

## Frequently Asked Questions

### What is covered

This Frequently Asked Questions (FAQ) document has been compiled from questions most frequently asked by adults living with Transverse Myelitis (TM), whether they have been recently diagnosed or have been living with the impact of the condition for some years.

Information on related conditions, Neuromyelitis Optica (NMO) and Acute Disseminated Encephalomyelitis (ADEM), are available via the following links:

- NMO (also known as Devics disease) - Booklets are available via the NHS's NMO Specialised Services website at [www.nmouk.nhs.uk](http://www.nmouk.nhs.uk) via the 'resources' menu link
- ADEM – Information is available via The Encephalitis Society's website at [www.encephalitis.info](http://www.encephalitis.info)

### Background

The Transverse Myelitis Society (TM Society or TMS), is a charity based in the United Kingdom (UK) with over 1,800+ members whose main aims are to offer information and support to those who may have, or know someone with, Transverse Myelitis or related conditions including Acute Disseminated Encephalomyelitis (ADEM) and Neuromyelitis Optica (NMO). For more information about the TM Society, including the support and services available to members, please refer to its website [www.myelitis.org.uk](http://www.myelitis.org.uk).

This FAQ was created in 2015/16. Contributors included the following volunteers from the TM Society: Barbara Babcock, Cindy Morelli and Leonie Ashenden. It was reviewed by:

- Kerry Mutch, RGN, BSc Hons, MSc, Advance Nurse Practitioner, The Walton Centre, Liverpool
- Rosie Gore, RMN, MSc, Advanced Nurse Practitioner (Neuromyelitis Optica), John Radcliffe, Oxford
- Anu Jacob FRCP, Consultant Neurologist, Walton Centre, Liverpool

This FAQ is due for review in 2018/19.

## **Please read before continuing**

We would ask that prior to proceeding further in your search for information about TM you take a few moments to read and consider the comments below particularly if you are newly diagnosed.

In some instances when people are affected by TM, the long-term prognosis can be very good, with people coming through the illness with little or no difficulties. However, because there are occasions where recovery is more limited, we have had to write this guide to cover a range of situations. Therefore the information provided here is extensive.

TM manifests itself differently in every person and so the recovery path is different for every person. The problems and difficulties stated here are therefore not reflective of every situation and some information may not be relevant to you.

Given that a TM diagnosis and the change it brings can be an emotional strain for the individual affected and family and friends, consider how much information you access at any one time.

The information provided here is from the patient-experience perspective, as the volunteers who work at the TM Society are not trained medical professionals and so cannot give medical advice. This document has been reviewed by medical professionals.

We encourage you to share the information included here with your medical and healthcare professionals involved in your care. The information is meant to support that relationship and not replace it.

If, as a result of reading this FAQ or other information, you have further questions regarding management of your condition or any other aspect of your rehabilitation, please speak to your consultant neurologist and/or GP in the first instance. Any choices and decisions you take as a result of reading this document are your responsibility and the TM Society cannot be held liable for them.

Throughout this FAQ, information about the services and activities of other charities, organisations and the UK government, which meet the needs of TM Society members, is provided as well as links to their websites. If the links are long, they are embedded in this document and the full link is available at the end of this document in the endnotes.

Where companies are mentioned, it is to signpost where specialist equipment or services can be obtained. It is not an endorsement by the TM Society for these products and services nor has the TM Society received anything in return for mentioning them.

This FAQ was created for members of the TM Society so the information about charities, organisations, statutory benefits and companies is specific to the UK. If you are reading this document and not from the UK, you will still find much of the information useful.

If you have any questions, comments or concerns after reading this document, you can contact us at [info@myelitis.org.uk](mailto:info@myelitis.org.uk) and we will endeavour to respond within a few working days. Also, if you know of a frequently asked question that is not in this document, send that to us too.

Thank you.

The TM Society Committee

## Table of Contents

An overview of Transverse Myelitis .....	5
Initial Diagnosis & Treatment .....	6
Physiotherapy & Exercise.....	14
Medical.....	17
Symptom Management .....	19
Diet.....	25
Social & Family .....	26
Psychological Impact.....	29
Returning to work .....	32
Finances & Benefits.....	33
Driving & Transport.....	35
Travel.....	37
End notes .....	39

## An overview of Transverse Myelitis

TM is a rare neurological disorder, one of a group of "neuroimmunological" diseases of the central nervous system, which also include NMO, ADEM, Optic Neuritis (ON) and Multiple Sclerosis (MS). "Neuroimmunological" means that the disease is neurological and autoimmune. These conditions all involve inflammatory attacks in the central nervous system. They are differentiated primarily by the location of the attack – brain, spine and/or optic nerve - and by the attacks being either monophasic (one off) or multiple episodes. These disorders share common mechanisms and have many common symptoms.

We recommend you first read the [Brain & Spine Foundation's \(BSF\) booklet on Transverse Myelitis](#)<sup>1</sup>, a companion to this FAQ. It gives you an overview of TM by answering the following questions:

- What is Transverse Myelitis?
- What causes TM?
- What are the symptoms of TM?
- Is there a cure?
- How common is TM?
- Can you catch TM from someone else?
- Is TM hereditary?

The questions in the remaining sections of this FAQ expand on what is written in the BSF TM booklet.

---

## Initial Diagnosis & Treatment

### 1. Who gets TM?

TM is a rare disorder with approximately 300 new cases per year in the UK. Age at onset can be from infancy to later life (less than a year old to 80+ years). The peak age for TM appears to be 10-19 and 30-39 years. Male and females are equally affected. In majority of TM cases, a person has only a single episode.

### 2. I am experiencing the following symptoms. Is this normal? Should I be worried?

When TM occurs, you may experience some or many of the following symptoms in your body below the level of the spinal cord where the inflammation is.

- Pain in back (not just lower back pain), extremities or abdomen
- Muscle weakness and/or paralysis
- Sensory alteration/loss - Numbness, tingling, stabbing pain, pins and needles, burning, crawling sensation
- Pain cause by temperature or physical stimuli
- Tight banding around torso, arms, and/or legs
- Electrical shock like sensation through spine to feet (known as 'Lhermitte's Sign')
- Muscle spasms and tightness (spasticity)
- Cold and/or hot sensations in an isolated part of your body
- Diminished temperature sensation
- Bladder and bowel issues – Incontinence, bladder urgency or inability to pass
- Sexual dysfunction
- Fatigue

Some people will experience the symptoms equally on both sides of their body. Some people will experience the symptoms more on one side of the body than the other, or even on one side only. As the recovery process starts, you may find these symptoms start to lessen. Sometimes some symptoms may only start occurring later during the recovery process, e.g. pain and spasms for example.

### 3. How is TM diagnosed?

A significant aspect of any diagnosis of TM is the 'history' of what has happened. The neurologist will take your **medical history** and use their clinical judgement in making a diagnosis. Because TM is rare, the neurologist has to ensure all other possible causes have been eliminated. This allows the clinician to define your problem and potential causes. You will be asked questions regarding

the onset of your symptoms, their duration, how long they last, where they occur, what they are like, their severity, whether anything preceded the symptoms (such as stress, lack of sleep, prior infection, etc.).

Several conditions may lead to TM or mimic the presentation of myelitis and should be investigated at the time of acute symptoms. You may therefore have the following tests to rule out what you do not have.

A **neurological exam** will be done to evaluate the functioning of your central nervous system. This can be completed in a doctor's office with a few instruments such as reflex hammers, lights, pins, and tuning fork. Using these instruments, the clinician will assess your reflexes, coordination, gait, balance, ability to feel sensations and mental status.

An **MRI scan of the entire spine** is important as sometimes (not in all cases) the inflammation may be higher in the spinal cord than the presenting symptoms seem to indicate. A MRI also helps to rule out other problems such as compression of the spinal cord caused by a tumour, herniated disc, stenosis, hematoma or abscess.

An **MRI scan of the brain** to look for other neurological inflammatory conditions such as Acute Disseminated Encephalomyelitis, Multiple Sclerosis or Neuromyelitis Optica.

A **lumbar puncture** helps to identify whether or not there are markers of inflammation in the cerebrospinal fluid.

The **Visual Evoke Potential/Response (VEP/R)** test checks the health of the optic nerve – nerves that carry signals from the eyes to the brain.

The neurologist will want to identify if there is any underlying cause of the inflammation in your spine by also checking through a **range of blood tests** for the presence of a systemic inflammatory disease such as Sjögren's syndrome, lupus, or neurosarcoidosis and test for infections like HIV, syphilis, and for deficiencies of vitamin B12 and copper levels.

The neurologist will also want to **assess if the cause of your symptoms could potentially be non-inflammatory** and will consider tests for blood vessel blockages, vascular malformations, radiation, fibrocartilaginous embolism or nutritional/metabolic causes.

#### 4. What treatment can I expect to receive?

In the UK, TM is treated by a 3 or 5 day course of intravenous (through veins in your arm) steroids – often given soon after the attack and even before a diagnosis. The steroids help to reduce the inflammation in your spinal cord. Whether you are given a 3 or 5 day course of steroids depends

on the practice in the hospital where you are being treated and how severe the inflammation is thought to be. Alternatively, steroids can be given orally.

In some cases, plasma exchange, also referred to as PLEX, is also administered. However, it is not a routine treatment. PLEX may be given if there has been a poor response to steroids. PLEX is similar to dialysis where blood is removed from your body, and plasma (which contains the proteins including bad antibodies that are suspected to be causing the inflammation) extracted and discarded and new plasma or equivalent fluid returned.

You may also receive Intravenous Immunoglobulin (IVIg), which is a mixture of blood proteins (including good proteins called antibodies) that are made by the immune system and this mixture is administered intravenously, through a vein in your arm. Antibodies are created when the immune system encounters foreign substances that cause infections such as viruses or bacteria. They protect us from infections. Immunoglobulins are extracted from many donors' blood and are used to treat a number of medical conditions.<sup>2</sup>

Physiotherapy can help with mobility, gait, coordination, strength, pain, spasticity, sensory and balance issues. The first wave of physiotherapy in hospital is geared to helping you regain any lost mobility and core muscle strength. Though most physiotherapists can help, a 'neuro-physiotherapist' may have more experience in treating TM and related conditions.

Occupational therapy can help you find alternative ways of approaching everyday tasks you may be finding difficult due to the impact of TM. An occupational therapist can help you break down the activity into smaller steps and practice it, teach you a different way to complete the activity, and advise which devices and equipment can make the activity easier to do.

## **5. How can I get the most from my medical appointments to ensure I get my needs met?**

The relationship with your consultant neurologist, GP or other healthcare professional is an important one. It is also a mutual and collaborative relationship where you both have something to contribute. Your medical or healthcare professional has an expertise to draw on and share with you to help you manage the impact of TM. You have the experience of TM to share with them to help them help you.

To get the most from your appointments, it is useful to prepare. Write down, or even better use the computer to create a document, the course of your illness with dates. Almost every health professional will want to know this. Prepare a list of medications you are on, for how long you have been on them, the dosages, and for what. You don't want to spend 10 minutes during your appointment remembering them when you can be asking important questions.

Keep a diary of your symptoms as this will enable you to give a clear description of how you experience the impact of TM. Also note down questions as they occur to you. Prior to an



appointment, review your diary and questions. Given that medical appointments are often not very long, it is helpful to prioritise your questions so you get your most important questions answered. When you prepare, it is helpful to do this with someone who sees a lot of you like a partner, another family member or friend. They may remind you of something you forgot or were not even aware of. They may have questions themselves.

If possible, bring a family member or friend to your appointment to act as your 'second pair of ears', note taker and/or advocate. Sometimes you can be given a lot of information during an appointment and some people can find this overwhelming. Having someone with you means you are less likely to lose important information. Also, having someone take notes frees up your attention to focus on what the medical or healthcare specialist is saying.

Have your specific questions ready and ask your highest priority questions first. If you don't understand their reply, be prepared to say what you do understand and ask for clarification where you haven't understood it.

Also ask the medical professionals if there are key milestones they are looking out for in your recovery. Knowing their measures of progress can help you track your progress at home.

The primary caregiver can also ask the medical or healthcare professional what they can do to help – often medical staff are pleased to have a caregiver there to help with a person's care.

There is a lot about the brain and central nervous system that is not known in the medical world. So there will be times when the neurologist, GP and healthcare professional will not have an answer to your questions, be able to predict the outcomes of treatment or your recovery, or be able to make a definitive prognosis. It will be a case of you and your clinician working together to find the best course of treatment and rehabilitation for you.

For helpful questions to ask your doctor at diagnosis (about treatment options, tests, scans, ongoing management of the condition), the Brain & Spine Foundation has a useful document, which you can access [here](#).<sup>3</sup>

## **6. What should a diary of my symptoms contain?**

Keeping a diary of your symptoms can help you track your progress over time, identify triggers and patterns in symptoms, allow you to articulate what you are feeling and noticing more clearly to medical and healthcare professionals, and therefore give you a greater sense of control.

Typical things that people tend to log in a diary or journal include:

- The symptoms you experience, the intensity of them, how you felt before any symptoms got worse, any potential triggers, how long the symptoms lasted

- The effect of medications
- Changes since your last appointment either improvement or worsening
- Your mood
- Number of hours of sleep and quality of it
- Exercise you do
- Any stressful experiences
- Anything you achieved

There are many apps available that allow you to set up a log, diary or journal.

### **7. How long should I expect to remain under the care of the neurologist?**

Once you are discharged from hospital, how long you remain under the care of a neurologist will vary from a few weeks to a few months to more than a year. It depends on how you have been affected by TM, your progress, whether the neurologist feels that they can contribute anything further to your recovery, and you feel you need to see them again.

The neurologist's role is very key in the acute phase when making the diagnosis and giving treatment. After you have received all available treatment that is appropriate for your case and you move into the recovery phase, management of any ongoing residual symptoms is often handed over to your GP and other healthcare professionals as and when their expertise is needed (pain specialists, urologists, neuro-physiotherapists, etc.).

It is not uncommon to be discharged from the care of the neurologist a few weeks or months after diagnosis. We appreciate that this may feel early for some people, particularly if you are still feeling the residual symptoms from TM. You may still be in some discomfort from the TM symptoms, wonder if you are well enough to be discharged and have a lot of questions.

Your neurologist would not discharge you if he or she felt that you still required their attention. If you are concerned about being discharged, please raise it with your neurologist, express the specific concerns you have as well as needs (for example, learning to manage bladder and bowel issues), ask what else they can do for you, and whether that can include a referral to any specialists.

Post discharge, the responsibility for your recovery, maximising it and ongoing management starts to shift to you.

---

**8. Once I am discharged by the neurologist, who is my main point of contact for any further medical treatment and management?**

Once you are discharged by the neurologist, your main point of contact will be your GP for ongoing medical management of any residual symptoms. Due to TM's rarity, it is not uncommon for a GP not to have treated a case of TM. Therefore, it will be helpful if you take some information about TM to them when you first visit such as the [Brain & Spine Foundation's booklet on TM](#)<sup>4</sup>, this FAQ, and the [TM Society's Condition Insight Report into TM](#).<sup>5</sup>

Your GP should be able to refer you to pain specialists, urologists, continence advisors, physiotherapists and occupational therapists as needed.

The TM Society can also be a point of contact for you for information and support.

**9. What should I expect in the recovery process? How long will it take?**

TM affects every person differently so there is no one recovery path that is applicable to every person. During the recovery process your symptoms may lessen and various issues improve, but how much and how long that will take varies from person to person.

The recovery process can start within a few weeks to months of onset. Many neurologists and healthcare professionals state that recovery may continue for up to 2 years. However, many people have reported that their recovery has continued for over 10 years. This highlights the importance of ongoing rehabilitation well past any 2 year window.

Regarding recovery, a standard guideline is about one-third of people affected with TM experience a full or good recovery from their symptoms. If the latter, they may experience some ongoing minor residual symptoms. Another one-third show fair recovery and are left with deficits such as mobility issues, sensory dysfunction, neuropathic pain, fatigue, and/or bladder/bowel issues. The remaining one-third show little recovery.

There is a lot you can be doing for yourself to maximise your recovery in many respects including physiotherapy and exercise, symptom management, diet, social and family, the psychological impact, returning to work, finances and benefits, driving and transport, and travel. The rest of this document is organised by these topics.

Consider keeping a diary of your symptoms, activity levels, sleep patterns, mood, and diet. This can help you and any healthcare professionals involved in your care identify where any issues are. A diary is also a useful reminder of the progress you are making in your recovery and it can help when completing benefits claim forms.

#### **10. Will I have another TM episode?**

TM is usually a condition that many people experience only once.

Some people may go on to experience further episodes but this is not common. For these people, it might be an underlying condition that causes the recurrence(s) of TM or it may be another related condition.

#### **11. After being discharged from the hospital, I am noticing new symptoms appearing. What does this mean and what should I do?**

It is not uncommon to experience new symptoms after being discharged.

Sometimes symptoms will come and go. If you notice new symptoms and they do not improve after 48 hours, especially if they affect your functions such as muscle weakness, continence, balance, mobility, seek medical advice.

If you are still under the care of a neurologist it would be best to try and speak to them as they are the specialist in this area. If you are not due to see them for some weeks/months, call their secretary and request to speak with them or a team member. If you have been discharged from the care of the neurologist, you can go to your GP for a referral back to the neurologist.

#### **12. My existing symptoms are getting worse. What should I do?**

It is common for your existing symptoms to fluctuate, they may get worse and then get better. Tiredness, fatigue, stress, illness, infection, hormonal changes, and changes in the weather can all cause a fluctuation of symptoms. Also, symptoms will sometimes fluctuate for no apparent reason. In the majority of cases, a worsening of symptoms is temporary. Sometimes symptoms will disappear for a period of time and then return.

If your symptoms are worsening and not improving after a few days, seek medical advice.

#### **13. I have a medical question but am not due to see my consultant neurologist for some weeks/months.**

There are two organisations that have advice lines you can call, the Brain & Spine Foundation and Spinal Injuries Association, which are staffed by nurses who may be able to assist you.

The **Brain & Spine Foundation** - [www.brainandspine.org.uk](http://www.brainandspine.org.uk) - Operates a helpline staffed by nurses familiar with TM and related conditions. You can call, email or write to them to ask your questions. You can also post a question in their online discussion forum.

The Helpline is open every weekday morning:

- Monday to Thursday: 9:00am to 2:00pm
- Fridays: 9:00am to 1:00pm
- Call the nurses free on 0808 808 1000

You can email them at [helpline@brainandspine.org.uk](mailto:helpline@brainandspine.org.uk) or by using their [online form](#).<sup>6</sup>

You can write to them at:

Brain and Spine Helpline  
Freepost LON10492  
London SW9 6BR

You can also access their online discussion forum [here](#).<sup>7</sup>

The **Spinal Injuries Association** – [www.spinal.co.uk](http://www.spinal.co.uk) – Has an advice line staffed by a nurse who can also answer questions. The Advice Line Officer can help you understand more about spinal cord injury and provide the support and practical information you need for day to day living. The Freephone number is 0800 980 0501 and is available 11am-4.30pm and is for anyone affected by, or interested in spinal cord injury.

Text SIA and your enquiry to 81025 (charged at your provider's standard rate).

You can email the advice line at [advice@spinal.co.uk](mailto:advice@spinal.co.uk).

---

## Physiotherapy & Exercise

### 14. How can physiotherapy help in the recovery process?

You may have received **physiotherapy in the hospital**, when it is often to teach you how to walk again or how to get in and out of a wheelchair.

Physiotherapy can also help on an **ongoing basis** with the following issues: mobility, gait, coordination, strength, pain, spasticity, sensory and balance.

The TM Society recommends you work with a neuro-physiotherapist. A neuro-physiotherapist may have received additional formal education and/or on-the-job training on treating people with neurological conditions. Not all neuro-physiotherapists may have treated someone with TM before, but if they have treated people with Multiple Sclerosis (MS), then that is good experience. This is due to the similarities in how TM and MS affect people; people living with TM and MS often experience the same ongoing symptoms.

For physiotherapy to be effective, it is important to do the exercises regularly. This will maximise your rehabilitation. If you stop, you may lose what you have gained.

If you need assistance doing some of the exercises, it may be helpful to have a family member or friend attend physiotherapy sessions with you so they can learn what you need to do and so help you with the exercises in between physiotherapy sessions.

Functional Electrical Simulation (FES)<sup>5</sup> is a treatment used by some neuro-physiotherapists for specific issues. FES helps to improve muscle functioning through the application of small electrical charges to muscles.

Depending on your issue, there may be devices you can be fitted with to help with functioning, such as foot drop. Your neuro-physiotherapist can advise what may be appropriate for you.

### 15. How can I access neuro-physiotherapy?

You can be referred for physiotherapy by your GP. You typically receive 6 sessions of physiotherapy.

If you struggle to get physiotherapy in the community through your GP, the TM Society offers members 2 free sessions of neuro-physiotherapy with a private neuro-physiotherapist through the neuro-physiotherapy bursary scheme. The neuro-physiotherapist will give also you specific exercises to do and provide advice and recommendations which focus on the issues you have.

Often the private physiotherapist will point people to NHS services if requested. To apply for a neuro-physiotherapy bursary, please email Lew Gray at [Lew.Gray@myelitis.org.uk](mailto:Lew.Gray@myelitis.org.uk).

Alternatively you can contact your local TM Society Support Group Leader to find out if they know of any neuro-physiotherapists with experience of treating TM. Or you can contact Lew Gray at the above email address as he keeps a list of neuro-physiotherapists recommended by our members.

You can also access neuro-physiotherapy privately. You can find a neuro –physiotherapist via the [Chartered Institute of Physiotherapists](#)<sup>8</sup> with a neurological speciality. Search the Physio2U box on the homepage.

### **16. Can I exercise?**

Yes – by not exercising you are limiting your overall health.<sup>9</sup> If you do not know what exercises to do, ask your GP to refer you to a physiotherapist, preferably a neuro-physiotherapist.

You may find that you get tired more easily when you exercise and/or that you are more tired than usual the following day. That is normal after TM. You may wish to exercise for shorter periods of time and/or build time for a rest period or nap after exercising. It is a process of learning what your body is capable of.

Many people with TM find that yoga and/or pilates can be good for improving core muscles. Others benefit from swimming or walking their dog. It is important that you find the kind of exercise/movement you enjoy doing.

It is important to do the exercises regularly to maximise your rehabilitation. If you stop, you may lose what you have gained. Also, remember that you may not feel immediate benefit from the exercise and that it may take a while to build up your strength. So you may not notice improvements very quickly. Balance exercises, for example, can make a huge difference to your stability walking, but you may not be able to feel the improvement for a number of weeks. So be patient and make physiotherapy, exercise, movement part of your daily routine.

The [MS Trust](#)<sup>10</sup> and [MS Society](#)<sup>11</sup> websites both contain good resources on exercise. The information is applicable to people living with TM as the issues experienced by people living with MS and TM are similar.

### **17. I use a wheelchair. How can I exercise?**

If you use a wheelchair full or part-time, you can continue to exercise from a seated position to strengthen your core muscles, arms and legs. A good upright posture is especially important to increase lung capacity and reduce chest infections.

Websites with chair exercises include

- [British Heart Foundation](#)<sup>12</sup>
- [NHS Living Well Website](#)<sup>13</sup>
- The MS Trust website contains explanations of several [sitting exercises](#)<sup>14</sup>; select the 'sitting exercises' option.
- The MS Society website's section on exercise contains [videos](#)<sup>15</sup> which demonstrate how the exercises can be done from a sitting position.

There is also a wide range of DVDs available for seated forms of exercise including yoga and tai chi. Searches on Google, YouTube and online stores such as Amazon will enable you to find them but a sample used by members include:

- Seated Yoga for life an introduction with Graeme Waterfield, Julian Treble and Jas Panesar
- Seated and chair based Tai Chi and Chi-Kung
- Move or Lose It

#### **18. Is hydrotherapy recommended as part of the rehabilitation process?**

Many TM Society members have reported feeling benefits from hydrotherapy. It is not available in every area, but if it is available in your area, you can get referred to it through your GP or physiotherapist. You will typically get a 6 week programme. If there is no hydrotherapy available in your local area, an alternative is to use a pool local to you which is heated. Also check if the pool near you has a disability session as the water temperature may be slightly warmer.

Some people find that the warmth of the water has the effect of reducing their strength. Others find that the feel of water against their skin causes pain. If water touching your skin causes pain, you can still try hydrotherapy under guidance to see how you get on with it.

#### **19. I have been recommended to purchase equipment to help with my rehabilitation. Is funding available to help with this?**

The TM Society offers an [equipment grant scheme](#)<sup>16</sup>, which will pay up to 50% of the costs up to £1,000 maximum to help with rehabilitation, daily living, and to maintain independence. The TM Society helps fund equipment not be available through statutory services (local council, NHS, etc.).



---

## Medical

### **20. I've heard that it is good to take vitamin D can be linked to neurological auto-immune issues like TM. So should I be taking vitamin D?**

Up to 70% of people in the United Kingdom may be deficient in Vitamin D (which is important for bone health) and that includes those with TM. Vitamin D may have also some beneficial effects on the immune system and it is therefore not unreasonable to ensure that the daily required amount is being taken. The normal requirement is 2000 International units /day. Many people simply obtain it over the counter at their local pharmacy. It is worth visiting your GP to have your vitamin D level checked. Note that it is not proven that vitamin deficiencies cause TM.

### **21. I hear Multiple Sclerosis (MS) often being mentioned along with TM. What is the difference between TM and MS?**

TM and Multiple Sclerosis (MS) are both inflammatory disorders of the central nervous system where the immune system becomes abnormal and attacks the nervous system. TM is largely a "one-time" disease (monophasic) that involves only the spinal cord. MS is always a "many-time" disease (multiphasic) that involves the brain, optic nerves and spinal cord. Regardless of the regional specificity and temporality, the underlying mechanisms of these two diseases are largely similar. In some cases TM can be the first presentation of MS. However, a second TM episode and further tests would be needed to obtain a firm diagnosis of MS. 15% to 43% of TM patients may ultimately be diagnosed with MS.<sup>17</sup>

Due to the similarities of ongoing residual symptoms between TM and MS, a lot of the information on managing MS symptoms is relevant to people living with TM. So if you come across information for people living with MS on managing pain, fatigue, bladder, bowel and sexual dysfunction, the information will help you.

### **22. Is it safe to have a vaccination after TM?**

Some people have developed TM after a vaccination, however, it is not proven that vaccinations cause TM.

Many people have flu vaccinations each year after the onset of TM. Having a vaccination, whether it is for flu or another disease, is a matter of choice. It is weighing up the risks of what the impact of the disease would be if you were not vaccinated and caught it, as compared to the potential unproven risk of having a vaccination.

There are no definitive guidelines as to whether people living with TM can have vaccinations or not. You may find it helpful to consult with your GP and/or neurologist if you have further

questions or concerns. Most doctors feel that the risks from bad flu are much higher than the risk of any serious harm from the vaccine.

The Transverse Myelitis Association in the USA created a podcast on TM and vaccinations and you can listen to it [here](#)<sup>18</sup> This will give you more information about the relationship between the two.

### **23. Can I donate blood after having TM?**

According to the National Blood Service ([www.blood.co.uk](http://www.blood.co.uk)), they do not accept blood donations from people who have been diagnosed as having TM. If you require any more information please call the Donor Helpline on 0300 123 23 23, Monday to Friday, 8am to 7pm, where they can transfer you to your local Referral Team who can deal with more complex issues.

### **24. I am due to have an operation. Can I have local and/or general anaesthetic?**

Many people living with TM have gone on to have operations successfully under local or general anaesthetic. Anaesthetics will affect each person differently. Before the operation be sure to tell the doctor/anaesthetist about the episode of TM you had, any current impact it still has on you, and discuss the pros and cons of the anaesthetic they are proposing to use.

---

## Symptom Management

### **25. I notice when I get ill (with flu, fever, a cold, infection, etc.), my symptoms get much worse and it seems to take longer to recover. What is happening?**

This is a common experience when you get ill or have an infection after having TM. Your body is already working hard coping with the effects of TM. When you are ill, it also has to fight off the illness on top of that. Hence you may feel your symptoms more and it may take you longer to recover from the illness. You will find that once you recover, your symptoms should reduce. If they continue and there is no improvement after you have recovered from the illness, or you have questions, please seek the medical advice of your GP or consultant neurologist.

### **26. I find isolated parts of my body feel cold or hot. Or I feel hot when it is cold outside or cold on really warm days. What does this mean?**

TM can impact how your body regulate temperature so one part of your body may feel cold or too hot while the rest of your body feels normal. Some people experience feeling cold on warm days and being too hot on cold days. Other people will not have these temperature regulation issues. If you have only recently contracted TM, the temperature regulation issue might improve with time. Much of this is due to the involvement of nerve fibres in the spinal cord that normally carry sensations of heat and cold from skin to the brain.

The Brain & Spine Foundation provides useful information on heat sensitivity and hot temperatures and [useful coping strategies](#).<sup>19</sup>

### **27. What recommendations do you have for managing neuropathic pain?**

Neuropathic pain is a different kind of pain from muscular/skeletal pain. Neuropathic pain is caused by dysfunction or damage in the nervous system and so incorrect nerve signals are sent to the brain. Neuropathic pain is felt differently by every person. It can be described as like pins and needles, burning, crawling, stabbing, shocking, or freezing pain. It can be felt as a short and sharp pain or constant. It can be difficult to pinpoint the cause of neuropathic pain.<sup>20</sup>

Neuropathic pain can be treated with anticonvulsant (epilepsy) drugs such as gabapentin or pregabalin (Lyrica) or carbamazepine. Anti-depressants such as amitriptyline and duloxetine have also been known to help treat neuropathic pain.<sup>21</sup>

Some individuals find opiates such as Morphine, Oxycodone, Fentanyl, and Tramadol can help with neuropathic pain.<sup>22</sup>

Drugs such as ibuprofen or paracetamol may also help pain particularly if there is coexisting musculoskeletal pain.

If pain is caused by spasticity, excessive muscle contraction, then Baclofen, Tizanidine and Diazepam may be prescribed to help manage it.<sup>23</sup>

There is no one medication or dosage that works for every person who experiences neuropathic pain. Many people often find it is a case of trial and error to find which medications and dosages help. Medications can also have side effects, some which can affect one's quality of life, so be sure to discuss the pros and cons of a particular medication and its dosage with your GP and/or neurologist.

Many times, we expect that once we know the cause of the pain, there will be a treatment for it that should make the pain will go away. That may not be the case with neuropathic pain. Medications may only reduce the pain to levels that are manageable.

Psychological approaches have been known to markedly help people examine their relationship with pain and find coping strategies including Cognitive Behavioural Therapy (CBT), counselling, psychotherapy and coaching. Your GP can refer you for CBT, counselling and/or psychotherapy. The TM Society offers a [Coaching Bursary Scheme](#)<sup>24</sup> for members.

People have found complimentary therapies helpful in managing pain including mindfulness/meditation, acupuncture, reflexology, aromatherapy, relaxation techniques and shiatsu to name a few. One modality will not work for everyone so it is a case of trying a variety of complimentary therapies and learning what works for you. Management of sleep and diet can also help. Keep in mind that an alternative therapy, sleep or diet changes may not fully fix an issue but help partially with it. Also, they may help with one symptom but not another and different things may work at different times. Being flexible and willing to change your approach and try new therapies can help you learn a variety of ways to manage pain.

The following organisations also provide a range of tips, ideas and references to other services for managing pain.

- British Pain Society – [www.britishpainsociety.org.uk](http://www.britishpainsociety.org.uk)
- Pain Concern – [www.painconcern.org.uk](http://www.painconcern.org.uk)
- The Pain Toolkit – [www.paintoolkit.org](http://www.paintoolkit.org)
- Pain Talk – [www.pain-talk.org.uk](http://www.pain-talk.org.uk)
- Pain Support – [www.painsupport.co.uk](http://www.painsupport.co.uk)
- Self-Management UK - [www.selfmanagementuk.org](http://www.selfmanagementuk.org)

Pain is individual to every person and has physical and even psychological components. So how you manage pain will be unique to your needs.

## **28. What advice do you have on managing bladder and bowel issues?**

The **Bladder & Bowel Foundation** - [www.bladderandbowelfoundation.org](http://www.bladderandbowelfoundation.org) - is a charity that provides information and advice on bladder and bowel issues. Their website contains informational booklets, FAQs and more. They also have an advice line, which you can call with questions on 0845 345 0165.

If you use urology/bowel management equipment such as catheters, Peristeen, etc., the [Spinal Injuries Association Healthcare](#)<sup>25</sup> provides a service where they will deliver this equipment plus any medications you take to your home. The service includes a personal advisor who will get to know you and your individual needs, combined deliveries of supplies and medication that will arrive when you need them, and a flexible approach to placing your order each month by email or they will ring you. The service can even deliver to you while you are on holiday.

## **29. What advice do you have on managing bladder and bowel issues when I am outside my home?**

A radar key is used to operate the door on public disabled toilets and so is useful to have when you are out and about. It can be purchased from [Age UK](#)<sup>26</sup> for £1.09 to £1.99.

If you have a smart phone you can download an app called WheelMate. It uses your location to point you to the closest disabled toilet as well as parking. If you do not own a smart phone and are going out for the day, you can enter your destination into the [WheelMate website](#)<sup>27</sup> and it will show a map of nearby toilets and where you can park. You can also enter toilets, which you have found and are not listed. This app is a worldwide app so can also be used on holiday.

For £5 you can purchase a [just can't wait](#)<sup>28</sup> toilet card. This encourages shops to help out if and when you are in need of the toilet.

## **30. I am experiencing sexual dysfunction. What can I do?**

In addition to bladder and bowel issues, people often feel embarrassed or awkward asking such a question. Sex in its many forms is an important part of our life and impacts our relationships. It is a very valid question.

In the UK, it is possible to obtain a referral via the NHS to a psycho-sexual doctor. However, this area of medicine is underfunded in the NHS so coverage across the UK may not be consistent. You can obtain the referral from a GP, urologist, gynaecologist, psychiatrist or psychologist.

A psycho-sexual doctor is a trained medical doctor who has had further training in helping people find ways to approach sexual dysfunction. They are typically members of the Institute for Psycho-Sexual Medicine. They can examine the physical symptoms and prescribe medication, equipment and lubrications. They will not give you a 'treatment plan' in the traditional sense for the psychological side of the matter, but they will listen, help you find what is at the heart of the matter, and help you identify strategies for moving forward in this area. They can also signpost you to other sources of information and support.

Here are additional sources of information on sex, intimacy and relationships which can help.

- Podcasts, videos from conferences, and articles on sexual dysfunction and TM and related disorders are available on the Transverse Myelitis Association's website [here](#).<sup>29</sup>
- Very good information is available for men and women on the Brain and Spine Foundation's website [here](#).<sup>30</sup>
- A section of the Multiple Sclerosis (MS) website focuses on the [sex and relationship issues](#)<sup>31</sup> men and women experience and offers information and signposts to further support. Even though TM is not MS, the way ongoing residual TM symptoms are managed are the same as many MS symptoms. So the information on the MS Society's website will help you.
- The MS Society also produces a booklet on sex, intimacy and relationships which you can access [here](#).<sup>32</sup>
- Dr. Beverly Whipple, a professor and noted researcher on sexual health, conducted research on the sexual experiences of women with spinal cord injury and you can access the article summarising it [here](#).<sup>33</sup> The advice given includes people who have lost feeling in the genital areas as a result of a neurological disorder.
- A recommended book is *The Ultimate Guide to Sex and Disability: For All of Us Who Live with Disabilities, Chronic Pain, and Illness* by Miriam Kaufman. The book covers a range of disabilities including chronic fatigue, spinal cord injury, multiple sclerosis, among others. This book can be purchased online via the store SH mentioned below and Amazon.

Here are websites and organisations that provide further information or services.

- **Sexual Advice Association** – [www.sexualadvice.co.uk](http://www.sexualadvice.co.uk) – An organisation that provides information and advice in relation to sexual issues
- **Spokz** - [www.spokz.co.uk](http://www.spokz.co.uk) - For sex aids, wheelchairs and wheelchair equipment

- **Spokz People** - [www.spokzpeople.co.uk](http://www.spokzpeople.co.uk) - Aims to empower people, enhancing their lives, relationships, mental and sexual wellbeing. Spokz People provides disability counselling, support and groups for people with physical disabilities, their partners and health professionals, and counselling on sex and relationship support.
- **Enhance the UK** - <http://enhancetheuk.org/enhance/sex-and-disability> - An organisation that challenges perceptions and attitude around disability and provides information on sex and disability.
- **SH** - [www.sh-womenstore.com](http://www.sh-womenstore.com) - Female-focused shop selling toys and goods. Also offers couples' classes. (Your browser and/or network settings may be set up to block access to this site.)
- **Relate** - [www.relate.org.uk](http://www.relate.org.uk) - Provides counselling, support and information for relationships and sex.
- **The College of Sexual and Relationship Therapists** – [www.cosrt.org.uk](http://www.cosrt.org.uk) – An organisation that provides specialist counselling for sexual and relationship issues. Also provides a list of counsellors by geographical area.
- **Outsiders** - [www.outsiders.org.uk/outsideclub](http://www.outsiders.org.uk/outsideclub) - A social, peer support and dating club, run by and for socially and physically disabled people. Also offers support on relationships, sexuality, dating and sexual services to all disabled people, therapists, and health and social care professionals. They have a sex and disability helpline, 07074 993 527, open weekdays 11am-7pm weekdays, or you can email them at [sexdis@Outsiders.org.uk](mailto:sexdis@Outsiders.org.uk)

### 31. What recommendations do you have to help manage fatigue? <sup>34</sup>

Fatigue is an overwhelming surge of tiredness that interferes with your ability to do what you would like to do and hence your quality of life. It is common to experience fatigue as one of the ongoing symptoms of TM. It may lessen in time as you recover.

You might find you become tired even after activities like going to the shops, watching television or talking with your friends. Keeping active is an important part of your recovery but you might need to think of ways to conserve energy.

Causes of fatigue can include:

- **Disability** – Fatigue can be a direct consequence of TM.
- **Sleep** – Not getting enough sleep or getting too much sleep causes an imbalance of energy.
- **Diet** – Sugar/Junk food causes a rise in sugar but it also causes sugar levels to drop dramatically afterwards too. A balanced and healthy diet and increased fluid intake is important.
- **Medications** – The side-effects of some medications can cause fatigue.
- **Mood** – Stress can lower our mood and so our energy dissipates.
- **Exercise** – Doing too little or too much. Doing exercise in small chunks can give you more energy.

Fatigue can be:

- Physical– The effort involved to do activities.
- Cognitive– Mental tiredness which is linked to low mood, not being able to think straight, and difficulties with memory
- Psycho-social – If you are tired you will not want to go out and socialise, leading to low mood.

If you are trying to do everyday tasks in the same way as you did prior to TM's onset, this could exacerbate fatigue. You may have to learn a different way to do everyday tasks in order to conserve your energy. An occupational therapist can help with suggestions.

Being able to pace yourself is very important. You may find that working in the same way you did prior to TM can exacerbate fatigue. You need to plan what are the most important things for you to achieve and prioritise them. Ensure everything you do is in smaller steps rather than big ones. Ensure you take breaks regularly. You will need to plan more time to accomplish things, and you may need help, but you will be able to accomplish them. The [spoon theory](#)<sup>35</sup> provides a useful way of looking at how to do this.

One of the main factors that helps fatigue is drinking plenty of water – it can give you energy, gives your skin a healthy glow, stop headaches and relieves constipation. Instead of having huge glasses in one go, have a bottle and regularly take sips of water throughout the day.

Pain can adversely impact sleep and it will be a process of learning to manage the pain so you can get adequate sleep. Refer to the Symptom Management section for information on managing pain.

If you have poor posture, this can trigger fatigue. Obtain help from a physiotherapist to improve your posture.

Even a small change in temperature can affect your energy levels

An infection, illness or anaemia can cause fatigue.

It is understandable that at times you will feel down about your energy levels and the need to plan much more than pre-TM. Remember to keep in mind how you were a few weeks to months ago, rather than yesterday. Improvements can be small and over time are bigger than we normally think.



## Diet

### 32. Is there a good diet to follow for neurological inflammatory conditions like TM?

Members have tried a range of diets to help manage their TM and what works for people is a very individual matter. Members have reported that reducing sugar, take-aways and processed food have helped to reduce the impact of their ongoing symptoms. The key thing is to eat a healthy diet of protein, complex carbohydrates and lots of fresh vegetables. The [NHS Health Eating website](#)<sup>36</sup> gives a standard guideline that ½ your plate should contain vegetables, ¼ protein and ¼ complex carbohydrates.

Please consult with your GP for further advice. Your GP may also be able to refer you to a dietician or nutritional therapist for expert advice.

### 33. Can I drink alcohol?

In modest amounts, alcohol is fine for most people with TM. For some people, drinking alcohol can temporarily exacerbate the residual symptoms one may have after the TM episode. Others may feel the effects of drinking alcohol more quickly. For others, drinking alcohol does not have much impact. Sometimes side effects of medications can be more pronounced when you consume alcohol e.g. dizziness. Please read the leaflet that came with your medication(s) and ask your pharmacist, GP or consultant for guidance.

---

## Social & Family

Your social support network including family and friends is very important at this time.

Due to its rarity and the chance you may have not yet met anyone with TM who gets what you are going through, TM can feel socially isolating. Isolation is not good for your wellbeing, therefore it is important to keep dates with friends and enjoying your social life as much as you can.

### **34. Is it ok to go out socially while I am recovering?**

Yes, as mentioned above, your social network is important. You may find you do not have the energy to stay up late or socialise for long period of times, so pacing yourself is important. Do what you can.

### **35. No one seems to understand how TM is affecting me. Is there a way to explain it to help friends and family understand better what I am going through?**

Although explaining what TM is like can be difficult, many have found that explaining to family and friends in a way they will understand helps them have realistic expectations of what you can and cannot do. So here are some recommendations based on members' experience.

Firstly, give your family and friends information about TM including the [Brain & Spine Foundation's booklet on TM](#)<sup>37</sup>, this FAQ, and the [TM Society's Condition Insight Report](#)<sup>38</sup>. The website for the [Transverse Myelitis Society](#), the UK-based TM organisation, is another good starting point. The website for the [Transverse Myelitis Association](#)<sup>39</sup>, the USA-based TM organisation, also contains very good technical information about TM and related conditions and research that is occurring in the USA. Information helps to demystify the unknown and can be very reassuring.

It is helpful to explain that some of the ongoing residual symptoms such as fatigue and pain are invisible. Just because you may look well on the outside, does not mean you feel well on the inside. In a society that tends to equate illness with looking ill on the outside, this can be a harder thing for people to get used to. However, in time as they learn more about TM, they do begin to understand that invisible symptoms can be difficult to live with.

Sometimes family, friends, work colleagues, and the average person on the street assume that recovery from TM means your body goes back to the way it was before TM. For some people, recovery can go in this direction. However, many people live with a degree of ongoing residual symptoms. So this definition of 'recovery' can be misleading because you live in a changed body.

---

Some people find having a simple explanation can be useful particularly when answering the questions of people you do not know well. Here are some examples using Multiple Sclerosis (MS) as it is also neurological inflammatory condition and many people have heard of it.

- TM is a MS like condition but whereas (relapsing remitting) MS happens more than once, TM happens only one time.
- TM is like a cousin of MS, but typically happens only once and is rarer.

Or you can skip the MS reference and say that TM is a spinal cord injury that doesn't break the spine.

### **36. How can family and friends help?**

Family and friends know you well and can play an important role in supporting you through these changes and adjustments. Here are some tips we typically give family and friends and you can share these with them.

- Focus on the progress the person affected with TM has made, encourage them and celebrate when they overcome challenges and find new ways to do things.
- Lovingly help the affected person find new ways to do things.
- There are times though where the person affected is just having a bad day and is in a negative mood. This could be due to the pain, fatigue, the general physical and mental struggle of learning how to navigate all the changes to their body and life, or for another reason. During these times, rather than trying to fix the situation, being supportive by sitting with the person, listening, holding their hand or giving a hug may be the best thing you can do.
- More planning to get out of the house may be required due to limited mobility, fatigue, trying to figure out how to manage bladder and bowel issues or for another reason. Family and friends can help by providing logistical assistance, driving and taking you to places you wish to go to.
- Some carers have understood the difficulties faced by the person with TM by 'living' in the affected person's shoes for a few hours. For example trying to get from car to upstairs bathroom in a wheelchair.

Family and friends may be keen to help but not sure how and may look to you for guidance on the help you need and want. However, you may feel guilty asking for help and be feeling more dependent on others for what can seem like basic living requirements. You may also feel that you should be able to do it all yourself. People living with TM have learned that it is ok to ask for help, it can take a little time getting used to doing this, but the sooner you can, the easier it becomes to navigate all the changes. Many times your family and friends are eager to help you. Help them to help you by letting them know specifically what they can be doing.

The article, [Coping with a Chronic Illness](#)<sup>40</sup>, gives a good overview of the emotional experience of an illness and includes the impact on family and how they can help.

We also encourage you to read back issues of the [The Magazine](#)<sup>41</sup> as it highlights how your family and friends can help you, and also how primary caregivers can look after their own needs.

We encourage your family and friends to become supporter members of the TM Society so they can also receive updates on services, activities, information and research from us. Membership is free and all they have to do is complete the [Supporter online form](#)<sup>42</sup> on the TM Society's website.

### **37. Can I have a baby after being diagnosed with TM?**

Many people have gone on to have a healthy baby after TM. Do not be worried if you require extra help at birth or are given extra check-ups. Depending on where the lesion is you may not feel the contractions therefore from around 28 weeks you may be checked regularly for signs of an early birth.

---

## Psychological Impact

### 38. I sometimes feel low and depressed. Is this normal?

The experience of TM or a related condition can be traumatic because it can happen so suddenly and unexpectedly, and you initially have no idea what is happening to you. The story that is your life, and that of your family, is suddenly interrupted and changes forever. Furthermore, you don't know of anyone else who has had this experience.

It can take time to adjust to living with the resulting changes including living with a changed body and the impact on self-image, the impact on relationships, your work, etc. It is not uncommon to feel frustrated and depressed as a result. Also, these adjustments highlight the difference between how you are now and how you were before TM's onset. So it is common, and normal, to miss your 'old self', to feel loss and even anger.

The article, [Coping with a Chronic Illness](#)<sup>43</sup>, gives a good overview of the emotional experience of an illness and practical ideas of what you and your family can do.

How long it takes to adjust to this change is different for every person. Many people do adjust and the following can help you through that process:

- The TM Society's [Support Group network](#)<sup>44</sup> is a great way to meet others with TM and related conditions and learn from them.
- We encourage you to read back issues of the [The Magazine](#)<sup>45</sup>, the TM Society's magazine, as they contain many people's TM stories.
- You can browse the rest of the [TM Society's website](#)<sup>46</sup> to obtain further information, support, and practical help. Make sure to become a member of the TM Society so you receive updates on services, activities, information and research from us. Membership is free and all you have to do is complete the online form [here](#).<sup>47</sup>

There may well be times when you feel that you would like some additional help from someone outside of your circle of family and friends to navigate the changes you are experiencing.

The TM Society offers a [Coaching Bursary Scheme](#)<sup>48</sup> for its members, which is a form of emotional/psychological support to help you find ways to resolve issues, achieve something new, or to find ways to adjust living with the impact of TM, ADEM, or NMO. It is for members who are 18+ whether they have TM or a related condition or are a primary caregiver.

There are also a range of talking therapies available including counselling and psychotherapy. Your GP can refer you to the service in your area.

Your employer may operate an Employee Assistance Programme (EAP), which typically provides counselling free of charge to employees. Speak to your HR department for more information.

If you have a private health insurance plan, you may be able to work with a therapist who is registered with the private health insurance company. Check if your insurance provider will require you to obtain a referral from your GP.

If you are a student, your school, college or university will most likely have a student counselling service.

If you wish to find a counsellor, psychotherapist or psychologist yourself, you can do so via directories online and professional associations for counsellors, psychotherapists and psychologists.

- Counselling Directory – [www.counselling-directory.org.uk](http://www.counselling-directory.org.uk)
- The British Association for Counselling and Psychotherapy (BACP) - [www.itsgoodtotalk.org.uk/therapists](http://www.itsgoodtotalk.org.uk/therapists)
- The United Kingdom Council for Psychotherapy (UKCP) - <http://members.psychotherapy.org.uk/find-a-therapist>
- The British Psychological Society - [www.bps.org.uk/bpslegacy/dcp](http://www.bps.org.uk/bpslegacy/dcp)
- NHS's Improving Access to Psychological Therapies (IAPT) - [www.iapt.nhs.uk](http://www.iapt.nhs.uk)

The **Samaritans** – [www.samaritans.org.uk](http://www.samaritans.org.uk) - Offers support to anyone in the UK and Ireland who is in distress 24 hours a day via phone, email or letter

- Phone - UK and Republic of Ireland – 116 123
  - Some organisations may restrict the numbers you can call from their premises. If you are unable to call the 116 123 number from where you are, go to the Samaritans website to look up the phone number of the nearest branch to you - [www.samaritans.org/branches](http://www.samaritans.org/branches)
- Email: [jo@samaritans.org](mailto:jo@samaritans.org)
- Letter: Freepost RSRB-KKBY-CYJK, PO Box 9090, STIRLING, FK8 2SA

### **39. I feel isolated. Where can I speak to other people with TM?**

Meeting others who have been through the same thing as yourself is a good thing. It helps to reduce any sense of isolation and it is an opportunity to share information and advice and support one another.

The TM Society runs support groups across the UK. To see if there is a support group near you, click [here](#).<sup>49</sup>

The TM Society can help with travel costs to the meeting. The Support Group leader can help you with this in the first instance and all claims are kept confidential within the TMS.

There are also a number of Facebook groups where people living with TM come together to share information and support one another.

The main Facebook group is a closed group called [Transverse Myelitis Society](#).<sup>50</sup> You will need to request to join the group and you may receive a message asking you to verify that you have TM. Only people with TM, their family and carers are allowed to join the group. Once you respond, your request to join will be accepted and you will then be a member of the group and can post a question and read what others have to say.

At the top of this group under 'files', members have included information that they have gathered for others' benefits such as books about TM and related conditions, help with daily living and filling in benefit forms. Note that these have been created by members for members and the TM Society does not take responsibility for any incorrect information contained within these documents.

Other Facebook groups are:

- [Transverse Myelitis Family, friends and Carers](#)
- [Parents of children with Transverse Myelitis](#)
- [Transverse Myelitis](#)
- [People living with Transverse Myelitis](#)
- [Devics disease \(NMO\) UK](#)
- [Devics Disease](#)
- Acute Disseminated Encephalomyelitis (ADEM) Discussion Group - This Facebook group is not run by the TM Society. For more information, contact Rob Reeves at [reevesrob@ymail.com](mailto:reevesrob@ymail.com)

Several TM Society Support Groups have their own Facebook groups or pages and these can be useful for obtaining localised help and information.

- [Midlands](#)
- [Scotland](#)
- [London](#)

We also recommend The Magazine, a magazine put together by members for members and sponsored by the TM Society. You can read back issues [here](#).<sup>51</sup>

---

## Returning to work

### 40. I have a job and want to return to it, but I'm worried about it.

Another charity called Headway has produced a [guide on returning to work](#).<sup>52</sup> It was written for people with head/brain injuries, however substitute 'brain injury' with TM and the information is applicable to you. It contains advice on dealing with your employer and how to structure your return to work to ensure it is a successful one.

The Brain Charity also offers [employment support](#)<sup>53</sup> to help with keeping your job or to provide guidance on alternative careers and re-training. You can contact them at 0151 298 2999 or [info@thebraincharity.co.uk](mailto:info@thebraincharity.co.uk).

The Spinal Injuries Association (SIA) [Vocational Support Service](#)<sup>54</sup> covers a range of areas and is designed to give you the support, guidance and encouragement you need when considering a return to work, education, volunteering or sport after an injury. The services include support at your local spinal cord injury centre, work trials at companies, skills training, sharing experience with others in a similar position, publications and one-to-one support. To learn more contact the SIA's Vocational Support Manager at 01908 604 191 or [advice@spinal.org.uk](mailto:advice@spinal.org.uk).

The SIA's booklet on [Employment – Your Rights to Employment](#)<sup>55</sup> is also a useful read to understand your rights in the workplace and the role you can play.

The Backup Trust has the [Back Up to Work course](#)<sup>56</sup> offering you the chance to:

- reveal your talents and enhance your CV
- receive advice on job hunting, including advice on how/when to declare a disability
- practice your interview techniques with real recruiters in a supportive and encouraging environment
- be put in touch with specialists for benefits and financial support and advice

This course is not about finding a job for you but about equipping you with the knowledge and confidence you need to work towards your employment goals. They also offer tailored one-to-one support post-course based on your goals and aspirations. To learn more, contact them at [courses@backuptrust.org.uk](mailto:courses@backuptrust.org.uk) or call on 020 8875 1805.



---

## Finances & Benefits

### 41. What benefits can I claim?

If you are under 16 you will be able to apply for [Disability Living Allowance](#).<sup>57</sup>

If you are 16-65 you can claim [Personal Independence Payments](#).<sup>58</sup>

If you are over 65 you can claim [Attendance Allowance](#).<sup>59</sup>

If you require more than 35 hours care a week, the person caring for you can claim [Carers Allowance](#).<sup>60</sup>

You could get [Housing Benefit](#)<sup>61</sup> to help you pay your rent in part or all if you're on a low income. How much you get depends on your income and circumstances. You can apply for Housing Benefit whether you're unemployed or working.

If you have a specially adapted bathroom or have extra space for a wheelchair in the property you may be able to get a [council tax reduction](#).<sup>62</sup> You do this by contacting your local council who will come out to assess you.

Also if you have to pay yourself for an adapted car, wheelchair, medical appliance, repairs to motor vehicles, adjustable beds, building works such as ramps, widening doors, adapted bathroom or installing specialist equipment, you will not have to pay Value Added Tax (VAT) on these items.

Double check which benefits you may be eligible for at [www.directgov.uk](http://www.directgov.uk) as they can change.

You could also apply for a **Blue Badge**, which allows you to park in disabled parking bays. This is done through your local council or online [here](#).<sup>63</sup>

The following organisations can provide further information and answer your questions regarding benefits:

- **Citizens Advice Bureau** – [www.citizensadvice.org.uk](http://www.citizensadvice.org.uk) – You can find your local branch via their website
- **The Brain Charity** - [www.thebraincharity.org.uk](http://www.thebraincharity.org.uk)
- **Spinal Injuries Association's Advice Line** – [www.spinal.co.uk](http://www.spinal.co.uk)
- **Fightback 4 Justice** – [www.fightback4justice.co.uk](http://www.fightback4justice.co.uk) - Welfare rights advocacy organisation

The TM Society offers various [bursaries](#)<sup>64</sup> to help people with TM in the UK. These are currently a coaching bursary, equipment grant scheme, neuro-physiotherapy bursary scheme and the travel bursary to help people attend support group meetings.

#### **42. Where can I obtain financial/debt advice?**

The following organisations provide information related to financial issues.

**Age UK** - [www.ageuk.org.uk/money-matters](http://www.ageuk.org.uk/money-matters)

- Age UK provide a range of information and advice about a wide range of money matters from paying for services to claiming benefits.

**Citizens Advice Bureau** - [www.citizensadvice.org.uk](http://www.citizensadvice.org.uk)

- Provides a free and impartial money advice service that offers help to those struggling with financial difficulties. It also offers benefits advice. You can find details of your local branch in the local telephone directory, in libraries or on their website.

**National Debtline** - [www.nationaldebtline.co.uk](http://www.nationaldebtline.co.uk)

- Offers free confidential advice on how to deal with debt problems.

**Stepchange** - [www.stepchange.org](http://www.stepchange.org)

- Assists people who are in financial difficulty by providing free, confidential debt advice and no-fee debt solutions. Their online debt counselling service, Stepchange Debt Remedy, provides instant, anonymous advice, a personalised budget and a realistic recommendation. No commitment is required and the service is free of charge.

---

## Driving & Transport

### 43. Can I still drive? Do I have to inform the DVLA of my condition?<sup>65</sup>

You must tell DVLA if you have a driving licence and:

- you develop a ‘notifiable’ medical condition or disability
- a condition or disability has got worse since you got your licence

Notifiable conditions include epilepsy, strokes, other neurological and mental health conditions, or physical disabilities and visual impairments that could affect your ability to drive safely. TM is not currently on the list of notifiable conditions. However it does say that the notifiable conditions are anything that could affect your ability to drive safely.

If your neurologist or GP have not explicitly said you are safe to drive and you are unsure, ask them for their advice.

For more information on UK government regulations regarding driving and medical conditions and disability, go [here](#).<sup>66</sup>

If you’re in Northern Ireland, contact the [Driver and Vehicle Agency \(DVA\)](#).<sup>67</sup>

If you feel you would benefit from an independent assessment that checks your ability to drive safely you could approach a [Mobility Centre](#).<sup>68</sup> These are located throughout the UK.

A useful way to consider it is if on a bad day you feel you would be a danger to yourself or other road users, then do not drive.

People that have reported this condition to the DVLA are reviewed every 3-10 years either via a retest or asking the driver and a GP/Neurologist to confirm that the person is still safe to drive.

If you have an accident or are stopped by the police, and you have chosen not to inform the DVLA, they may fine you up to £1,000. They may also send you for an assessment. If at the assessment it is deemed that you should have informed them this may invalidate your insurance not only causing you a problem now, but also in the future when you renew your car insurance. If you were involved in an accident, this could result in a prosecution.

#### 44. What sources of support are out there to help me get out and about?

The **Blue Badge** scheme provides a national range of parking concessions for disabled people with mobility problems who have difficulty using public transport. For more information including who is entitled to a badge and how to apply for it can be found [here](#).<sup>69</sup>

**Disabled Motoring UK** - [www.disabledmotoring.org](http://www.disabledmotoring.org) - is a UK charity that can answer questions on accessible parking, vehicle adaptations, congestion charging and other issues that affect its members. It publishes a monthly magazine with the latest news and review of vehicles, scooters and mobility aids.

The **Freedom Pass** is a concessionary travel scheme to provide free travel to people who have a disability. It is a national scheme and applications are handled by your borough of residence.

The **Motability Scheme** – [www.motability.co.uk](http://www.motability.co.uk) – Enables disabled people to exchange either their Higher Rate Mobility Component of Disability Living Allowance/Personal Independence Payment or their War Pensioners' Mobility Supplement to obtain a new car, powered wheelchair or scooter.

#### 45. I would like to find an all-terrain wheelchair. Can you point me in the right direction?

The following companies provide all-terrain wheelchairs.

- Molten Rock - [www.moltenrock.co.uk](http://www.moltenrock.co.uk)
- All Terrain Wheelchairs - [www.allterrainwheelchairs.co.uk/extreme-x8](http://www.allterrainwheelchairs.co.uk/extreme-x8)
- Terrain Hopper - [www.terrainhopper.com](http://www.terrainhopper.com)
- Mybility All Terrain Wheelchairs - [www.mybility.co.uk/wheelchair/four-x-dl-sss](http://www.mybility.co.uk/wheelchair/four-x-dl-sss)

## Travel

### **46. I was diagnosed with TM in the past year. Can I travel?**

Travelling in a plane or on a train/bus is not an issue, and a holiday can be very restful and helpful in that regards. However, be sure you feel well enough to travel. You may want to attempt a shorter trip first before long-haul trips. Also keep in mind that when you travel to different climates, the weather at your destination may affect any ongoing residual symptoms you have (sensory alteration, etc.) differently than at home.

### **47. I want to travel but what do I need to know about travel insurance now that I have TM?**

The following links provide general information which can help in relation to travel insurance when you have a long-term condition like TM and/or a disability.

The Travel Insurance Guide website - [www.travelinsuranceguide.org.uk](http://www.travelinsuranceguide.org.uk) – provides a guide to travel insurance.

An article on travel insurance for pre-existing medical conditions, from the Travel insurance Guide website is available [here](#).<sup>70</sup>

### **48. Which companies provide travel insurance?**

Travel insurance companies that offer insurance to people with pre-existing medical conditions are listed below, as well as two sites which allow you to compare quotes. If you require travel insurance for a child, you will need to call to double check if these companies cover them. Each company is hyperlinked to its website so just click on it to learn more about what the company offers.

Be aware that one issue people have encountered is that TM may not be listed as Transverse Myelitis or TM. It was found to be listed with one insurer as 'spinal myelitis'. So if the insurer does not recognise the condition's official name, try a variant: myelitis, spinal myelitis, spinal inflammation, spinal lesion, or if the lesion was at the cervical level, cervical myelitis.

Some banks offer travel insurance free or at a low rate as a benefit for having an account with them. So check whether you get that benefit with your account and whether the insurance covers your pre-existing medical condition.

## Travel Insurance Companies

[AA Travel Insurance](#)

[Able2Travel](#)

[Age UK Travel Insurance](#)

[AllClear](#)

[Columbus Direct](#)

[En Route Insurance](#)

[Fish Insurance](#)

[Free Spirit](#)

[Good to Go Insurance](#)

[Insure for All](#)

[MS Society Insurance Services](#)

[Orbis Insurance Services](#)

[Saga Travel Insurance](#)

[Staysure](#)

[World First Travel Insurance](#)

## Comparison Sites

[Comparthemarket](#)

Transverse Myelitis is listed and they only require a few extra questions.

[MoneySupermarket.com](#)

---

## End notes

---

- <sup>1</sup> The Brain & Spine Foundation's booklet on Transverse Myelitis can be access at <http://brainandspine.org.uk/transverse-myelitis>
- <sup>2</sup> Intravenous Immunoglobulin Patient Guide, NHS, [www.ivig.nhs.uk/documents/ivig\\_patient\\_guide.pdf](http://www.ivig.nhs.uk/documents/ivig_patient_guide.pdf) (Retrieved 1 Dec 2015)
- <sup>3</sup> The questions to ask your doctor document compiled by the Brain & Spine Foundation can be accessed at [www.brainandspine.org.uk/questions-ask-your-doctor](http://www.brainandspine.org.uk/questions-ask-your-doctor)
- <sup>4</sup> The Brain & Spine Foundation's booklet on Transverse Myelitis can be access at <http://brainandspine.org.uk/transverse-myelitis>
- <sup>5</sup> The TM Society's Condition Insight Report into TM can be accessed at <http://www.myelitis.org.uk/resources.html>
- <sup>6</sup> The Brain & Spine Foundation's online form to obtain help and advice is available at <http://www.brainandspine.org.uk/helpline-contact-details>
- <sup>7</sup> You can access the Brain & Spine Foundation's online discussion forum at <http://www.brainandspine.org.uk/forum>
- <sup>8</sup> The Chartered Institute of Physiotherapists website is [www.csp.org.uk](http://www.csp.org.uk)
- <sup>9</sup> Zackowski, K (2015) Are there guidelines for exercising when you have TM? Retrieved from [www.myelitis.org](http://www.myelitis.org)
- <sup>10</sup> Exercises available on the MS Trust website are at <http://www.mstrust.org.uk/exercises>
- <sup>11</sup> Exercises available on the MS Society website are at <https://www.mssociety.org.uk/exercise>
- <sup>12</sup> Exercises available on the British Heart Foundation website are at <https://www.bhf.org.uk/heart-matters-magazine/activity/chair-based-exercises>
- <sup>13</sup> Exercises available on the NHS Living Well website are at <http://www.nhs.uk/Livewell/fitness/Pages/sitting-exercises-for-older-people.aspx>
- <sup>14</sup> Sitting exercises available via the MS Trust website are at <https://www.mstrust.org.uk/understanding-ms/living-ms/lifestyle/exercise-and-ms/exercises-people-ms-index>
- <sup>15</sup> Sitting exercises are included in the videos on the MS Society website at <https://www.mssociety.org.uk/exercise>
- <sup>16</sup> More information about the TM Society's Equipment Grant Scheme can be obtained at <http://www.myelitis.org.uk/our-services.html>
- <sup>17</sup> John Hopkins University Hospital (date unknown), The relationship between Transverse Myelitis and Multiple Sclerosis. Retrieved from [www.hopkinsmedicine.org](http://www.hopkinsmedicine.org)
- <sup>18</sup> The Transverse Myelitis Association's podcast of vaccinations can be accessed at <https://myelitis.org/resources/understanding-vaccinations-and-autoimmune-diseases/>
- <sup>19</sup> Information on coping with heat sensitivity and hot temperatures is available on the Brain & Spine Foundation's website at <http://www.brainandspine.org.uk/heat-sensitivity-and-hot-temperatures>
- <sup>20</sup> Neuropathic Pain, Brain & Spine Foundation, [www.brainandspine.org.uk/neuropathic-pain](http://www.brainandspine.org.uk/neuropathic-pain) (Retrieved 1 Dec 2015)
- <sup>21</sup> Neuropathic Pain, Brain & Spine Foundation, [www.brainandspine.org.uk/neuropathic-pain](http://www.brainandspine.org.uk/neuropathic-pain) (Retrieved 1 Dec 2015)
- <sup>22</sup> Neuropathic Pain, Brain & Spine Foundation, [www.brainandspine.org.uk/neuropathic-pain](http://www.brainandspine.org.uk/neuropathic-pain) (Retrieved 1 Dec 2015)
- <sup>23</sup> Neuropathic Pain, Brain & Spine Foundation, [www.brainandspine.org.uk/neuropathic-pain](http://www.brainandspine.org.uk/neuropathic-pain) (Retrieved 1 Dec 2015)
- <sup>24</sup> Information on the TM Society's Coaching Bursary Scheme is available at <http://www.myelitis.org.uk/our-services.html>
- <sup>25</sup> Information on the Spinal Injuries Association Healthcare service is available at <http://www.spinal.co.uk/how-we-help/sia-healthcare/>
- <sup>26</sup> Information on purchasing a radar key from Age UK is available at <http://www.ageukincontinence.co.uk/catalogsearch/result/?q=radar+key&order=position&dir=desc>
- <sup>27</sup> The WheelMate website is <http://www.wheelmate.com/en/>
- <sup>28</sup> Information on the 'just can't wait' toilet card is available at <https://www.bladderandbowelfoundation.org/resources/toilet-card/>

- <sup>29</sup> Access podcasts, videos and articles on sexual health and TM from the Transverse Myelitis Association's website at [https://myelitis.org/living-with-myelitis/resources/resource-library/?fwp\\_topics=sexual-dysfunction](https://myelitis.org/living-with-myelitis/resources/resource-library/?fwp_topics=sexual-dysfunction)
- <sup>30</sup> Information on sex, intimacy and relationships on the Brain & Spine Foundation's website is available at <http://www.brainandspine.org.uk/sexual-dysfunction-neurological-conditions>
- <sup>31</sup> The information on sex and relationship issues men and women with MS experience, and which will parallel the experience of people living with TM, is available at <https://www.mssociety.org.uk/what-is-ms/signs-and-symptoms/sexual-problems>
- <sup>32</sup> The MS Society booklet on Sex Intimacy & Relationships can be accessed at <https://www.mssociety.org.uk/ms-resources/sex-intimacy-and-relationships-booklet>
- <sup>33</sup> The article on Dr. Beverly Whipple's research can be accessed at <http://www.webmd.boots.com/sex-relationships/features/people-with-disabilities-still-have-sex-lives>
- <sup>34</sup> The response to this question is from the Managing Fatigue presentation delivered by Kerry Mutch (Nurse, NMO UK Service, Walton Centre NHS Trust) on 3 May 2014 at the TM Society's conference.
- <sup>35</sup> Miserandino C., *Spoon Theory*, Retrieved from [www.butyoudontlooksick.com/articles/written-by-christine/the-spoon-theory](http://www.butyoudontlooksick.com/articles/written-by-christine/the-spoon-theory) (Retrieved 1 Dec 2015)
- <sup>36</sup> The NHS Healthy Eating website is <http://www.nhs.uk/Livewell/Goodfood/Pages/the-eatwell-guide.aspx>
- <sup>37</sup> The Brain & Spine Foundation's TM booklet can be obtained at <http://brainandspine.org.uk/transverse-myelitis>
- <sup>38</sup> The TM Society's Condition Insight Report into TM can be obtained at <http://www.myelitis.org.uk/resources.html>
- <sup>39</sup> The Transverse Myelitis Association's website is [www.myelitis.org](http://www.myelitis.org)
- <sup>40</sup> The article Coping with a Chronic Illness can be accessed at <http://www.alpineguild.com/COPING%20WITH%20CHRONIC%20ILLNESS.html>
- <sup>41</sup> The TM Society's magazine is available at <http://www.myelitis.org.uk/the-tms-magazine.html>
- <sup>42</sup> The TM Society's online membership form for Supporters (family, relatives, friends, healthcare and medical professionals, equipment providers, etc) can be accessed at <http://membership.myelitis.org.uk>
- <sup>43</sup> The article Coping with a Chronic Illness can be accessed at <http://www.alpineguild.com/COPING%20WITH%20CHRONIC%20ILLNESS.html>
- <sup>44</sup> The TM Society's Support Group network can be accessed at <http://supportgroups.myelitis.org.uk/>
- <sup>45</sup> The TM Society's magazine is available at <http://www.myelitis.org.uk/the-tms-magazine.html>
- <sup>46</sup> The TM Society's website is [www.myelitis.org.uk](http://www.myelitis.org.uk)
- <sup>47</sup> The online membership form to become a member of the TM Society is available at <http://membership.myelitis.org.uk/>
- <sup>48</sup> Details about the TM Society's Coaching Bursary Scheme can be accessed at <http://www.myelitis.org.uk/our-services.html>
- <sup>49</sup> Information on the TM Society's network of support groups is available at <http://supportgroups.myelitis.org.uk/>
- <sup>50</sup> The TM Society's main closed Facebook group is available at <http://www.facebook.com/groups/5655147062/>
- <sup>51</sup> Back issues of the TM Society's magazine can be accessed at <http://www.myelitis.org.uk/the-tms-magazine.html>
- <sup>52</sup> Headway's guide on returning to work is available at <https://www.headway.org.uk/about-brain-injury/individuals/practical-issues/returning-to-work/>
- <sup>53</sup> Information on The Brain Charity's Employment Support services is available at <http://www.thebraincharity.org.uk/support-services/employment-welfare-benefits-advice>
- <sup>54</sup> Information on the Spinal Injuries Association Vocational Support Service is available at <https://www.spinal.co.uk/living-with-sci/life-after-injury/>
- <sup>55</sup> The Spinal Injuries Association Employment - Your Rights to Employment is available at <https://www.spinal.co.uk/how-we-help/news-resources/>
- <sup>56</sup> More information about the Backup To Work course is available at <http://www.backuptrust.org.uk/backuptowork>
- <sup>57</sup> Information on the Disability Living Allowance is available at <https://www.gov.uk/disability-living-allowance-children/overview>
- <sup>58</sup> Information on the Personal Independence Payment (PIP) is available at <https://www.gov.uk/pip/overview>



<sup>59</sup> Information on Attendance Allowance is available at <https://www.gov.uk/attendance-allowance/overview>

<sup>60</sup> Information on Carers Allowance is available at <https://www.gov.uk/carers-allowance/overview>

<sup>61</sup> Information on housing benefit is available at <https://www.gov.uk/housing-benefit/overview>

<sup>62</sup> Information on council tax reduction is available at <https://www.gov.uk/council-tax/discounts-for-disabled-people>

<sup>63</sup> More information about the UK Government's Blue Badge is available at

<https://bluebadge.direct.gov.uk/directgovapply.html>

<sup>64</sup> Information on the TM Society's bursary schemes is available at <http://www.myelitis.org.uk/our-services.html>

<sup>65</sup> Government Digital Service (2014, November 12) Health conditions and driving. Retrieved from

[www.gov.uk/driving-medical-conditions](http://www.gov.uk/driving-medical-conditions)

<sup>66</sup> Information on the UK government's regulations on driving, medical conditions and disability are available at

[www.gov.uk/driving-medical-conditions](http://www.gov.uk/driving-medical-conditions)

<sup>67</sup> The website of the Driver & Vehicle Agency (DVA) in Northern Ireland is available at

<http://www.nidirect.gov.uk/index/information-and-services/motoring/driver-licensing/telling-dva-about-a-condition.htm>

<sup>68</sup> You can find the Mobility Centre nearest to you at [http://www.mobility-](http://www.mobility-centres.org.uk/find_a_centre/listofcentres.htm)

[centres.org.uk/find\\_a\\_centre/listofcentres.htm](http://www.mobility-centres.org.uk/find_a_centre/listofcentres.htm)

<sup>69</sup> Information about the UK government's Blue Badge scheme is available at

[www.gov.uk/government/collections/blue-badge-scheme](http://www.gov.uk/government/collections/blue-badge-scheme)

<sup>70</sup> The travel insurance article on pre-existing medical conditions is available at

<http://www.travelinsuranceguide.org.uk/medical-conditions.html>