



Fundraising for the Transverse Myelitis Society

A how to guide

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Contents

1. Introduction.....	3
2. What is fundraising?.....	4
3. How to fundraise for the TM Society?	4
a) Event fundraising.....	4
b) Charitable collections	5
c) Trusts and foundations.....	6
d) Major donors.....	6
e) Corporate sponsorship	6
f) Legacy fundraising.....	6
g) Fundraising ideas.....	7
4. Handling cash	8
5. Press and social media	9
6. Top tips.....	10
7. Fundraising Pack.....	11
a) Downloadable resources.....	11
b) Items we post to you.....	12
8. Further information.....	12

1. Introduction

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.

Transverse Myelitis (TM) can strike anyone, at any age, anytime, anywhere; it is indiscriminate and unpreventable. TM is a rare disease of the central nervous system involving inflammation in the spinal cord. The inflammation causes swelling which disrupts the nerve impulses travelling along the spinal cord and their communication with the corresponding body parts/functions. This results in symptoms such as muscle weakness and/or spasms (spasticity), partial or total paralysis, bladder and bowel dysfunction, chronic pain, sexual dysfunction, fatigue, and depression. TM is life-changing - two thirds will be affected by symptoms throughout their lives, some disabled permanently. The onset of TM can be quick, in a matter of hours, or gradual over days, weeks or months. So for some people, they experience a life changing event very quickly. As with most neurological conditions, there is no cure for TM, ADEM or NMO.

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 does not currently receive funding from external sources (government, local council, etc.) 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.

Thank you for choosing to raise funds for the TM Society. Together we can make a real difference.



Representing the TM Society in the GRIM challenge has been our absolute pleasure and privilege. We would like to thank you and everyone who is part of the TM Society for all the work you are doing.

2. What is fundraising?

Fundraising is the process of asking for money to fund your charitable activity. But it is not actually about money. It is about necessary work that urgently needs doing. Money is just a means to an end.

Fundraising is a commitment between fundraiser and donor to make a difference to a shared cause. The fundraiser and donor are on the same side; and to be a fundraiser it helps to be a donor yourself, no matter how small your gift.

Fundraising needs to be done with honesty, integrity and transparency. These are values important to the TM Society and must be upheld by all who fundraise in aid of the TM Society.

3. How to fundraise for the TM Society?

The TM Society needs funds to deliver its key services to members and to sponsor special projects. If you are planning to fundraise for us, first visit the [fundraising section of the TM Society website](#) to understand more about our work as a whole and to find out about any specific fundraising appeals we may be running. You will also find [useful downloadable fundraising resources](#) including an online form for you to send to the TM Society telling us of your planned activity so that we can share information with all our members. The 'Get Involved' section of the website also explains how people can give to the TM Society online via to [Just Giving](#), [Virgin Money](#) or [CAF online](#) (Charities Aid Foundation).

Once you have identified your cause, i.e. what you want to fundraise for, be it the TM Society's work as a whole or one of its active fundraising appeals, you will need to decide how you would like to raise the money, eg bake sale, raffle, run, etc. (see section 3g for fundraising ideas) and much money you hope to raise.

There are a number of different types of fundraising, distinguishable by either the method of how funds are solicited or the audience they target. Below is an outline of those that relate to the TM Society.

a) Event fundraising

Organising events for the purpose of raising funds can be an effective way to involve people with the TM Society and to raise awareness of and money for our cause.

If organising a fundraising event you will need to consider:

- i. Licencing. In most cases the premises on which the event will be held must have a current licence under the Licencing Act 2003. This permits the staging of short-term, small-scale events, provided that the organisers send a Temporary Event Notice to the local licensing authority and police ten working days in advance of the event.
- ii. If you are planning on running a raffle you need to adhere to the regulations outlined in the Gambling Act 2005. If your raffle is private – i.e. run at a work place or club and only accessible by those on the premise; then a license is not required. Nor is a licence required if a small raffle is run

- as part of an event and is not the main focus of the event. Cash prizes cannot be offered, you cannot spend more than £250 on prizes (though there are no limits to the value of donated goods), and ticket sales and the announcement of results must take place during the event. A large raffle that is open to the public must be registered with the local council. Due to the legal and administrative complexities of this type of raffle, they are best avoided.
- iii. Health and safety. It is advisable to carry out a risk assessment for you, your helpers and participants. Visit the Health and Safety Executive website at www.hse.gov.uk for further information. If offering or selling food to the public you should contact the environmental health department of your local council to see which food safety laws apply. If first aiders are deemed necessary, the [British Red Cross](#) or [St John's Ambulance](#) can provide these at a cost. Please note that the TM Society cannot accept responsibility for any accidents or injuries that occur at fundraising events organised by its members/supporters.
 - iv. Safeguarding. Always ensure that children are safe and accompanied by a parent/guardian. Children should not be allowed to ask for or collect money without an adult.
 - v. Cost. There will be costs associated with running a fundraising event and these need to be considered against the projected fundraising target to determine whether or not the event is viable. The TM Society does not pay expenses for fundraising activities and fundraiser(s) organising such events should not deduct expenses from donations received.
 - vi. Events are a great way to raise awareness of a cause. Specific tips on how to engage the press/media are outlined in section 5.

Another way to engage in event fundraising is to participate in events organised by others, for example, a marathon. Event organisers usually offer advice on how to maximise fundraising potential as well as providing sponsor forms and other useful fundraising materials. You can solicit donations online by setting up fundraising pages on sites such as [Just Giving](#) and [Virgin Money](#). The TM Society advises against engagement in activities that may comprise the personal safety of its fundraisers or the Society's reputation.

b) Charitable collections

Collecting money in a tamper-proof bucket or collection box (where the lid is secured to the bucket or box) is a common way of raising funds for charity, but again regulations apply.

If you plan to hold a collection in the street or to fundraise house-to-house you must first obtain a licence from your local authority. The TM Society recommends that you do not undertake house-to-house collections for safety reasons. If your collection is open to the public but being held on private property, eg within a shopping centre, you must first obtain permission from the landowner/manager in addition to the local authority. Similarly, static collection boxes do not require a license but permission from the business owner should be obtained and the boxes must be secure and tamper proof. The TMS has several collection buckets it can loan fundraisers for their events.

Face-to-face fundraising is similar to charitable collections, though in this case the goal is to solicit committed gifts via direct debit or standing order, e.g. street fundraisers. Due to the legal complexities involved, this kind of face-to-face fundraising is not an area that the TM Society recommends its members/supporters engage in at this time. If you, your family or friends would like to make a donation or

gift via direct debit or standing order, you can do this by going to [Just Giving](#), [Virgin Money](#) or [CAF online](#) (Charities Aid Foundation). If you would like to donate regularly, you can set up a standing order via Just Giving or Virgin Money.

c) Trusts and foundations

There are approximately 10,000 grant-giving trusts in the UK, each with a designated set of aims/objectives. Charities which meet the criteria of a specific trust may apply for a grant. Grants can range from three to seven figures, but it is a competitive field and more requests are declined than successful.

This is an area of fundraising that the TM Society Committee is exploring. It therefore asks its members/supporters to contact the TM Society by emailing fundraising@myelitis.org.uk prior to making any approaches to trusts/foundations in order to avoid duplication.

d) Major donors

Major donor fundraising is the term applied to the process of securing transformational gifts from high net worth individuals (HNWIs). Many charities define a major gift as a single (not cumulative) gift of a minimum of £5,000.

Major donors are identified by their ability to give, their affinity with the cause, and the charity's ability to reach them. A strong relationship, in which both the charity and donor understand the difference that each other want to make in the world, is integral to effective major donor fundraising.

e) Corporate sponsorship

There is a culture in the UK of businesses of all sizes supporting UK charities, irrespective of the economic climate. These are often high-profile sponsorships, ie Costa Book Awards; or smaller partnerships, for example a high street printing company providing free marketing materials for a local charity event. Many businesses have a public corporate social responsibility agenda which will include charitable giving. Local businesses tend to respond on an ask-by-ask basis. In all cases approaches should be tailored to that business and should offer opportunities for the business to demonstrate its social responsibility to the community and to receive press/media coverage. Businesses are highly unlikely to pay charitable donations into the bank accounts of individuals.

Businesses can claim tax relief by deducting the value of its donations from its total business profits before it pays tax. See <https://www.gov.uk/tax-limited-company-gives-to-charity/overview> for further information.

f) Legacy fundraising

Many people choose to remember a charity in their will, and such acts of charitable giving often represent the largest gifts received by charities.

Legacy fundraising can be a sensitive issue so it is imperative that care is taken in this area of fundraising. You will find guidance on this, including suggested wording for inclusion in a will, on the TM Society website at http://www.myelitis.org.uk/uploads/1/5/8/2/15824690/tms_will_wording_v1.pdf.

You will also find information on how gifts can be left in memory of someone, i.e. for an anniversary, birthday, or wedding to mark a special occasion.

g) Fundraising ideas

Here is a list of fundraising ideas to help you start thinking about the type of fundraising activity you would like to do.

- **Organised sporting challenges** – Runs, marathons and tough ‘mudder’ challenges take place around the UK
- **Individual sporting challenge** – If you enjoy running, swimming, kayaking or whatever commit to doing a challenging distance for yourself several times over a specified period of time
- **Organise a sporting event** – Some people enjoy football, rugby, volleyball, netball, hockey and other team sports. Organise a match or tournament and invite family, friends and colleagues to it.
- **Bake sales** - You can bake yourself, ask family or friends for help or have a bring and buy sale. It can be made into a bake-off style competition as well.
- **Face painting** - Kids love to have their faces painted! Even just a few spots or stripes can be enough to keep children happy
- **Costume parties** - Get your guests to dress in your chosen theme. Guests pay an entry fee then give a prize.
- **Clothes swap** - This is a great way of clearing out unwanted clothes! Bring along any clothes you no longer wear/fit into, have a mirror available and you can try on other people’s unwanted clothes and get yourself a new item or 2 for your wardrobe! Any leftover clothes can be given to a charity shop.
- **BBQ** - Light up the barbie and invite your guests over for a burger!
- **Quiz or trivia night** - Challenge your family and friends to get together in pairs or teams. You can charge a fee to enter, sell drinks and snacks.
- **Wine tasting** - A fun way to get adults together. You can get guests to blind taste various types of wine, then after reading some tasting notes identify which are which.
- **Film night** - Invite friends to come to your house to watch a movie together, then charge for refreshments or ask for a donation (you cannot “charge” to watch the film because of copyright).
- **Decorate a tea pot and use it for collecting loose change** - You could get your friends to join in and offer a prize to the best design.
- **Open up as a shop for a night** - Ask people to donate unwanted quality goods and play shop.
- **Bring and buy plant sale** - A great way for gardeners to share their cuttings and get new ones.
- **Games/card night** - Charge people to enter board game challenges or card games (bridge, etc.) and see who can be the ultimate winner.
- **Silent auctions** - Ask local businesses to donate prizes and then have a silent auction. Golf clubs, football and rugby clubs, fitness clubs, hair and beauty salons, restaurants and shops are often good places to ask to donate prizes.
- **Book sales** - Ask around for used books then sell them at your event.

- **Raffle/tombola** - Ask around for donations of prizes among family, friends and local businesses. If doing a tombola for children, consider a chocolate or sweet themed tombola.
- **Guess how many...** sweets in the jar, pennies in the jar, Guess the weight of.... The cake, the book, the pumpkin
- **Name the Teddy**
- **Duck racing** - Get some rubber ducks (or anything else that floats), number them and ask guests to buy a number. You can then race the ducks along a nearby stream or river.
- **Who's who?** - Have a collection of baby photos and get people to identify who is who... you can use your family and friends or famous people but you need to make it known who is included.

The fundraising activity you choose will be influenced by your interests and if it is an event to which you will invite others, the type of people you are expecting to attend. Those with young children might choose to include guess the name of the teddy, have face painting or a chocolate tombola. Adults may like the idea of a wine tasting or a plant sale. This will ultimately be your event and so you can choose to organise it as you wish.

4. Handling cash

As a registered charity, the TM Society is required to record the money it raises each year and to submit its accounts to the Charity Commission. To ensure compliance with financial regulations, the TM Society asks all of its fundraisers to be mindful of the following:

- Records should be made of all donations given for specific purposes to ensure that the terms of that donation are complied with. For example, if a gift is made to support the TMS Family Weekend it must be spent on the costs of the Family Weekend.
- Fundraisers should not make any deductions for expenses or anything else from donations made to the Society.
- Cheques should always be made payable to the Transverse Myelitis Society and never to an individual.
- If a collection bucket is being used, it should have a lid which is visibly secure using plastic lock ties. The name of the charity and its registration number should appear on the lid or side.
- Cash ought to be collected, counted and recorded by two unrelated individuals, wherever possible.
- Unsecure cash should never be left unattended.
- Donations should be banked and submitted to the TM Society along with its [“Paying in Money” form](#) within 4 weeks of being raised. Alternatively cheques should be sent to the Transverse Myelitis Society with the Paying in Money form within the same timeframe.

5. Press and social media

Fundraising activity often attracts the interest of local press and media. If you have planned a fundraising activity in your area it is worth contacting the local press/media in writing to inform them what is happening, why, when and where, who's doing it, and how you can be contacted for further information. This can include your local radio and television stations, newspapers and magazines. A [sample press release template](#) and approved images are available for download on the TM Society website.

If your event attracts the attention of national media, please advise the TM Society Committee so that they can provide a quote/spokesperson as required.

Sticking to brand image can build donor loyalty as they start to recognise and get to know you through you using the same visual images consistently. It also helps if your cause can be distinguished from others. The TM Society has produced a logo for use by people fundraising in aid of its work. Visit the website to [download the 'In aid of the TM Society' logo](#). [Template A3 and A4 posters](#) are also available for download which you can fill in to advertise your event. More information about these downloads are in section 7 of this document.

Don't forget social media. Facebook, Twitter and other social networking sites are excellent ways of spreading news of the TM Society's work and encouraging people to give.

When using Twitter, tag the TM Society at [@T_M_Society](#).

When using Facebook, the name of our open public pages are listed below. Make sure to find us and let us know about your event.

If you are holding an event for TM Awareness Day on 9th June, you can also tag the TM Society at an additional Twitter Account [@TM_awareness_UK](#) and another Facebook page TM Awareness Day UK.

Including your link to your Just Giving and/or Virgin Money page in any tweets and Facebook posts, encourages people to give.



[Transverse Myelitis Society](#)

[TM Awareness Day UK](#)



[@T_M_Society](#)

[@TM_awareness_UK](#)



fundraising@myelitis.org.uk

6. Top tips

- i. *Inspire* people to give. Don't just ask.
- ii. Focus on the difference a donation can make rather than the need for money – the money is a means to an end. Let them know 'why' you are fundraising and how their donation will benefit the people it is meant to.
- iii. Tell stories about your beneficiaries to open hearts and minds. Donations will follow. The TM Society can provide you with examples if you need them. Please email fundraising@myelitis.org.uk.
- iv. Money is not the only form of giving. Be open to people volunteering time and in-kind gifts.
- v. Acknowledge and thank all donations.
- vi. People who can donate are your family, friends, colleagues, and people they all know. Talk to them and engage them in your fundraising activity.
- vii. Don't forget to ask about Gift Aid eligibility. Gift Aid allows charities to claim back up to 25% of the value of a donation from the government provided the donor is a UK taxpayer. To be Gift Aid eligible, donors need to provide their name and address and tick a box that indicates they are a UK tax payer. Donations must be sent to the TM Society via the Paying in Money form to enable it to process the claim. Visit the TM Society website to download the [Donation Form](#). Also consider having Gift Aid envelopes available. A [template for printing out the Gift Aid information on a C6 sized envelope](#) is available on the website.
- viii. When fundraising for a specific activity (eg Equipment Grant Scheme, Neuro-physiotherapy Scheme, TMS Family Weekend), make clear to donors that any money raised which exceeds the project target will be spent on other charitable activity with the TM Society. This allows the TM Society more flexibility in its spending and enables it to meet its stated annual priorities. Check the [TM Society's Our Services page](#) to know of current activities.

Remember, we don't expect you to know everything about the TM Society so if you have any questions please email fundraising@myelitis.org.uk.

7. Fundraising Pack

The TM Society offers each fundraiser a fundraising pack which consists of documents you can download from our website and items to help you organise and promote your event.

a) Downloadable resources

Visit www.myelitis.org.uk/fundraising-resources.html to download fundraising related forms and documents for your use.

Press release template	Use this document to write a press release to send to journalist and radio show hosts in your local area to advertise your event.
Donation form	Use this form when making a one-off or ongoing donation to the TM Society and/or to set up a standing order with your bank.
Template for creating Gift Aid donation envelopes	If you have C6 sized envelopes at home, you can use this template to print out envelopes with the Gift Aid donation information on the front. This enables donors to make a cash or cheque donation at your fundraising event and complete the necessary information to ensure the TM Society can claim Gift Aid.
Sponsorship form	Use this form when you are seeking sponsorship from others for your fundraising activity.
Paying in form	Once your fundraising activity is over, you can use this form when you send your fundraising monies to the TM Society.
Posters to promote your activity	We have two posters online you can download, print and fill out with details about your activity. They are the same poster but different sizes – A3 and A4.
In aid of TM Society logo TM Society logo Approved images	If you enjoy making your own posters or want to include TM Society images on your Twitter, Facebook or other social media pages, you can use these approved logos and images. We ask that you do not alter them.

b) Items we post to you

The pack also includes the following items which cannot be downloaded but we post to you.

- A few TM Society goodies for you as a thank you from us
- Promotional branded items to give public events that official and professional look
 - Balloons (blue and white)
 - Thank you stickers to give to people at events who have made a donation
 - TM Society Leaflets
 - TMS Magazine
 - Cardboard collection box
 - Posters you can complete with your event details to promote your activity (A3 & A4 size)

When you have set a date for your event and publicised it, let us know by emailing fundraising@myelitis.org.uk. Include the promotional items you need to advertise and promote your event and your postal address. If your event does not require any promotional items, then you do not need to order any.

8. Further information

Institute of Fundraising www.institute-of-fundraising.org.uk

Charity Commission www.charitycommission.gov.uk

Health and Safety Executive www.hse.gov.uk

St John's Ambulance www.sja.org.uk

British Red Cross www.redcross.org.uk

By fundraising for us you are helping us to make a difference to people with and affected by Transverse Myelitis (TM), Acute Disseminated Encephalomyelitis (ADEM), Neuromyelitis Optica (NMO), and Optic Neuritis (ON).

We thank you.