
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 to your GP). On the home page click on the Scotland flag to see information on Scotland group and dates of meetings

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.

Other websites with info are The Long Term Conditions Alliance Scotland www.ltcas.org.uk and The Towpath Trust at www.towpathtrust.org.uk & NHS24

How to Contact Transverse Myelitis Scotland

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 register on the website www.myelitis.org (click on ‘Become a Member’) to receive regular newsletters, information, invitations and notes on Support Group meetings etc.

New members in **Scotland** also contact Margaret Shearer 01292 476758 or email margaretshearer@myelitis.org

Other telephone contacts are Jan Lawson (Sec) 01389 878869 or Jane Batho (Treasurer) 01738 629562. There is no membership subscription or fee, although donations are appreciated.

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**Transverse
Myelitis
Scotland**

Transverse Myelitis Scotland is affiliated with the worldwide Transverse Myelitis Association (TMA). We provide information and support to those with Transverse Myelitis and related conditions (ADEM, Devic's Disease or NMO, Optic Neuritis) and to their carers, friends and families

OUR Goals

- To provide information and support to those with Transverse Myelitis and related conditions.
- To promote awareness to the public and professional sector about the conditions.
- To facilitate and support networking opportunities among members who are striving to ensure that the need for research is paramount to understanding correct diagnosis and causes.

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 being ADEM, Devic's Disease or NMO, Optic Neuritis 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 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 acute attacks of spinal cord inflammation with TM patients. Plasma exchange or more radical immunosuppressant therapies may also be used for NMO and recurrent TM because these people are at risk for multiple attacks and the treatments are to delay or decrease the chance of another attack or lessen its severity should it happen. 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 1-8 per million new cases each year.

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 (i.e. moderate degree of per-manent 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.
