
Newly Diagnosed? Where to Find Information and Help

The TMA website www.myelitis.org is the best source of information about TM – click on ‘About TM’. ‘Frequently Asked Questions’ cover topics such as treatments, exercise, fatigue, fever, recurrence, spasticity etc. The website also includes articles on pain, drugs, urological and sexual issues, plus scientific articles (to show your GP).

The UK section of the TMA website www.myelitis.org.uk includes 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 Brain and Spine Foundation, available at no cost from the BSF website or **Helpline 0808 808 1000**. The BSF Helpline is staffed by neuro specialist nurses and provides advice on TM and related conditions.

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

How to Contact the Transverse Myelitis Society

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 sufferers do improve significantly, over 1-2 years following onset.

Most TM sufferers 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 contact Geoff Treglown on 01539 434 677 or email geoff.treglown@btinternet.com and also register on the website www.myelitis.org to receive regular newsletters, invitations to support group meetings etc.

Other telephone contacts are Sally Rodohan (Chair) 020 8883 2721 or Lew Gray (Secr) 020 8568 0350. There is no membership subscription or fee, although donations are welcome as we are 100% member-financed.

Transverse Myelitis Society
35 Avenue Road
Brentford TW8 9NS

(Registered Charity No. 1108179)



The Transverse Myelitis Society

The Transverse Myelitis Society (TMS) is a UK registered charity affiliated with the worldwide Transverse Myelitis Association (TMA). The UK TMS provides information and support to over 400 TM sufferers, carers and families in UK. The TMS also supports people with other rare auto-immune neurological conditions eg ADEM and Devic’s Disease. Local TM support groups are active in London, Telford, Poole, Berkshire and Scotland plus informal contacts throughout UK.

TMS 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 and Devic's Disease. 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 have many common symptoms and the strategies to treat them are similar.

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 may also be used for Devic's Disease or if steroids don't work. All other treatments only address the symptoms at this time. Rehabilitation, especially physiotherapy, is essential. Patients should expect to follow a rehabilitation regime typical for any spinal injury.

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 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.
