



# Transverse Myelitis

S O C I E T Y

*Who is caring  
for the carer*



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## LETTER FROM THE EDITOR



ANNIE SCHOFIELD

**Dear Readers,**

First of all may I beg your indulgence to say a Very Happy Birthday to us. Yes, your magazine is celebrating its 1st birthday, and what a year it's been. We've had the inside story on the Mili Wives from one of its founder members, and followed the dream of Natasha Baker, who not only made it into the Paralympic team, but went on to win 2 gold medals (and as if that weren't enough, she has also been awarded an MBE for her achievements). We've had uplifting stories of people achieving their own personal goals, information on alternative therapies, and some hilarious slants on the problems of being disabled.

You may have noticed that each magazine has a 'theme', focusing on one aspect of coping with our lives post TM, and this time we are looking at that very emotive subject, carers.

Most of us dread old age and the possibility we may need to be cared for, but how do you cope when it happens suddenly, and much younger? Being struck down by TM is pretty devastating, but if it has left you with mobility problems there are other issues to contend with, being a carer, or being cared for. Barbara Babcock's excellent article will resonate with many of you I'm

sure, and offers some very sound advice. Then, on page, 5 Claire Manning shares her own experience of how she suddenly found herself the Carer – not something she had expected to be doing in her twenties.

For some people TM makes them more determined to achieve things, so as a qualified scuba diver myself I am full of admiration for Margaret Shearer who decided to take it up post TM. The weight of the equipment alone would be enough to put most people off, let alone getting on and off the boat, but we both know how liberating it is to be gliding along in this silent, vibrant world watching sea life drifting past you.

I do hope you will take time to read about TM Awareness Day 09 June on Page 11. This is your chance to get a bit of awareness out there, and it doesn't have to take up much of your time. If everyone just invited a few friends round for tea and a cup cake (which they pay for, of course), and gave them a copy of the magazine to take away, we could educate a huge number of people in just one day.

I can't tell you how delighted I am to see that we now have more than 390 members on our facebook page. This has proved, in a very short time, to be a place where people can share their concerns, or just talk to those who totally understand what they are going through. There must also be people who have done a TM search on-line and found this page, and only then realised that there was a TM Society. And, hopefully, from there they will see that we also have Support Groups around the country

Yes, let us not forget our Support Groups. I run one of these groups and see first hand how much our members care for each other. They feel free to talk openly about their neuro pain, (because they don't have to explain what it is), they discuss the benefits of Botox, self catheterisation, complimentary therapies etc. But above all it's friendship with people with whom they share a common bond.

Once again our wish is that we have included something for everyone, so keep those stories, letter and, most of all, your suggestions for future editions coming in to

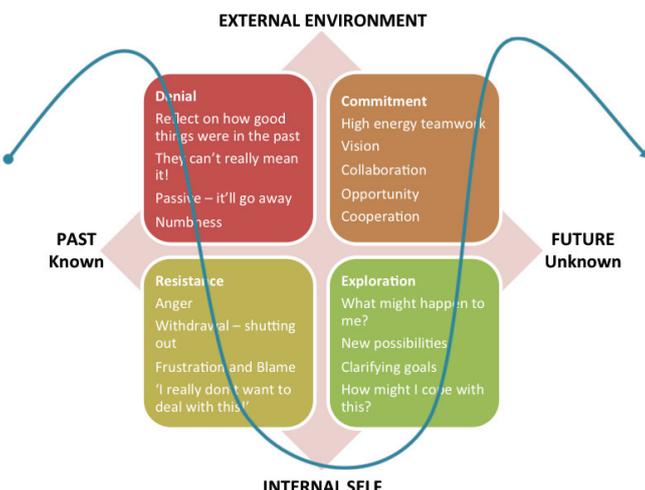
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# Who Is Caring For The Carer?

TRANSVERSE MYELITIS SOCIETY  
BARBARA BABCOCK HAS SOME USEFUL ADVICE

**When a loved one contracts TM/ ADEM/ NMO, it is a shock, very sudden and unexpected. It is a trauma, with a big T, that is experienced by the person who contracts TM and the loved ones that care for him/her, whether they be a spouse, parent, child, sibling, relative or friend. Everyone is impacted. We focus on what that experience is like and what the carer can do.**

Being a carer for someone who becomes seriously ill suddenly and unexpectedly is demanding. You may also have children at home requiring care and attention and/or you are already caring for someone else. Add to that the unknowns: learning about a rare condition, living with the daily uncertainty of how long recovery will take and to what extent, and what this mean for you, your loved one, and your lives together. Depending on recovery, changes in the family routine, in the short medium and possibly long term will need to be taken in to account to accommodate the needs of the condition. The initial trauma is over. A transition is now underway. The feelings associated with both are still there whether acknowledged or not and often follow a process, which is experienced by the carer and person with TM, as shown here.



On hearing the news, which often is about loss, the person experiences shock, followed by feelings of denial, numbness and/or passivity. There may also be a burst of activity to deal with the crisis. The next stage, resistance, is characterised by a focus on the individual's internal world, feelings of anger, frustration, blame, guilt, resentment and possibly withdrawal. A common response is 'why me?' In these two stages there is a focus on the past and what was good about it.

*“When a loved one contracts TM/ ADEM/ NMO, it is a shock, very sudden & unexpected. It is a trauma, with a big T, that is experienced by the person who contracts TM and the loved ones that care for him/her.”*

The third stage is still characterised by a focus on the individual's internal world, but there is a shift to the future and unknown, an exploration of possibilities and what one might do. It is not uncommon for the unknown and hence uncertainty to foster excitement and/or anxiety, both which can be a source of creativity when designing new possibilities and goals. The final stage is commitment to the future demonstrated by having a vision of what you want and working towards it. It is characterised by a good enough acceptance of your reality (it does not have to be 100% and/or a Pollyanna-like approach).

Every person's experience of change is individual. Some people may progress through these stages in a linear fashion, others will go back and forth and/or skip some stages completely. There is no time limit for each stage. Some people may pass through

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a stage quickly or it may take a while. One might feel all the feelings associated with each stage or only some of them. What you are feeling is normal; others are feeling something similar.

As a carer, a key consideration is what care you get to cope with this change. It is often said to care effectively for someone else, you have to care for yourself first. Here are a few ideas.

1. The basics are important: get exercise, eat healthily, drink alcohol in moderation, get good sleep.
2. You need a good awareness of your needs and a plan to meet them. No one else can do this for you. But people can support you, which is crucial. Without support, social and emotional isolation can set in, one of the most debilitating aspects of caring.

*“Every person’s experience of change is individual. Some may progress through these stages in a linear fashion, others will go back and forth and/or skip some stages completely. There is no time limit, some people may pass through a stage quickly or it may take a while.”*

3. You may have to ask for support. Some people may view this as a sign of weakness. But without it, you may not get what you need and want. Think of it this way, if a good friend asked you for help, chances are you would probably give it readily. So do not deny yourself.

4. Acknowledge how you are feeling, the good, the bad and the ugly. It is all normal. Giving expression to the full range of our feelings maintains our emotional health. You can write about it, draw, and/or talk to someone you trust who will listen non-judgmentally.

5. Sharing and connecting with others in a similar situation is

a powerful antidote to any isolation or low mood you may be feeling.

6. Talk to the person you care for. Work together to identify what you both want for yourselves as individuals and your relationship. Develop a plan to achieve it.
7. Participate in your local TM support group, offer a listening ear to other carers, and use your skills to benefit others. You will receive tenfold in return.

For more information for carers and on caring, go to

[www.carers.org](http://www.carers.org)

[www.carersuk.org](http://www.carersuk.org)

[www.nhs.uk/carersdirect](http://www.nhs.uk/carersdirect)

[www.dh.gov.uk/health/category/policy-areas/social-care/carers](http://www.dh.gov.uk/health/category/policy-areas/social-care/carers)

**Barbara Babcock is a TMS Committee Member, a professional coach, and consultant in the corporate and charity sectors.**

## A Message From Our Chairman



**YVONNE KOLESAR**

### Dear Members,

2013 is something of a milestone year for me. It's almost 10 years to the day since I was diagnosed with TM. I was less than well for at least 18 months and during that period I can clearly remember wondering, how long it would last, was there anyone else in the world who felt like me, why was I feeling so terribly depressed, and why was there seemingly no help? So I started to delve on the internet - just what everyone says you shouldn't do! There I discovered that a few TM sufferers met at the National Hospital for Neurology in Queen's Square, London, so I turned up at their next meeting, and was completely bowled over to find other people in exactly the same position as me.

**“The Society Committee is run entirely by very willing volunteers and our first aim is one of support”**

Since those early tentative days almost 9 years ago, I've been involved with the group who became what we know today as the TM Society. We now have well over 1000 members, there are numerous Support Groups around the U.K. and, we hope, more being formed. The Society Committee is run entirely by very willing volunteers and our first aim is one of support. That's why we started meeting all those years ago, and even today, with a much larger society, we still feel that is the most important part of what we do.

However, as we grow, we realise we need to do more to make the Society really flourish. I've said that we're all volunteers and, although willing, we need more help from you, our members. We are currently doing an evaluation of our objectives, deciding on the roles we want to create to make the Society more efficient. We know we would like more Support Groups around the country, (we are aware that there are areas where there are no active groups at all). We are also very aware that the website is out of date, but hopefully within a very short time our brand new sparkly version will go live.

**“We will be asking you to give us some help. Have you got a financial background, do you enjoy organising events? Have you been involved in raising money for charity?”**

All these things take time and energy, so we will be asking you to give us some help. For example, do you have specific skills which may be useful to us? Have you got a financial background, do you enjoy organising events? Have you been involved in raising money for charity? We will be looking for experienced people in all of these areas, and more, from the membership. After all, you know what it's like to have this strange condition of ours and will empathise more with others.

Nick Heal and I visited the Spinal Injuries Association before Christmas. Apart from hearing about that thoroughly worthwhile charity, it was interesting to learn that they started out in 1974 as a small table top charity and have grown immensely. Their work is invaluable and whilst we have a long way to go, they are certainly an Association to emulate.

So here I am, 10 years down the line, and whilst I could well do without feet that never feel normal, 'banding', and all the other irritating problems, I've had a fascinating time meeting people and being involved in something which I feel passionately about - and hope that you do too.

As ever, a huge thank you to all involved in the production of the magazine and those who have written articles

**Yvonne**

## Caring for Mum

**Claire Manning wasn't prepared for suddenly becoming a Carer in her mid twenties. Here she tells how she came to terms with her new role in life. When not busy caring for her Mum she runs a book blog called Project to be Read**

Being a carer for someone with TM is a strange mix of support and cheerleading. My Mum Jackie was diagnosed in 2009 and spent five months in hospital. It was a huge adjustment for both of us to have my active Mum come out of hospital in a wheelchair, barely walking at all. Caring for a parent is difficult as it changes your relationship dynamic, essentially reversing your roles. We've gradually found equilibrium but there were times where it was incredibly difficult.

**“I wasn't sure what to expect when I took on a carer role, but it certainly wasn't what I got”**

I wasn't sure what to expect when I took on a carer role, but it certainly wasn't what I got. I'm in my mid-twenties and quickly discovered there is no support for a carer like me. I'm too old to be a young carer, I'm too young to be caring for an elderly parent, I'm not caring for a husband or my children and I'm not from a minority ethnic group. I balance my caring role with my own health issues, which means I have to deal with paid carers, some of whom have bizarre attitudes, that by sometimes needing their help I'm made to feel entirely useless. It frustrates me to listen to them complain, when they get paid to do what I'm doing for free.

Being a carer has taught me many things. Some people are ignorant of disabled people refusing to talk to my mother, even when that means leaning over her to talk to me. Others interfere often causing more harm than good (grabbing a wheelchair to “help” and ripping the skin from my Mum's knuckles because she was self-propelling). Doctors aren't always right. Shops aren't as accessible as you would think (those cardboard display units should be banned). Occasionally, someone will actually be helpful and they make the world a brighter place.

Some days being a carer is hard, both emotionally and physically. There are days where I have to give up things because I cannot be in two places at once and I'm needed to help Mum, days where I'd give anything to have my Mum better because my

*“Don't smother the person you're caring for, they will get annoyed. Support them, offer a shoulder when they need it, celebrate their successes and just be there.”*

heart bleeds watching her be unable to do something she wants. There are the days where I stand by my Mum and feel incredibly proud of her. I have videos of the first time she walked, I was an active participant in her rehab programme and even now I'm still having new moments of pride as she does things her neurologist ruled as impossible.

Looking back to when I first became Mum's carer, I'd give myself some advice. Don't smother the person you're caring for, they will get annoyed. Support them, offer a shoulder when they need it, celebrate their successes and just be there. Find time for yourself and people you can talk to away from your role, especially if you can find people who don't know the person you are caring for and encourage them to do the same. Above all, find something you can do together that you both love that is nothing to do with TM (movies, books, music, crafts).



## Diving into the Deep

## MARGARET SHEARER TELLS HOW YOU TOO COULD BE A SCUBA DIVER



**Margaret Shearer was diagnosed with TM in 2002 with a lesion T2 through T8 which required a body brace and splints on legs and arms. She had reoccurrences in 2006 and 2007 with lesions up to C3. She is a founder member of the TM Scotland Support Group which was started in 2003**

Scuba diving may not be the first new hobby to come to mind when you have been paralysed by TM, but in 2003 I read the story of Cody Unser (USA), (paralysed by TM at the age of 12), who took up scuba diving, and now several years on is dedicated to sharing the physical and mental benefits of the sport. So I decided that would be my challenge, I would become a fully qualified scuba diver! My 2 older sons (both divers) were cautious about my wish but I started training with a physio at a local swimming club for people with disabilities and gradually increased my stamina so that I could swim the required 25 lengths of the pool. I then had to convince my consultant to allow me to try out the scuba equipment, as I needed a medical certificate to do so.

That August, I completed my ocean dives in the warmer waters of the Mediterranean to gain my Open Water Scuba Diving Certificate. The fact that I was in a wheelchair made no difference, it was simply carried aboard with me in it! Initially in the Med I didn't wear a wet suit as I had no sensory to temp of water anyway, however, for dives in deeper water and in Red Sea you need one. My instructors never let me get away with anything less than they expect from able bodied divers, so having checked my equipment with my 'buddy' while seated, I get on my hands and knees, or slide along the floor, to the diving platform at the rear of the boat. Once on the platform I put on my fins, BCD

**"The fact that I was in a wheelchair made no difference, it was simply carried aboard with me in it!"**

vest and tank equipment, then with assistance I fall overboard. When the dive is up I take off BCD vest and tank in the water (taking advantage of buoyancy), hand them over to an assistant, then using waves to propel me onto the platform, I remove my

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fins and crawl back into boat - exhausted!! Normally divers shouldn't make too much arm movement, but only my left leg obeys brain signals. I did try out a mermaid fin that takes both feet, but couldn't move it much so the instructor was happy that the left fin alone did the work, with better effect. As my arms have to do the rest of the propulsion through the water, and my right arm has decreased strength, I wear gloves with webbed fingers that allow my movement to have better effect, yet be as streamlined as possible. These gloves were available at the dive class and also on my dives. Due to weakness on the right my left side was much stronger, so I had to be careful when underwater that I did not go round in circles, and did take a

certificate in buoyancy to be more aware of my personal issues.

In 2004, and each year since, I have been diving in Australia and have now progressed to Advanced Level and specialised certification in Deep Sea Dives. I have explored shipwrecks and aeroplanes, at depths below 33 metres.

In 2010 I dived in the Red Sea and loved every moment underwater exploring the awesome sea life there including colourful fish, coral, turtles, and smaller sharks. My youngest son also took up diving on that holiday and “buddied” me within a few weeks, making the holiday all the more memorable.

Diving is an expensive hobby but it has

increased my confidence tremendously and if I can do it despite all the above, so can you. Why not contact the

[Scubatrust@hotmail.co.uk](mailto:Scubatrust@hotmail.co.uk)

for info on their trial dives in Berkshire to see if it's the new hobby for you. Good Luck.

TM has changed my life in so many ways, and through it I have been privileged to meet some wonderful people, which has been both gratifying and joyful. No words could express the level of kindness and support shown to me.

## The Patient Managed Neuromodulation System

TRANSVERSE MYELITIS SOCIETY

JULIA LINE TRIALS IT FOR HERSELF

**Julia Line was very fit and healthy until she was suddenly struck down with Transverse Myelitis in August 2010. The attack left her paralysed from the waist down. Julia has since got most movement back and is managing to walk again, albeit slowly and painfully.**

Experts at Southampton's teaching hospital have been trialling a revolutionary device to help people overcome embarrassing bladder problems at the click of a button – without drugs, needles or surgery.

The Patient Managed Neuromodulation System, which involves a small patch placed on the lower back together with a remote control, is the first device to halt the symptoms of overactive bladder (OAB) syndrome from outside the body via wireless technology.

Results of a four-week clinical trial with 64 patients, presented at the International Continence Society, showed that 63% of patients achieved at least a 50% reduction in incontinence, while around the same number (66%) reported better quality of life.

Although I was not part of the clinical trial, my urologist asked me to participate in a 1 month independent trial for his own information.

*“The system delivers a signal through the skin via a patch to stimulate the sacral nerves, similar to a pacemaker and treats patients who suffer from urinary frequency, urinary urgency and urge incontinence”*

The system delivers a signal through the skin via a patch to stimulate the sacral nerves, similar to a pacemaker. The system treats patients who suffer from urinary frequency, urinary urgency and urge incontinence. Each patch lasts a week and then has to be replaced. Any benefits will only be felt while the patch is being worn.

When I first started using the system at the end of August 2012, I was visiting the loo 10-14 times each day even though I was taking urine retention tablets each day and catheterising 9-11 times per day in order to leave the house. By the end of the third week of the trial I noticed significant improvements, so I paid

for a 2nd month's supply. Unfortunately there was a weeks' gap before I could get the new supplies and when I started using them again, I was back to square one. Again, at the end of the 3rd week, I noticed improvements, so I purchased a 3rd month's supply but no improvements were evident and I was not much better off than in the beginning. On the fourth week, I put one of the patches on about an inch too low and suddenly I improved (I am only 5ft tall). So I bought a 4th month's supply and purposely put the patches on lower. They worked, but not as well as during that week in the 1st month.

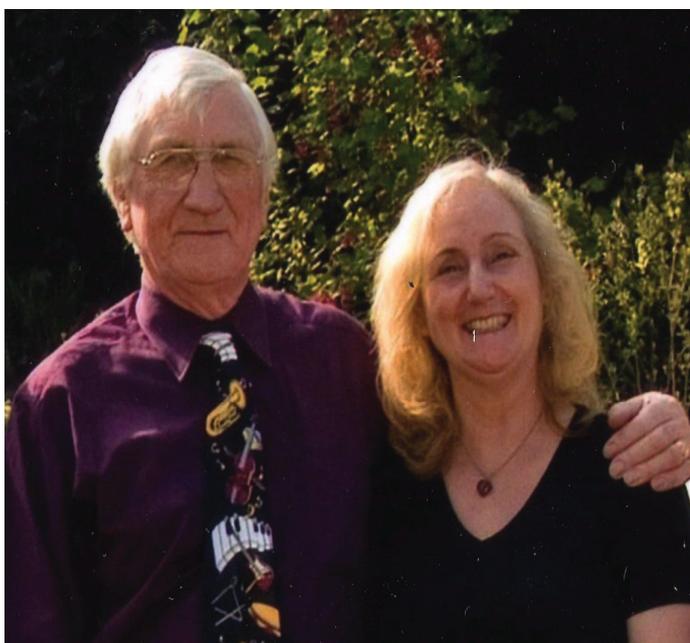
*“The patches were reasonably comfortable to wear, although I had to be careful they did not show through my clothes”*

A company called Verv markets the patches. The number to contact is 0800 800 7888. The patches were reasonably comfortable to wear, although I had to be careful they did not show through my clothes. However, they are awkward to put on and they have to be checked and reset every day. It definitely needs a second person to put them on plus any creases in the outer edges means that water gets in when you wash and I often had to shower wrapped in clingfilm!

I paid £225 for four weeks supply plus the cost of the remote system. If you are as desperate as I was, while I was trying to get Botox treatment, then they may well be worth a try.

If you are wondering whether a sacral nerve implant would work for you, this could be a good way to test the water as it appears to be very similar to the external implant you would be required to wear before that treatment could be carried out.





**Ruth Wood was a singing teacher and actress before she contracted TM in In Sept 2006, followed by further attacks in 2008, 2009 and 2010. Since then she has taken up creative writing and published a lighthearted account of living with TM called 'In my dreams I'm dancing'**

"Darling" I say, looking across the table at my CC (chauffeur/carer) – who is also my husband.

"Mmm?"

"There's a Carers Group in the village. Why don't you join?"

He looks up.

"Whatever for?"

"Well – you could get some support, talk to other people who understand what you're going through."

"Why would I want to do that? I'm not going through anything"

This was going to be harder than I'd thought. I'd picked up the leaflet at the GP's surgery, where I'd already registered CC as my carer.

"Well – mutual support is always a good idea, isn't it? And then you could get information and so on".

"They'll all be women. I don't want to be in a group of women".

"Not necessarily. Lots of men are carers as well".

"Bet they don't join groups".

Against my better judgement I plough on,

"You could have a good old moan about it all".

*"When we married, nearly nine years ago now, I was relatively healthy, working full time and quite a bit younger than he was. His four grown up sons sighed with relief that their father would have company and someone to look after him in his old age."*

The wrong thing to say – I know it immediately, but it's too late.

He puts down the paper.

"I have nothing to moan about. Anyway, if I can't get Carers Allowance then I'm not a Carer am I?"

He picked up the paper again and hid in its depths. End of subject. End of conversation. It's true, we can't get (CA) – he's a pensioner.

I often find myself feeling guilty about the amount of responsibility I'm placing on CC's shoulders. Broad and manly though they are, they were not built for this – were they? When we married, nearly nine years ago now, I was relatively healthy, working full time and quite a bit younger than he was. His four grown up sons sighed with relief that their father would have company and someone to look after him in his old age.

Less than two years later all that changed with my first attack of TM. I've now had five – each one exacting its toll. Through it all he has never complained, never shirked his responsibilities, never made any decisions that did not take into consideration how it would affect me.

Feeling gratitude out of proportion to the usual emotions that go with a good marriage – love, happiness, putting the other person first – is a bitter pill to taste. I wanted to be sexy, a woman of mystery and allure, and instead I ended up having to be helped onto the loo and having my bottom wiped. It's not what either of us signed up for.

Yet he just quotes part of our marriage vows at me – "in sickness and in health", smiles and gets on with things. It's making me more determined to work hard at my exercises and improve my mobility any way I can. I've even begun to work part time and am driving again.

But as I become more independent, trying to pull my weight in this wonderful relationship, he finds it tricky.

As I refuse his help getting my walker out of the car, he sighs, theatrically.

"Do you have to be so damned independent?" he says.

# TM Awareness Day 9th June 2013



TRANSVERSE MYELITIS SOCIETY

## HOW YOU CAN HELP

**June 9th 2012 was an exciting day for the Transverse Myelitis (TM) Society - it was the first ever UK TM Awareness Day! We are now looking forward to 2013.**

The aim of the day is to raise awareness of TM by doing something, however small, that introduces and provides information to others on the condition in an informative and educational way. The TM Society would like this to be an annual event, with ongoing interaction and education throughout the year. Many of us will relate to the responses we receive from others such as "Transverse Myelitis, I've never heard of that" or "We're not quite sure what is wrong with you".

We need to better educate both professionals and those personally known to us, and we hope that raising the profile of TM will permeate to a wider audience. You can help by distributing this magazine to your GP, Consultant or Physiotherapist next time you attend an appointment.

*"Being involved and spreading the message can be quite simple. If you have access to the internet, you can use email, Facebook, Twitter and other social media to spread the word."*

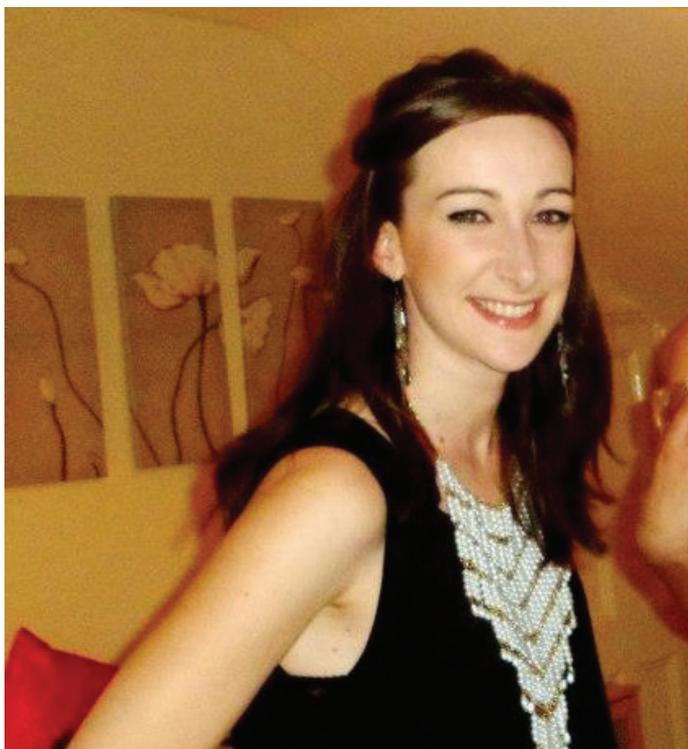
Being involved and spreading the message can be quite simple. If you have access to the internet, you can use email, Facebook, Twitter and other social media to spread the word. Last year members used Facebook to post a blue ribbon and a short status which briefly explained TM. Other members sent out emails with information and links to websites. Alongside raising awareness, a number of you also held fund raising events. Poole & Bournemouth support group organised a "sponsored spin" where they used exercise bikes to cycle a cumulative 120km and raised in excess of £250, others held Plant Sales, and Afternoon Teas, each of which raised over £300, and we even had a Shed Sale.

This year we are encouraging you to:

- **Wear something blue**
- **Make a ribbon** - Take a short piece of royal blue ribbon, fold and safety pin it onto your clothing
- **Distribute all the information** you have to family, friends and healthcare professionals
- **Hold a tea party** - invite friends, family, and colleagues to join you for afternoon tea. Make it fun, go vintage! Dust off your tea sets, bake a few cakes and socialise. You could ask for a 'donation' per head to cover your costs and raise money for the society.

The society also needs enthusiastic people to help promote awareness of the condition. There is an email, a twitter account and a Facebook page for TM awareness, which needs regular updates. If you are keen to get involved in spreading the word please get in touch with [jo\\_gilfillan@hotmail.com](mailto:jo_gilfillan@hotmail.com)





**Following the huge success of the TM society facebook group launched by Amy Edwards and Rob Reeves, Laura Symonds, trainee in journalism, highlights the benefits of social networking for TM sufferers and their families.**

The timing of getting Transverse Myelitis couldn't have been more mocking for my 13year old sports enthusiast brother Ben. He was about to run 500m on his school's sports day when he felt a prickling in his hands and feet that gradually spread around his body. By the end of the day, he was paralysed from the neck down and on a ventilator in intensive care.

That day changed Ben's life. Now 18yrs, his right side is weak, and he needs crutches and a leg splint to walk even short distances.

Due to its rarity, the likelihood of meeting someone with TM face-to-face by chance is pretty low. However, through social media and online forums, connecting with people who are going through a similar experience is now relatively easy. Not everyone with TM is able to (or wants to) go to one of the nine face-to-face support groups in the UK but are still able to share on Twitter,

Facebook, and through the UK TM forum, even though they may live miles apart.

With any life-changing illness, people may want to look for more information, emotional support, and signs of what might lie ahead, although this is not everyone's approach. When I asked Ben if he has ever searched for information on TM he genuinely replied: "Nope, you strange person" - a typical brotherly response!

On the other hand, there are over 390 members of the Transverse Myelitis Society Facebook group, where the activity is frequent and the mutual support is clearly evident. When asking the users about the benefits they get from this group, people gave nothing but praise. Here are some examples of their responses:

"I belong to a couple of TM groups on FB and find that they all offer support from people who understand what I'm going through on a day to day basis. Although we all have different symptoms, it's reassuring that there are people out there who will listen, offer support and encouragement, and a sense of humour. It's hard having an illness that even the medical profession find confusing or have never encountered. It's changed my life in so many ways and the people on here and in the physical TM Society keep me sane."

"I feel less lonely! These people on the TM sites along with other FB friends, I laugh with, I cry with, I feel their suffering because I know their suffering. And TM sites give detailed information and that empowers us!"

"I'm a member of more groups than I should be! People on these sites understand and I find that I can ask quite personal questions, which I most certainly would not share with friends."

Not only sufferers, but their carers and families can also use these social networks for support.

Although Ben does not actively seek information himself, my mother and I will continue to follow the inspirational stories and advice on Facebook.

We know our family is not alone in dealing with TM after all.

[Link to TM Society facebook group](https://www.facebook.com/groups/5655147062/)  
<https://www.facebook.com/groups/5655147062/>

find us on  
facebook



## NEWSBITES/ THANK YOU FOR YOUR SUPPORT

### **Botox licensed as an over-active bladder treatment**

*Botox has now been licensed by the MHRA to treat over-active bladder symptoms, commonly experienced by people with TM. While it was under trial it was only available at a limited number of hospitals, but hopefully from now on it will be much easier to find a centre near you. While it will only work for some, its licensing is a welcome step in increasing the variety of available treatment options. To find out whether Botox might help you, talk to your neurologist or continence nurse.*

### **Amy Edwards launches a new TM Resources pack**

If you are a frequent visitor to our Facebook site you are probably already aware of this already, but I have taken it upon myself to create a resource for TMers. The Brain and Spine Foundation already have a brilliant booklet on the medical facts of TM, but I wanted to create something more practical, with advice on day to day living. So far I have decided to get information on; bowel and bladder (non-medical, however there will be stuff about links to medical helplines and websites), benefits, information about travelling (airports etc.), where you can get help for costs of medical aids, where to find good wheelchair, stair lifts etc., along with some other practical information such as days out (there are some great 2 for one offers for people who are disabled and their carers). If there is anything that people would like to request for the resource then please let me know. As you can appreciate, this is a huge undertaking, so if anyone wants to help out, that would be great. amyacheledwards@hotmail.co.uk

### **Your thoughts count- we want to hear from you!**

The TMS magazine is published to provide useful information and advice to the TM society. Please let us have your views on the articles, write a letter commenting on the publication, a topic of interest or something you've found that helps you deal with TM that might be beneficial to others. Are you a budding journalist or writer? Would you like to contribute to future editions of the magazine? We're planning a series of themed publications, is there anything that you'd like to hear about that we've not covered? All ideas and suggestions will be gratefully received.

### **Take Your Magazine with You**

*Next time you have an appointment with a health professional, be it Doctor, Nurse, Physio, etc., why not print off a copy of our magazine and take it along? I did this recently when visiting a Physio, and not only did he read it himself with great interest, he then presented it to the entire hospital team at one of their staff meetings.*

### **New TMS Membership Form**

The TM Society has a new membership form on its website, the first stage of a whole new TMS website. Most of you reading this will already be members of TMS, but the new form also allows for potential supporters and contacts to sign up, and be kept up to date with news and events from TM Society. There is also an option to volunteer to help TM Society, and TMS will use the resulting 'skills bank' to enlist volunteers for TMS events and initiatives. The New Member Form for supporters is for "health professionals, researchers, journalists, friends, family and all other supporters..." You can find it at <http://tmsmembership.weebly.com/>

# Thank You

## Stephen Moffat



and friend competed in the 'Hell Up North' run in November 2012. As the after picture shows, there was everything from running tracks and trails, to water-filled areas and plenty of steep hills! Given his brother-in-law was diagnosed with TM in 2012, Stephen is keen to raise as much

awareness and funds possible. So in 2013, he will also be doing the Edinburgh Marathon and Coast to Coast Cycle Ride! Thanks for all your efforts Stephen!

## Martin Lambert



completed the Great North Run in September 2012 after 12 months of serious illness including contracting TM in 2011 and then having a kidney removed due to cancer in 2012. He completed the 13.1 mile course in 2 hours and 16 minutes. Martin said it wasn't his fastest time

but after what he had been through, finishing was a relief and personal triumph. We agree, and what an inspiration!

*If someone is doing a fundraising activity for the UK TM Society, did you know they get a free t-shirt for as a thank you for their efforts? Ideal for wearing during training and/or on the day of the event itself. Just send the size t-shirt you want together with your address to [barbara\\_babcock@myelitis.org.uk](mailto:barbara_babcock@myelitis.org.uk) You can also purchase t-shirts, cost £15 each (this includes postage).*

## TM Awareness Day

On 20 April 2013 from midday the Poole/Bournemouth Support Group will be repeating their very successful fundraising event for last year's TM Awareness Day with a sponsored 'spinning'. There will be stalls selling donated items, a raffle/ tombola, and refreshments will be served during the day. All information will be on the TM website. For more details contact Lance Harris [lv.harris@hotmail.com](mailto:lv.harris@hotmail.com)

**Belinda Pierce** held a Black bag party in aid of the TM Society, a brilliant way to have fun and raise money for TM at the same time 'This is a great chance to spring clean your wardrobe. Just empty everything that you don't wear, don't like, or doesn't fit you, into a black bag (shoes/accessories/make up/ all welcome). Bring your black bags to the party. We all hold up the contents of our own / some-one else's black bag, and anyone who likes what they see, can try it on. If you find something you want to keep you give 50p to the person whose black bag it came out of and 50p into the charity hat in the middle. As a bonus you get to meet new people as well as catch up with friends over wine and nibbles'

### LONDON SUPPORT GROUP

SUPPORT GROUP MEETINGS ARE: 16 MARCH & 13 APRIL (AGM)

**Venue:** ECHQ, 34 York Way, London N1 9AB. The venue is wheelchair friendly, and car parking is FOC from 1.30pm on Saturdays in York Way. There is no London Congestion Charge on Saturdays. ECHQ is a short 3-4 min walk from King's Cross Station. For further details please contact Yvonne Kolesar, [yvonnegk50@msn.com](mailto:yvonnegk50@msn.com) tel. 01737 552869 or Lew Gray, [lewgray@blueyonder.co.uk](mailto:lewgray@blueyonder.co.uk)

### SOUTH EAST SUPPORT GROUP

SUPPORT GROUP MEETINGS ARE: 23 MARCH, 15 JUNE, 14 SEPTEMBER & 07 DECEMBER (CHRISTMAS LUNCH)

We're delighted to announce this will be our third birthday, and we go from strength to strength. Last year we had Speakers on such diverse subjects as bladder, bowels, and holistic therapies, and we kick off this year with a Pilates Instructor (the perfect exercise for anyone with TM).

**Venue:** Pembury Village Hall, High Street, Pembury, Kent TN2 4PH. It is wheelchair friendly with disabled loos. There are 2 disabled parking bays and 10 further parking places outside. Additional parking on the road. For further details contact Annie Schofield, [annie.schofield@myelitis.org.uk](mailto:annie.schofield@myelitis.org.uk), Carol Preece [preece.carol@googlemail.com](mailto:preece.carol@googlemail.com), or Peggy Hughes, [mail@peggyj.com](mailto:mail@peggyj.com)

### POOLE/BOURNEMOUTH SUPPORT GROUP

SUPPORT GROUP MEETINGS ARE: 20 APRIL, 20 JULY & 19 OCTOBER

Our meeting in April is to be an open day similar to the TM awareness day held last year.

**Venue:** We now have a new venue, The Multiple Sclerosis Society Bournemouth Branch, The Osborne Centre, Church Lane, West Parley, Ferndown, Dorset, BH22 8TS For further details please contact Group Leader: Lance Harris, [lv.harris@hotmail.com](mailto:lv.harris@hotmail.com) or Secretary: Barbara Houston 01425 673173 [barbs@houston19.freeserve.co.uk](mailto:barbs@houston19.freeserve.co.uk)

### BRISTOL SUPPORT GROUP

SUPPORT GROUP MEETINGS ARE: 02 MARCH, 02 JUNE, 01 SEPTEMBER & 01 DECEMBER

**Venue:** The Reception area of the Holiday Inn, north Bristol. For further details please contact Steve Collins, [steve.collins@blueyonder.co.uk](mailto:steve.collins@blueyonder.co.uk)

### EAST MIDLANDS SUPPORT GROUP

NEXT SUPPORT GROUP MEETING: 16 MARCH

**Venue:** The Village hall, Lullington, Nr Swadlincote. DE12 8EG. For further details contact Janet Ashenden, [jan.nig@tiscali.co.uk](mailto:jan.nig@tiscali.co.uk)

### TELFORD SUPPORT GROUP

**Venue:** Ketley Community Centre, Holyhead Road, Ketley, Telford, Shropshire, TF1 5AN. The venue is wheelchair friendly with easy access. For further details please contact Anna Paulsson-Habegger on 07581708597 [annaph@blueyonder.co.uk](mailto:annaph@blueyonder.co.uk)

### TRANSVERSE MYELITIS SCOTLAND

NEXT SUPPORT GROUP MEETING: 08 JUNE

Established in 2003, we have over 80 Scottish members and the group is open to all patients with TM and its associated conditions living in Scotland, and to their families, carers and friends. The group is a member of The Neurological Alliance of Scotland, Long Term Conditions Alliance Scotland, registered with The Towpath Trust, The Princess Royal Trust for Carers and NHS24.

**Venue:** Conference Room, Philipshill Ward, Spinal Injuries Unit, Southern General Hospital, 1145 Govan Road, Glasgow G51 4TF  
Dates of our meetings are posted on our webpage [www.myelitis.org/scotland](http://www.myelitis.org/scotland) and travel directions can be seen by clicking on the Events link. For any further details contact: Margaret Shearer on 01292 476758 or email [margaretshearer@myelitis.org](mailto:margaretshearer@myelitis.org)

## Useful Contact Information

### **Bladder & Bowel Foundation**

0845 345 0165  
www.bladderandbowelfoundation.org

### **Brain & Spine Foundation**

0808 808 1000  
www.brainandspine.org.uk

### **Carers Direct**

0808 802 0202  
www.nhs.uk/carersdirect

### **Carers: The Princess Royal Trust**

0844 800 4361  
www.carers.org

### **Continence Foundation**

www.continence-foundation.org.uk  
info@continence-foundation.org.uk

### **Depression Alliance**

0845 123 2320  
www.depressionalliance.org

### **Disability Information Advice Line (DIAL)**

01302 310 123  
www.dialuk.info

### **Disability Law Service**

0207 791 9800  
www.dls.org.uk

### **Disabled Living Foundation**

0845 130 9177  
www.dlf.org.uk

### **Disability Now Magazine**

01454 642 444  
www.disabilitynow.org.uk

### **Driving: Disabled Motoring UK**

01508 489 449  
www.disabledmotoring.org

### **Driving Licences: DVLA Drivers Medical Unit**

0870 600 0301

### **Gardening**

www.gardeningfordisabledtrust.co.uk

### **Mobility aids: Just Mobility**

01923 265 577  
www.justmobility.co.uk

### **Motability Car Scheme**

0845 456 4566  
www.motability.co.uk

### **Neuromyelitis Optica (NMO) [Formerly Devics Disease]**

www.nmouk.nhs.uk

### **NMO: The Walton Centre, Liverpool Nurse Specialist**

0151 529 8357  
**NMO Service Coordinator**  
0151 529 8131  
nmo.advice@thewaltoncentre.nhs.uk

### **NMO: John Radcliffe Hospital, Oxford Nurse Specialist**

01865 231 905  
**NMO Service Coordinator**  
01865 231 900  
nmo.advice@orh.nhs.uk

### **Pain Concern**

0300 123 0789  
www.painconcern.org

### **Pain: British Pain society**

0207 269 7840  
www.britishpainsociety.org

### **Welfare & Disability Benefits (Dept. of Work and Pensions)**

0800 882 200  
www.dwp.gov.uk

### **Transverse Myelitis Society**

35 Avenue Road  
Brentford TW8 9NS  
www.myelitis.org.uk  
U.K. registered charity 1108179  
Contact Yvonne Kolesar  
(chair) 01737 552869 or  
Lew Gray (Secr) 020 8568 0350  
Email: lewgray@blueyonder.co.uk

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