# Transverse myelitis



The **Brain & 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 commonly asked questions. Any medical information is evidence-based and accounts for current best practice guidelines and standards of care.

# Contents

Introduction	2
Common questions	3
Tests and investigations	9
Possible treatments	
Possible treatments	14
RecoveryLonger-term effects	15
Longer-term effects	16
Relapses	21
Other demyelinating conditions	22
Future treatments	24
Useful contacts	25
Useful contacts Support groups	3
Further reading	3
Further readingReferences	3
Thank you	

### Introduction

This booklet provides information on transverse myelitis (TM), describing the condition, common symptoms, tests and investigations, and possible treatments. It also provides information on recovery, long-term effects, other demyelinating conditions and future treatments. 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 condition of the central nervous system involving inflammation in the spinal cord. 'Transverse' refers to the inflammation being across the width of the spinal cord though often it may not affect the whole width. The word myelitis is derived from Greek words 'myelos' (spinal cord) and 'itis' (inflammation). The inflammation impairs messages (nerve impulses) travelling along the spinal cord.

The inflammation can damage or destroy myelin (the fatty insulating substance that covers nerve cell fibres). It often leaves behind permanent scars which interrupt the transmission of messages between the spinal cord nerves and the rest of the body.

The parts of the body affected are determined by the segment of spinal cord that is injured. Inflammation can occur in the cervical (neck), thoracic (chest), lumbar (lower back) and/or sacral (tail bone) region.

#### The central nervous system

The central nervous system is made up of the brain and spinal cord. Messages (nerve impulses) travel along the spina 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.

### Initial symptoms

Most people with transverse myelitis experience muscle weakness, back pain and numbness or changes in sensation (unusual feelings) at the levels below the inflammation. Symptoms can rapidly progress to include bladder and bowel problems and paralysis.

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

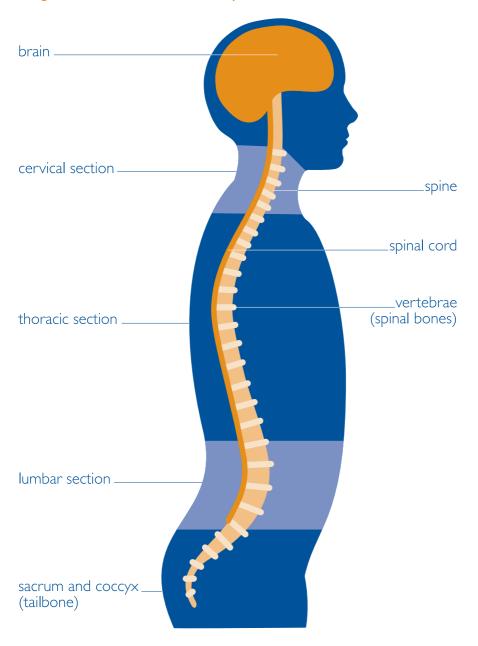
#### The spinal cord

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 move and some carry sensory messages 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.

### Diagram of the central nervous system



#### What causes transverse myelitis?

The exact cause for transverse myelitis is not known, although the inflammation is thought to be the result of the immune system mistakenly attacking the spinal cord. This is called an autoimmune reaction. When a cause cannot be identified, it is called idiopathic transverse myelitis.

Transverse myelitis often develops at the same time as, or soon after, a viral or bacterial infection. These cases 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 which is stimulated to fight the infection, mistakenly, also attacks the spinal cord.

In rare cases, vaccinations may be associated with transverse myelitis, although the underlying cause has not been proven. It is thought that the immune system is triggered to respond to the vaccination and mistakenly attacks the spinal cord.

For some people, transverse myelitis can be linked to autoimmune diseases such as lupus, HIV, HTLV virus, vitamin B12 deficiency, MS and systemic lupus erythematosus (SLE), Lyme disease, syphilis, and some cancers (which can cause an autoimmune reaction) although this is rare.

#### The immune system

Our immune system protects us from being infected by bacteria, viruses and parasites which can make us ill. An autoimmune reaction occurs when the immune system mistakenly attacks our body's own tissue rather than just attacking the foreign bacteria or virus.

In some cases, transverse myelitis may occur because of other disorders, such as multiple sclerosis (MS) and neuromyelitis optica (NMO). People with transverse myelitis should be evaluated for MS and NMO, as these may require different treatments. There is more information on transverse myelitis and MS on page 22 and NMO on page 23.

#### How common is transverse myelitis?

Transverse myelitis is rare. Up-to-date figures are not available, but it is estimated that there are about 300 new cases in the UK each year.

### Is my family at risk?

Currently no hereditary risk or genetic factors have been identified for transverse myelitis. It is not possible to catch transverse myelitis from another person.

### What are the symptoms?

The symptoms of transverse myelitis depend on which section of the spinal cord is affected by the inflammation, the severity and how much damage has been caused. The spinal cord in the neck (cervical), the chest (thoracic) and low back (lumbar) can all be affected. TM on the cervical cord may affect arms and legs while the thoracic or lumbar cord TM may not affect the arms.

The main symptoms of transverse myelitis are muscle weakness in the legs and, less commonly, in the arms and hands. Changes in sensation in the body, pain, problems with the bladder and bowel and/or sexual dysfunction are not uncommon.

During the onset, people might also experience tiredness, muscle spasms or stiffness (spasticity), loss of appetite and a general feeling of being unwell.

Commonly, the first symptoms people with transverse myelitis experience are pain in their back and a sudden change in sensation in their legs (unusual feelings such as burning or tingling) 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, tingling, burning, stabbing and crawling sensations, and a heightened sensitivity to touch and temperature. The feel of clothing on the skin might cause pain. People might experience extreme heat or cold, or lose the ability to tell the temperature of water or objects.

Sometimes, people may experience a tight banding or girdle-like sensation around the torso, which may be very sensitive to touch.

Bladder and bowel problems might include incontinence (a loss of control over bowel movements or passing urine), needing to go to the toilet with increased urgency or feeling the need to urinate and being unable to go (retention).

### Tests and investigations

Transverse myelitis is not always a straightforward condition to diagnose.

People who experience a sudden onset of their symptoms are likely to seek urgent medical attention and go directly to hospital. If the symptoms develop more slowly, it is more likely that people will see their GP, who could then refer them to a neurologist.

A combination of weakness in the legs and unusual sensations is a common 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, a stroke or a tumour. People with any of these conditions will require specific treatments.

A diagnosis of transverse myelitis relies on the patient's medical history, physical examination, MRI, possibly a lumbar puncture and blood tests.

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

### Magnetic resonance imaging (MRI) scan

The key investigation 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 the scanner can be very noisy.

The results of the scan will usually (but not always) pick up the cause of the problem. (You might be interested in reading our fact sheet 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/inflammation are indicated by abnormalities in the 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. Afterwards, you might be asked to lie on your back for between one and three hours and to drink plenty of water to prevent getting a headache.

### Possible treatments

Currently there is no cure for transverse myelitis, but treatments and medical interventions are used to reduce the severity of the event, hasten recovery and relieve the symptoms and the after effects.

#### Drug treatments

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.

Corticosteroids are also known as steroids. They should not be confused with anabolic steroids which can boost muscle strength and whose illegal use is associated with sports people and bodybuilders.

They are commonly given to people to reduce inflammation, suppress the immune system, and replace hormones.

Usually, corticosteroids are given in short courses to reduce the risk of unwanted side effects. Your doctor will discuss the possible side effects with you.

You might be given a three or five day course of corticosteroids intravenously (methylprednisolone is given through a drip into a vein in your arm). This may be followed by an oral course of prednisolone for a variable length of time, days to weeks. The length of the treatment depends on your progress which might continue over several weeks.

### Plasma exchange (PLEX)

If corticosteroids are not effective, you may be given a treatment called plasma exchange (PLEX), also known as plasmapheresis. This treatment is not 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 returned into the body with new plasma — or an equivalent fluid. It is likely that the plasma exchange will happen over three to five sessions rather than all at once.

#### Other treatments

#### Immunoglobulin

In some cases you may be given a treatment called intravenous immunoglobulin (IVIg). Immunoglobulin is a solution of antibodies, made by the immune system and taken from healthy donors (they are used to treat a number of medical conditions). The body uses antibodies as a means of regulating immune responses. IVIg reduces and alters the immune system's response.

#### **Medications**

Different medications may be required to improve/reduce your symptoms like pain, spasms, bladder and bowel.

During the acute stage of your symptoms, you might not be able to move and will receive nursing care. If you are experiencing paralysis, you will be cared

for by nurses in order to prevent and treat complications specifically associated with paralysis. These complications may include pressure ulcers (a breakdown of the skin and underlying tissue, caused when an area of skin is placed under pressure) and autonomic dysreflexia (a sudden onset of excessively high blood pressure, which can be potentially life-threatening.) Autonomic dysreflexia is more common in people with paralysis as a result of a spinal cord injury in the middle of their chest or higher.



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, flexibility and to help reduce stiffness and spasms. An occupational therapist can assess and give advice on activities that affect your independence such as personal care, domestic tasks, hobbies and employment activities.

Carers and those supporting you may be advised to help move your limbs manually to improve flexibility and strength and to reduce the likelihood of pressure ulcers developing.

# Going home

You may be transferred to a rehabilitation unit prior to being discharged home. If you require walking aids such as a stick, crutches or a wheelchair, you might be assessed for these before you leave the hospital.



Before being discharged home it is important that arrangements have been made for you to receive the support you need. You may be referred to your local social services, local community physiotherapy or occupational therapy services.

A community physiotherapist can assess your physical problems. An occupational therapist can offer practical support and advice on everyday skills and activities, such as using kitchen equipment and getting around your home safely.

## Recovery

Transverse myelitis affects everyone differently, and the recovery process will vary for each individual. Nerve damage can cause problems including weakness in the legs, muscle spasms, spasticity, difficulty walking, numbness and tingling, balance and strength difficulties.

Recovery from transverse myelitis usually begins within a few weeks of the onset of symptoms and can continue for up to two years, or sometimes longer. Early treatment may facilitate recovery. People usually make the best recovery between three and six months after the onset of symptoms. Even if your recovery is slow, it is still important to persevere with physiotherapy and rehabilitation, as these can benefit your long-term health and support you to maintain the recovery you have made.

Approximately a third of people with transverse myelitis can expect to make a good or full recovery with very limited or no long-term effects. Approximately 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), pain, fatigue, spasticity and/or problems with their bladder and bowel. Approximately a third of people with transverse myelitis make no recovery.

It is very difficult to predict what sort of recovery an individual will make. A significant recovery seems to be more difficult in people who experience a sudden onset of symptoms and do not experience much improvement within the first three to six months. A good or full recovery is possible even after severe symptoms. The myelin sheath surrounding the nerves in the spinal cord are able to repair themselves, although not always fully. Some areas of the spinal cord are only temporarily damaged by the inflammation and it is possible for them to return to normal.

## Longer-term effects

#### Pain

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 such as muscle spasms or strains, or related to the injury in the spinal cord (musculoskeletal pain). Messages (nerve impulses) might not be able to travel properly within the spinal cord, confusing the brain and causing it to interpret them as pain signals. People with transverse myelitis may also experience numbness, neuropathic pain and/or musculoskeletal pain (including gait disturbances and spasticity).

Neuropathic pain is hard to describe and is different for everyone. It can include a range of sensations such as burning, tingling, shooting, searing, stabbing or electric shock type feelings. It may be worse at night. It can also cause a range of associated symptoms including insomnia, anxiety, depression and weight changes. It is often difficult to find the cause of neuropathic pain, but the aim of the treatments is to reduce the pain.

Neuropathic pain is caused when the nerves within the peripheral or central nervous system are injured in some way and incorrect signals are sent to the brain, which leads to continuous chronic pain. 'Neuro' means nerves and 'pathy' means abnormality.

If you are experiencing neuropathic pain (pain caused by damage or disease affecting the nervous system) ordinary pain medication (e.g ibuprofen and paracetamol) may not be effective. However, there are other medications and non-drug approaches which may be helpful.

The main medications recommended for neuropathic pain include amitriptyline, gabapentin, pregablin, duloxetine and tramadol.

Other treatments for neuropathic pain can include management programmes, acupuncture and other complementary or alternative therapies, such as reflexology and aromatherapy. It may be possible to attend a pain clinic for assessment, management and advice on living with chronic pain. For more information speak to your GP or consultant.

The type of treatment that suits you will depend on the type of pain you are experiencing. Often a trial and error approach can help to find the most effective treatment for you.

For more information on any of the treatments available speak to your doctor. If the medication isn't effective or you experience unpleasant side effects, your GP may refer you to a pain clinic or neurologist.

People who experience these problems may find physiotherapy beneficial.

#### Bladder and bowel problems

It is common for people to have problems with their bladder or bowel after transverse myelitis due to the disruption of signals between the brain and bladder/bowel.

Bladder symptoms include not being able to empty bladder (retention), having to empty bladder as soon as the urge comes (urgency), having to empty bladder a lot (frequency) and emptying bladder at night (nocturia). There are medications that can help control the bladder and you might need to learn to self-catheterise to empty your bladder. There are new treatments (such as botox treatment for spastic bladder) available for bladder problems.

The most common bowel problem is constipation due to reduced mobility and sensation. Sometimes diarrhoea (or overflow) may be a problem. You may discuss with your GP if it's necessary for you to be referred to your local continence adviser or nurse for an initial assessment and advice on managing the symptoms.

#### Sexual problems

Following transverse myelitis, people may experience sexual problems including decreased libido, erectile and ejaculatory dysfunction and pain in men. Women may have decreased arousal, lack of vaginal lubrication, lack of sensation, anorgasmia and pain. These can be made worse by physical symptoms such as spasticity, bladder or bowel incontinence, or due to medication side effects and problems as a result of psychological factors.

It can be difficult to talk about sexual problems, but it is important to communicate your feelings to your partner. You may find it helpful to discuss your sexual problems and concerns with a neurologist, your GP or a counsellor. Other things that may help include medication and alternative approaches.

### **Fatigue**

Fatigue is an overwhelming sense of tiredness, with no obvious cause. You may find that you become extremely tired after little activity, wake up feeling as tired as when you went to sleep, experience heavy limbs and a temporary worsening of your symptoms. Fatigue can have a profound effect on you and you may find that you become very tired after everyday activities.

Fatigue affects people in different ways, and how it affects you may change over time. It can also be very difficult to explain what you are experiencing to other people. You may also experience good and bad days, which can be confusing.

People with transverse myelitis may experience fatigue due to the condition itself, symptoms related to the condition, medication and/or other medical conditions.

There are things that can help you to manage your fatigue. Planning and prioritising what you need to do can help, especially if you include periods of rest. It is important to pace yourself, to try and listen to your body. Try to be realistic about what you can do and what you need to achieve. You could ask friends and family to help you with certain things, if necessary. You may find it helpful to return slowly to your usual everyday activities rather than trying to do too much too soon.

It is important to pace the activities you do throughout the day and take regular short rests. Exercise can help your body and improve strength, fitness and mood, so you may find a gentle exercise such as walking or swimming helpful. A healthy diet and a good fluid intake will help to improve your mood and help with your fatigue. Meditation is another approach which many people find helpful.



Photo: Sebastien Wiertz

There are lots of things which can also worsen your fatigue, such as sleep disturbances, emotional upset, pain, infection or medication. Everyone is different and you are likely to experience good and bad days. It is important to listen to your body and not put too much pressure on yourself.

#### Depression

People find it difficult coming to terms with the impact of transverse myelitis on their lives. You might feel tearful, angry, anxious or depressed. These are all normal reactions to a life-changing experience. Many people find that as time goes by and they begin to adapt to their situation, they start overcoming these feelings.

However, if you have ongoing feelings of sadness, lack of motivation, lack of self-esteem and self-worth it may be that you are experiencing depression. You may feel a sense of hopelessness, but there is treatment available to support people with depression. It is important to seek help and support if you think you are depressed.

It can be hard to express and explain to others how you feel and what you are experiencing especially as you might appear to have made a good physical recovery or be coping well. This can lead to feelings of isolation. It may help to talk to a friend or relative about how you are feeling rather than keeping things bottled up. You can also speak to your GP about treatment such as medication, cognitive behavioural therapy (CBT) or counselling.

# 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.

A recurrence of transverse myelitis is more likely if there is an underlying illness or disease and will require further tests for causes such as multiple sclerosis or neuromyelitis optica. Further investigations will be required such as an MRI scan, lumbar puncture (LP) and testing of blood for different markers.

#### "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 or full recovery. 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. Cold weather and stress can also exacerbate symptoms.

## Other demyelinating conditions

#### Transverse myelitis and multiple sclerosis (MS)

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).

If, after being diagnosed with transverse myelitis, you experience further neurological symptoms and 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 affect the optic nerves, causing visual problems. 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.

(You might be interested in reading our fact sheet **Multiple sclerosis** for further details.)

#### ADEM (acute disseminated encephalomyelitis)

ADEM often involves inflammation and damage in the brain and spinal cord, and it usually follows a mild viral infection or immunisations, and there may be a delay between the infection and developing ADEM. Symptoms include fever, headache, nausea and vomiting, confusion, ataxia (problems with balance, coordination and speech) and sensory changes. Diagnosing ADEM is likely to involve a lumbar puncture, MRI and blood tests. Treatment for ADEM involves steroids, IVIg or plasma exchange. Some people who experience ADEM

may have long-term impairments such as cognitive difficulties, weakness or numbness. Even if the person makes a good physical recovery they may experience psychological changes such as a change of personality. It is possible to have recurrences of ADEM. Some people who are initially diagnosed with ADEM go on to develop MS. ADEM affects children more than adults.

### NMO (neuromyelitis optica)

NMO, or NMOSD (neuromyelitis optica spectrum disorder), commonly causes inflammation and damage in the spinal cord and to the optic nerves. Most patients with NMO have a protein in their blood called anti-aquaporin 4 (AQP4) antibody which causes the disease. NMO can be a relapsing disease which means that symptoms come and go. Relapses are often known as 'attacks'.

People are likely to experience relapses of transverse myelitis or optic neuritis (attacks on their vision) over months or years, however some people may remain stable for long periods of time. Sometimes the brainstem may be affected and nausea, vomiting and hiccoughs may be a sign of a relapse. Diagnosing NMO requires a detailed medical history, an MRI of the brain and spinal cord, a blood test for AQP4 and may include a lumbar puncture and ophthalmological tests.

### Future treatments

There are other areas of research which may be of interest to people with transverse myelitis.

- The NMO UK Specialist Services are conducting ongoing research into various aspects of NMO. For more information on this you can contact the service (see Useful contacts).
- There is ongoing research into MS which may be beneficial for people with transverse myelitis. For more information speak to your GP or contact the MS Society.
- The UK is a major centre for research into stem cells, regenerative medicine and spinal cord injury. This may be beneficial for the treatment of people with demyelinating conditions like transverse myelitis and MS. However, there is still a long way to go with this research.

### Useful contacts

#### **Brain & Spine Helpline**

Brain & Spine Foundation LG01 Lincoln House Kennington Park I-3 Brixton Road London SW9 6DF

Helpline: 0808 808 1000 helpline@brainandspine.org.uk 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.

#### Transverse Myelitis Society

35 Avenue Road Brentford TW8 9NS

info@myelitis.org.uk www.myelitis.org.uk

Support and information on transverse myelitis. They provide free membership, a network of support groups, information, conferences, a magazine and bursary and grant schemes.

They can also provide the details of neuro-physiotherapists experienced in transverse myelitis and recommended by members.

#### **Transverse Myelitis Association**

www.myelitis.org

The website provides information on transverse myelitis, acute disseminated encephalomyelitis (ADEM) and neuromyelitis optica (NMO). They also offer regular Q&A webcasts with top American doctors, and these are made available as podcasts.

#### The Back-Up Trust

Jessica House Red Lion Square 191 Wandsworth High Street London SW18 4LS

Tel: 020 8875 1805 admin@backuptrust.org.uk www.backuptrust.org.uk

They provide information and support for those affected by spinal cord injury, their families and friends, as well as courses and a mentoring scheme.

#### The Brain Charity

Norton Street Liverpool L3 8LR

Tel: 0151 298 2999 info@thebraincharity.org.uk www.thebraincharity.org.uk

Provide emotional support, practical help, benefits advice and social activities to anyone with a neurological condition and to their family, friends and carers.

#### **Spinal Injuries Association**

SIA House 2 Trueman Place Oldbrook

Milton Keynes MK6 2HH

Advice line: 0800 980 0501 adviceline@spinal.co.uk www.spinal.co.uk

Support and information including a helpline on spinal cord injuries and paralysis, and returning to work advice.

#### **Multiple Sclerosis Society**

MS National Centre 372 Edgware Road London NW2 6ND

Helpline: 0808 800 8000 helpline@mssociety.org.uk www.mssociety.org.uk

Support and information on multiple sclerosis.

#### **Multiple Sclerosis Trust**

Spirella Building Bridge Road Letchworth Garden City Hertfordshire SG6 4ET

Helpline: 0800 032 3839 info@mstrust.org.uk www.mstrust.org.uk

Support and information on multiple sclerosis.

#### **Encephalitis Society**

The Encephalitis Resource Centre
32 Castlegate
Malton
North Yorkshire YO 17 7DT

Helpline: 01653 699 599 www.encephalitis.info

Support and information on encephalitis and ADEM, as well as a guide for GPs.

#### **NMO-UK Rare Illness Research Foundation**

43 Foxley Heath

Widnes

Cheshire

WA8 7EB

info@nmo-ukresearchfoundation.org www.nmo-ukresearchfoundation.org

Support and information for people affected by NMO, their families and carers.

#### **Bladder & Bowel Foundation**

SATRA Innovation Park Rockingham Road Kettering Northants NN 1 6 9 JH

Helpline: 0845 345 0165 info@bladderandbowelfoundation.org www.bladderandbowelfoundation.org

Support and information for people experiencing bladder and bowel control problems, including a confidential helpline, for anyone affected by these conditions as well as their families, carers and healthcare professionals.

#### **Spokz People**

2 Jordan Croft Fradley Lichfield WS13 8PN

Tel: 01543 899317 mel@spokzpeople.org.uk www.spokzpeople.org.uk

Can provide counselling, sex and relationship support where a condition results in sexual dysfunction.

#### The Chartered Society of Physiotherapy

14 Bedford Row London WCIR 4ED

Tel: 0207 306 6666 www.csp.org.uk

The website includes a 'find a physiotherapist' section, called Physio2U.

# Support groups

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

The Transverse Myelitis Society has information on local support groups. www.supportgroups.myelitis.org.uk

### Further reading

The Brain & Spine Foundation produces a range of information booklets and fact sheets including: 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 & Spine Helpline 0808 808 1000, helpline@brainandspine.org.uk. 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 Dr Anu Jacob (Consultant Neurologist), Dr M. Lunn (Consultant Neurologist), Kerry Mutch (NMO Specialist Nurse), the members of the Transverse Myelitis Society and Barbara Babcock.

This booklet was kindly supported by:



### Brain & Spine Foundation

Our mission is to improve the quality of life of people affected by neurological problems by providing expert information, support and education. We rely on donations to provide our services to anyone who needs us.

#### How to donate

- Online: www.brainandspine.org.uk/donate
- By phone: 020 7793 5900
- By post: send a cheque to the address below

#### Contact us

Brain & Spine Foundation LG01 Lincoln House, Kennington Park, 1-3 Brixton Road, London SW9 6DE

Telephone (switchboard): 020 7793 5900 info@brainandspine orguk

Helpline: 0808 808 1000 helpline@brainandspine.org.ul

Registered charity number: 1098528 © Brain & Spine Foundation 2016

Published: 2016

Next review date: 2019

www.brainandspine.org.uk





