



**SCI ACQUIRED  
THROUGH ILLNESS AND  
DISEASE**

## Spinal cord injury (SCI) acquired through illness or disease

### Introduction

Not all spinal cord injuries (SCI) are caused by trauma, such as car and sporting accidents. Illness or disease can cause similar levels of impairment to that of a traumatic incident. These conditions are rare medical events and include:

- Bacterial infections e.g. Tuberculosis
  - Viral infections e.g. Transverse Myelitis
  - Blood clots (thrombosis) or haemorrhage (bleeding)
  - Non-malignant growths (tumours) which press on the spinal cord
  - Birth defects e.g. Spina Bifida.
- 

### Transverse Myelitis (TM)

TM is a rare neurological disorder, affecting approximately 300 people per year in the UK. The exact cause cannot always be found. Almost one third of people affected by TM experience flu-like symptoms prior to or around the time of the start of neurological symptoms. It is thought there may be an autoimmune reaction involved.

The main identifiable causes of TM are:

- autoimmune reaction against the spinal cord
- bacterial or viral infection
- following vaccination - very rare and difficult to prove.

TM can happen very suddenly, even overnight or the symptoms may develop over several weeks. It usually occurs at the chest (thoracic) level or lower, occurring across the spinal cord giving rise to different degrees of damage.

**The symptoms** of TM are very variable between individuals and depend on which part of the spinal cord is affected, but may include:

- pain in the lower back (this may be the first symptom)
- general feeling of being unwell
- weakness in the legs, which can result in complete paralysis
- changes in sensation in the lower body e.g. burning or tingling
- raised sensitivity to touch and temperature
- degrees of loss of control over bladder and bowels

- headaches, raised temperature
- fatigue
- muscle spasms

### Diagnosis

TM can be a difficult disorder to diagnose, with symptoms continuing for weeks or even months, prior to a definitive diagnosis. A thorough history of events by the patient is very important, as is a thorough physical examination.

Investigations include: MRI scans, lumbar puncture and blood tests.

Approximately two thirds of people affected by TM make a degree of recovery within 1-2 years. Many people are able to walk with the aid of sticks or crutches.

Longer term, sexual problems, chronic pain, tiredness, depression, psychological issues, can develop in some individuals. Relapses (a further episode of TM) occur in a minority of people and often this is associated with an existing illness.



For Support and further information contact:

### Transverse Myelitis Society UK (TMS)

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

The TMS works closely with Transverse Myelitis Association which is a worldwide organisation. The TMS hold a bi-annual conference and other special educational events. Regional meetings are held regularly across the UK with talks given by TM specialists and outside speakers.

### Brain and Spine Foundation (B&SF)

**T:** (Helpline) 0808 808 1000

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

The B&SF have produced a booklet on TM. This can be downloaded from the website. There is also a helpline run by neuroscience trained nurses, providing support and information on all aspects of neurological conditions for patients, their families, carers and also health professionals.

### Cauda Equina Syndrome: (CES)

Cauda Equina is Latin for 'horse's tail'. CES is a rare neurological condition and results when damage occurs to the lumbar and sacral nerve roots. There is narrowing (stenosis) of the lumbar spinal canal causing compression of the spinal cord.

CES can happen very suddenly. It can sometimes be misdiagnosed thereby wasting vital time which could affect a person's outcome. Early diagnosis is crucial and it should be treated as a medical emergency. Often young people are affected who are otherwise healthy individuals.

#### Causes:

- Prolapsed disc
- Haemorrhage
- An abscess
- A tumour
- An infection
- Trauma



***CES is a medical emergency. The sooner a diagnosis is confirmed and treatment given the better the outcome. Treatment is usually by surgery to relieve pressure on the spinal cord***

#### Symptoms:

Symptoms vary greatly depending on the degree of damage to the nerves of the cauda equine, but can include:

- Pain in lower back
- Bladder and bowel dysfunction e.g. difficulty passing urine, controlling bowel actions
- Saddle numbness – loss of sensation around the anus and / or genitals
- Sexual dysfunction
- Changes in sensation in legs, heaviness, warm feeling
- Drop foot.

#### Investigations

Urgent MRI scan to determine if there is compression of the lumbar and sacral nerves.

Full history from the patient and thorough physical examination.

#### Longer term

- Pain – many different types of pain are experienced, with people describing their pain as burning, stabbing. Pain varies from mild to severe and can become chronic.
- Skin problems
- Walking and balance can be compromised
- Psychological problems, such as anxiety, “no-one explains what’s happening”, concerns regarding future outcomes, how relationships will be affected and future employment opportunities.

For Support and further information:

**CES Charity UK**

**T:** (Ann Glover) 07563589792

**T:** 0845 6021993

**@:** [cesukcharity@gmail.com](mailto:cesukcharity@gmail.com)

**W:** [www.caudaequinauk.com](http://www.caudaequinauk.com)

**The Cauda Equina Syndrome Association (CESA)**

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

**T: (Helpline)** 03335 777113

**CES Support Group**

The Walton Centre (NHS) Neurological Centre, Liverpool

**W:** [www.thewaltoncentre.nhs.uk](http://www.thewaltoncentre.nhs.uk)

---

## Spinal Stroke

A spinal stroke can occur when there is disruption in the blood supply to the spinal cord. This disruption is usually caused by a blood clot, which blocks or partially blocks a blood vessel. Another cause of a spinal stroke is when there is bleeding from a blood vessel due to a small tear. Spinal strokes are rare, being much less common than a stroke affecting the brain.

Common underlying causes of spinal stroke are:

- damaged arteries – due to hardening, weakness and narrowing.  
Contributory factors are high blood pressure, smoking, diabetes
- malformed blood vessels

**Blood clots** can block or partially block arteries supplying the spinal cord. Clots can form in these arteries or form in a blood vessel elsewhere in the body and travel to the spinal cord.

**Bleeding** (haemorrhage) from an artery is another cause of spinal stroke. High blood pressure damages and weakens the arteries making them more likely to tear. Aneurysms (balloon-like swellings in the arteries), which burst, may also lead to a spinal stroke.

Abdominal surgery is a risk factor.

### Symptoms

The symptoms are dependent on the level at which the spinal cord is damaged and severity of the stroke. Symptoms usually occur suddenly and can include:

- Weakness in the legs, which can progress to complete paralysis, very quickly
- Change in feelings / sensation in the lower half of the body – this is often described as burning, tingling; there is sometimes a heightened sensitivity to touch and
- Temperature
- Bladder and bowel problems – there may be incontinence or urgency to use the toilet
- Pain
- Muscle spasms.

**Diagnosis** is usually established by an MRI scan. Patient history and fully physical examination are important too.

#### **Longer term effects**

- paralysis, in some cases
- bladder and bowel problems
- sexual problems
- depression
- pain

For further information:

**Brain and Spine Foundation**

**T: (Helpline) 0808 808 1000**

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

## **Tumours**

Spinal tumours are rare, with about 750 new cases per year in the UK. They can be classified as:

- Malignant
- Non-malignant (benign tumours)
- Secondary tumours

#### **Malignant primary tumours**

- Tend to be fast growing and spread into surrounding tissue
- Progress and effects are unpredictable
- In some cases it may be possible to completely remove a malignant tumour.

**Symptoms** occur over a short period and may include:

- Change in sensation / feeling in 1 or more limbs – people report having numbness, pins and needles
- Raised sensitivity to touch / items touching the skin, e.g. heavy bed clothes

- Raised sensitivity to temperature – this can be both body temperature or some people may lose the ability to tell when an item is hot or cold.
- Pain
- Bladder and bowel problems
- Sexual problems

### **Non-malignant primary tumours**

- Cause is unknown
- Tumours can occur anywhere along the spinal cord
- Tumours can take many years to grow to a size when symptoms develop
- Surgical removal of the whole tumour is often possible.

There are many different investigations and tests which can be carried out at a District General Hospital or specialist cancer (oncology unit) – see booklet ‘Spinal Tumours’ produced by the Brain and Spine Foundation for more detailed information.

**Secondary tumours** (metastases) can occur in the spinal cord or the bony structure, the spinal column. More commonly secondary cancerous deposits appear in the bone, this weakens the bone and can result in compression of the spinal cord. Secondary deposits result most often from primary cancers of the lung, breast, bowel and prostate.

For Support and further information contact:

**Brain and Spine Foundation**

**T: (Helpline) 0808 808 1000**

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

**Cancer Help UK**

**T: 0808 800 4040**

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

**Macmillan Cancer Support**

**T: 0808 808 000**

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

**Spinal Cord Tumour Forum**

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

**@: [info@spinalcortumour.org.uk](mailto:info@spinalcortumour.org.uk)**

---

## Arteriovenous malformations (AVM) of the spinal cord

AVM is the name given to the malformation of blood vessels (both arteries and veins). The 'tangled' knot of blood vessels can occur anywhere in the body. People affected by this condition may experience vague symptoms during childhood which are never fully investigated. More usually, the person may be unaware they have this condition for many years. Significant symptoms often occur between 20-40 years of age, by then resulting in damage to the spinal cord.

AVM's normally cause symptoms once the damage they cause has reached a critical level. The damage to the spinal cord is due to lack of oxygen or bleeding from a damaged artery.

### Symptoms can include:

- Sudden acute pain, due to lack of oxygen or bleeding from a blood vessel
- Bladder, bowel, sexual problems
- Sensory changes.

There are many different types of AVM affecting both the spinal cord and brain but the cause is unknown. Many develop in the womb and are therefore present at birth. In very rare cases the condition can run in families.

For Support and further information contact:

### AVM Support Group

W: [www.avmsupport.co.uk](http://www.avmsupport.co.uk)

### Brain and Spine Foundation

W: [www.brainandspine.org.uk](http://www.brainandspine.org.uk)

---

## Cavernous malformations (cavernomas)

A cavernoma resembles a blackberry but is purple in colour. It is formed by abnormal, enlarged blood vessels. Usually occurring in the brain but can affect the spinal cord too.

The condition can run in families. Although it can grow in size, the malformation does not turn cancerous.

### Symptoms if occurring in the spinal cord can include:

- Weakness and numbness
- Tiredness, difficulty concentrating.



**Diagnosis** is generally by MRI scan.

For Support and further information:

**Cavernoma Alliance UK**

**T:** 01305 213876

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

**Brain and Spine Foundation**

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

---

**Spinal cord injury can be what is termed 'complete' or 'incomplete'.**

### **Complete SCI**

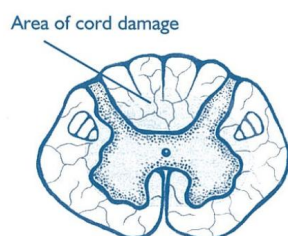
Refers to injuries where there is no muscle function or sensation below the level of injury. This affects both sides of the body to the same degree. Complete injury does not necessarily mean the spinal cord has been severed. This in fact rarely occurs.

### **Incomplete SCI**

Refers to injuries where there is some muscle function and sensation below the level of injury. There may be sensation but not movement in one limb or one side of the body or there may be movement but no sensation.

There are other types of incomplete spinal cord injury, most of which have the potential for some recovery:

### **Central Cord Syndrome**



- In CCS there is damage is to the central area of the spinal cord
- There is usually complete loss of arm movement, but some leg function and feeling remains
- Bladder and bowel problems are often minimal

- 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

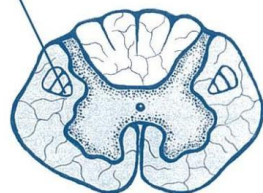
Area of cord damage



- In BSS there is damage to one side of the cord, often as a result of stab injuries.
- Function is affected on the injured side, but pain and temperature sensation are relatively normal.
- The opposite is true on the non-injured side: function is normal, but pain and temperature sensation are affected.
- Therefore, people often have movement in one or both limbs but have 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.

## Anterior Cord Syndrome

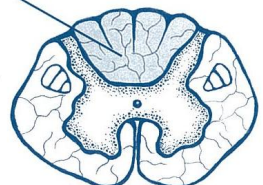
Area of cord damage



- Anterior cord injury results in loss of muscle power
- There is also reduced pain and temperature sensation below the level of injury
- Other sensations such as touch are usually not affected.

## Posterior Cord Syndrome

Area of cord damage



- Posterior cord injury results in loss of deep touch sensation below the level of injury
  - Movement, pain and temperature sensation are not affected
  - Unfortunately the affected person loses awareness of the position of their legs and this can limit their ability to walk properly.
- 

## Guillain-Barre Syndrome (GBS)

GBS is an acute inflammatory condition of the peripheral nervous system. The peripheral nerves carry information to and from the central nervous system, they branch off, in pairs, from the spinal cord and supply the rest of the body.

GBS can happen at any age with about 1,200 people affected in the UK every year.

### Symptoms

- Muscle weakness – which can be very sudden
- Loss of normal sensation but feelings of numbness and pin and needles can occur
- Paralysis of legs, arms, muscles for breathing and facial muscles can occur in severe cases.

**Cause** is unknown but around over half of sufferers have experienced a viral or intestinal infection in the previous 2 weeks.

### Longer term

Only a minority of cases experience lasting effects of numbness, weakness and pain with about 80% of people making a full recovery.

For Support and further information:

### Guillain-Barre Syndrome Support Group

**T: (Helpline)** 0800 374803

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

## Sacral Sparing

The affected person will have the ability to feel their bladder and bowel working but they are unlikely to have any control over them.

---

## Spina Bifida

*“Spina bifida literally means ‘split spine’*



***A fault in the development of the spinal cord and surrounding bones (vertebrae) leaves a gap or split in the spine. The spinal cord has not formed properly and may also be damaged". (taken from Shine website).***

**The cause of spina bifida is unknown but several risk factors have been identified:**

- Lack of folic acid prior to and at the start of pregnancy – for more information go to [www.gofolic.co.uk](http://www.gofolic.co.uk)
- Family history - If a family member has a neural tube defect, this increases a woman's chance of giving birth to a baby with spina bifida
- Drugs - some types of medication prescribed to treat epilepsy, have been linked to an increased risk. Also, certain medications prescribed to treat mood disorders
- Obesity and Diabetes.

**There are several types of spina bifida:**

### **Meningocele**

In this type of spinal bifida, spinal fluid and the membranes covering the spinal cord, protrude through a hole in the spinal column. The symptoms vary, while some people experience no symptoms, others may be completely paralysed accompanied by bladder and bowel dysfunction.

### **Myelomeningocele**

This is the most serious and rarest form of spinal bifida. The spinal column (vertebrae) remains open. The membranes surrounding the spinal cord and the spinal cord itself, are pushed out and form a sac. This usually results in symptoms such as:

- A degree of paralysis of the legs
- Bladder and bowel dysfunction
- Loss of sensation.

Most babies with myelomeningocele will also develop hydrocephalus, (excessive fluid surrounding the brain).

### **Spinal Bifida Occulta**

This is the least serious type of spina bifida. The opening in the spine is very small and not visible from the outside.

To find out about surgical treatment and other important information about spina bifida, go to the Shine website, the organisation which supports people living with spina bifida [www.shinecharity.org.uk](http://www.shinecharity.org.uk)

## Polio



***“Polio is an infectious disease caused by one of three types of polio viruses. It enters the body through the nose or mouth and develops in the throat and intestines. The polio virus may go on to invade the central nervous system, destroying or damaging the nerve cells (motor neurons) that control the muscles.***

***Polio can be prevented by vaccination”***

(taken from the British Polio website).

In the early 1960s, the UK launched a vaccination programme which resulted in the number of notified cases dropping from over 6,000 in 1955 to nil today. Most countries in the world are free from polio but the virus could be imported into a Polio-free country.

### Symptoms of Polio

Most people experience flu-like symptoms, e.g. sore throat, high temperature and headaches.

### There are 2 types of Polio:

**Non-paralytic:** In addition to flu-like symptoms, this type of Polio causes stiff neck, back and muscle pain. No paralysis.

**Paralytic Polio:** Affects only 1-2% of people. The virus causes weakness, muscle cramps and pain. Motor neurons are damaged, leading to paralysis but sensory nerves appear not to be affected, therefore pain is an issue.

The virus can affect the brain stem, which controls the respiratory centre therefore leading to breathing and swallowing difficulties, facial weakness and even cardiovascular problems.

### Post Polio Syndrome (PPS)

PPS affects people who have had Polio. A long time after the original viral infection, some people develop new symptoms, mainly fatigue, pain and weakness. These symptoms can of course be caused by other disorders so correct diagnosis is important. These symptoms can occur at any age and can affect people with both non-paralytic and paralytic Polio.

For Support and further information:

**British Polio Fellowship**

**T:** 0800 018 0586

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

---

## Summary

The conditions discussed in this fact sheet are rare medical events. They present with very similar symptoms, in varying degrees, a few having some expectation of recovery.

Diagnosis can be difficult in some conditions and MRI scans are often used to assist and / or confirm diagnosis.

In a few conditions there is evidence of an inherited factor or risk, but this is small and in many non-trauma conditions, it is difficult to know whether either gender is more affected than the other.

## Disclaimer

This factsheet has been prepared by SIA and contains general advice only which we hope will be of use to you. Nothing in this factsheet should be construed as the giving of specific advice and it should not be relied on as a basis for any decision or action. SIA does not accept any liability arising from its use. We aim to ensure the information is as up-to-date and accurate as possible, but please be warned that certain areas are subject to change from time to time. Please note that the inclusion of named agencies, companies, products, services or publications in this factsheet does not constitute a recommendation or endorsement by SIA.

---

**Revised July 2014**

## About SIA



The Spinal Injuries Association (SIA) is the leading national user-led charity for spinal cord injured (SCI) people. Being user led, we are well placed to understand the everyday needs of living with spinal cord injury and are here to meet those needs by providing key services to share information and experiences, and to campaign for change ensuring each person can lead a full and active life. We are here to support you from the moment your spinal cord injury happens, and for the rest of your life.

For more information contact us via the following:

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

**T:** 01908 604 191 (Mon – Fri 9am – 5pm)

**T:** 0800 980 0501 (Freephone Advice Line, Mon – Fri, 11am – 1pm/2pm – 4.30pm)

**W:** [www.spinal.co.uk](http://www.spinal.co.uk)

**E:** [sia@spinal.co.uk](mailto:sia@spinal.co.uk)

Charity No: 1054097

Brought to you by:



## Please support SIA

**SIA relies on fundraising, donations and gifts in wills to provide services that help spinal cord injured people rebuild their lives.**



With your help, we can provide the right support to spinal cord injured people and their families and friends so they can enjoy a full and independent life after injury. Your donation today will go towards changing someone's life.

I would like to give: £15 ☐ £20 ☐ £53 ☐ other amount £.....

### Method of payment

☐ I enclose a cheque/postal order/CAF voucher made payable to Spinal Injuries Association.

☐ I would like to pay by Mastercard/Visa/Maestro/Switch (delete as appropriate)

Card number

Start date

Expiry Date

Security Code

Signature

Date...../...../.....

Name.....

Address .....

.....

Postcode ..... Tel no.....

Email address.....

Please gift aid my donation ☐

If you tick the box it means for every £1 you donate we can claim an extra 25p from the taxman, at no extra cost to you. You need to pay an amount of income tax or capital gains tax at least equal to the tax we reclaim from HM Revenue and Customs – currently 25p in every £1 you give.

Please send your donation to: FREEPOST SPINAL INJURIES ASSOCIATION or you can donate online at [www.spinal.co.uk](http://www.spinal.co.uk)

**Thank you for your support!**