
How Can I Help?

It might be difficult for your friend / family member to explain how they feel, or what they need help with. Ask how you can best be of help, and be willing to do nothing except listen and try to understand.

Don't expect the person to be able to do everything they could before they were ill. However, encourage them to do things for themselves, if they are able and want to.

Where to Find Information and Help

The TMA website www.myelitis.org is the best source of information about TM, symptoms, treatments etc. The UK section of the website www.myelitis.org.uk has UK-specific information about NHS Neuro services, local support groups and other sources of information and support.

The best general introduction to TM in UK is a short booklet published by the British Brain and Spine Foundation, available through their website www.brainandspine.org.uk or their **Helpline 0808 808 1000**.

The Neurological Alliance also publishes an excellent booklet "Getting the Best from Neurological Services" available from www.neural.org.uk.

For carers, try the following websites for more help and advice:

www.carersonline.org

www.carersuk.org

www.crossroads.org

Local Support Groups

Contact your local support group and come to a meeting. Current groups are:

London: Yvonne Kolesar 01737 552869

Poole, Dorset: Mary Bergin 01590 683824

Berkshire: Angela Dunbar 01628 810638

Scotland: Margaret Shearer 01292 476758

Telford: Anna Paulsson 01952 270987

East Midlands: Janet Ashenden 01827 373997

Bristol: steve.collins@blueyonder.co.uk

Southeast: annie.schofield@spoilyourself.co.uk



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TRANSVERSE MYELITIS

**A Guide for Friends and Family of
Those Affected by TM**



What Is Transverse Myelitis?

TM is a rare disorder, involving an inflammatory attack in the central nervous system. This can happen anywhere along the spinal cord, causing a 'lesion' usually visible on an MRI scan.

Attacks are normally one-off episodes, but sometimes recur in different places along the spinal cord. Many people, even if severely affected initially, will make a good recovery within a few months following an attack. But most people are permanently affected to some degree.

At the point of attack, the outer sheath of the nerves is damaged, causing a disturbance in the signals sent along the nerve to the corresponding muscles. Imagine an electrical lead that has lost part of its insulating plastic cover. The appliance attached to this lead is likely to 'short circuit' and be unreliable. The same is true for muscles which are controlled by the damaged nerves.

This type of nerve damage is known as 'demyelination', and TM is a 'demyelinating disease' in the same family of conditions as Multiple Sclerosis. Other rare conditions in this family include ADEM which affects the brain as well as the spinal cord, and Devic's Disease (NMO) which also affects the eyes.

How Does It Feel to Have Transverse Myelitis?

People are affected by TM in very **different** ways and with different degrees of severity. **Not all** people will have all of these symptoms. Also many symptoms are invisible. It is important to remember that just because you can't see what is wrong, it doesn't mean the TM sufferer is not feeling pain or discomfort. They may find it difficult to explain exactly how they feel.

You may also notice that people with TM have 'good days' and 'bad days'. Over time we can learn what triggers the bad days. Typically stress, overdoing things and getting hot and bothered can worsen symptoms, or contracting another illness.

Symptoms are often felt in the legs and feet, and/or the arms, hands and chest, depending on the position of the lesion.

Tiredness

One of the most common symptoms is extreme tiredness or fatigue. This is often hard to understand if you have previously known this person to have lots of energy.

Muscle Weakness / Spasm

The muscles affected by TM will tire quickly, and also be prone to spasm, which is like a sharp cramp that can last for days. Sometimes the limbs affected can twitch, which may look a bit strange if you are not used to it.

Walking Difficulties

Almost everyone with TM suffers some degree of difficulty with walking. Some people may need to use a wheelchair. Others may need a stick or crutches to support their walking. Standing and walking balance is also affected sometimes, causing the sufferer to be at risk of tripping and stumbling.

Embarrassing Problems

It is likely that your TM sufferer will have some problems with their bladder, bowel or sexual function. They may not want to talk about this, but naturally it affects their quality of life.

Depression

When a person discovers they may well never completely recover from a medical condition, it is understandable to feel 'depressed' about it. With TM however, there seems to be a physiological basis for more serious clinical depression, which needs to be *treated*.

Other Symptoms May Include:

- Paralysis
 - Pain (different sorts)
 - Sensory Impairment
 - Numbness / Pins&Needles
 - Headaches / Backache
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