

## Where to find more help and information

The website address for the TM Society is [www.myelitis.org.uk](http://www.myelitis.org.uk). Our website contains information for newly diagnosed patients, carers and for parents that have children with TM. There is also information on Support Groups as well as resources for dealing with symptoms and living with a disability.

The UK's Brain & Spine Foundation (BSF) has prepared a 24-page booklet called 'Transverse Myelitis'. The booklet is an excellent source of comprehensive information. You can download it from the 'Newly Diagnosed' section of our website or you can ask for a printed copy of the booklet from the BSF Helpline 0808 808 1000. The BSF Helpline is staffed by neuro specialist nurses and provides advice on TM and related conditions.

The Transverse Myelitis Association (TMA) is the US and world-wide organisation for TM. It is the best source for further technical and medical information. Their website address is [www.myelitis.org](http://www.myelitis.org).

## How to contact the Transverse Myelitis Society

Most people with TM never meet anyone else with the same condition - isolation is unhealthy! Meeting others who have suffered TM helps, not only with practical tips and suggestions, but also to maintain a positive attitude in the face of a bewildering range of symptoms.

New members should register on the website [www.myelitis.org.uk](http://www.myelitis.org.uk) (click on 'Become a Member') to receive regular newsletters, UK information, and invitations to support group meetings.

Email the Secretary Lew Grey ([lew.gray@myelitis.org.uk](mailto:lew.gray@myelitis.org.uk)) for further information or telephone on 020 8568 0350.

We have no membership subscription or fee, although donations are welcome as we are 100% member-financed.

### **Transverse Myelitis Society**

35 Avenue Road  
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Registered Charity No. 1108179



The Transverse Myelitis Society (TMS) is a UK registered charity affiliated with the worldwide Transverse Myelitis Association (TMA). The TM Society provides information and support to over 1000 people with TM, their carers and their families. The TMS also supports people with other rare auto-immune neurological conditions eg ADEM and NMO (Devic's Disease). Local TM support groups are active in London, Telford, Poole, Berkshire, Bristol, Southeast, East and West Midlands and Scotland, plus informal contacts throughout UK.

### **TM Society Goals**

- To facilitate support and networking opportunities among members
- To promote awareness and provide information about TM
- To support improved treatment and research

## What is Transverse Myelitis?

TM is a rare neurological disorder, one of a group of 'neuroimmunologic' diseases of the central nervous system, which also include ADEM, NMO (Devic's Disease) and MS. These conditions all involve inflammatory attacks in the central nervous system. They are differentiated primarily by the location of the attack, and by the attacks being either monophasic (one off) or multiple episodes. These disorders share common mechanisms and have many common symptoms.

There is tremendous variability in the presentation of symptoms, which are based on the level of the spinal cord affected and on the severity of the damage to the myelin and the neurons in the spinal cord. The symptoms of TM include muscle weakness, paralysis, parasthesias or uncomfortable nerve sensations, neuropathic pain, spasticity, fatigue, depression and bladder, bowel and sexual dysfunction.

TM can be acute or slow developing. There are several variations of TM diagnosis as well.

## Causes of Transverse Myelitis

TM may occur in isolation or with another illness. When TM occurs without apparent underlying cause, it is referred to as idiopathic. Idiopathic TM is assumed to be a result of abnormal activation of the immune system against the spinal cord. TM often develops alongside viral and bacterial infections.

Approximately one third of patients with TM report a flu-like illness with fever, around the time of the onset of neurological symptoms. Vaccinations may also be linked with TM and especially ADEM, but causation cannot be proven.

## What treatments are available?

Corticosteroid drugs are typically used as a treatment for spinal cord inflammation with TM patients. Plasma exchange or more radical immunosuppressant therapies may be used if steroids don't work. All other treatments only address the symptoms at this time. Rehabilitation, especially physiotherapy, is essential.

## Who gets TM and what are the chances for recovery?

Age at onset of this condition can be from infancy to older adult (5 months to 80 years). The peak ages for a TM diagnosis appear to be 10-19 and 30-39 years. Males and females seem to be equally diagnosed. TM is a rare disorder with an incidence estimated at 300 new cases p.a. in UK.

Recovery from TM generally begins within 8 weeks from onset. Recovery is often rapid during months 3-6 and may continue for up to 2 years after onset. One third of those diagnosed with TM make a good recovery, one third have only a fair recovery (ie moderate degree of permanent disability), and one third show no recovery. TM affects people in very different ways, and no two people have exactly the same symptoms or experience of TM. However the vast majority of people with TM do improve significantly, over 1-2 years following onset.

TM is generally a monophasic illness (one-time occurrence). However a small percentage of patients may suffer a recurrence, especially if there is a predisposing underlying illness.