > driving
- > money and benefits
- > preparing to go home; life after leaving hospital; employment, travel and holidays and managing carers or personal assistants.

Often SCI people who have been injured for some time will come in as part of, or in addition to, the sessions, to talk to you about their experiences of living with a spinal cord injury.

While these education sessions will provide you with the knowledge and understanding you need, you will also need to learn many new skills. For example, how to manage your bladder and bowel care independently, how to insert a urinary catheter or insert suppositories for your bowel care. You will also need to learn about the medication you may be taking so you take it correctly and safely. The members of your team will be responsible for introducing you to these new skills at an appropriate point during your rehabilitation.

You may find it hard to focus on this training when most of your energy is taken building up your physical strength, attending physiotherapy sessions and learning to use your wheelchair. Research has shown that this combination is often the most successful in enabling you to gain the knowledge and skills to re-establish your independence. You will also receive written information packs designed especially for those with a spinal cord injury. Sessions may also be organised for relatives, to teach them about spinal cord injury and your needs when you return home.



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**Your care team**

While you are in hospital, whether a general hospital or an SCI Centre you will have a team of healthcare professionals involved in your care. Although general hospitals have similar healthcare professionals they may not work in the same way as those based within an SCI Centre and are highly unlikely to have any specialist skills in the treatment and management of patients with spinal cord injury.

With the advent of Spinal Cord Injury Centres, the first of which opened in 1944 under the direction of (Sir) Ludwig Guttmann, a philosophy of care was born. This being, that a multidisciplinary team consisting of lots of different health care professionals work together for the benefit of the spinal cord injured person and their family. The main aim to enable the newly injured person to regain control over their life and return to their local community. Although much has changed within society, and advances in medicine and rehabilitation have been clearly established, this primary aim has largely remained unchanged. Therefore, during your time in a centre you will be the central part of a care team consisting of a range of health care professionals, who are described in the diagram below.



**Nursing**

Spinal cord injured individuals require specialist nursing throughout their stay in hospital, although the emphasis changes as you progress from acute, through rehabilitation and your continuing care following your discharge. Nurses are the people that you are likely to have the most contact with during your stay. The nurses have a crucial responsibility to prevent secondary complications and teach you to manage all aspects of your care including respiratory problems, pressure sores, bladder and bowel problems. SCI Centre nurses are usually highly trained, and many have taken specialist courses in caring for the spinal cord injured patient.

The majority of the nurses work within the ward areas; however, there are also nurses working in other areas who are usually very experienced in SCI nursing. These include community liaison or case management (depending on the SCI Centre), the outpatient department, training and education, and a patient education programme. In some centres there are nurses trained in advanced skills such as Nurse Practitioners and a Nurse Consultant.

While SCI Centres structure their nursing teams differently, when you are in hospital you will have a 'named nurse' who is responsible for your care and you will be told their name. This was introduced as part of the Patients Charter issued in 1991. This 'named nurse' will be responsible with others for ensuring that you understand and consent to the care that they provide.

Nurses are fundamental in supporting you through all the phases of care. This involves the nurse explaining the effects of your SCI together with providing you with the information and training that you will need to become as independent as possible in your own care. It is important to note that the concept of independence differs for people with different levels of SCI. For example, those with paraplegia may become physically independent with tasks such as personal care, transfers from wheelchair to bed, car etc. While independence for those with tetraplegia will range from some independence with some physical and practical tasks to an inability to perform tasks themselves, but with the ability to direct and instruct others to provide for their needs.

On the whole, nurses will provide all the personal care that you need until you have the knowledge and skills to take over that care. This includes care to prevent further deterioration of your condition, particularly in the acute phase of care, and actions to prevent complications associated with SCI. It also includes pressure sore prevention, involving moving and turning you regularly, feeding you and care to maintain your continence; that is attending to your bladder and bowel to prevent accidents and infections.

“I got to learn about how my body works from my primary nurse, she taught me all those embarrassing and really intimate things in a professional and non patronising way, she got me to learn and even taught me how to smell my urine! It’s their down to earth approach and how they encourage you, how they get it across that is so vital.”

Nurses will also support you during the difficult times, when you are beginning to come to terms with what has happened to you, on your good days and on your bad days. Working through your acute care and rehabilitation is demanding, it will be hard at times and as they provide care day and night, they will always be there to provide psychological support and encouragement when you need it. With your consent, they will be involved in preparing you, your family and carers or personal assistants, for going home.

### **The Medical Team**

Most SCI Centres will have doctors with different levels of knowledge and skills. The spinal injuries consultant will be very experienced in the management of SCI throughout all the phases of care. You will have a named consultant responsible for you, together with the care team. However, it is important to note that the consultants at a Centre will support each other and it is likely that you will come to know the others.

There may be a variety of other doctors such as associate specialists, specialist registrars, staff grade and senior house officers providing support to the consultants. Although you may see your consultant frequently, you are likely to see the other doctors on a day-to-day basis as required.

### **Physiotherapy**

The physiotherapists have a vital role in your care, particularly during the acute and rehabilitation phase. They will also contribute to your continuing care needs at home if you need them. These are the ways they might help you:

**Breathing:** In the first period after injury physiotherapists will provide assistance with breathing and coughing. If you have a high lesion you may need assistance to cough, which is essential to keep your lungs clear, as you may have limited control of your chest and diaphragm. They will teach you breathing exercises to help prevent chest infections.

If you have difficulties with breathing or if you use a ventilator they will spend a lot of time with you ensuring that your chest and breathing is at its best.

**Movement and muscle strengthening:** All paralysed limbs will need to be moved regularly to maintain a full range of movement. Once your injury has stabilised, you will begin exercises to strengthen non-paralysed muscles. What can be achieved depends on the level of your lesion. Those with high-level tetraplegia may not be able to do all the things mentioned below.

**Sitting up and balancing:** One of the first things you must re-learn is how to sit up and how to balance your body, now that you cannot control your trunk, legs and feet.

“At the time, the physios were a pain in the \*\*\*\*. In retrospect, it was fantastic for my independent living and 23 years later, I’m still living independently. Not only that, but my physio introduced me to swimming. I swam like a fish before my accident but the sessions with the physio gave me the confidence to swim in my local pool.”

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"I think I have always found physios the best people. They are always pushing you to fulfil your potential when you just don't know how to manage. To find someone who works with you to find new ways to cope is essential."

**Wheelchair skills:** Once you are able to sit in a wheelchair, you will learn correct posture, and to lift yourself every 15 minutes to relieve pressure. Some physiotherapists will also encourage you to lean forwards if you are able to do so safely. Those with paraplegia can usually do this without assistance, and in time, some people with tetraplegia can also develop muscles strong enough to do so.

"Sitting directly opposite me in another wheelchair was a patient, and he was leaning forward almost touching the floor with his hands and moaning and groaning as if in terrible pain. "Blimey," I thought to myself, "where's he been?" and as if they were mind-reading, the nurse said, "Gary (the wheelchair banshee), how was physio?"

"Physio, Jesus, what do they do to you down there?" I thought to myself. Anyhow, as it turned out, he was just doing a form of pressure lift. It helps you avoid pressure sores. I was learning fast."

You will be taught wheelchair skills, and helped to develop the muscles required to propel or operate the chair. Depending on the level of your lesion, you will learn pushing on level and sloping ground, turning around, and back-wheel balancing, generally known as 'wheelies' to mount steps and kerbs.

**Transfers:** Once you have developed basic balance and muscle strength, the physiotherapist will also teach you how to transfer from your wheelchair to the bed, toilet, bath, floor, easy chair and car. It can often take some time to achieve these and not everyone will be independent in all the transfers mentioned above. Often people find that once they have built up their strength and learnt the transfers and other techniques such as dressing, they become independent almost overnight.

**Standing:** Most patients achieve this by using a standing frame for short periods at a time. Initially, you may use a tilt table to enable you to get used to being more upright and prevent feeling dizzy or faint. Regular standing helps to improve circulation, reduces spasm and may help bowel function. People with paraplegia learn how to use a standing frame safely and independently.

**Sport:** You will be encouraged to take part in sports such as archery, darts, snooker, table tennis, fencing, swimming and wheelchair basketball, all of which help to develop your balance, strength and confidence whilst enjoying yourself. Some people continue with the sport after their discharge and may go on to compete at a national and international level including the Paralympics.

#### **Occupational Therapy (OT)**

Occupational Therapy aims to enable you to become functionally independent; to get dressed, transfer from your bed to your wheelchair, move around, get into and if possible drive a vehicle, pick up and grip things, prepare and eat food, open doors and cupboards, and in general be able to do all the things you need for daily living.

While you are still on bedrest, the occupational therapist, often with your physiotherapist will assess you for your wheelchair and cushion, ensuring that they are right for you. Initially, you will be supplied with a wheelchair by the hospital. The OT will also provide the aids you need for daily living while still in the Centre. Once you are able to get up, if you are paraplegic you will learn to dress yourself. If you are tetraplegic, you may be provided with hand splints and provided with the appropriate straps, gloves and other aids to enable you, if possible, to feed, drink, wash, brush your hair, clean your teeth and shave.

If necessary, you will also be taught to sign your name, type on and use a computer, use the telephone, use page turners for books, magazines and newspapers and use other forms of environmental controls for tasks such as watching television. The OT departments in some SCI Centres have a daily living assessment suite, flat or assessment bungalow and sometimes driving assessment equipment too.

Soon after your injury, sometimes while you are still on bed rest, the OT will make a 'home visit'. This is to assess its suitability for you as a wheelchair user. She may make contact with your community occupational therapist from the local social services department. Social workers, from both the hospital and local authority, will usually be involved. This process has to be started as soon as possible, because getting alterations designed, agreed, funded and carried out usually takes many months. Together with funding for your care team if you need one, this is often the biggest obstacle to your leaving hospital.

### **Clinical Psychologist**

Spinal cord injury is traumatic, both physically and emotionally (psychologically). If you are to regain control over your life, you will need to make a whole range of difficult psychological adjustments. The process is likely to place great strain both on you, your partner if you have one, family and friends. It's not surprising that many people suffer from anxiety, and some become depressed. However, SCI Centres usually have a clinical psychologist, or share the services of one with other departments in the hospital. The psychologist may be involved in your treatment and rehabilitation. They may counsel you and or supporting nurses and other members of staff who give you counselling. They may be involved in helping you cope with the consequences of your SCI, including both physical and emotional pain; sexual problems; and in providing support and counselling for your family.

The psychologist will help you to identify aspects of your SCI that are manageable and will help you develop problem-solving and coping skills, which can increase your sense of coping and personal control. This should enable you to improve on and develop new skills in problem-solving.

Many people are frightened of psychology and don't like to admit that they might benefit from the help of a psychologist, who should not be confused with a psychiatrist. Try to set aside any prejudices you may have. At least accept that someone who is meeting other spinal cord injured people every day and observing how they deal with their situation is likely to have some ideas and experience that could be useful to you.

### **Social Workers**

Social Workers in the SCI Centre or hospital are usually employed by the local authority social services department. In the period immediately after your injury, they may spend a good deal of time with your family or friends, explaining what has happened and offering reassurance and support. They will also help with form filling, contact with police, insurance companies and solicitors, etc., as appropriate.

They will advise you or put you in contact with agencies who can advise you and your family on DSS benefits, housing, education, and any immediate assistance required while you are in hospital, including assistance with fares. Together with OTs, nurses and other team members, they play a key role in helping you plan your return home and ensuring that when you do, an appropriate package of care is available to meet your needs and establish your independence.

### **Specialist roles in SCI Centres**

Many of the centres have health care workers with different specialist roles who contribute to your treatment throughout the phases of your care following SCI. These may include respiratory specialists, spinal practitioners (may be a nurse), patient teacher or nurse consultant. All of these specialist roles have been developed to improve the services available to those with SCI.

# 13

## Visitors

SCI Centres and hospitals are usually very flexible about visiting times, and can arrange overnight accommodation for members of your family in the first days or possibly weeks after your injury. Because you will almost certainly be in hospital for many weeks and perhaps months, visitors are especially important. Even if you intend to live on your own or with paid personal assistants when you leave hospital, it is important to involve your family in discussions about your future. Sometimes if you are feeling low, trying to be happy and trying to 'entertain' visitors can be difficult, particularly if there is a constant stream of them. You may find it helpful especially in the early days if someone can arrange for your visitors to come a few at a time; having too many at once can be overwhelming. Some families and friends set up a rota for themselves, especially if they have to travel a long distance.

### Help with fares

If your family has to travel far, fares and travelling expenses may be a heavy drain on finances. Ask for advice from the hospital social worker. If your visitor is your partner, a close relative, or a close friend, and on Income Support, they can make a claim for a Community Care Grant from the Social Fund; forms are available at the DSS office which administers visitor's Income Support claims. Because the Social Fund is discretionary, there is no automatic right to payments. They should ask for a review of the decision if they get turned down.

Some hospitals and SCI Centres have limited funds to help relatives, or can suggest charities that may be able to assist. The Spinal Injuries Association (SIA) has a Relatives' Travel Fund which can make a small number of grants. Requests for assistance should be made via the hospital social worker, who will then liaise with SIA.

### Family

"My family were shocked, scared, very loving, but confused as to what the future held for me and themselves."

"My fiancée, Vanessa was at the pool-side where I had my accident, and just kept reassuring me that I'd be okay. My parents were on holiday themselves, and so it was left to Vanessa to ring them. It must have been an awful thing to do. They were just terribly shocked."

Everyone who cares about you will be deeply shocked by your injury. Most will never have experienced anything similar. People respond to such shock in very different ways, but everyone concerned needs help and support, not just you the injured person; often, whatever the circumstances of your injury, family members feel guilt and ask themselves what they might have done to prevent your accident.

Your family will experience anxieties about the future too. They will wonder who will look after you when you come out of hospital; whether they can cope themselves; how they will manage financially, especially if they previously relied on your income; how adaptations to your home will be paid for; how they will cope when you are at home, especially if they are out at work. They may also be concerned about their own deeper feelings towards you; will they feel the same and love you in the same way?





# 14

## Possible difficulties when in hospital

### Friends

"I found out who my friends were. Most people who were around at the time of the accident, apart from those who came to the hospital once out of curiosity, I'm still in touch with but lots have drifted away. That might have happened anyway. Close friends were brilliant. Being in hospital, so far from home, I don't know how I would have survived without the books, magazines, nightie-washing, food and drinks, not to mention the visits."

Most people find they lose some of the friends they had before they were injured. Often this is because you are no longer engaged in the common activity or interest that brought you together. Although you are still the same person, you may find that your interests and priorities have changed. Some of your friends may feel so shocked, anxious and uncertain how to talk to you that they 'run away'. Most people will feel more at ease if they can 'do something' to feel useful, so don't reject their offers of help, such as sending magazines or whatever, even if you don't really need them. You may also find that you develop closer relationships with friends that you were not particularly close to prior to your injury. This can often be a positive aspect, enjoy their friendship.

While you are in hospital, you will spend many weeks cooped up in the hospital unit, spending most of your days with the same group of people. It is a time of great emotional stress, your life has just been turned upside down and you are completely uncertain about your future. Your body has changed radically and you may well feel that you are no longer the same person. So it's hardly surprising if the strain is sometimes visible: you may become quiet and withdrawn; you may cry, feel angry and possibly vent your anger in the form of verbal abuse directed at staff, nurses or other people. You may get drunk, take excessive risks such as doing wheelchair stunts; and occasionally misuse drugs. Remember that each SCI Centre will have expectations of how you conduct yourself and may not allow anyone to drink alcohol on the hospital premises, they also usually have policies relating to illegal drugs and substances as well as unacceptable behaviour.

While many feel that crying is unacceptable, and may be determined not to cry, staff are there to support you, and sometimes feel that some people need a 'good cry' either in private or with someone to support them, so do not be afraid or embarrassed to cry if you feel the need. Often patients find a person, maybe a member of staff, whom they feel they can share their feelings, you may find it helpful to talk to someone.

The majority of injured people are young and male, and if you are different, you may find the social atmosphere difficult. Women sometimes feel oppressed, and that their different needs, interests and concerns are not catered for. Most people find the lack of privacy difficult to cope with. Try to talk to someone about how you feel.

Just as in any hospital ward, in SCI Centres there is a routine of daily tasks and activities geared to meeting your essential needs, such as personal hygiene, meals and various treatments together with motivating you to get physically stronger and learning to take over your care and look after

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yourself. To varying degrees, the staff and other injured people expect you to fit in with the routine. While everyone appreciates that you are going through a difficult time, and allowances can be made at the appropriate time, it is essential that you work with staff and the system. If you don't try to fit in it is possible that you will be regarded as 'a difficult patient'.

"At times I became very frustrated and was then told I was being difficult and uncooperative."

Some people refuse care, or insist on not taking part in their rehabilitation programme. When this behaviour is prolonged or persistent they may find their relationship with the staff can become strained as they are encouraged to participate. If you find yourself in this position, choose someone to talk to, such as the Clinical Psychologist, a nurse or therapist.

There isn't necessarily any cure for these problems, but if you experience them, don't bottle up your feelings. SCI Centre staff recognise that it can help the injured person to express anger or have a good cry. Try to find a member of staff in whom you can confide, or explain the difficulty to a visitor or one of the injured people returning for a check-up or who visit as peer support workers. If there is a patient advocate or hospital chaplain, you could talk to them.

Most people find it helpful to talk to other spinal cord injured people and find out what their experience has been. It is important to remember that everyone is different, and comparisons may not always be helpful; ask staff if you are unsure. People who were injured in the past return to their SCI Centres for regular check-ups, and a number of them visit the wards as volunteers; take every opportunity to talk to them. Whether you have been transferred to an SCI Centre or not, you can read about the experiences of others; join the Spinal Injuries Association and make contact through the SIA Link Scheme and *FORWARD* magazine. There are also some interesting and useful personal experiences of those with a spinal cord injury on the SIA website.

## 15 The continuing care phase

The continuing care phase refers to the care that you will receive once you have been discharged, often called 'life-long care' or 'life-long follow up'. During your rehabilitation, you will have learned how to be as independent as possible at home. All SCI Centres will provide follow-up care, which generally includes a community liaison service and outpatient clinics; most will have a telephone advice service. In addition, some centres also provide a drop-in service, where you can see a member of staff, usually a nurse, who will refer you to a doctor if necessary. The aim of these services is to support you at home, identify problems or complications early on and to promote your well-being. Your SCI Centre will encourage you to seek advice from your District Nurse or GP first.

### Nursing at home

Most SCI Centres employ nurses to visit you at home in the period after your discharge. They are known as 'peripatetic nurses' or 'community liaison nurses'. Their main focus is to provide you with the support you need as you adjust to being at home, and help you to deal with any medical problems you may experience. One of the most common is the development of pressure ulcers. It is important to contact your nurse for advice and assistance sooner rather than later. They will also discuss your care arrangements and liaise with your district nurse and other sources of support in the community.

Some centres also have OTs and physiotherapists working as part of the Outpatient Team. Their role is to provide you with practical advice and treatment as necessary. You will find, as you grow older, that some activities may become more difficult and you may need additional help or advice, this is only natural. If you wish to discuss any issues like this, you should always give them a call.

### Outpatient clinics

The SCI Centres have outpatient clinics usually run by nurses, where you can see a doctor, usually a spinal injury consultant, an OT or a physiotherapist if required. Some centres have clinics run solely by nurses, where you will not see a doctor unless the nurse identifies the need. The clinics are usually organised for different purposes such as routine check ups, seating and posture, urology and sexual function.

During routine check ups it is likely that you will have some investigations performed. You may have a renal ultrasound, a scan of your kidneys, to assess their function to ensure that there is no evidence of deterioration. You may also have blood tests, an abdominal X-ray, be weighed and have your blood pressure checked. If you have an injury of some kind or a pressure ulcer, these will also be assessed and a plan of care will be discussed with you.

Referrals to other services or specialists can be made at these clinics, which could include community liaison for a follow up visit, your local continence nurse adviser, wheelchair services, the list is vast. Remember the consultation is for you, it provides you with the opportunity to discuss any problems you have, or ask for some advice. If you have questions to ask, you may find it helpful to write them down before you leave home so that you do not forget the issues concerning you. If you would like a copy of the letter that is sent to your GP, please ask and it will be posted to you.

### Re-admission to an SCI Centre

Many people with an SCI find that they need further hospital care, from time-to-time, usually to investigate a complication of SCI and usually for short periods. Often these admissions are for a day or two only, although some can be for a longer period, if it is for treatment of a pressure ulcer, or for major bladder or bowel surgery.

Although centres make every effort to keep the waiting times as short as possible, it may be some time before a bed becomes available. In an attempt to reduce the waiting time your spinal consultant may also refer you for the same treatment to your local hospital as you may be seen more quickly. You may prefer to be admitted to your own centre but it may not always be possible or appropriate. Other hospitals have different services, which you may need, that are not available in centres. It is important to remember that following your rehabilitation your knowledge of SCI will be very good and you can direct your care if you are unable to be independent. If you encounter difficulties, please contact your centre for advice, either for yourself or for the staff in your local district hospital.

***Remember the SCI Centres are there for you. If you are ever unsure about an aspect of your care or need some information, pick up the telephone and call for advice.***

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## 16 Is there a cure for SCI and will I get well again?

The two most natural questions in the world for someone who is ill or gets injured are 'Will I get well again?' and "Is there a cure?" At the moment, there is no cure for spinal cord injury. However, there is a good deal of encouraging research taking place around the world.

Spinal cord injury is caused by an accident or disease that results in a physical injury to the cord itself; it can never be cured by drugs. Unlike broken bones, which can be set and grow together again, or damaged skin which heals and can be grafted to reduce scarring, the nerve cells in the spinal cord are unable to spontaneously reproduce or regenerate. Even when the bone or foreign bodies that caused the damage are removed, and the neck or back is perfectly aligned, the spinal cord is unable to repair itself. No amount of bed-rest, and no amount of exercise will enable the nerve cells of the spinal cord to bridge or work their way around the damaged area of the spinal cord. Equally, recovery is not a case of 'mind over matter'. Determination is useful in achieving goals during rehabilitation but it cannot repair damaged nerves.

It is quite natural to think that if the spinal cord is like a cable, with thousands of tiny wires, then why can't it be rejoined? Unfortunately, it can't. No surgery, however fine, has yet succeeded in joining or replacing the damaged nerve cells of the spinal cord.

The most hopeful path for progress seems to lie in exploring ways (chemical and genetic rather than surgical) to induce spinal nerve tissues to regrow, and to inhibit the natural mechanisms blocking growth. Research is progressing on a number of fronts, and hope is always present, but it's important that you accept that, at present, there is no cure for spinal cord injury.

If the damage to your spinal cord is incomplete, in the months after your SCI you may gradually recover some of the sensation and or motor control in limbs below the point of injury. This happens as swelling and bruising subside, not because the cord itself is regenerating. For this reason, doctors will tend to be very cautious in replying to your questions about recovery. They may not know for certain how complete your paralysis will be until a year or more after your injury.

The answer to the question "Will I get well again?" depends what we mean by 'well'. Many people with spinal cord injury would say that they are very well, indeed in excellent health. They live in their own homes and apart from periodic outpatient check-ups they seldom, if ever, spend time in hospital. Their bodies may function differently, but they have learned to adapt to that, and find that they can do many or most of the things they want to do. They have also learned to accept there are some things they cannot do and will need to get others to do for them. None of us is an island, and we all depend on others to do for us things that we cannot or choose not to do ourselves. The key is not what we can and cannot do, so much as what we control. Independence is threatened not because we need someone else to help, but when they are not available when needed, or try to help when it is not wanted.

# 17

## Current medical research

**Acknowledgement:** This text was prepared by the Research Division of Spinal Research.

### Medical Research

In spinal cord injury many cellular, anatomical and chemical events conspire against any single therapeutic intervention. It has been long appreciated that to substantially repair the damaged spinal cord will take the combined efforts of many. It will require a multidisciplinary approach with finesse of the highest order.

Spinal Research has published its third Research Strategy in the medical journal Spinal Cord. Below are a number of general therapeutic approaches being investigated by scientists around the world.

### Cell- and gene-based therapies

Major progress has been made in the areas of cell and gene therapy. Cell-based therapy includes transplanting olfactory ensheathing cells, to encourage regrowth, and also other types of cells, including stem cells, to replace the tissue that is lost by injury. In gene-based therapies genetic material is either introduced directly into cells in the injured spinal cord, or transplanted cells are genetically modified before transplantation.

### Neuroprotection

In the weeks following initial injury to the spinal cord, natural processes can magnify the size of the lesion and so worsen the resulting paralysis. Neuroprotective strategies, which aim to minimise the damaging effects of additional trauma and inflammation, are expected to form the basis of emergency treatments to be applied at the scene of the accident, at the roadside or on the sports field for example, or as soon as possible after the event.

When the spinal cord is injured, the damaged cells release chemical signals that alert surrounding tissue to the trauma. In most parts of the body, these signals are vital to the healing process, but in the spinal cord they trigger inflammation and other processes that damage surviving cells, or even cause them to self-destruct. Spinal cord injuries thus consist of an area of direct injury and a surrounding zone of secondary injury, increasing both the size of the lesion and the extent of the resulting paralysis.

By protecting uninjured nerve fibres, neuroprotective treatment could reduce or prevent the spread of the lesion. One approach being investigated is to block the communication between cells at the injury site.

### Inhibitory factors

The spinal cord contains many inhibitory molecules that stop nerve fibres from growing further once they have reached their final positions in the developing spinal cord. Scientists are developing strategies to prevent the inhibitory effects of several of these molecules and so coax nerve fibres to regenerate following spinal cord injury.

### Guiding regrowth

Researchers have successfully used growth factors to stimulate significant regrowth of nerve fibres following injury. To function effectively the regrowing fibres must also connect with the appropriate targets. One area of research is concentrating on how connections are formed correctly during development and applying this in an attempt to direct the regrowing fibres to their correct destination. Researchers are also developing synthetic guidance channels that provide 'scaffolding' along which the regenerating fibres can grow.

### Spared spinal cord cells and fibres

In most cases, injury does not completely destroy the spinal cord, even though the results can still be complete paralysis and loss of sensation. It is estimated that, providing 10% of the nerve fibres in the spinal cord survive, patients may still be able to walk. It is therefore important to determine ways to measure how much of the spinal cord remains intact after injury, and how to enhance its function most effectively. To recover function it is important to learn how to strengthen the surviving connections and to stimulate the surviving fibres to develop new connections with other fibres.



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**Combinatorial therapies**

Several independent mechanisms contribute to the outcome of a spinal cord injury. A combination of potential therapies is therefore likely to be more effective than a treatment directed at one mechanism only. This is proved by recent studies that combine cell transplants with drugs to increase the connections between nerve fibres. It is likely that more effective combinations are possible, and combination therapy is likely to be a cornerstone of future strategies to treat spinal cord injury.

**Complementary treatments**

Complementary therapies, which include functional electrical stimulation (FES), treadmill training and intensive physiotherapy, are intended to improve quality of life following injury rather than repair the spinal cord directly. FES uses electrical implants to activate paralysed muscles, giving patients control of, for example, bladder function and hand grasp. In addition, intensive physiotherapy helps maintain bone and muscle mass, which is important for general health.

Complementary treatments do not directly 'repair' the spinal cord, but there is increasing evidence that they cause beneficial changes in the strength of connections between nerve fibres, and drive and enhance plasticity of spinal and brain tissue, which can lead to improvements in function.

More information is available from the International Spinal Research Trust (Spinal Research), Bramley Business Centre, Station Road, Bramley, Guildford, Surrey GU5 0AZ

Tel: 01483 898786

Website: [www.spinal-research.org](http://www.spinal-research.org)

Other SCI Research Web addresses:

Christopher and Dana Reeve Foundation Paralysis Resource Center: [www.paralysis.org](http://www.paralysis.org)

Reeve-Irvine Research Center: [www.reeve.uci.edu](http://www.reeve.uci.edu)

# 18

## Functional Electrical Stimulation (FES)

**Acknowledgement:** This section was prepared by the National Clinical FES Centre at Salisbury District Hospital.

Functional Electrical Stimulation (FES) is a means of producing contractions in muscles, paralysed due to central nervous system lesions, by means of electrical impulses to produce useful function. The electrical stimulation is applied either by skin surface electrodes (self-adhesive pads) or by electrodes implanted surgically. In its basic form, FES is used for exercise to strengthen muscle to aid function in the case of incomplete spinal cord injury or to have physiological benefits in complete injuries, such as improving blood flow. In these applications, it is often referred to as Neuro-Muscular Electrical Stimulation (NMES).

Much of the early work in applying FES with spinal cord injured people was directed at producing standing and walking in paraplegics. Several surface electrode systems have been developed; the ParaStep system enables basic gait over short distances while the Odstock standing system used knee angle feedback to ensure that standing can be safely maintained. Implanted systems continue to be investigated, but these are still under research and development programmes. One example is the LARSI system; developed at University College London and trialled in Salisbury, it uses electrodes implanted within the spinal canal.

FES can also be used to improve mobility following incomplete spinal cord injury. A common problem is the inability to lift the foot as the leg is swung forward while walking. The Odstock Dropped Foot Stimulator (ODFS) is a single channel device, controlled by a foot switch placed inside the shoe. When pressure is taken off the switch, a stimulus is delivered via skin surface electrodes, causing the foot to lift. The device has been shown to reduce the effort of walking, making gait faster and safer.

A two-channel version of the same technology is available, allowing the activation of additional muscles to correct more complex walking problems. An implanted stimulator (STIMuSTEP)

is also available; implanted electrodes are inserted into the two nerves that help to lift the foot and position it correctly for placement. These FES devices are available through Odstock Medical Ltd, an NHS-owned company based at the National Clinical FES Centre.

More recently, there has been growing interest in FES cycling and rowing for paraplegics as a means of maintaining fitness as well as a recreational pursuit. In FES-cycling, recumbent tricycles are used and distances of several miles are possible. Systems using static exercise bikes are also available. In FES-rowing, static systems are used, but there is work being undertaken to trial the system on open water.

Several research teams have investigated the use of FES for hand function in tetraplegia. One device is the Ness H200 (formerly the Handmaster). Intended for C5 lesion tetraplegics, this system uses skin surface electrodes mounted on the underside of a brace that supports the hand and wrist in a functional position. Users are able to open their hand and grasp objects such as a fork, cup or pen. An alternative implanted system is the Freehand developed by Case Western Reserve University in the USA. This device stimulates eight electrodes in the forearm and hand; aimed at C5 and C6 tetraplegics, producing a functional key and power grasp, enabling objects to be grasped and released, brace free. Unfortunately due to commercial reasons it was withdrawn from market.

Finally, perhaps the most successful FES devices used with the spinal cord injured population is the FineTech-Brindley (also known as the VOCARE) Bladder system. This medical device has been used by many people to empty their bladder, or urinate, on demand. Secondary uses of the device are to aid bowel evacuation and promote penile erection.

### Who can use FES?

FES can be used if the spinal cord injury is at T12 or above. Below this level, the nature of the spinal cord changes, it degenerates if damaged and is not excitable. Nerves can also be damaged at the level of the spinal cord injury, also resulting in non-excitabile muscles. Side effects are few. There are occasional skin irritations to surface electrodes and spasticity can be adversely affected. People with lesions above T6 can also be affected by autonomic dysreflexia in response to the stimulation. Implanted systems carry the usual surgical risks.

All forms of FES require commitment from the user to follow regular and often lengthy treatment protocols. Therefore, motivation is important if good results are to be achieved. FES should always be used under expert clinical supervision.

Contact details: National Clinical FES Centre, Department of Clinical Science and Engineering, Salisbury District Hospital, Salisbury, Wiltshire, SP2 8BJ.

Tel. 01722 429065,  
Website: [www.salisburyfes.com](http://www.salisburyfes.com)

Related weblinks:

The International FES Society: [www.ifess.org](http://www.ifess.org)

VOCARE:  
[www.finetech-medical.co.uk/product-bladder.htm](http://www.finetech-medical.co.uk/product-bladder.htm)

Ness H200: [www.nessltd.com/hcp/nessh200.ecp](http://www.nessltd.com/hcp/nessh200.ecp)

FES-rowing: [www.fesrowing.org](http://www.fesrowing.org)

FES-cycling:  
[www.medphys.ucl.ac.uk/research/impdev/idg/cycling.htm](http://www.medphys.ucl.ac.uk/research/impdev/idg/cycling.htm)

Odstock Medical Ltd: [www.odstockmedical.com](http://www.odstockmedical.com)

LARS: [www.medphys.ucl.ac.uk/research/impdev](http://www.medphys.ucl.ac.uk/research/impdev)

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## Feeling and Coping Strategies

### 19 Tendon Transfers

**Acknowledgement:** This section was written by Julie Esnouf.

Upper limb re-constructive surgery or tendon transfer surgery is now an accepted procedure around the world to improve upper limb and hand function for tetraplegics. Several centres around the UK now offer this service. It is very important to be assessed by experienced surgeons and therapists to determine whether surgery is applicable for you. The surgery available will not fully restore your previous upper limb function.

A person who has tetraplegia will lose the ability to use some of the muscles in the arm and hand. The number of remaining muscles left working will depend largely on the level of the spinal cord lesion and on any nerve damage outside the spinal cord. The remaining muscle may duplicate movements provided by other muscles, or provide less important movements. By disconnecting one end of the tendon and reconnecting it to another site, the muscle can be made to perform a new movement, which will be of more benefit.

The aim is to improve the hand or arm function that you have. The benefits are different depending on what muscles you are able to move. Possible aims may be to gain active elbow straightening, to assist with transfers, wheelchair mobility and reach or to provide a key pinch or power grasp. Active wrist or finger extension may also be possible.

SCI individuals who have had procedures carried out speak of improved function and ability and improved quality of life, examples include being able to transfer more easily from wheelchair to car, eating, brushing teeth and writing without splints. If you are interested, you need to speak to your Spinal Consultant or ask your GP for a referral.

### 20 Your emotional needs

**Acknowledgement:** Sections 20 -24 were written by Kate Lobleby (C5/6).

During rehabilitation the emphasis is likely to have been centred around practical matters and learning how to physically cope. You may have felt that you 'just have to get on with it' and that 'no one has any idea how I feel inside'. You may even appear to be functioning quite normally. Spinal cord injury causes a great trauma to the body and you have suffered a tremendous loss, which has probably also had a devastating impact on you and your life as you knew it.

***It is equally as important for you to take care of your emotional needs as it is for you to take care of your physical and practical needs.***

Just as there is no magic cure for an injured body, there is no instantaneous way of healing psychological pain. It may help, though, to know that all your feelings, whatever they are, are a natural and understandable response to what has happened to you. You are not alone. Other people with spinal cord injury, and those with other serious illnesses also experience these feelings. Try to express your feelings, share them with others and if necessary talk to a professional counsellor for support.

At first, you may find it hard to take in all that has happened. You may find it difficult to understand what you are being told. You may also be confused and surprised by the power and overwhelming nature of the feelings you are experiencing.

#### **Understanding Your Feelings**

It is only natural that you may experience your loss as a bereavement; grieving in your own way and in your own time. It may help you to deal with your feelings by understanding some of the emotions you might go through. There is no set order to the way you may respond. You may fluctuate between all sorts of feelings and emotions at any time and at any stage.

**Disbelief and Shock:** It is possible that your first reaction will be disbelief and shock, most often described as a feeling of numbness. It is a sense of being unreal or unfamiliar to oneself, as if you are not really involved with what is happening to you. It can also seem as if your feelings are so strong that they are 'turned off'.

**Denial:** You may also experience denial. This is a natural defence against feeling overwhelmed with emotional pain. Believing that you will soon get better, and all your suffering will go away, is a coping mechanism that can help you to get through the day.

If you already understand the physical reality of what has happened to you, you may not feel these things, but some people need to take their time to acknowledge what has happened.

"I kept thinking that this is me. I'm not a disabled person. I must be different, and get better, because I'm not meant to be disabled."

"I didn't know that if you broke your neck you would be paralysed. I'd never even thought about it before. I found it hard to understand that this was true."

"When I was told I'd broken my back I knew exactly what had happened to me and resolved quite early on to just get on with it. I couldn't change the situation, but I could get as strong, fit and healthy as possible, to lead an active life."

**Exhaustion and Confusion:** Grief and stress can take its toll with physical exhaustion, sleep disruption, headaches, infections, stomach upsets and racing pulse. You may also have times when you feel unable to think straight or make even the simplest decisions. You could feel confused and 'slow' or suffer temporary memory loss. Inner turmoil can deplete energy and make you feel disorganised, so try to get all the rest, exercise and nutrition you need to help you get through this.

**Anxiety and Stress:** It is understandable if you have feelings of anxiety and stress. The whole environment and situation is unfamiliar and can seem quite frightening. You may have fears of losing control of your feelings, feelings of panic, of not being able to cope, of never getting over this or ever feeling better.

There is also the enormous anxiety of the unknown and how to manage physically. You are likely to have worries about making the right decisions on so many important things. You may have to decide where to live, what type of adaptations you will need, studying, going back to or changing your career, which can all be stressful for you.

You may be finding it difficult to cope with managing ongoing responsibilities. You may be worrying about not being able to pay the mortgage or other financial commitments. There are so many things that can add to feelings of anxiety or stress.

"All the time I was confined to bed I worried about my pregnant wife and young child left at home to manage everything. Visiting was difficult too, because she had to get someone to bring her. It was a very stressful time, but somehow we got through it."

You are likely to miss family, friends and your home environment. SCI Centres are regional, so you may be some distance from home, making visits difficult for your family and friends.

"It was tough only being able to see my family once a week. Friends managed to visit when they could. At least I could see them or speak on the phone. I actually missed my dog more! When I saw her after some months, we both went mad with delight!"

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While you are in hospital you have little or no control over even the most elemental bodily functions, the very ones over which the acquisition of control marked the passage from infancy to childhood. You seem to have no privacy and to be reduced to the status of an object, to be turned, fed, evacuated and washed. To some it can feel like a very shaming experience and be difficult to come to terms with. This is especially so if you have previous body image inhibitions, fear of intimacy, or abuse issues, to add to your distress. These can all have a huge impact on how you react to what is happening to you.

"A nurse said 'Remember not to mind anything that is done to your body while you're here, or what your body does to you. In fact view it as if you have left your chastity bag on the doorstep on the way, which, hopefully, you'll pick up on the way out.' This was the best possible advice anyone could have had and such a good description. I had always been so independent and it had never occurred to me that I could lose control over my bodily functions."

"At least being on a spinal unit there was a lot of comradeship, but with my back injury, I felt guilty 'moaning and moping' about it, when there were worse neck injuries. It shouldn't have to be like that."

"I don't remember much about when it happened. I was a child, but I remember feeling frightened, embarrassed and vulnerable. I found rehabilitation hard and I was criticised for not trying hard enough, particularly with bladder management."

**Anger:** You could have times when you feel angry. You may feel angry with yourself for being in this position and not feeling able to do anything about it. Your anger could be against the doctors or nurses for telling you the bad news or not helping you enough. You may even feel angry against your God or fate for being unfair. You could just feel angry with everyone and everything, as well as resentful to see life going on as normal around you, while your life is in turmoil.

"By the time I got out of bed I was so frustrated and angry. I pushed myself so physically hard in physio, just to get out of that place as quickly as I could."

Anger is a natural survival response and can be a healthy way to defend and ensure our well-being and to want more. Use it as a stimulus to overcome as many obstacles you can, and to get on with taking responsibility for how you can manage this traumatic time.

Anger can also be destructive if not channelled in a positive way. Anger expressed in an aggressive way is not constructive and can be demoralising for yourself and others. It may be instinctive to have outbursts of fury or even internal rage, but it is not helpful or constructive in any way.

The traumatic experience of your spinal cord injury may bring to the surface other previously unresolved psychological difficulties, like how you felt about yourself and your life before, or problems in your relationship with your partner, family or friends. If this happens, it is important to try to recognise these other factors separately and not necessarily as a consequence of your injury. It may feel easier to blame your disability, but it won't make it easier to resolve the issues.

You may idealise the lifestyle you had, whatever the difficulties before. This is quite understandable, because at least it was a life that you chose.



**Depression:** You could possibly go through a time of depression after the trauma you have experienced, as well as the day-to-day stresses and difficulties of living with a disability. You may even feel so low sometimes that you just don't want to see anyone or do anything. This phase is a powerful statement that you need the time to acknowledge your emotional pain and to work it through, before you can face the world again.

There is a difference, however, between experiencing sadness and bereavement for your loss, as feeling depressed; and clinical depression. The first is a stage of temporary despair and despondency, combined with an acknowledgement that you need to face the challenge before you.

Clinical depression can manifest itself when the same feelings of despondency and despair become a relentless preoccupation, which can be overwhelming and debilitating. Your self-esteem and feelings of worth may be so low that it could be easy to think 'what is the point'. You may even feel suicidal sometimes. You don't have to feel so bad all the time. You don't have to feel ashamed of being depressed, either. Sometimes after a trauma and during stress the body physically becomes chemically unbalanced, making you feel this way. With the right help, this is something that can be overcome.

"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."

"Two months into my rehab someone mentioned to me that I was coping well and didn't seem depressed. They said that if I was to come to terms with my injury I should have been depressed by now! I went to see a psychologist to see if they could help but was told that not everyone gets depressed and that my response was quite in character for me. He added that I should keep coping in the way that suited me."

You may experience a delayed reaction, appearing to cope well at first, or having times of hopefulness and planning for the future, and then later on, when life throws up difficult challenges, find yourself feeling depressed. There are no guidelines on emotions, no right or wrong. It is just how you feel.

**Resolution:** In your own time, you will realise that there are ways of coping, beginning a new life and having aims and ambitions. You will find that it is possible to discover a manageable acceptance of what you need to do, to make your new life work for you. You can also find satisfaction in the things that you can do.

#### **Relationships**

Relationships can be particularly stressful early on, when there may be a lot of uncertainty about your future. Those close to you will be experiencing their own emotional stress and anxiety about possibly also having to adjust to new roles and responsibilities with you.

You may feel that you have to be strong for them. When you are not feeling well or feeling depressed it can be very difficult to talk, and you may feel resentful and frustrated about having to cope with other people's emotions as well.

You may even be feeling guilty about having your accident, being a burden or upsetting those close to you.

"My family were brilliant. Still are. But none of us were 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 a scab and made it bleed."

You may find that your family, friends and colleagues feel unsure about how to respond to you. There may be some who will irritate you by being over-protective or come across with false jollity. Others may become distant rather than risk saying the wrong thing. It is important to remember that these initial reactions may have much more to do with their own past experiences and their own powerful emotions, rather than to do with you personally.

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They may wait for you to say what you are wanting, and want you to approach any issues between you. Sharing how you feel, what is happening and being as open about your needs, fears and hopes as you can, will help others to attempt to understand what you are going through, enabling you to face the challenge of SCI together.

Your relationships will inevitably change in some way. This is something that you do need to work on together, when you are clear about your future needs and desires. This is not only true with partners, but with other family members and friends who are close to you. Many relationships have been deepened and enhanced by the honest sharing of feelings, closeness and love they feel for each other after SCI.

Only you will know the relationship that you have with your partner, and how you will both deal with the impact a spinal cord injury has on your lives.

"My wife was amazing and between us we managed to get through all the problems together."

"I had only been going out with my girlfriend for three weeks before my accident. She didn't stick around and I don't blame her. We weren't really suited for a long term relationship anyway."

Children, as with adults, may react in many different ways to your injury. Some of these can be hard to deal with. Remember, bad behaviour, withdrawal or becoming clingy may be covering up feelings of insecurity or anxiety. Adolescents may become angry and resentful, fearing that they are being forced back into the family, just at the time when they are wanting to gain their independence.

Try to explain what is happening to your children in ways they can understand, otherwise they will know you are hiding things from them and worry. The fear of the unknown is just as hard for them as it is for you. Reassure them that you still love them and will still 'take care' of them. This is the most important issue.

### Body image

Even if you didn't have the perfect figure or ideal body before your accident, it was still your familiar body; for all its 'faults', you were probably accepting and living in it happily enough. It can seem hard for a person to actually like their body now it doesn't function 'normally', doesn't feel like their own familiar one, feels like 'public property' and feels scarred or shapeless.

"I was devastated when a physio said my legs were very spastic. I don't think she realised just how traumatic an impact that had on me."

It is possible over time, to become familiar with the way your body functions. SCI Centres teach you all the necessary procedures, and you will learn how your own body works for yourself. It is also possible to learn to like yourself again. You are still you. Enhance your assets and look as good as you can. Find information on clothing to allow you to do the activities you want, to suit how you want to look, and for ease of use to put on and take off.

"In hospital, the nurses barely had time to wash and feed me. I felt embarrassed asking my sister to pluck my eyebrows when she visited, but it was better than having bushy eyebrows. The first thing I learnt in OT was to put my mascara on."

Attractiveness, as well as sexuality, is more a way of being rather than what someone actually looks like. A disabled person can also be a very attractive and sexy person. Attractiveness shows from within. If you feel that you are inwardly worth loving, you will radiate this to others.

Read more about sexuality in *Sex Matters*, another booklet in this series.

# 21

## Outside - in the community

### Other people's reactions

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

People can often make a number of assumptions about what a disabled person is like and what they can and cannot do or even should and shouldn't do. Most people will, as hoped or expected, not treat you any differently, but it is usually that one comment that upsets us, that we tend to remember. You may be feeling particularly sensitive, and having someone 'pointing out' the disability can be particularly upsetting.

They can behave in ways that are perhaps evasive, such as a refusal to make eye contact. They can be patronising, assuming that you are incapable of doing something or knowing something. They may treat you as if you are not there, as in "Does he take sugar?" Some may be condescending, such as "It's such a shame, you're so young". They may also ask intrusive questions, like "How do you go to the toilet?" Some people can be just rude. It can be tough not to react to this behaviour, but such people have their own unresolved personal issues and they are likely to be projecting their own 'stuff' on to you. They are in need of being informed and educated about the real you. Humour can sometimes help.

"When someone once said to me 'It's such a shame, you're so pretty', my immediate reply was 'Yes, it should have happened to someone really ugly'. Everyone fell about laughing and it was obvious what a silly comment it was."

It may also be helpful to separate the impact some people's comments have had on you from their intentions. They may have no idea how they effect you. They may even be trying to pay you a compliment, but it came out wrong. Some people do just say silly things because they feel that they have to say something.

"I'm often told how brave I am and that they wouldn't be able to 'do it'. I tell them that I don't really fancy the alternative right now."

### Self-esteem and identity issues

We tend to like, value and judge ourselves by our achievements. Our identity in life is often defined by what job we do, and if you can no longer do it because of your disability, you may go through feelings of inadequacy.

You may also doubt your abilities in fulfilling normal roles in life, such as a husband or wife, father or mother, friend, etc. It is important to remember that you are still the same person, with the same personality. You are just as capable of fulfilling these social roles as you were before.

"After my injury I found it very depressing to read women's magazines. I felt as if they just didn't relate to me any more. I was not able to be a 'normal' female. Being 18, I felt that no man would want me anymore and imagined I would lead a lonely life without even a career as compensation. I did get a boyfriend, who helped me a lot, not only with realising my sex life wasn't over, but with my self esteem as well. I went on to have other relationships and trained for a career. I am now in a deeply fulfilling, long-term relationship and still enjoying a good career. I also feel 100% woman!"

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Remember that you will always have a role in life, whatever it is, even if you think you are managing it badly. Even if you are not able to have as much physical input as before, none the less you can still organise things, be responsible for the activity/ situation and give emotional support. Value your contribution. Many SCI men and women find that they are doing just as much and feel just as 'put on' as before!

Self-esteem and the esteem of others can also be regained by a sense of achievement in the completion of realistic tasks, however 'small', and also by being allowed to experiment and work things out in your own way, having been given the necessary information, guidance and encouragement of others. People have an intrinsic need to feel useful and productive. Take every opportunity you can to be in control of your life, and to make the most of your abilities and talents. It is possible to adapt your abilities, learn suitable new skills and enjoy a new career.

Many people and society in general have negative beliefs about disability. You may have held these attitudes yourself. Such prejudices make it natural for a newly injured person to despair and feel that they won't be able to do anything worthwhile. There is plenty of hard evidence to the contrary, in the life experiences of many thousands of people who lead happy and interesting lives after SCI. Seek as much information as possible and talk to other SCI people about how they manage.

You may feel that 'It's all right for them, but they're not me' or believe that 'I obviously feel worse than them and have more problems' or 'I know I will never feel happy again or be able to cope'.

"I felt that if I tried to come to terms with it, I'd be admitting I was disabled and I didn't want to do that."

Many SCI people start from some or all of these assumptions, then go on to enjoy a good quality of life. This might seem strange and unlikely, but it is a tribute to the personal strength and adaptability of most ordinary people when faced with extraordinary circumstances.

### Independence

Being independent has come to be associated with being self-supporting and self-reliant. Not being able to do some things for yourself may make you feel that you have lost your independence. Remember that no one is entirely self-sufficient. Even the most powerful people in the world rely on others to do some things for them.

The important thing is not what you can physically do for yourself, but what you can organise, manage and control to get your needs met. Being in control means being able to decide what you want to happen and then making it happen. So even if you need day-to-day care, you are still being independent by deciding and choosing what you want, where you want to live and how you want to go about doing it. It need not matter that you cannot dress without assistance, provided you choose when, how and what you want to wear.

### Being sociable

Loneliness and feeling isolated can become an issue when you are physically unable to get out-and-about to all the places you would like to go. It is important for everyone to have friends and a variety of interests. Make every effort to stay in touch with friends and to meet new people.

The opportunity to meet people is obviously important. If you are working, have a social life and get out-and-about generally, then you are more likely to meet different and interesting people. If you are not meeting lots of people, then you may need to consider making a conscious effort to place an emphasis on your leisure time, not only to broaden your interests, but to socialise. Your ability to meet people and lead an active social life may depend on you sorting out a few basic problems, such as transport and requiring personal assistance. It is important for you to do this, if you don't want to miss out on a valuable part of life.

If you already employ a personal assistant and cannot go out or travel without them, make sure that you go out with them on a regular basis, just to socialise with others. Social needs are so often forgotten in the false belief that it is not strictly necessary and it is asking the assistant to do even more. You are also entitled to go out 'for no definite reason'.

You may have times when you feel alone even when surrounded by others, particularly when you feel that they don't understand your disability, or that you don't feel as if you are able to fully participate in the activity. Your presence is still valid and you are contributing by just being there. There is no obligation to do anything that you don't want to or are unable to do. Try not to let an experience like this put you off going places or doing something. Just do it anyway. The next time, or the time after, may be more enjoyable.

It is also important to accept that there may be times when you just do not want to mix socially and prefer to be on your own. It is unlikely that you will want to talk and be open all the time. Everyone needs some time alone. Time spent focussing on yourself can be a powerful statement that your life is still your own.

## 22 Coping with physical stress

### Pain

Living with physical pain can be very debilitating and overwhelming. It can distort how we are able to function. If we feel controlled by pain, we can feel helpless. It is important to explore as many options as you can and not to let pain dominate your life.

Some professionals may underestimate how deeply physical pain can affect how you feel. They may not be able to understand how someone who is not supposed to have any feeling below their level of injury can feel such pain. There is well-documented evidence that this pain is real. It is often called 'root pain'. There are now Pain Clinics offering advice and information on this. Even if you are unable to 'make it go away' completely, it is possible to learn strategies and ways of making pain more manageable. This will enable you to get on with life, rather than feel so distracted by pain.

"As a woman with pain, the medical professionals fell back on the 'hysterical female' theory. Because it is unseen it is difficult to prove. Living with chronic pain used to be a battle - I'd force myself to fight it and tried to conquer it with morphine and willpower. It was exhausting. Now, thanks to a great pain clinic and consultant, together with the use of alternative therapies, I try to live with it peacefully and accept it as part of me."

Coping with physical pain is covered in more detail in the *Moving Forward* booklet - *Your Health and Well-being*. You may also like to try one of the therapies detailed in *Complementary Therapies*, another booklet in the series. See page 56 for more details.



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### Post Traumatic Stress Disorder (PTSD)

PTSD is a natural emotional reaction to a deeply shocking and disturbing experience. It is a normal reaction to an abnormal situation. Often the traumatic event is re-experienced with recurrent and intrusive distressing recollections, including flashbacks and dreams. There may even be an acting out or feeling as if the event was actually recurring. There will also be distress at exposure to cues that resemble an aspect of the traumatic event.

"I woke up after a long operation, some years after my neck injury, believing that I was recovering consciousness after my car accident. I was very frightened, because no one around me believed me when I asked them to take care of my neck."

'Every day' symptoms of PTSD can be like anxiety attacks, which you may experience when you are overstressed. Reactions also include: difficulty in falling or staying asleep, irritability or outbursts of anger, difficulty concentrating, hyper-vigilance and an exaggerated startle response.

"Whenever I hear a sudden loud noise I 'jump out of my skin' and my body just shakes, even after I've mentally assessed that I'm not in danger. I am remembering the crash.

Understanding this reaction has really helped and I am able to not let it bother me. If someone witnesses my reaction I laugh and say 'Ohh, me nerves!'"

Other reactions include: feelings of detachment or estrangement from others, markedly diminished interest or participation in significant activities, efforts to avoid anything associated with the trauma and a sense of a foreshortened future.

There has been much research into PTSD and many counsellors are trained to work with these issues. If you feel that you have PTSD symptoms, which affect how you function in life, it may be worth seeking help.

## 23 Coping with...

### Depression

Some people's emotional make-up means that they don't get depressed. You may experience your disability in problem-solving and managing terms, and deal with the situation in this way.

You may, however, find yourself feeling depressed all the time and feel so overwhelmed with apathy that it prevents you from dealing with the challenges, moving on and building a new life and relationships. You may feel despair, helplessness and hopelessness. You may also feel an emptiness and withdraw from activities and friends, or not sleep or eat as usual. It may be useful to seek some help and support with these feelings, while you learn how to deal with them. Your doctor can discuss with you whether you need a temporary course of anti-depressants or counselling, just to help you through, until you are able to realise that you can have a rewarding and enjoyable life.

There will always be times in life when people feel sad, unhappy and generally depressed. Sometimes it can feel like life is filled with frustration, pain, loss and the unpredictable actions of others. Try not to overgeneralise, believing that your life is 'all bad', because of your disability. Some things you can't change, but you can change the way you let such events affect you.

Try to understand whether you are feeling emotionally depressed because you are sad or because you are frustrated. What is it that has triggered these feelings? You may be able to narrow it down to a particular issue or situation. Try to separate different feelings and situations, rather than feel overpowered by seeing everything as wrong. Focus on one thing at a time. Assess what you can do about it. Seek as much emotional support and information as possible.

Decide to turn adversity into a challenge and get involved in making your life work better for you. Believe that you do have choices in how you deal with situations. Expect some frustration, sorrow and disappointment, but decide to focus on what you can do, rather than what you can't.

## Anger

It is almost impossible not to get frustrated about things you cannot do or cannot have. Some anger can actually be a motivating force to make the positive changes you want in life. Take these opportunities and use them for your own good.

Be aware that anger towards others can put people on the defensive and less likely to help you to get your needs met. Expressing angry feelings in an assertive manner is more productive and respectful. If necessary, back away from a situation and 'take time out' to recover your judgement, before addressing the issue again.

"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 co-operate, but everything became normal and settled down as the years went by."

The first stage in resolving anger is working out what you are specifically angry about and why. This can be more complex than you first think, because what you may think is the obvious reason may be the result of some other deep-rooted feeling. If you feel that your anger is limiting your ability to resolve situations, you may find it useful to talk it through with a professional counsellor who can help you to identify the underlying reasons or causes.

"Going to a therapist for a talking cure seemed very self indulgent and slightly sad that I had to pay someone to listen to me. What I talked about was me, but most of it had very little to do with my SCI. I learnt that it's OK to be angry. It never was at home, no-one did it. It's OK and safe to express it appropriately."

Your anger can affect every area of your life, if you are unaware of how powerful it is or how to deal with it. Unexpressed anger can lead to cynicism and hostility and general grumpiness. Let off steam in a way that causes no harm. Scream (where you will not startle anyone). Punch a pillow. Remind yourself that the world is not 'out to get you'. You may have real and inescapable difficulties, but the best attitude is to focus on how you can handle the problems. Resolve to do your best, and not to punish yourself or others. It is much more rewarding to know that you are dealing with adversity with your best intentions and efforts.

Cultivate your sense of humour. Try to see the funny side of things, however unlikely that may seem. Even life's most tragic occurrences contain things that can be absurd and can trigger laughter. It may appear inappropriate, but underneath anger and emotional pain is a natural capacity for joy. Laughing is a great positive energy booster and can help to release the emotional pain.

"When I feel frustrated and angry I say to myself 'I'm a bit upset' and then laugh at the understatement. It actually helps me to let go of pent up emotions."

## Fear

Fear of the unknown, of being able to cope, being alone, intimacy, ageing and any other issue, can make someone feel stuck and unable to do anything about their situation. Some fear is instinctual and healthy and keeps us alert to trouble. It enables us to perceive when we are actually at risk. Other fears are because of lack of confidence and self-esteem. Confronting your inner fears and just 'doing it anyway' can help to build self-confidence and a sense of achievement. Believe in yourself and acknowledge your strengths.

Not only can we fear failure, we can also fear success. You may desperately want to make changes in your life, but because it has been such a long time since your injury, you may feel that you have to face justifying why you didn't do something before. It is just that the time is right for you now, but it wasn't before. There is no shame in timing, however many years it takes for you to manage to overcome or do something.

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### Confidence

To some people confidence comes naturally, whilst others have to learn how to be more confident. There are likely to be many times when you will need to be assertive to get your needs met. You are also responsible for learning how to manage your disability, and how you are going to live your life. Becoming spinal cord injured is usually a sudden and unexpected event and you need to equip yourself with new tools and develop an understanding for how you can achieve this.

Initially you will have been shown different ways of doing things, which you adapt to suit your own needs. Life is a learning process and along the way there will be many occasions when you will need to work out how to accomplish something.

Start with small, easy tasks or gains. Divide each major task into sequences of less complicated actions. If you start with unrealistic goals or time frames you will almost certainly be unsuccessful or overstretch yourself. Don't aim for perfection. Your best is good enough. Try not to expect too much of yourself. Give yourself permission to not always succeed. 'Failure' can be a learning tool. Think of it as a temporary by-product of creativity or inventiveness. Take informed risks and tolerate the setbacks. See possibilities, and remind yourself that no achiever gets there without some failure.

It takes energy and effort to succeed, so in the meantime try not to lose track of the incentives. Acknowledge all achievements, however small. Give yourself credit. Get something out of simply going after your goal, of doing something positive and taking responsibility for yourself.

Accept offers of help. You don't need to 'prove' your independence all the time. Learn everything you can to help you to realise your goal. The right knowledge is your tool to achieving your aim. Spend time with people who are rewarding, interesting or fun, rather than those who are critical or judgemental either of you or of others. Find good role models who can inspire you and encourage you.

### Stress

The day-to-day coping with the many physical difficulties, emotions, other people and organising your needs will inevitably be stressful. There will be times when you may feel that you cannot cope with the stress. Notice your distress rather than ignore it. Learn to recognise what specifically triggers your stress. Review the situation. How can you make things work better?

Stress and over-stretching yourself can lead to exhaustion. Stop and prioritise. What actually needs doing or sorting out first? Put things in perspective. How important is it really?

Be kind to yourself. Try to take time out from your problems and treat yourself to something you will enjoy.

### Motivation

How you cope with being disabled depends on your attitude and how you appraise your situation. In many ways it is not about what has happened to you, but your attitude towards life in general. If your attitude is that you are living in a disabling environment and need to find new resources to enable you to get on with living the life you want, you will find it much easier to cope emotionally. If you believe you are a victim of your disability and cannot do much, then you may feel that you are only going through the motions of life and that there isn't really any point in doing anything.

The assumption that life is over will result in a greater level of withdrawal. Believing that you can do something about a situation can help you to feel better about it and therefore feel more in control of your destiny. There is practical and emotional help and support 'out there', if you are motivated to access it.

***Acknowledge your emotional pain and feelings of loss as a profound and influential part of your life. No one can underestimate or undervalue how strong these feelings can be. Respect the sensitive part of yourself. Try to use how you feel in a valuable way, rather than let your emotions work against you.***



Deep experiences, however negative, can offer new insights, into both ourselves and other people. We can learn, grow and find inner strengths. A crisis in life may actually offer new opportunities to explore what we really want from it. Looking at our priorities in life again can also enable us to be more open-minded, tolerant and compassionate not only to others, but just as importantly, towards ourselves.

Remind yourself of ways you have coped in the past. Concentrate on your strengths and achievements rather than focusing on failures and expectations of helplessness. When you are depressed or anxious, it is typical to be more aware of the slowness of your recovery and achievements and to lose sight of your overall progress. Learn to go at your own pace. Try not to compare yourself with others. What is important is to find what is right for you.

## 24 Being heard

The professionals you will encounter, including doctors, nurses, physiotherapists, social workers, district nurses and others, have the usual human range of virtues and failings. Sometimes the fact that they are dealing with the problems of disability every day can make them seem insensitive to your needs and feelings. They are, however, invaluable for providing vital support to enable you to live your life.

Professionals in the community have rarely or perhaps never come across a person with a spinal cord injury before, and may have no real understanding of your situation. It is your responsibility to ensure that they are informed. Sometimes you may have to be insistent about your needs.

It is important that you keep in touch with your SCI Centre and consultant. They can monitor your particular needs and keep you informed of new developments, which might benefit you. Some centres have Liaison Nurses and Social Workers who can be a great help when you are trying to get your requirements understood by a local authority or in a general hospital.

Do get the most out of your time with consultants, GPs, Social Workers and other official bodies. These people often have limited time. You may be tempted to let some of the issues that you wanted to discuss wait until another time, then find that you are not managing as well as you could. Make sure that you do get any problems solved as they arise. Write down all the questions you want to ask and the issues you want to talk about. This will help you to focus when dealing with emotionally difficult issues.

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Check-ups and assessments can feel like a demoralising experience when the focus is usually all on what you can't do. Some issues may feel too painful to share. This is understandable, but don't let this prevent you from getting your needs met. Your SCI Centre is used to dealing with most subjects and situations so don't let fear or embarrassment put you off asking for advice or information.

It is essential to keep copies of all correspondence when you are dealing with any official body. Ensure that you make notes of the date and time of phone calls, the departments and the names of the people to whom you were speaking. You will then find it easier to resolve any delays or difficulties, should they arise.

If you have important needs, which are not being heard or met, you may want to consider taking an advocate or a friend to support you during the appointment or meeting. The SIA Freephone Advice Line can also advise you on appropriate procedures for your case.

SIA has produced a factsheet entitled *Emotional Support*, available at [www.spinal.co.uk](http://www.spinal.co.uk)

## 25 Support

You may want to share your experiences with other SCI people who have gone through similar experiences to your own. The SIA Freephone Advice Line can give you information about the Link Scheme and put you in touch with other SCI people. You can also contact other SCI people through the SIA website chat rooms.

Website: [www.spinal.co.uk](http://www.spinal.co.uk)  
Freephone Advice Line: 0800 980 0501

In times of anxiety and stress, some people find it helpful to talk to someone like a counsellor who is outside their immediate family setting or circle of friends. Emotional difficulties linked to SCI are not always easy to talk about and are often hardest to share with those closest to you. They may even be a part of the situation you want to work through and you need an empathic person who is not involved.

On-line therapy may be a solution if you have difficulty finding an accessible counsellor or are actually unable to talk. Another advantage is that you may feel able to 'talk' more freely and honestly when the other person cannot see you. A disadvantage is that they may uncover all sorts of difficult issues, which you will then have to deal with alone. Face-to-face counselling can offer a more supportive relationship and allow you more time to fully explore the issues.

Whichever type of counselling you decide on, always check the counsellor's credentials and choose one registered with BPS, BACP, UKCP or BABCP. These are all recognised bodies and have a code of practice to which counsellors must adhere. You could also choose by recommendation if you know someone who has found a particularly good counsellor. Counselling has many different approaches and all counsellors have their own personalities, which they bring to their work. To know if they are offering what you want and to see if you are going to be able to establish a rapport with them, it is essential to talk to them, ask questions and to be as honest as you can about what you are expecting from them.





The following contacts can all offer information on locating a counsellor or therapist in your area.

**British Association for Behavioural and Cognitive Psychotherapies (BABCP)**

BABCP, Victoria Buildings, 9-13, Silver Street,  
Bury, BL9 0EU  
Website: [www.babcp.com](http://www.babcp.com)  
Tel: 0161 797 4484

**British Association for Counselling and Psychotherapy (BACP)**

BACP House, Unit 15, St. John's Business Park,  
Lutterworth, Leicestershire, LE17 4HB  
Website: [www.bacp.co.uk](http://www.bacp.co.uk)  
Tel: Information Line 0870 443 5219

**Samaritans**

PO Box 9090, Sterling, FK8 2SA  
Website: [www.samaritans.org](http://www.samaritans.org)  
Tel: 08457 90 90 90

**UK Council for Psychotherapy (UKCP)**

2nd Floor, Edward House, 2, Wakley Street,  
London, EC1V 7LT  
Website: [www.psychotherapy.org.uk](http://www.psychotherapy.org.uk)  
Tel: 020 7014 9955



## 26

## Appendix 1

## Common medical terms associated with SCI

**Acknowledgement:** This section of medical terms was written by Paul Harrison MAEd

**ambulant** walking, able to walk.

**ankylosing spondylitis** arthritis of the spine.

**anterior cord syndrome** a lesion in the spinal cord that causes loss of movement, pain and temperature sensitivity, but preserving *proprioception* (see below).

**aperient** see *laxative*.

**arachnoiditis** thickening and scarring of the membranes which surround and protect the nerve roots. Cysts or adhesions develop, causing pressure on the cord, back pain and or additional loss of nerve function. It can be caused by diseases such as *meningitis* and tuberculosis of the spine. More commonly, it develops in people with spinal cord injury, or who have had operations on the spine. In the past it was often caused by the use of oil-based dyes injected into the spinal column to make myelograms. These dyes are no longer used. Milder forms of arachnoiditis are now believed to be the cause of the chronic back pain suffered by many able bodied people.

**AUS** Artificial urinary sphincter – an inflatable cuff surgically fitted around the neck of the bladder, controlled by a pump located in the scrotum or labia.

**automatic bladder** where the nerve impulses between the bladder and the spinal cord remain intact and the bladder can be trained to empty by reflex, spastic, action.

**autonomic** the 'unconscious' nervous system which is separate from, but linked to that of the spinal cord. It controls the bladder and bowels, blood circulation and sweating.

**autonomic dysreflexia** an autonomic reflex causing a sudden, severe, increase in blood pressure in response to pain or discomfort, usually originating below the level of paralysis. Tetraplegics are more prone to this complication as their autonomic nervous systems are unable to oppose the reflex. Commonly caused by an over-full bladder or bowel it presents as profuse sweating, flushing and a

blinding headache. It is a medical emergency, and if untreated can cause death.

**baclofen pump** a pump and reservoir implanted to deliver a measured dose of the drug baclofen to the spinal cord to suppress spasm.

**bladder neck closure** an operation to close off the urethra and neck of the bladder and insert a suprapubic catheter.

**Brown-Séquard syndrome** occurs when one side of the spinal cord is damaged, common when injury is caused by a stab wound. On the injured side of the body there is reduced movement and reflexes, while on the opposite side there is a loss of sense of pain and temperature.

**bursa, bursitis** a pocket of fluid which collects between tissue and the bone, caused by pressure or bumps, and which can cause a pressure ulcer.

**calculus/calculi** a 'stone' in the bladder, kidney or gall-bladder.

**carpal tunnel syndrome** a common, painful condition of the wrist and hand due to nerve compression within the soft tissues due to inflammatory swelling or trauma.

**catheter** a fine tube made of plastic, rubber or silicone which is inserted into the bladder to empty it.

**cauda equina** the 'horse's tail', the three inch bundle of fine nerves leaving the lower end of the spinal cord, below the level of the second lumbar vertebra (L2).

**central cord syndrome** incomplete lesion, usually at cervical level. Usually presents with loss of hand and arm function but with some preservation of bladder, bowel and sexual function. Walking may be possible.

**cervical the neck area** the cervical section of the spinal cord contains eight nerve roots (C1–C8) which control neck movement, breathing and the shoulders, arms and wrists.

**chest** see *thoracic*.

**coccyx, coggygeal** the coccyx is the tail. In humans this consists of four tiny bones fused together at the base of the spine.

**colposuspension** an abdominal operation to support the bladder neck by elevating the vagina using dissolvable sutures.

**contractures** stiffening of the joints of paralysed limbs caused by wasting and shortening of muscles—can be diminished or prevented by exercise and physiotherapy.

**CSF** cerebro-spinal fluid, a colourless liquid within the skull and the spinal canal which nourishes the brain and spinal cord and acts as a watercushion.

**CT scan** computerised tomography, a non-invasive scan which provides more detail than a standard X-ray.

**cystic myelopathy** a spinal cyst. See *syringomyelia*.

**cystitis** infection of the urinary bladder.

**cystogram** a series of X-ray films of the bladder, usually obtained during *cystoscopy*, *IVP/IVU* or *urodynamics*.

**cystoplasty** operation to enlarge the bladder by incorporating a section of the bowel into it.

**cystoscopy** visual examination of the bladder with a tiny instrument inserted through the urethra.

**decubitus ulcer** pressure ulcer.

**detrusor** the muscle in the wall of the bladder, which contracts to squeeze out urine to empty it.

**diaphoresis** profuse sweating.

**discs** pads of gristle which separate the spinal vertebrae and surround and cushion the spinal cord.

**DVT** Deep Vein Thrombosis—a blood clot in a vein, usually in the leg, which may cause swelling. If untreated, it can be a cause of death if a portion of the clot breaks away and reaches the heart.

**dysaesthesias** painful sensations experienced below the level of lesion following spinal cord injury. Often described as burning, numbness, pins and needles or tingling.

**enema** technique for emptying the bowel by introducing liquid into the rectum to loosen the faeces and provoke a bowel motion.

**epididymitis** swelling of the tube leading from the male testicle to the *urethra*.

**expressing** exerting gentle pressure over a full bladder, to empty it.

**Feneley procedure** see *bladder neck closure*.

**FES** Functional Electrical Stimulation, a way of stimulating the muscles of paralysed limbs, usually the legs and occasionally the arms, by using computer-controlled electrical current. FES aims to provide arm function in tetraplegia and to restore some degree of walking in paraplegia. It can also reduce muscle wasting and osteoporosis.

**flaccid bladder** where the nerves between the bladder and the spinal cord have been damaged, the bladder lacks reflex activity, and cannot be trained to empty.

**haemorrhoids** piles, varicose veins inside or outside the rectum.

**heterotopic ossification** the development of abnormal bone in soft tissue, usually close to the hip or knee, which may interfere with full movement of the joint. The cause is not known.

**HRT** Hormone Replacement Therapy, given to some women close to or after the menopause to provide a continued supply of some of the hormones secreted by their bodies during the menstrual cycle. Usually given to prevent osteoporosis, it is believed by some to promote general well-being and to slow the natural ageing process.

**hydrocele** swelling of and fluid on the testicles.

**hypersensitivity** when some parts of the body or skin become acutely sensitive to touch – a side-effect of spinal cord injury in some individuals.

**hypertension** high blood pressure. See *autonomic dysreflexia*.

**hyperthermia** excessive rise in body temperature, to which some high-level tetraplegics are prone, because the *autonomic* system controlling their body temperature is impaired.

**hyponatraemia** a less than normal concentration of sodium in the blood – usually a complication of excessive water intake or inadequate excretion. May lead to confusion, convulsions and collapse.

**hypotension** low blood pressure. See *postural hypotension*.

**hypothermia** excessive reduction in body temperature which can lead to frostbite in limbs and possibly to death.

**ileo-conduit** see *urostomy*.

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**ischial tuberosities** the bony points at the base of the pelvis—one of the most vulnerable points for pressure sores when sitting.

**indwelling catheter** a tube usually made of rubber or silicone which remains inserted in the bladder at all times to drain urine.

**intermittent catheterisation** introduction of a catheter into the bladder at regular intervals to empty it.

**IVP/IVU** intravenous pyelogram/urogram. A radio-opaque dye is injected into the body. As it is excreted through the kidney it will appear visible on an X-ray film, allowing doctors to assess kidney health and any stones, *calculi*, present.

**kyphosis** a forward curvature of the spine.

**laxative substance** (food or medicine) taken to cause a bowel movement.

**lesion** a cut, sore or injury. Often used to describe the site of injury to the spinal cord (e.g. 'a C5 lesion...').

**lithotripsy** ultrasound treatment to break up bladder or kidney stones.

**lordosis** backwards curvature of the spine.

**lumbar** the lower back area. The lumbar section of the spinal cord contains 5 nerve roots (L1–L5) which control the muscles of the legs.

**meninges** the silky linings of the skull and spinal canal which protect the brain and the spinal cord.

**meningitis** inflammation of the meninges, the linings of the skull and spinal canal. Usually caused by a virus, and sometimes fatal, especially in children. Meningitis serosa circumscripta or *arachnoiditis* is a rare condition that affects some people with spinal cord injury.

**micturition** urination, peeing.

**motor function** the ability of muscles to move parts of the body.

**MRI scan** magnetic resonance imaging, a non-invasive technique of body scanning which produces very good images without side effects. Used to examine the spinal cord, e.g. to detect *syringomyelia*.

**MSU** a mid-stream specimen of urine, collected after discarding the first 60mls or so of the urine stream.

**myelogram** X-ray of the spine after injection of an X-ray opaque dye into the spinal column.

**neck** see *cervical*.

**oedema** swelling, especially of the feet and ankles, caused by water retention and poor circulation.

**omentum** an apron-like flap of tissue which hangs from the underside of the stomach and aids circulation in the abdomen.

**osteoporosis** abnormal weakening or softening of the bone, common in elderly people, and some women after the menopause.

**ostomy** see *stoma*.

**paraplegia/paraplegic** paralysis caused by injury or damage to the spinal cord below the neck which leaves the upper limbs unaffected.

**peristalsis** the process of contraction and expansion by which food is moved through your intestines and into your bowel.

**piles** see *haemorrhoids*.

**poikilothermia** a term used to describe the fact that SCI affects a person's ability to control their body temperature. Instead, the paralysed body adopts the temperature of the local environment.

**posterior cord syndrome** a lesion in the spinal cord that causes loss of *proprioception*, whilst preserving movement, pain and temperature sensitivity.

**postural hypotension** sudden drop in blood pressure which produces a blackout or feeling of faintness, experienced by the newly injured and by tetraplegics on changing too quickly from a lying to an upright position.

**pressure sore** see *decubitus ulcer*.

**pressure studies** see *urodynamics*.

**proprioception** a conscious awareness of limb positioning. Signals originate from stretch receptors in and around joints. Some form of SCI may affect proprioception signals travelling to the brain.

**pyelonephritis** infection of the kidney – usually one that ascends from the bladder.

**quadriplegia/quadruplegic** see *tetraplegia*.

**reflux (of urine)** the backing up of urine into the ureters and/or kidneys. This happens when the bladder is full and is not regularly emptied.

**reflux (of stomach acid)** heartburn.

**root pain** intense pain in the damaged nerve endings or nerve roots, which afflicts some SCI people, especially in the early days of paralysis.

**sacral** the area at the base of the spine, where the five sacral vertebrae are fused together. The five sacral nerve roots (L1–L5) control the bladder and bowel.

**SARS/SARSI** Sacral Anterior Root Stimulator/Implant - a surgical implant which restores bladder control in some people with spinal cord lesions.

**scoliosis** lateral (sideways) curvature of the spine.

**sensory** to do with the senses (of touch, sight, smell, hearing, taste).

**SIU/SIC** specialist spinal injury unit/centre.

**Spasm/spastic/spasticity** terms relating to spontaneous, uncontrolled muscle activity or jerking of paralysed limbs. Increases in previously established levels of spasticity may be an early indicator of a painful or irritating complication developing in the paralysed parts of the body e.g. pressure sore, ingrown toenail or bladder stone.

**SPES** Sub-Perception Electrical Stimulation—a technique which applies minute electrical currents to the body to help control pain.

**sphincter** circular muscle at base of bladder neck and also around the anus, which controls opening of the bladder and bowel respectively.

**sphincterotomy** operation to cut the external sphincter of the bladder to aid urinary drainage.

**spina bifida** abnormal split or opening in the spinal column, normally caused by a genetic defect and present from an early stage of the development of the foetus in the womb.

**spinal block** technique for controlling pain or spasticity by injecting drugs into the spinal column.

**spinal shock** the early stage of the body's response to spinal cord injury, usually lasting between 2 and 6 weeks, and during which paralysis appears complete.

**stoma** a small opening cut into the wall of the abdomen to create an exit for a *supra-pubic catheter*, bladder or bowel diversions.

**stone** see *calculus*.

**suppository** bullet-shaped capsule inserted into the anus or vagina. Used to deliver various medicines rectally, to stimulate bowel movement, to treat *haemorrhoids*, and in women to deliver various medications to the vagina and cervix.

**suprapubic catheter** a tube inserted through a small puncture hole in the lower abdomen into the

bladder where it remains to provide a continuous urinary drainage system.

**swelling** see *oedema*.

**syringomyelia** a condition affecting some able-bodied as well as some people with spinal cord injury. A cavity in the spinal cord fills with cerebrospinal fluid. The resulting pressure further enlarges the cavity and damages the nerve tissues of the cord. In SCI people this tends to occur above the level of the original injury, causing pressure on nerve roots and pain or further loss of sensation in upper limbs.

**syrinx** a cavity in the spinal cord. See *syringomyelia*.

**TENS** Transcutaneous Electrical Nerve Stimulation – a technique for pain relief involving electrical stimulation of the skin surface with small electrodes.

**tetraplegia/tetraplegic** paralysis caused by injury or damage to the upper or cervical section of the spinal cord.

**thoracic** the chest area. The thoracic section of the spinal cord contains 12 nerve roots (T1–T12) which control the muscles of the ribs, chest and abdomen. trochanters the tops of the thigh bones, a high-risk point for pressure sores when lying down.

**ureters** the tubes which carry urine from the kidneys to the bladder.

**urethra** the tube which carries urine from the bladder, exiting via the penis in males and in front of the vagina in females.

**urodynamics** a special investigative procedure for assessing bladder function. Radio-opaque dye is introduced into the bladder via a catheter which also contains pressure sensors, allowing doctors to observe the bladder working, to measure the efficiency of bladder emptying, voiding pressures and to assess potential for renal (kidney) problems.

**UTI** Urinary Tract Infection – general term to describe infection of the urinary system.

**vertebrae** the 33 bones which make up the spine. Each vertebra has a hole in its centre, so that when stacked on top of one another they form a long channel called the vertebral canal, through which the spinal cord runs.

**voiding** see *micturition*.



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## Appendix 2

### UK and Irish Spinal Cord Injury Centres



#### 1. GLASGOW

##### **The Queen Elizabeth National Spinal Injury Unit**

Southern General Hospital  
1345 Govan Road, Glasgow G51 4TF  
General Enquiries: 0141 201 2550  
[www.spinalunit.scot.nhs.uk](http://www.spinalunit.scot.nhs.uk)

#### 2. BELFAST

##### **Spinal Cord Injuries Centre**

Musgrave Park Hospital  
Stockmans Lane, Balmoral, Belfast BT9 7JB  
General Enquiries: 028 9090 2120

#### 3. MIDDLESBROUGH

##### **Golden Jubilee Spinal Cord Injuries Centre**

James Cook University Hospital  
Marton Road, Middlesbrough, Cleveland TS4 3BW  
General Enquiries: 01642 850850

#### 4. WAKEFIELD

##### **Yorkshire Regional Spinal Injuries Centre**

Pinderfields General Hospital  
Aberford Road, Wakefield WF1 4DG  
General Enquiries: 01924 212358



**5. SOUTHPORT**

**The North-West Regional Spinal Injuries Centre**

Southport and Ormskirk General Hospital  
Town Lane, Kew, Southport PR8 6NJ  
General Enquiries: 01704 704345/6

**6. DUBLIN**

**The National Spinal Injuries Centre**

Mater Misericordiae University Hospital  
Eccles Street, Dublin 7, Eire  
General Enquiries: 01 8032354

**7. SHEFFIELD**

**Princess Royal Spinal Injuries and Neurorehabilitation Centre**

Northern General Hospital  
Osborn Building, Herries Road, Sheffield S5 7AU  
General Enquiries: 0114 2715609

**8. OSWESTRY**

**The Midlands Centre for Spinal Injuries**

The Robert Jones & Agnes Hunt  
Orthopaedic Hospital  
Oswestry, Shropshire SY10 7AG  
General Enquiries: 01691 404406

**9. STOKE MANDEVILLE**

**National Spinal Injuries Centre**

Stoke Mandeville Hospital  
Mandeville Road, Aylesbury, Bucks HP21 8AL  
General Enquiries: 01296 315800  
[www.spinal.org.uk](http://www.spinal.org.uk)

**10. CARDIFF**

**Welsh Spinal Injuries and Neurological Rehabilitation Centre**

Rookwood Hospital  
Fairwater Road, Llandaff, Cardiff CF5 2YN  
General Enquiries: 02920 31 3833

**11. STANMORE**

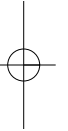
**The London Spinal Injury Centre**

Royal National Orthopaedic Hospital  
Brockley Hill, Stanmore HA7 4LP  
General Enquiries: 020 8909 5583/8  
[www.rnoh-stanmore.org.uk](http://www.rnoh-stanmore.org.uk)

**12. SALISBURY**

**The Duke of Cornwall Spinal Treatment Centre**

Salisbury District Hospital  
Odstock Road, Salisbury SP2 8BJ  
General Enquiries: 01722 336262  
[www.spinalcordinjurycentre.org.uk](http://www.spinalcordinjurycentre.org.uk)



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## A-Z of useful addresses and contacts

### **British Association for Behavioural and Cognitive Psychotherapies (BABCP)**

BABCP, Victoria Buildings, 9-13, Silver Street,  
Bury BL9 0EU  
Website: [www.babcp.com](http://www.babcp.com)  
Telephone: 0161 797 4484

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

BACP House, Unit 15, St. John's Business Park,  
Lutterworth, Leicestershire LE17 4HB  
Website: [www.bacp.co.uk](http://www.bacp.co.uk)  
Telephone: Information Line 0870 443 5219

### **Cauda Equina Syndrome Resource Center**

Website: [www.caudaequina.org](http://www.caudaequina.org)

### **Christopher and Dana Reeve Foundation Paralysis Resource Center**

Website: [www.paralysis.org](http://www.paralysis.org)

### **FES-cycling**

Website:  
[www.medphys.ucl.ac.uk/research/impdev/idg/cycling.htm](http://www.medphys.ucl.ac.uk/research/impdev/idg/cycling.htm)

### **FES-rowing**

Website: [www.fesrowing.org](http://www.fesrowing.org)

### **The International FES Society**

Website: [www.ifess.org](http://www.ifess.org)

### **The International Spinal Research Trust (Spinal Research)**

Bramley Business Centre, Station Road, Bramley,  
Guildford, Surrey GU5 0AZ  
Website: [www.spinal-research.org](http://www.spinal-research.org)  
Telephone: 01483 898786

### **LARSI**

Website: [www.medphys.ucl.ac.uk/research/impdev](http://www.medphys.ucl.ac.uk/research/impdev)

### **The National Clinical FES Centre**

Department of Clinical Science and Engineering,  
Salisbury District Hospital, Salisbury,  
Wiltshire SP2 8BJ  
Website: [www.salisburyfes.com](http://www.salisburyfes.com)  
Telephone 01722 429065,

### **Ness H200**

Website: [www.nessltd.com/hcp/nessh200.ecp](http://www.nessltd.com/hcp/nessh200.ecp)

### **Odstock Medical Ltd**

Website: [www.odstockmedical.com](http://www.odstockmedical.com)

### **Reeve-Irvine Research Center**

Website: [www.reeve.uci.edu](http://www.reeve.uci.edu)

### **Samaritans**

PO Box 9090, Sterling, FK8 2SA  
Website: [www.samaritans.org](http://www.samaritans.org)  
Telephone: 08457 90 90 90

### **Spinal Injuries Association**

Website: [www.spinal.co.uk](http://www.spinal.co.uk)  
Freephone Advice Line: 0800 980 0501

### **UK Council for Psychotherapy (UKCP)**

2nd Floor, Edward House, 2, Wakley Street,  
London EC1V 7LT  
Website: [www.psychotherapy.org.uk](http://www.psychotherapy.org.uk)  
Telephone: 020 7014 9955

### **VOCARE**

Website: [www.finetech-medical.co.uk/product-bladder.htm](http://www.finetech-medical.co.uk/product-bladder.htm)



## About the Spinal Injuries Association

The Spinal Injuries Association (SIA) is the leading national organisation for spinal cord injured people. As a user-led organisation, our aim is to provide a range of services to meet the needs of spinal cord injured people. We also campaign on their behalf to improve their life chances and choices.

SIA offers a pathway of support to spinal cord injured people from the moment of injury and for the rest of their lives. We provide information, advice and peer support to enable people paralysed through spinal cord injury to rebuild their lives. We also support relatives and all those concerned with the needs of spinal cord injured people, including health professionals from the wide range of disciplines involved in post-injury rehabilitation, both medical and social.

*Moving Forward* brings together the wealth of knowledge gathered by SIA based on the experiences of spinal cord injured people. It covers all aspects of living day to day with this impairment and is essential reading for both paralysed people and medical and social-care staff.

SIA has a wide range of publications for spinal cord injured people of all ages and for healthcare professionals. You can view the full range and make purchases in the online shop at [www.spinal.co.uk](http://www.spinal.co.uk)

Members of the Association receive the bi-monthly magazine *forward* in addition to having access to SIA's wide-range of services. To find out more about joining either visit [www.spinal.co.uk](http://www.spinal.co.uk) or telephone 0845 678 6633 extension 206.

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- 8 Your Rights**
- 9 Children and Teenagers with SCI**
- 10 Work Matters**
- 11 Ageing**
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- 13 Personal Injury Compensation**
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1

## Spinal Cord Injury – in the early days

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

Telephone 0845 678 6633  
Freephone Advice Line 0800 980 0501  
Fax 0845 070 6911  
Email [sia@spinal.co.uk](mailto:sia@spinal.co.uk)  
[www.spinal.co.uk](http://www.spinal.co.uk)

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