



TM Awareness Day Guide

Awareness Day: 9 June 2015

"Let's make a difference together."

Foreword



Dear TM Society members and supporters

The UK TM Awareness Day started in 2011. This year we are making a bigger push to promote Awareness Day and to engage members in doing an activity or organising an event which will educate people about TM and related conditions, and about the work of the TM Society.

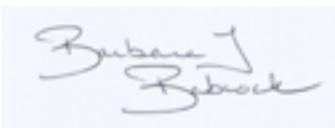
Of course we raise awareness on an ongoing basis through our support group network, bursary schemes, recent campaigning/advocacy activities and involvement in research initiatives. But TM Awareness Day is a time to come together for one day to speak as one voice. If we each do something - however small or big - together it can be the start of a bigger change. So, if you can, I would encourage you to do something to mark the day.

This year is very much about building the foundations and setting benchmarks against which the success of future Awareness Days can be measured. We know we will not get everything right this year, and our aim is to learn from what works well and identify what could be done differently in the future.

This Guide is part of a new range of resources we have introduced to help members who want to get more involved in awareness-raising activities. We hope you will find them helpful.

Thank you for your support.

Best wishes,

A handwritten signature in blue ink that reads "Barbara J Babcock". The signature is written in a cursive style.

Barbara Babcock
Chair, TM Society

Background to the TM Society

The Transverse Myelitis Society aims to enable people with and affected by Transverse Myelitis (TM) and related conditions - Acute Disseminated Encephalomyelitis (ADEM), Neuromyelitis Optica (NMO) and Optic Neuritis (ON) to live well with the impact of these conditions through the provision of information and support in the acute and rehabilitation stages.

Founded in 2004, the TM Society is a volunteer-run, unincorporated charity (registered charity number 1108179). Membership is free. The TM Society offers a number of services for its members including a network of 17 support groups across England, Wales and Northern Ireland, with an affiliate group in Scotland. These support groups, of which 12 meet regularly, provide a range of information, advice and events for its members. It also works with the medical profession and other health charities to promote awareness and understanding of TM.

The TM Society usually does not receive funding from external sources (government, local council, and so on) and is entirely reliant on individual fundraising and donations to sustain its activities. Administration costs are kept to a minimum, for example the TM Society does not have office space, thereby ensuring that the majority of donations are spent directly on projects that benefit our members.

10 Key facts about Transverse Myelitis

1. Transverse Myelitis (TM) is a rare disease of the central nervous system involving inflammation in the spinal cord.

Around 300 new cases are diagnosed each year in the UK. Related conditions include ADEM (Acute Disseminated Encephalomyelitis), NMO (Neuromyelitis Optica, or Devic's Disease), ON (Optic Neuritis) and MS (Multiple Sclerosis).

2. TM is not hereditary or contagious.

You cannot pass on an increased risk of getting TM to your family.

3. Transverse Myelitis can affect anyone, at anytime, anywhere.

TM affects people of all ages from 5 months to 80 years. However the peak ages for a TM diagnosis appear to be 10-19 and 30-39 years. Men are equally likely to be diagnosed as women.

4. Everyone with TM is affected differently.

The main symptoms of TM are muscle weakness in the legs (and, less commonly, in the arms), change in sensation (unusual feelings) in the lower half of the body, pain, and problems with the bowel and bladder. People might also experience fever, headache, tiredness, muscle spasms (spasticity), and a general feeling of being unwell. But symptoms vary depending on what section of the spinal cord is affected.

5. Recovery is difficult to predict.

Around one third of people with TM will make a good or full recovery. Another third will experience some recovery and may have a moderate degree of disability. The remainder will make little or no recovery and have a permanent disability. Recovery usually begins within two months and can continue for up to two years and beyond.

6. Nobody knows what causes TM.

It is not always possible to identify the cause of TM. When inflammation happens it is thought to be the result of the immune system mistakenly

attacking the spinal cord. TM often develops at the same time as, or soon after, a viral or bacterial infection and, rarely, after vaccinations.

7. TM is a 'hidden disability'.

Whilst some people with TM may use a wheelchair for all or part of the time, others may have no visible symptoms. Just because the person looks healthy, it does not mean they are feeling fine. A person with TM may not dwell on their condition, or may minimise the effect it has on them as a coping strategy.

8. Average GP sees a case of TM once every 100 years.

The condition is so rare many GPs have not heard of TM. This can complicate diagnosis.

9. Diagnosing TM is not straightforward.

The onset of TM is often sudden, and can be at its most severe state in just hours. For others, symptoms develop slowly over several weeks. Common first symptoms can include pain in the back, torso or extremities, mobility issues, and a burning or tingling feeling in the legs. Key tests to diagnose TM is MRI scan of the spine and brain, lumbar puncture, eye evoke potentials and blood work.

10. There is currently no cure for TM.

The most common form of treatment is corticosteroids, intravenous immunoglobulin, and sometimes plasma exchange. Pain relief medication for neuropathic pain is prescribed where needed. Issues with balance, mobility, spasticity, and pain can also be treated through neuro-physiotherapy. Support the TM Society and help reduce the isolation many people living with Transverse Myelitis and related conditions feel.

Facts used are taken from the TM Society (www.myelitis.org.uk) and the Brain & Spine Foundation (www.brainandspine.org.uk).

What is 'awareness-raising' and why do we do it?

Awareness-raising is a broad, and seemingly vague term, yet most people understand what it means. However, it can be difficult to describe.

In his 'Principles of awareness-raising' guide for Unesco, Richard Sayers (2006) describes awareness-raising as:

"...part of an ongoing, interactive communication process which opens up opportunities for information exchange in order to improve mutual understanding, and to develop the competencies and skills necessary to enable changes in social attitude and behaviour."

Put simply, awareness-raising is about communicating in a way that will get people talking, and behaving differently, and which leads to a positive and lasting change. This could be a change in the way they behave, or a change to their practice or policies.

Awareness-raising is anything that involves people understanding, learning or doing something new; about developing visions for the future of how things should look; working out how to change something about how people live or work; or about talking to other people about what they've done. All of these are part of the process of raising awareness about the need for change in social attitude and behaviour, or, put differently, the need for the 'normal' way things are done to change.

What does awareness-raising look like in practice?

Awareness-raising covers a huge range of activities using a mix of communication methods that will get all the different people who we want to listen to us talking.

In practice, awareness-raising activities could be large, noisy events that get huge publicity, or quiet conversations with people who are already in a place to make change happen. The most appropriate method of communication will depend on who we want to communicate with (our audience). To be effective, awareness-raising must meet the needs and interests of all those involved.

There is no set 'how to' model of awareness-raising. It is about finding the right balance of a range of different communication approaches including, for

example, public relations (PR), advocacy, personal communication, mass communication, and educational workshops.

Raising public awareness of any issue is not easy, and achieving lasting and positive change is hard. It is an ongoing process, not a one-off event. Part of that process is about identifying the main purpose of your awareness-raising work/campaign, what changes you want to happen and why (what difference it will make), and ways of evaluating (measuring) how well it has worked.

8 key things about awareness-raising

1. Know your purpose - with awareness-raising it is important to be clear about what you want to achieve. If you don't identify your main purpose(s) it is possible the awareness-raising campaign message will be unclear (see 2)
2. Let your purpose guide and inform your message.
3. Know your audience - you need to understand who it is you want to share your awareness-raising messages with so you can communicate with the right people, in the right way.
4. Anticipate problems and find solutions, or manage the risk - things will not always go to plan, so it's worth thinking ahead about what might go wrong and how you will deal with any problems that arise.
5. Ensure credibility with your audience - it is vital they trust you and believe what you say.
6. Present information using a variety of approaches and techniques and ensure each is appropriate to your purpose, message and audience - it's important to use a range of different types of communication, such as personal communications (e.g. emails), mass communication (e.g. websites, social media, posters and leaflets), press releases, and so on.
7. Communicate a little at a time - aim for quality over quantity. Awareness-raising is an ongoing activity.
8. Assume that any communication has been unsuccessful until you have evidence to the contrary - make sure you have practical ways of getting useful feedback from your audience so you know what worked and what could be improved.

Planning an awareness-raising campaign

Awareness-raising campaigns can be one of the most efficient and effective means of communicating information about a particular topic or issue to a large, wide-spread body of people such as the general public, or to a section of the public such as health and social care professionals. However, to be successful they must be carefully planned.

An awareness-raising campaign will either communicate one main message (or a range of messages that link together) to a single audience (or a range of audiences) using different approaches. The message(s), audience(s) and approaches are then usually described in a document called a Communication Plan/Strategy, which will last for a given period of time.

Developing a TM Society Communication Plan

The TM Society has been working with a member volunteer to plan an Awareness Day campaign based on the awareness-raising principles mentioned above. As part of this work, the TM Society committee and volunteer have worked together to develop an Awareness-raising Project Plan which will build the foundations and set benchmarks against which the success of future awareness-raising work can be measured. We have begun to identify our purposes and the audiences we want to speak to, as well the different methods of communications we could be using.

For 2015, our main audience is our members and our focus is on engaging more members in doing an activity or holding an event to celebrate TM Awareness Day. The TM Society hopes this guide, and the awareness-raising resources described in it, will encourage and support its members to do something for TM Awareness Day 2015.

Raising awareness for the TM Society

Raising public awareness of any issue is not easy, and achieving lasting behavioural change is hard. It is particularly challenging to get heard when you are a small organisation trying to raise awareness of rare conditions which many people have never heard of, and may never experience. However, Awareness Day gives the TM Society a chance to have a louder voice by encouraging and supporting its members to speak together as one.

About TM Awareness Day

The TM Society first supported a UK TM Awareness Day in 2011. On and around the 9 June each year, TM Society members, groups and supporters hold events, or do activities, that educate people about TM, and about the work of the TM Society.

TM Awareness Day is an opportunity for TM Society members and supporters to work together to make a difference to the lives of people affected by Transverse Myelitis (TM) and related conditions Acute Disseminated Encephalomyelitis (ADEM), Neuromyelitis Optica (NMO) and Optic Neuritis.

Why get involved in TM Awareness Day

Living with a rare condition can be lonely. Raising awareness of TM, ADEM, NMO and Optic Neuritis helps those affected feel less isolated, and Awareness Day brings everyone around the UK together for one day giving them a strong voice.

Individually, and in our groups and committees, we are awareness-raising at a local level all the time by speaking to friends and family about how we feel, telling health professionals what treatments work and don't work, writing and sharing information leaflets, or attending meetings on behalf of the TM Society, and so on. Awareness Day is a great opportunity to work together to raise awareness at a national level.

What difference will it make to our members?

We believe Awareness Day activities and events will make a difference to lives of people living with TM, ADEM, NMO and Optic Neuritis in the following ways.

- **TM Society members will feel less isolated** - people will be talking about what they are doing for Awareness Day with friends and family, on social media, in their groups, in their local community, and with committee members.
- **TM Society members will feel good about being part of a bigger group/campaign/cause** - members around the UK will come together on and around Awareness Day.
- **More people with TM, ADEM, NMO and Optic Neuritis will be diagnosed and treated quicker** - over time, Awareness Day activities and events will bring the conditions to the attention of health professionals who do not know much about them.
- **More people living with TM, ADEM, NMO and Optic Neuritis, and their families and carers, will get support from the TM Society, including peer support** - Awareness Day activities and events will bring the TM Society to the attention of those who do not know about us - and along with any funds raised through Awareness Day activities - will help us do more.
- **An increased awareness of TM, ADEM, NMO and Optic Neuritis will lead to more research and improved treatments and services** - over time, a coordinated approach to Awareness Days will help raise the profile of these rare conditions within the research community.

How you can get involved

There are four main ways you can get involved in Awareness Day.

Support an existing activity or event

If you would like to join in with something that is already happening, then you can search the Awareness Day map to find out what activities or events are happening near you. You could offer to help the organiser by promoting the event in your local area using the Awareness Day poster and by sending out Awareness Day invitations, or write to your local media using the Awareness Day Press Release. Alternatively, you could help the organiser out by going along on the day.

Organise your own activity or event

If you prefer, you could organise your own activity or event. There are lots of ideas shared on the [Awareness Day website](#), on the Awareness Day [Facebook](#) and [Twitter](#) pages. We also have a range of Awareness Day planning resources

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you can download from the website including posters, invitations, registration sheets, photograph permission forms and TM Society leaflets, and magazines. And of course there are balloons and other promotional items available to order to liven up your venue. You can download an order form from the website.

Join the social media campaign

The TM Awareness Day Facebook and Twitter pages have been brought back to life! If you are on social media, you can [like our Facebook page](#) and join in the Awareness Day discussions, get ideas for awareness-raising activities and learn about opportunities for getting involved. You can also help us spread the word by sharing posts with your friends. We also have plans for a special Facebook Awareness Day campaign on 9 June which we will only happen with your help.

If tweeting is your thing, you can also [follow us on Twitter](#) for awareness-raising ideas and news, and help us reach out to a much wider audience by retweeting and by mentioning @TM_awareness_UK in your tweets.

Do something as an individual

There are also lots of ways you can support us as an individual. For example you could order a TM Society pin or wristband to wear on the day, or download the TM Society ribbon and add it to your Facebook profile for the day.

If raising awareness amongst your local health professionals is a priority for you, why not use our Introductory letter template to let them know what they could be doing to help people with TM, ADEM, NMO and Optic Neuritis.

Alternatively, you could drop off some TM Society information at your local health centres, physiotherapy practices, GP, hospital or rehabilitation centre. You can download TM leaflets and magazines from the website, or order copies to be sent by post. It's best to hand these to someone you know will make sure they are shared with the right people.

You can keep a record of who and where you have sent leaflets, magazines, press releases and letters to using our Awareness Day Distribution Record and send this to us so we can gather them together and see how far and wide our message is being shared.

Register your activity or event

Please make sure you tell us about your plans for Awareness Day. Every activity or event - however big or small - matters a lot to us, and lets

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others affected by TM, ADEM, NMO and ON know you are thinking of them on Awareness Day.

Once you register we will add your activity or event to the event map, so others can see what's happening near them, and you will also be given the option to order TM Society promotional items.

How we can help

We realise that our members lead busy lives and have health and other challenges to deal with. So we have introduced a range of resources that we hope will help you join in with our Awareness Day activities.

Awareness Day Pack

We have created a pack of TM Society promotional materials for those that are doing public events. You can order them online - but please note that all items are offered subject to availability since stocks are limited.

- Balloons
- Stickers to give to people who make a donation
- TM Society leaflets
- TM Society magazine
- A4 & A3 Awareness Day Poster to advertise your event
- A4 & A3 TM Society Poster to promote the TM Society and its work

Awareness Day planning resources you can download

As well as this guide, you can download the following awareness-raising resources.

Awareness Day Planning resource	What to use it for
Photo Permission form	For making sure we have people's permission to use photographs they are in for TM Society publicity purposes
Introductory Letter to Healthcare Professionals	To send to local healthcare professionals to introduce yourself, tell them a little about Transverse Myelitis and the TM Society, and give ideas on how they can help. You can adapt this letter but please do not change any facts.
Feedback Sheet	To tell the TM Society how your Awareness Day activity or event went. Please send this to you after your activity or event has happened. Your feedback on what worked well and what could be improved will be used to help us plan future Awareness Days.
Register	For you to keep a record of the number of people who attend, including those who give permission to be added to the TM Society membership list so that they can keep up-to-date with the latest news and activities. Please send us your completed register after your event so that we can record the number of people reached across the UK, and contact anyone who has asked to be added to the TM Society membership list.

<p>Press Release template</p>	<p>For you to use when promoting your Awareness Day activity or event in local papers, magazines, radio stations, and so on. You can adapt the press release if you wish to by adding your own choice of heading for example, but please do not change the Editor's notes at the foot of the press release. For more tips and advice on writing a press release, download the Fundraising Press Release template.</p>
<p>10 Key Facts about Transverse Myelitis</p>	<p>10 key facts you can use in your awareness-raising activities, publicity and press releases, when speaking to health and social care professionals and others who attend your events.</p>
<p>A4 & A3 Awareness Day Poster</p>	<p>To promote your activity or event. You could print this yourself onto good quality paper or card, or take it to a local print shop for them to print professionally.</p>
<p>A4 & A3 TM Society Poster</p>	<p>To promote the TM Society. You can print this yourself onto good quality paper or card, or take it to a local print shop for them to print professionally. These can be handed out with leaflets and magazines wherever you think people affected by TM, ADEM, NMO or Optic Neuritis - or health and social care professionals supporting them - will see them.</p>

Awareness Day invitation	This matches the Awareness Day posters and you can use it to invite people to your activity or event. You can print this yourself onto good quality paper or card, or take it to a local print shop for them to print professionally. All you need to do then is pop them into an envelope, and add the name address and stamp (or write the name and address on the back of the postcard if you're handing them out).
TM Society Magazine	A downloadable version of the 10th Anniversary issue.
TM Society Leaflet	Downloadable version of the TM Society leaflet.
Distribution Record	To keep a record of who you give out leaflets, magazines and posters to.
TM Society Awareness Day logo	New version of the ribbon logo for you to use for promotional purposes.
TM Society Fundraising logo	New version of the logo with 'in aid of' added underneath to use when you are raising funds.

Promote your activity or event on the Awareness Day map

When you register what you are doing for Awareness Day on the website, we will then add your activity or event to the interactive Awareness Day map. This will let others see what is happening around the UK, and will help promote your activity or event more widely.

When you register we will also promote your activity or event on the Awareness Day Facebook and Twitter pages to reach an even wider audience, and to give others' ideas for what they might want to do.

Awareness Day Newsletter

To keep you up-to-date with all the latest Awareness Day news, we have introduced an Awareness Day newsletter. These will be sent out regularly in the lead up to Awareness Day. You can sign up online from the [Awareness Day website page](#).

Got a question?

If you have any questions that are not answered here, or are still not sure how to go about planning your Awareness Day activity or event, then you can [email Lynn](#), our Awareness Day volunteer and she will do her best to help.

You can also ask questions on the Awareness Day Facebook page, or check the FAQs on the website.

Help with fundraising

Members often combine awareness-raising activities with raising funds for the TM Society. The two can go hand-in-hand, but it's up to you whether you decide to raise money at your activity or event or not. There are some guidelines to follow when fundraising for a charity, and if you would like to find out more a good place to start would be to read the new TM Society 'How to' Fundraising Guide.

To download Fundraising resources visit the [Fundraising website page](#) and follow the links.

To download Awareness Day planning resources, sign up for the Awareness Day newsletter and register your event [visit the Awareness Day website page](#) and follow the links.

Awareness-raising tips

Here are a few tips to help you plan your Awareness Day activity or event.

Be clear about what you want to achieve

Ask yourself: 'What is the purpose of my activity or event? If you are clear about what you want to achieve by getting involved with Awareness Day, it will help you identify what kind of activity or event to do, and what message you want to share. If it's about reducing feelings of isolation, a social event would be good. If it's about educating health professionals, it may be better to write to them using the letter template provided or dropping by to hand them information leaflets and posters.

Identify the people you want to reach

Knowing who you want to educate about TM, ADEM, NMO or Optic Neuritis and the TM Society will help you identify how best to get your message across. Make sure you use a method of communication that works for you, but is also appropriate for the people you want to reach. If it's the general public, something like social media is good. If it's the media, then a press release is best. If it's local families and friends, a social event with information leaflets may work best. And if you want to get your voice heard by your local HealthWatch, then put yourself forward to attend a meeting.

State the facts

It's important your message is trustworthy and accurate. Use the TM Society '10 Key Facts about Transverse Myelitis' sheet, or the resources on the TM Society website as these have all been checked for accuracy. And if you're writing a press release, use the templates provided but make sure you keep the 'Notes for Editors' section at the end intact. If you are considering sharing a personal story this can be a great way to raise awareness, but make sure you say what actually happened (our memories can fail us at times), and if your experience was a negative one, focus on sharing positive suggestions for how things can be improved.

Get feedback

Look for practical ways you can get feedback on how successful your Awareness Day activity or event was. This can be something simple like recording the number of people who attend an event, or collecting press cuttings from the local paper. You could give people sticky notes to write their thoughts and put these up onto a sheet on the wall, or contact them personally afterwards with a few questions you would like to ask. You can then use this feedback on what worked well, and what could be improved, to help you plan any future awareness-raising activities you do.

Get permission to take photos

Photos are a great way of recording your activity or event. Snap a shot of any professional who you hand a leaflet, magazine or poster to. Or take some photos of people enjoying eating any lovely cakes you've baked. Make sure you ask their permission to use them for TM Society publicity purposes - there's a form you can download from the website. And then please, please send them to us so we share them, or share them yourself on the TM Awareness Day Facebook or Twitter pages. We are looking forward to seeing what you are all up to!

Enjoy yourself!

Most of all please choose something you want to do, or will enjoy doing for Awareness Day. You should believe whatever you are doing will make a difference, and knowing it is will make you feel good.

If in doubt, get in touch

If you are not sure about anything, please get in touch and we will do our best to help. We know many of you will have years of experience, but others may be awareness-raising for the first time. You can contact us via the [TM Awareness Day Facebook page](#), or by [email](#).

Thank you for supporting TM Awareness Day!