

Transverse Myelitis



Brain & Spine
Foundation

A guide for patients and carers

The Brain and Spine Foundation provides support and information on all aspects of neurological conditions. Our publications are designed as guides for people affected by brain and spine conditions - patients, their families and carers. We aim to reduce uncertainty and anxiety by providing clear, concise, accurate and helpful information, and by answering the common questions that people ask. Any medical information is evidence-based and accounts for current best practice guidelines and standards of care.

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Introduction

This booklet provides information on transverse myelitis. This booklet provides information on the acute stage of transverse myelitis, describing the condition, what happens in hospital, tests and investigations, and possible treatments. It also provides information on recovery from transverse myelitis, common symptoms and feelings. Sources of further support and information are listed in the Useful Contacts section. References are available on request.

Common questions

What is transverse myelitis?

Transverse myelitis is a rare disease of the **central nervous system** involving inflammation in the **spinal cord**. ('Transverse' refers to the inflammation being across the width of the spinal cord and 'myelitis' refers to the specific part of the spinal cord affected.) The inflammation causes swelling which can block messages (nerve impulses) travelling along the spinal cord.

The Central Nervous System

The central nervous system is made up of the brain and spinal cord.

Messages (nerve impulses) travel along the spinal cord and control activities of the body such as movement of the arms and legs or function of the organs.

The peripheral nervous system (the network of nerves outside the central nervous system) carries messages between the central nervous system and the rest of the body.

The inflammation can also damage or destroy the **myelin sheath** surrounding the **axons** in the spinal cord, probably by damaging the specialised cells which produce myelin (the oligodendrocytes). Messages (nerve impulses) cannot be transmitted properly as myelin is stripped off the axons causing scarring.

The inflammation most commonly occurs in the **thoracic** section of the spinal cord (the middle section below the neck and above the stomach). The damage

affects this area but it can also affect the areas of the spinal cord below the thoracic section: the lumbar section (lower back) and the sacrum (between the hips).

Most people with transverse myelitis experience weakness and a change in sensation (unusual feelings) in the lower half of the body and have problems with their bowel and bladder.

Commonly, the onset of transverse myelitis is sudden and it can progress to its most severe state very quickly, often in just 24-48 hours. However, for some people affected by transverse myelitis, their symptoms develop slowly over several weeks.

The Spinal Cord

The spinal cord carries messages (nerve impulses) from the brain to the body and from the body to the brain.

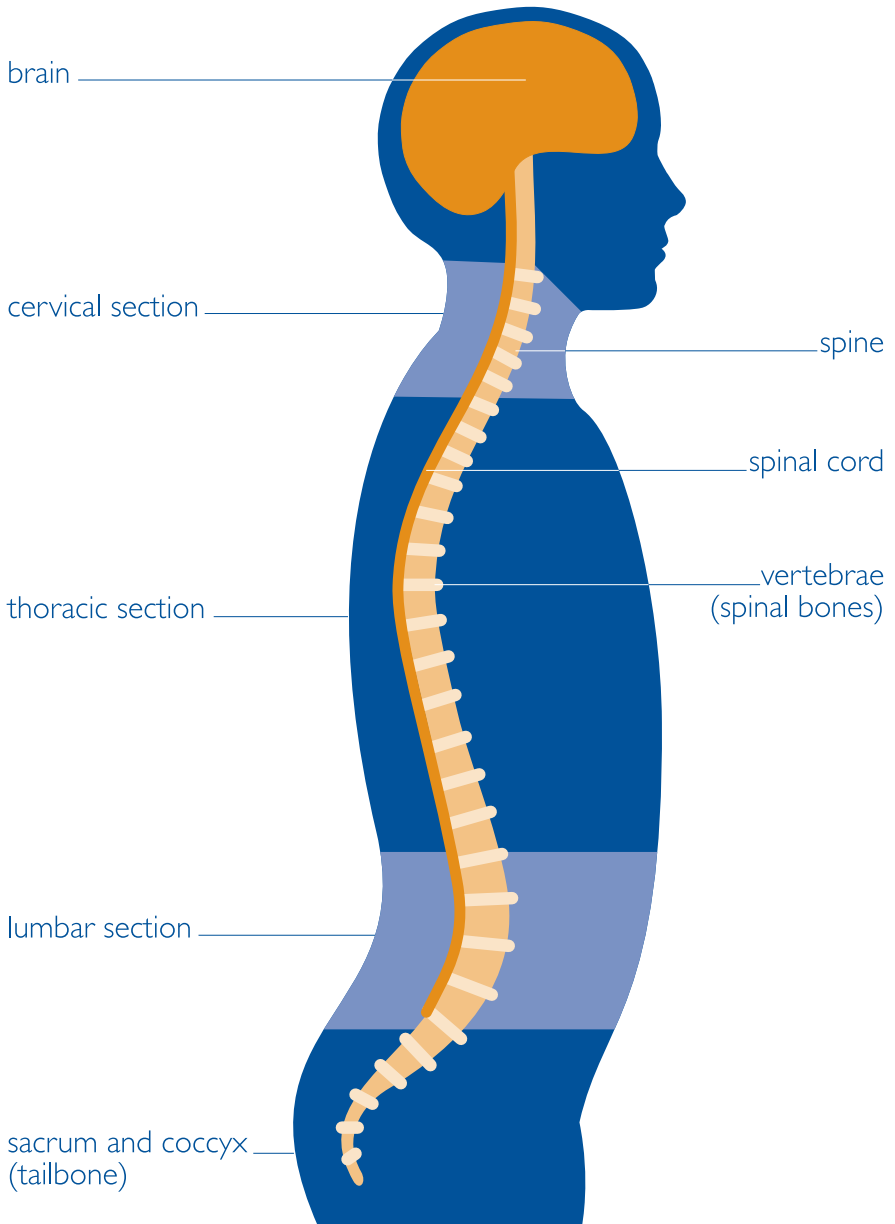
It is made up of different types of cells. The cells responsible for transmitting messages are called **neurons**. Neurons have long extensions called axons which carry the messages up and down the spinal cord. Axons are arranged in bundles called tracts.

Some of the tracts carry motor function messages which stimulate muscles to produce movement and some of them carry sensory messages which control sensations such as touch, pain and temperature.

To increase the speed at which the messages travel, most axons are surrounded by a whitish fatty substance called **myelin** which forms a protective covering (sheath) around them. Myelin is produced by specialised cells called oligodendrocytes.

Common questions

Diagram of the central nervous system



What causes transverse myelitis?

It is not always possible to identify the cause of transverse myelitis. When a cause cannot be identified, it is called idiopathic transverse myelitis.

Although a cause cannot be established in cases of idiopathic transverse myelitis, the inflammation is thought to be the result of **the immune system** mistakenly attacking the spinal cord. This is called an autoimmune reaction.

The immune system

Our immune system protects us from being infected by bacteria and viruses which can make us ill. It also fights bacterial and viral infections when we are ill with them.

An autoimmune reaction occurs when the immune system mistakenly attacks our bodies' own tissue rather than just attacking the foreign bacteria or virus.

Transverse myelitis often develops at the same time as, or soon after, a viral or bacterial infection. These cases of transverse myelitis are also believed to be the result of an autoimmune reaction. Rather than the viral or bacterial infection itself directly causing the inflammation, it is thought that the immune system is stimulated to fight the infection and, mistakenly, also attacks the spinal cord.

Transverse myelitis can also develop after vaccinations, although this is very rare. Again,

it is thought that the immune system is triggered to respond to the vaccination and mistakenly attacks the spinal cord.

Common questions

For some people, transverse myelitis can be linked to other diseases, although this is rare. Some autoimmune diseases (such as lupus), measles, Lyme disease, syphilis, and some cancers (which can cause an autoimmune reaction) have all been linked to transverse myelitis.

How common is transverse myelitis?

Transverse myelitis is rare. A large regional neuroscience centre is likely to see just five or six people affected by transverse myelitis each year. Accurate figures are not available, but it is estimated that there are no more than 300 new cases in the UK each year.

Are my family at risk?

No. No hereditary risk or genetic factors have been identified for transverse myelitis. You cannot pass on an increased risk of getting transverse myelitis to your family.

It is not possible to catch transverse myelitis from another person.

What are the symptoms?

The symptoms of transverse myelitis depend on what section of the spinal cord is affected by the inflammation. The severity of the symptoms depends on how bad the inflammation is and how much damage it does.

The main symptoms of transverse myelitis are muscle weakness in the legs (and, less commonly, in the arms), change in sensation (unusual feelings) in the lower half of the body, pain, and problems with the bowel and bladder.

People might also experience fever, headache, tiredness, muscle spasms (spasticity), and a general feeling of being unwell.

Commonly, the very first symptoms people with transverse myelitis experience are pain in their lower back and a sudden change in sensation in the legs (unusual feelings such as burning or tingling). These unusual sensations are called paraesthesia.

Muscle weakness in the legs can progress to a complete loss of movement (paralysis) very quickly.



The unusual feelings (paraesthesia) that people experience can include numbness, pins and needles, and a heightened sensitivity to touch and temperature. The feel of clothing on the skin might cause pain (allodynia). People might experience extreme heat or cold, or lose the ability to tell the temperature of water or objects. Sometimes, a horizontal line or band can be drawn around the torso (the trunk of the body) or around the waist where the unusual sensations begin. Bowel and bladder problems might include incontinence (a loss of control over bowel movements or passing urine) or needing to go to the toilet with increased urgency.

Tests and investigations

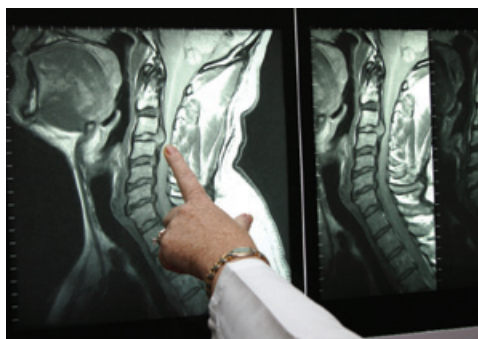
Transverse myelitis is not always a straightforward condition to diagnose.

People who experience a sudden onset of their symptoms are more likely to seek medical attention urgently and go straight to hospital. If your symptoms develop more slowly, you are more likely to see your GP. Your GP should refer you to a neurologist.

Your medical history will be checked and you will have a physical examination as part of your assessment. The combination of weakness in the legs and unusual sensations (paraesthesia) is a symptom of problems in the spinal cord whatever the cause. It is important to rule out any conditions which might be causing pressure on the spinal cord such as a slipped disc, an abscess, an abnormal collection of blood vessels (arteriovenous malformations), or a tumour. People with any of these conditions will require specific treatments for them.

As bladder problems are common with transverse myelitis, a doctor might physically examine you for signs of your bladder being overfilled with urine. This can be checked by feeling your stomach for signs of swelling.

You might also have blood tests to check for any underlying conditions or illness which might cause your symptoms.



MRI scan

The key test for transverse myelitis is an MRI scan.

An MRI scan produces pictures of the spine using strong magnetic fields and radio waves. It differs from a standard X-ray as it produces very detailed pictures.

During the scan, you will lie in a long tube. The scan is painless but, unfortunately, the scanner is very noisy.

The results of the scan will be checked to rule out any conditions causing pressure on the spinal cord. The scan pictures will also be checked to look for any areas of inflammation in the spinal cord.

(You might be interested in reading our fact sheet on brain and spine scans for further information.)

Lumbar puncture

The spinal cord is surrounded by a clear liquid called cerebrospinal fluid (CSF). For some people with transverse myelitis, the signs of a possible infection are indicated by abnormalities in their CSF.

To take a sample of this fluid, a needle is passed between two vertebrae (spinal bones) at the lower end of the spine (the lumbar area) into the space containing the CSF. A small amount is drawn off in a syringe and sent to a laboratory for examination.

Some people find this procedure uncomfortable but you will be given a local anaesthetic first to numb the area. You might be asked to lie on your back for between one and three hours and to drink plenty of water afterwards to prevent getting a headache.

Possible treatments

Unfortunately, there is no cure for transverse myelitis.

The most common form of treatment is a short course of **corticosteroids** to reduce the inflammation and reduce the immune system's activity in the spinal cord. The length of the treatment depends on your progress but might last several weeks if you are prescribed a corticosteroid drug to be taken by mouth. Alternatively, you might be given a three or five day course of corticosteroids through a drip (into a vein in your arm).

If corticosteroids do not work for you, you might be given a treatment called plasma exchange (also known as plasma exchange therapy or plasmapheresis). This treatment is not available in all hospitals and might not be suitable for all patients. Some of the substances which attack the spinal cord as part of the autoimmune reaction are found in the plasma (a colourless fluid in our blood). The aim of plasma exchange is to remove these substances from the blood. Plasma exchange involves running the patient's blood through a machine which separates the blood cells from the plasma. The blood cells are then mixed with replacement plasma and the new blood (consisting of the patient's own blood cells and the replacement plasma) is returned to the patient. It is likely that the plasma exchange will happen over two or three sessions rather than all at once.

Other treatments

It is common for people with transverse myelitis to experience some form of pain. This can be constant pain, or pain that comes and goes. The pain might be related to physical problems (muscle spasms or strains) or related to damage in the spinal cord. Messages (nerve impulses) might not be able to travel properly in the spinal cord, confusing the brain and causing it to interpret them as pain signals.

Possible treatments

Various types of pain-relief medication are available for the different forms of pain people might experience. If you are given pain-relief, the particular type will depend on your individual situation.

If you have bladder problems, you might need a catheter inserted into your bladder to prevent it overfilling with urine. This is usually a short-term measure and you will be assessed regularly.

During the acute stage of your symptoms, you might not be able to move from bed and will receive general nursing care. If you are experiencing paralysis, you might be cared for by nurses who specialise in preventing and treating complications specifically associated with paralysis.

If you have physical symptoms such as weakness in your legs, muscle spasms (spasticity), stiffness or paralysis, you are likely to be assessed by a physiotherapist. The physiotherapist will recommend movements and exercises designed to increase muscle strength and flexibility and to reduce stiffness and spasms. You might be transferred to a specialist rehabilitation unit for physiotherapy.

Going home

Before you are discharged from hospital, it is important that arrangements have been made for you to receive the support you need when you are back at home. This might mean you are referred to your local social services, or to your local community physiotherapy or occupational therapy services.



A community physiotherapist will assist you with any physical problems you might have and an occupational therapist will offer practical support and advice on everyday skills and activities such as using kitchen equipment and getting around your home safely.

If you need a wheelchair or walking aids like a stick or crutches, you might be assessed for these before you leave hospital.

Recovery

Recovery from transverse myelitis usually begins within two months of the onset of symptoms and can continue for up to two years. People usually make the best recovery between three and six months after the onset of symptoms.

A good or full recovery is possible even after severe symptoms. The myelin sheath surrounding the axons in the spinal cord is able to repair itself, although not always fully. Also, some areas of the spinal cord are only temporarily damaged by the inflammation. They return to normal after the inflammation has gone.

Around a third of people with transverse myelitis can expect to make a good or full recovery with very limited or no long-term effects. Around a third of people with transverse myelitis can expect to make only a limited recovery and are left with significant effects such as physical problems affecting their ability to walk, unusual sensations (paraesthesia) and problems with their bowel and bladder. Around a third of people with transverse myelitis make no recovery.

It is very difficult to predict what sort of recovery an individual will make but recoveries seem to be more difficult for people who experience a sudden onset of symptoms and do not experience much improvement within the first three to six months.

Longer-term effects

Physical problems

If you have physical problems like weakness in your legs, muscle spasms (spasticity) or difficulty walking, it is likely that you will benefit from physiotherapy. A physiotherapist will recommend movements and exercises to assist your recovery and help you regain the strength, flexibility, feeling and movement in your legs that you might have lost. They will also recommend movements and exercises to help you maintain any strength, flexibility, feeling and movement that you still have. The physiotherapist might show your friends, family or carers how to assist you with some of the exercises so you are able to practise them at home between appointments.

Bowel and bladder problems

It is common for people to have problems with their bowel or bladder after transverse myelitis. You might be referred to a health professional who specialises in continence problems for advice.

Sexual problems

You might have sexual problems after transverse myelitis. This might be something that you find difficult to talk about. It might be that you, or you and your partner, find it helpful to discuss your sexual problems and concerns about your sex life with a counsellor or therapist.



Longer-term effects

Fatigue

It is common to experience fatigue (extreme tiredness). You might find that you become exhausted even after commonplace activities like going to the shops, watching television, or talking with your friends. Keeping active is an important part of your recovery but you might need to think of ways to conserve your energy. It can be helpful to return slowly to your usual everyday activities rather than



trying to do too much too soon.

Try building up your activities over a few weeks. It can also be helpful to take regular short breaks throughout the day.

Depression

Many people find it difficult coming to terms with having had transverse myelitis. You might feel depressed, tearful, angry or anxious. As time goes by, it can be hard to express and explain to others how you feel and how you have changed, especially as you might appear to have made a good physical recovery or be coping well with

your physical symptoms. This can lead to feelings of isolation. It often helps if you can talk to a friend or relative about how you are feeling rather than keeping things bottled up inside. You might want to talk to your GP about seeing a clinical psychologist or a counsellor.

Relapses

Recurrent transverse myelitis

Transverse myelitis is usually a condition that people experience only once. Very rarely, people experience further episodes. For these people, it might be that they recover fully then experience a relapse, or that during a seemingly good recovery they experience a worsening of their symptoms before continuing to recover. Recurrences of transverse myelitis are more likely if there is an underlying illness or disease.

“Pseudo relapses” in transverse myelitis

Some people can experience a temporary worsening of their symptoms after transverse myelitis but go on to make a good recovery or recover fully. They do not experience any new inflammation so it is not a true relapse. These “pseudo relapses” can be due to reduced transmission of messages (nerve impulses) through the injured part of the spinal cord and can be linked to over-exertion or other changes in the body such as fever, infections (for example, urinary tract infections), constipation, menstruation, or temperature changes caused by warm weather or a hot bath.

Other demyelinating conditions

Transverse myelitis and multiple sclerosis (MS)

For most people, transverse myelitis is a one-off event. However, for a small number of people who experience a relapse, transverse myelitis is a forerunner for other neurological conditions, especially multiple sclerosis (MS).

If, after being diagnosed with transverse myelitis, you experience further neurological symptoms and, after tests and investigations, are subsequently diagnosed with MS, your care and treatment will be the same as it is for anyone with MS.

Like transverse myelitis, MS is a condition affecting the central nervous system. However, people with multiple sclerosis might experience inflammation and nerve damage throughout their central nervous system (in the brain and the spinal cord). MS can also damage the optic nerves, affecting people's vision. As with transverse myelitis, the inflammation causes damage to the myelin sheath surrounding the axons which carry messages (nerve impulses) in the brain and spinal cord.

MS and transverse myelitis are both considered to be part of a group of neurological conditions called **demyelinating conditions** (conditions involving inflammation and damage to the myelin sheath).

(You might be interested in reading our fact sheet with information on multiple sclerosis for further details.)

Clinically Isolated Syndrome (CIS)

Sometimes when a person experiences their first episode of neurological symptoms, they are diagnosed with Clinically Isolated Syndrome (CIS). CIS is a possible indication that the person might subsequently develop MS. The likelihood of developing MS is higher if an MRI scan shows abnormalities in the brain.

Clinical trials suggest that treating people diagnosed with CIS with one of the disease-modifying drug therapies used to treat MS might reduce the risk of relapses and delay the progression from CIS to MS.

Other demyelinating conditions

ADEM (Acute Disseminated Encephalomyelitis) – ADEM involves inflammation and damage in the brain and spinal cord. The symptoms might be similar to transverse myelitis and also commonly include headache, fever, stiff neck and confusion. The main treatment is with corticosteroids. ADEM affects children more than adults.

NMO (Neuromyelitis Optica) or Devic's disease – NMO involves inflammation and damage in the spinal cord and to the optic nerves (the nerves connecting the eyes and the brain). The symptoms might be similar to transverse myelitis and also include visual problems with one or both eyes (blurred vision or loss of vision). People might also experience pain in one or both eyes. The main treatment is with corticosteroids. People are likely to experience recurrences of NMO / Devic's disease.

Optic neuritis – Optic neuritis involves inflammation and damage to the optic nerves (the nerves connecting the eyes and the brain). The main symptoms are visual problems in one or both eyes (blurred vision or loss of vision). People might also experience pain in one or both eyes. The main treatment is with corticosteroids. People are likely to experience recurrences of optic neuritis.

Future treatments

Currently, transverse myelitis is not the subject of any major clinical trials and there is not a lot of evidence to prove the effectiveness of different potential treatments.



However, researchers are investigating a variety of potential treatments some of which might prove to be effective for people with transverse myelitis. For example, some researchers are hopeful that stem cell treatments will be helpful for people with transverse myelitis. Currently, research into stem cell treatments is only in its initial stages.

Useful contacts

Transverse myelitis:

Brain and Spine Helpline

Brain and Spine Foundation
3.36 Canterbury Court
Kennington Park
1-3 Brixton Road
London SW9 6DE

0808 808 1000

www.brainandspine.org.uk

Run by neuroscience nurses, providing support and information on all aspects of neurological conditions for patients, their families and carers, and health professionals.

The Transverse Myelitis Society

35 Avenue Road
Brentford TW8 9NS

www.myelitis.org.uk

Support and information on transverse myelitis.

The Spinal Injuries Association

SIA House
2 Trueman Place
Oldbrook
Milton Keynes MK6 2HH

0800 980 0501

www.spinal.co.uk

Support and information on spinal cord injuries and paralysis.

Useful contacts

Multiple sclerosis and related conditions:

The Multiple Sclerosis Society

MS National Centre
372 Edgware Road
London NW2 6ND

0808 800 8000

www.mssociety.org.uk

Support and information on multiple sclerosis and related conditions.

The Encephalitis Society

The Encephalitis Resource Centre
7B Saville Street
Malton
North Yorkshire YO17 7LL

01653 699 599

www.encephalitis.info

Support and information on encephalitis and ADEM.

Physiotherapy:

Association of Chartered Physiotherapists Interested in Neurology (ACPIN)

The Chartered Society of Physiotherapy
14 Bedford Row
London WC1R 4ED

020 7306 6666

www.acpin.net

Physiotherapists specialising in neurological conditions. Contact through the Chartered Society of Physiotherapy.

Support groups

The Brain and Spine Foundation's online discussion forum offers the opportunity to post messages, exchange views, share experiences and ask questions.

www.brainandspine.org.uk/applications/discussion

The Transverse Myelitis Society has information on local support groups.

www.myelitis.org.uk/ukmeetings.htm

Further reading

The Brain and Spine Foundation produces fact sheets with information on brain and spine scans, and multiple sclerosis.

References

Details of medical references used for this booklet are available at www.brainandspine.org.uk/references or on request from the Brain and Spine Helpline 0808 808 1000.

Please note that transverse myelitis is a rare condition and is not currently subject to any clinical guidelines.

Thank you

We would like to thank everyone who contributed to this booklet, especially Anu Jacob (Consultant Neurologist), Simon Hawke (Consultant Neurologist), Lew Gray, and members of the Transverse Myelitis Society.

Brain and Spine Foundation



The Foundation provides support and information to those affected by the many conditions associated with the brain and spine. The charity relies heavily on voluntary donations and fundraising events to provide the services which have helped many thousands of people across the UK.

You can help the future work of the Brain and Spine Foundation by

- Making a donation
- Organising or taking part in a fundraising event
- Offering your time as a volunteer
- Remembering the Brain and Spine Foundation in your will

Further details available from the address/telephone number below or from www.brainandspine.org.uk.

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