

November 2021

Open Door

Quarterly magazine of the MS Trust

Multiple
Sclerosis
Trust

MS

Living with
MS and life at
the Tower of
London

Mobility problems

Could a mobility aid help you to get out and about more?

Stem cell transplantation

Chris Wasey talks about his personal journey with MS and HSCT.

Ask the expert

How does MS affect speech and swallowing?

Welcome to the November issue of Open Door



Hello and welcome to the November issue of Open Door. As always, it's been a busy few months at the MS Trust and time has flown since the last issue. I can hardly believe that it's November and we're already starting to talk about Christmas.

With that in mind, turn to page 16 for some tips and advice on coping with the festive season.

We've also been lucky enough to catch up with the fascinating Andy Merry. Andy works as a Beefeater at the Tower of London and on page 18 you can read all about his journey with MS.

Plus we speak to a physiotherapist about mobility issues (page 8) and a speech and language therapist talks us through common speech and swallowing problems which can occur in MS (page 12).

Over the last few months, we have been reviewing all of our publications and communications in consultation with you, our supporters. We want to make sure that we are providing the information you want in the formats you prefer. We also want

to ensure that all of our communications are accessible and sustainable. The result of this is that we have made the difficult decision to stop Open Door in its current format. Meaning that sadly this issue of Open Door will be the last. However, we have lots of exciting ideas about ways to bring you more of the content you enjoy and rely on and we will share these with you in the new year. We will continue to communicate with you using print, online and via email.

As 2021 draws to a close I also want to say a huge thank you for all of your unwavering support. We really couldn't do what we do without you.

As always, we welcome any feedback you have on any of our communications, so do get in touch via email at comms@mstrust.co.uk or via post at MS Trust, Spirella Building, Bridge Road, Letchworth Garden City, Hertfordshire SG6 4ET.

David Martin, Chief Executive Officer, MS Trust



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What's inside?

3. Latest MS news

We welcome a new MS nurse and update you on MS treatments.

5. Research updates

How does MS affect relationships and dating? Plus an early clinical trial of a possible remyelination drug.

7. Information you can trust

Meet Corinne from the MS Trust Enquiry Team.

8. Mobility problems

Physiotherapist Jody Barber, talks about how mobility aids could help you.

10. Stem cell transplantation

Chris Wasey talks about his personal journey with MS and HSCT.

12. Speech and swallowing

In our Ask The Expert series we talk to a speech and language therapist.

16. How to have a merry little Christmas

Tips on managing stress, fatigue and your mental health over the festive period.

18. Personal story: Andy Merry

Yeoman Warder Andy Merry, talks to us about his life with MS.

20. The Big Give

This Christmas your donation can work twice as hard for people with MS.

21. Get involved

Details of all the latest fundraising you can get involved in, in the run up to Christmas.

22. 15 minutes with...

Volunteer and podcast host Will Berard talks to us about his MS and how he began his volunteer journey with the MS Trust.



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Latest MS news

MS Trust funds a new MS nurse in north Wales

Recently, the MS Trust was delighted to announce that we have funded an additional MS nurse to cover north Wales, through the Walton Centre, Liverpool.

We chatted to Michelle and her fellow MS Nurse, Yvonne, about the difference the new role will make and what their priorities are for the service in north Wales.

How are you settling into your new role?

Michelle: It's going really well. I've got a really supportive team. Yvonne is brilliant, she's extremely knowledgeable and patient with me. There is a lot to learn, but I'm doing that gradually. It's a really interesting role and I'm learning a lot.

What difference do you think the role will make for people with MS in north Wales?

Yvonne: I think Michelle's contribution will definitely enhance the service. We'll have increased capacity, which has always been a huge issue for us in north Wales. Patients will have more timely access to the service and we're going to reduce those waiting lists, which have always been such a significant problem. We're going to be more responsive too. I think people are going to really appreciate the extra resource.

Now Michelle is on board, what are the priorities for the service over the next six months to a year?

Yvonne: As far as the priorities go, it's about getting those waiting lists down as I mentioned, making sure that we're more accessible to patients and that we're responding to patients in a more timely way. So, when they need us, they can get hold of us, hopefully by the next working day. We need to be responsive to patients who are struggling with changing symptoms, or relapses; and to be available for newly diagnosed patients as well.

Michelle and I have spoken about how it would be really valuable for us to improve our networking with colleagues across north Wales. We want to make sure that we're more visible to other health care professionals; doctors, nurses and allied health professional colleagues; so that they know how to contact us for advice. MS can be misunderstood and we need to help make a difference to improve everyone's understanding of the condition.

What would you say are the biggest challenges you've got ahead of you?

Michelle: I think mine is obviously the complexity of the disease. If you were to do a mind map of the condition, there'd be branches going off

everywhere, but that's what MS looks like. There are branches about DMDs, relapses, treating symptoms, to name just a few. But it's also important to remember, if it's complex for us, then imagine the frustration and concerns of the patient.

Yvonne: The changing landscape of MS is challenging. We've had several new treatments in recent years. Obviously Covid has also been a challenge and has impacted the whole NHS. Although in a way, there are positives from the pandemic. A couple of years ago, we didn't offer patients routine telephone follow up appointments or video appointments, it was all face to face appointments, but now we have access to the technology and patients have more choice. Lots of patients find the long journey to hospital and the stress of parking can be difficult, but now we have other ways to keep in touch. It's helped to improve the service and reach more people in a way that's more convenient for them.

How important do you think the role of the MS nurse is for people with MS?

Michelle: I think it's very important. It's so vital that people with MS have a base to touch in with. Something that the Walton Centre and north Wales offer is their advice line - it can be an absolute lifeline to have someone at the end of the phone.

Yvonne: The MS nurse role supports people from the point of diagnosis right through their lifetime with the condition, as well as their families. The role is crucial because we're involved in all aspects of the condition from helping people to understand their diagnosis, manage their symptoms, make treatment choices and offer guidance along the way.

It's fantastic that we've got another MS nurse in north Wales. I'm looking forward to Michelle getting to know all the patients. It's really positive. A huge thank you to the MS Trust for all your support!



New MS nurse Michelle Cole

For more information on MS services near you visit mstrust.org.uk/map

New report highlights barriers to accessing Sativex across the UK

Despite a recommendation by NICE that Sativex is a cost-effective add-on treatment for MS spasticity, fewer than 13% of people who are eligible in England can access it, according to a report from the MS Society. People across Wales, Scotland and Northern Ireland also face significant difficulties accessing NHS prescriptions for this treatment.

Sativex (nabiximols) is a licensed cannabis-based medicinal spray for the treatment of MS-related spasticity. When used, the number of sprays is gradually increased each day until a dose is reached which relieves muscle stiffness but with the fewest side effects.

Limited access to Sativex on the NHS means that some people obtain a private prescription and pay the full cost of the drug themselves. This is an expensive option and prevents it

from being available to everyone who may benefit from it. The MS Trust has added its voice to the campaign, asking for fair access to this drug.

"The MS Trust has called for a fair assessment of Sativex since it was licensed in 2010 and we have made strong cases for its approval in appraisals by NICE and other decision makers. Sativex doesn't work for everyone but when it does it can greatly improve quality of life for people with MS and their carers. The MS Society's report highlights the problems people continue to face and we support their recommendations to ensure that everyone eligible can access this treatment."

David Martin, Chief Executive Officer of the MS Trust.

For more information and the full report visit: mstrust.org.uk/news/new-report-highlights-barriers-accessing-sativex-across-uk

Ponesimod (Ponvory) rejected by NICE

The MS Trust is very disappointed to learn that NICE does not recommend ponesimod (Ponvory) as an NHS treatment for relapsing remitting MS in England and Wales.

In its draft recommendation, NICE acknowledges that ponesimod reduces the number of relapses and brain lesions compared to Aubagio (teriflunomide) but is unsure of ponesimod's ability to slow down disability progression. As a result, ponesimod is not considered to be cost-effective for the NHS.

This is NICE's initial decision and they have asked the manufacturer for more detailed evidence and analysis of the data. The MS Trust has been taking part in the appraisal of ponesimod and we will be replying to NICE's initial decision.

About ponesimod

Ponesimod is taken as a tablet, once daily. A low dose is taken initially which is gradually increased over the first week. This reduces the risk of slowing the heart rate.

In a two year clinical trial, ponesimod reduced the risk of relapses by 30% compared to Aubagio (teriflunomide) and reduced the number of new active lesions seen on MRI.

People on ponesimod also had a statistically significant improvement in fatigue symptoms compared to Aubagio. There was a trend toward less disability progression on ponesimod, but this was not statistically different to Aubagio.

Ponesimod belongs to the same class of drugs as Gilenya (fingolimod). It works by retaining lymphocytes (immune cells) in lymph nodes. The number of lymphocytes reaching the brain is decreased, which reduces the immune attack on nerve cells in the brain and spinal cord.

The NICE appraisal committee will meet again to review all the comments received in relation to this recommendation and expects to publish its final decision later this year.

For more information visit mstrust.org.uk/ponesimod



How does MS affect dating and romantic relationships?

Multiple sclerosis can affect marriages and long-term romantic relationships, sometimes in positive and sometimes in negative ways. But little is known about the impact of MS on dating and building romantic relationships. This study took an in depth look at the dating experiences of a small group of people living with MS.



The study

Researchers in Ireland recruited participants by advertising their project on social media and websites. Participants were eligible if they were aged 18 or over, had a diagnosis of MS, were single and not living with a partner. A series of questions were developed and used to gather information from two online focus groups. The group discussions were analysed and underlying themes identified.

The results

Seven people took part in the study, five women and two men who had been diagnosed for 4–16 years. Six participants had relapsing remitting and one had primary progressive MS.

Disclosing MS is a personal choice

Deciding when and how to disclose is very personal and is based on past experiences and how you feel about a potential partner. Early disclosure can be a way of 'weeding out' partners who might be unsuitable while others prefer to get to know someone before sharing this private aspect of their life. Some participants also worried that disclosing MS might lead to rejection and chose to hide their MS for as long as possible.

Negative perception associated with MS which you first need to address yourself

Addressing misconceptions about MS and reassuring a new partner can be exhausting and tiring. Some people expressed relief at not being in a relationship at the time of diagnosis, allowing them to come to terms with MS without the burden of dealing with someone else's concerns. Information available to the public was not perceived as helpful; there was a view that the person with MS themselves is the best source of information about their MS.

MS can impact dating and dating activities

MS symptoms, such as pain or fatigue, can limit activities or require more planning. The unpredictable nature of MS can be challenging for couples. Participants felt that it takes a certain

'type' of partner to deal with this – someone who is patient, understanding and willing to learn how to adapt to the uncertainty of MS. Participants recognised that open and honest communication is very important to avoid a partner misunderstanding why plans change at the last minute.

Online dating can be intense, but COVID-19 has been a leveller

Online dating provides an opportunity to meet more people and get to know them better before meeting face to face. However, some find it more intense or emotionally difficult as it requires the strength to 'put themselves out there'. It can be more demanding than in-person dating, and impressions gained from online dating may not match what a potential partner is like in real life. Lockdown has had a positive impact on online dating as options have been limited for everyone so more people are now using dating apps and websites.

What does it mean?

Although the study included just seven participants (and only two men), the focus group sessions did reflect a wide range of different experiences and opinions. Interviews showed very clearly that MS has a significant impact on dating and can make searching for romantic partners more difficult. Not surprisingly, the experience of dating with MS is highly personal and influenced by past experiences and beliefs. Key concerns centred around personal decisions about disclosing MS and the need to keep adjusting to the variability of MS with partners in new and developing relationships.

Authors: Tabassum K, et al.
Hynes SM.

Title: Dating with a diagnosis: the lived experience of people with multiple sclerosis.

Journal: Sexuality and Disability
2021 May 26; 1–18.

Read the full study: www.ncbi.nlm.nih.gov/pmc/articles/PMC8153848/

**For more info
on Sex and MS visit:**

For women
mstrust.org.uk/213

For men
mstrust.org.uk/356



Temelimab - Early clinical trial suggests potential for remyelination

There is a growing list of drugs for relapsing remitting MS, with Ocrevus approved for early, active primary progressive MS and Mayzent approved for active secondary progressive MS. All of these drugs act by reducing the immune attack which causes inflammation and damage to the myelin coating around nerve cells in the brain and spinal cord.

Although these drugs can reduce damage to myelin, they can't stop it completely or repair damage that has already happened. Your body can replace damaged myelin but this process is impaired in MS. A protein (called HERV-W-ENV) found in MS lesions has been shown to reduce the brain's ability to remyelinate cells by preventing the development of oligodendrocytes, cells which maintain the myelin coating of nerve cells; the protein also activates microglia, immune cells that cause inflammation in the brain. A potential new treatment, temelimab, blocks the action of this protein and laboratory studies have indicated that it could promote remyelination. Its potential in people with MS has been assessed in an early, phase 2, clinical trial.

The study

270 people with relapsing remitting MS were recruited to an international study. Participants took one of three doses of temelimab or placebo, given as an intravenous infusion every four weeks. After 24 weeks, people in the placebo group switched to one of the three temelimab doses while those who had started on temelimab remained on their original dose. Treatment continued for up to 96 weeks. The main measure of the study was the number of active lesions visible on MRI scans at week 24; other measures including presence of other types of lesions, brain tissue loss (atrophy) and improvement in MRI markers of remyelination (magnetization transfer ratio) were also taken during the course of the study.

The results

At 24 weeks, there was no difference in the number of active lesions between the three doses of temelimab and placebo. People who had taken the highest dose of temelimab throughout the study had fewer T1-hypointense lesions. This type of lesion, also known as a black hole, is associated with MS disability and progression. There was also a reduction in brain tissue loss and improvement in MRI markers of remyelination. There was no significant difference in side effects reported between people taking temelimab or placebo.

Amongst those taking temelimab, one person was diagnosed with breast cancer 20 months after treatment and one person developed drug-induced liver damage which initially improved, then came back again.

What does it mean?

These results suggest that temelimab has little effect on the inflammatory MS activity which is responsible for relapses. However, its effect on MRI markers suggest that it may promote remyelination and prevent loss of nerves.

These are encouraging results, but it is too early to draw definite conclusions. The researchers consider that the doses of temelimab used in this study were too low and that some effects of temelimab may have been masked by inflammatory MS activity. They have set up an additional study in people with relapsing remitting MS who have increased disability despite taking a highly effective disease modifying drug for at least 12 months. Participants are taking higher doses of temelimab or placebo for 48 weeks; the main aim of the study is to check that higher doses are well-tolerated. MRI markers of progression are also being captured. The study is underway and results are expected in the first half of 2022.

Find out more...

Temelimab is one of several potential treatments being developed for MS. Visit our page on Drugs in Development for more details <https://mstrust.org.uk/about-ms/ms-treatments/drugs-development>

Find out about the different stages involved in making a new medicine <https://mstrust.org.uk/a-z/drug-development-process>

Authors: Hartung HP, et al.

Title: Efficacy and safety of temelimab in multiple sclerosis: Results of a randomized phase 2b and extension study.

Journal: Multiple Sclerosis Journal 2021 Jul

9:13524585211024997 [Epub ahead of print]

Read the full study: <https://journals.sagepub.com/doi/10.1177/13524585211024997>

Information you can trust

Each year the MS Trust Enquiry Service answers thousands of questions from people with MS and their families. But what's it really like to hear from people affected by MS everyday? We chat to Corinne, an Information Officer at the MS Trust who has been in her role for just over two years.

Hi Corinne, what's a typical day like on the Enquiry Service?

My days are very varied. There are calls from people seeking all sorts of different information relating to life with MS. There are now seven of us in the team and we answer calls, reply to emails and respond to queries which have come through social media. I'm usually on the phones, so I get to speak to a lot of the people who call up, which I love doing. We use a virtual telephone system, meaning we can all answer calls from home which is great as we are still working remotely. I spend my days tucked in my little back room at home, ready and waiting with my headset and laptop to answer your enquiries.

What do people ask about when they call the Enquiry Service?

Absolutely anything that might relate to any symptom they are experiencing such as pain, cognitive issues or fatigue. When you are living with MS it's more than just a medical issue and we talk to people who need pointers to help at work, with benefits or other aspects of life with MS. We also talk to people who are worried they might have MS and don't know what to do next.

Did you get different questions during the pandemic? How did it change as time went on?

Yes, as lockdown started and different guidelines were published regularly, we had lots of enquiries from people asking if they should be shielding or if it was safe for them to go to work. The team had to really pull together to get through them all. As the guidelines changed so frequently, my colleagues worked hard to update the Covid-19 page with any new information. It was quite hectic at times. As the pandemic progressed the type of enquiry changed. For example, we started to get a lot of people asking if it was safe for people with MS to have the Covid vaccines or return to work or travel.

Are calls only from people with MS or do you get calls from family and friends too?

We get all sorts of calls and enquiries from family members, friends, work colleagues and health professionals as well as



Call us for free on: **0800 032 3839**
or email us: **ask@mstrust.org.uk**

from people with MS. It's great that they can come to us for information to help better support the person they know with MS. Having more information on anything from the social care available to MS symptoms can be invaluable.

What advice would you give to someone who is thinking about contacting the Enquiry Service, but is not sure if we can help?

Please just ask! You can call us for free or email in your question. We're here to help and if we can't answer your question we will let you know someone who can.

What have you learned from your role at the MS Trust? Has anything particularly surprised you?

I learn something new about MS every day! I always say that although we aren't medically trained, we do have years of experience as a team, talking to people about their MS and the many questions that can arise. I'm always surprised by what a difference we can make, just by talking through people's concerns and pointing them to resources which may help.

How do your colleagues in the Enquiry Service support each other?

We always make sure we stay in touch, especially as we're working remotely. If I need some advice with an enquiry, one of my colleagues is always there to help. When we were in our office of course, it would be to make a round of tea and coffee! I'm so lucky to work with such friendly and caring people across the charity as a whole.

You've done quite a bit of fundraising for the MS Trust, what inspired you to do that?

I've always enjoyed a bit of a challenge and I found running a way of getting some headspace and fresh air after a busy day which I combined with fundraising. I've heard first-hand how hard life with MS can be at times and I feel, by raising money for the MS Trust, I can help support even more people affected by MS. The people I speak to everyday inspire me!

Ask the expert

Mobility problems

Identifying mobility problems early on can be really helpful when it comes to preventative treatment and prolonging the use of certain muscles. In this article we talk to Jody Barber about common mobility problems in MS. Jody has worked as a physiotherapist with people with MS for around 30 years. She is co-Chair of the Therapists in MS group (TiMS).



Mobility problems can be common in MS. What are the early signs people should look out for?

The earliest symptoms are usually temporary sensory changes. For example, this might mean that you're less aware of where your foot is on the ground when walking. This can be unnerving and make you cautious about how you move. When you feel something is wrong, instinctively you won't use it as much. If you don't use something, it will get weaker over time.

A physiotherapist can't bring the sensation back, but we can look at how you manage it and ways of maintaining your muscle strength. If you start noticing these symptoms, don't ignore them. Talk to someone about it. There's lots of advice and help available.

Many people with MS worry about starting to use a mobility or walking aid. How does someone know it's the right time to introduce one?

A lot of people are understandably wary of using a stick, walking frame or any form of walking aid. However, the aid is all about enabling you to carry on doing things that were becoming a struggle. It's a tool that helps you to get out and about.

As a first step, I advise people to have a fold up stick in your bag. Then you can have a moment of fatigue or a wobble when you're out and you have something available to support you.

One of the signs that you might need something more permanent is noticing that you're always holding on to something when moving around the house. Therapists might call that furniture walking. If you're doing this a lot, you might benefit from a walking aid.

What advice do you give to people who are considering using a wheelchair?

I encourage people to have early conversations about wheelchairs. Talk to your family, friends and healthcare professionals. Discuss what you're currently able to do and the ways you might access a wheelchair in the future, if you feel you need to. You may get to a point when intermittent use of a wheelchair will help you. For example, it could prevent you from getting too fatigued, giving you more energy to do the things you want to do.

There are lots of places where you can borrow a wheelchair for a period. This can be useful if you're going on holiday with family or friends and are worried about keeping up with them. Often, people then realise that they were able to do more family activities with a wheelchair, whereas previously they would have missed out.

There are a lot of different mobility aids available. How do you decide what's best for you?

With walking sticks there are different types of handles to consider. If you're purchasing one or being provided with one from the NHS, make sure it has comfortable handles for you to hold on to. There are some that are moulded, called Fischer sticks, which have a left- or right-handed handle. I personally like those because they enable you to have a better interaction between your hand and the stick and they encourage a more comfortable and effective hand hold. If you've got intermittent hand numbness or sensory loss a Fischer stick might be a better option than a standard one.

Rollators are another device which are readily available. They are three or four wheeled walking devices, which help to provide support. Some of the three wheeled ones have casters, so they turn and move quite quickly, but they're also a bit more stable than two sticks.

There are mobility shops located around the country where you can try out scooters, wheelchairs and walking aids to find what works best for you. These centres have experienced staff who can advise on the equipment available and what may work best for you.

How do people go about funding mobility aids? Some of them can be quite expensive.

This will differ between NHS providers. Some will have an equipment budget and be able to purchase small bespoke items, whereas some will have a list of what they can provide. Often the functionality of the aid is the same as, or similar to, more expensive items, but the look may not quite be what you want. So, if you want a different look or colour, you might need to purchase it yourself.

Do you have any advice on the best way to use your mobility aid?

Try not to push down and rely on your arms too much. The more you push down on the walking device with your arms, the less work your legs are required to do. Pushing down on the frame or walking aid too much will cause your arms to feel tired. Your leg muscles store a lot of energy and power, so if you don't use them, you won't burn as many calories. If your leg muscles aren't working as hard, they will get weaker over time. Your balance may also be challenged.

One useful exercise is to have your rollator in front of you and hold it lightly. Gently roll it away and back with the lightest finger touch possible, whilst keeping your balance. Make sure you have something soft like a bed or chair behind you in case your legs give way. This is a good way to test if you're pressing down and putting a lot of weight through your arms. By doing this you can test yourself in a safe place, in a safe way.



If you do notice you're overly relying on your walking frame, there's usually a reasonable margin of time in which you can recapture some of that strength. The muscles may not have been exercised, but they're still there and a physio can help you exercise them and recapture some strength. They can boost your balance and muscle strength. There's an awful lot that can be recaptured. It's not all lost. It's just knowing how to do that and where to start.

Where would you direct somebody who hasn't been doing any exercise? How would they go about starting to exercise?

One of the advantages of the pandemic is that an awful lot of exercise classes have been converted to online resources, making them really accessible. If you're not used to doing any exercise at all, then start with the seated classes first. A seated class will involve a lot of arm exercises, which will strengthen your trunk. This will improve your ability to stand without holding on.

The key with exercise is to find something you enjoy. Sometimes you might have to go through a little bit of discomfort to change your habits. If you're not enjoying it after giving it a good go, then look for something different. There are lots of choices available, so find one that agrees with you.

We're all different. Some of us like really prescribed exercises that we follow and some of us like more of an activity. For example, it could be a specific exercise class with instructions like 'Now lift your arm' or it could be an activity such as archery or dance. As the world is opening up a little bit more, there are gyms that have specialist exercise classes, so find out what your local gym is offering.

Mix it up and shake it up! I'm a firm believer that you should try new things out and learn new things. You get a huge endorphin and oxytocin release with exercise anyway.

Finally, what would you list as your top tips for maintaining mobility?

- Using a walking aid isn't necessarily the beginning of the end, it's a way of enabling you to do more.
- With walking aids you're relying on them a little, so think about exercises that can enhance what you still have by making the muscles work a little bit harder. This will help you to avoid losing them.
- Talk about the elephant in the room! Talk about your feelings with friends, family and your health professionals.
- Think about what it gives back not what it takes away.

Despite all these tips, I think it's important to acknowledge that getting to the stage of needing a walking aid or wheelchair can be hard. I think acknowledging that it's hard and having space to come to terms with it is really important.

For more information on walking difficulties visit mstrust.org.uk/a-z/walking-difficulties

My personal journey with HSCT

Stem cell transplantation or HSCT is a treatment used in MS, where your own stem cells are used to reboot your immune system. The results suggest that this treatment can delay or halt further progression. In this article, Chris Wasey gives us his account of the treatment process and the impact it had on his MS.



Hi, Chris, it's lovely to speak with you today. Could you start by talking about the beginning of your MS journey, including things like your initial symptoms and diagnosis?

The journey began about 15 years ago, when I was 21. I woke up one day and couldn't walk straight. There were other things too, like slow speech, my memory wasn't very good and I had a slight blurring of vision.

Over a period of a month, I went to the doctor maybe five times. It was only when I went to see a locum doctor and my wife, who was a student nurse at the time, suggested to them that I might have an MRI, that they put me forward for that. I had a lumbar puncture, the MRI, and then was diagnosed with clinically isolated syndrome. About 18 months later, I had my first relapse and an official MS diagnosis.

Did your MS team discuss DMD options with you?

The first things that were offered to me were disease modifying drugs (DMDs). I was given pamphlets and agonised over what I wanted to do. In the end, I went with Rebif before moving onto Avonex. I failed on that twice so they referred me for Lemtrada. I did two rounds and then failed about eight months later. That's when HSCT was first mentioned.

I had a choice of HSCT or a third round of Lemtrada so I opted for a third round which failed again. I know that there are discussions about whether HSCT should be operated as a first line treatment to approach MS aggressively, but for me it was more of a last chance approach.

What were some of the things you had to consider when you thought about having HSCT?

I do a lot of freelance work but I also have a job teaching. Knowing that there was going to be time off work was a concern. Fertility was the biggest discussion point though. My wife and I had been trying for a baby for about a year when the

treatment was offered and had hoped we'd fall pregnant before it went ahead. I was keen to wait another year, rather than have to try IVF later, but my wife was adamant that I not wait any longer.

What was the referral process like for you?

After my third round of Lemtrada, my MS nurse referred me to a consultant neurologist. We talked about the transplantation and then he made an appointment for me to go and see the haematologists.

They were really supportive and explained all the risks that would go along with having that kind of chemotherapy, from your first round, right through to isolation at home and diet. Then we booked a time for me to go in.

You were the second person with MS to receive HSCT on the NHS in that hospital. Was that something you thought about a lot?

I knew I was the second one and they were very upfront about that. They explained everything and because they had been giving HSCT to people with cancer, I wasn't concerned.

How did you feel during the process?

The transplantation comes in three stages. Round one, when you're going through your first round of chemo as a day patient, nobody feels good but I didn't feel as bad as I thought I was going to. You also wait for your hair to fall out at this stage. Then you've got your activation injections, they do bloods and get your stem cells. After that, it's back in for your Hickman line, then all of the inpatient stuff. It was unpleasant but not as awful as it could have been. Knowing what it was doing to my wife to see me looking the way I did and even more than that, my son, who was four at the time, was difficult. He couldn't get his head around it but we tried to keep him involved.

What sort of aftercare did you receive and how did your health professional team manage this?

Aftercare was really good. I had the benefit of the NHS but when you leave, they give you an enormous bag of medication to take to protect your body from infections because you have no immune system. It's difficult to come to terms with the fact that you're going to have to be very careful for quite a long time. Even though you're taking those things, you're still going to get sick if you go out into the world.

What did recovery look like for you?

When I first came out of hospital, my son was going into nursery so I spent three or four weeks at my parents' house before coming home. Overall, I stayed in the house for roughly three months, but would go out for walks.

I didn't go to places where there were many people for the three months following that and I was off work for around five months. I was back at work for roughly three weeks before coronavirus started and then immediately had to go back home and start isolating again for another period of several months.

What was it like going back to work afterwards?

My colleagues were lovely. They took on a lot of my workload so that I could do a phased return. I wanted to get back into it quickly but realised very early that it was exhausting. By the time I was ready, things went a bit strange with the entire world and I had to go home again.

It's been two years since you received HSCT. Have you noticed any differences in yourself?

My understanding is that HSCT doesn't generally make improvements. I know that everybody's experience will be different but if you get improvement, it's really fortunate. The main aim is to stop progression.

For a period of time after the transplantation, things will get worse while your body is still trying to figure itself out again. Things like my coordination and stability were quite poor but got better and are now back to roughly where they were before, outside of relapse. Beforehand, I was having a relapse every year to 18 months. It's been two years now which is my longest period without relapse since diagnosis, 15 years ago, so that's fantastic.

HSCT has been in the media quite a lot recently with Nicola Chapman Haste and Selma Blair both sharing their journeys. How do you feel about the topic being discussed more widely?

To have someone in the public eye with MS, that other members of the public will take note of, is really important. I know it's a big responsibility to take on but for these celebrities to open up and talk about MS and HSCT can be of huge benefit to everybody who has got the disease.

I know that when I talk to people about having MS, they seem to feel uncomfortable so most of the time, I don't mention it. But if there's somebody famous they have heard of, and you can point towards them and say, "Look, this is what it is," it makes that initial conversation much easier.

What advice would you give to others who might be considering HSCT for their own MS?

Do as much research as you possibly can. Ask for resources from people like your neurologist and your MS nurse.

If you decide that you're going to do it, plan and prepare as much as possible. For me, it was a case of having lots to do while I was in there, but everybody will be different in terms of what's best for them. Consider what your life will be like for six weeks stuck in a single room. What do you need to get through that? You can't really help how your body is going to react to the medication but you can manage your mental state.

For more information on HSCT visit:
mstrust.org.uk/stemcells



Ask the Expert

Speech and swallowing problems

Some people with MS may experience problems with their speech and ability to swallow. This can include slurred speech, poor voice quality, difficulty remembering words, feeling as though food is stuck in your throat and finding it difficult to chew. These problems can be frustrating and, at times, can result in distressing experiences. We spoke to speech and language therapist, Suzanne Buckley to find out what causes these problems and learn about some practical ways to help.



Speech problems

Q What causes speech problems?

Suzanne: Speech is a wonderful thing; it's our most human characteristic and it is, without a doubt, the most highly skilled activity that we do. And we do it without even thinking! Speech involves the precise and rapid co-ordination of more than 80 different muscles, many of them paired. And your brain does all of this by sending and receiving 1,400 motor commands per second! These motor commands help to coordinate the muscle movements involved in speaking.

To help us understand the speech system and be able to explain it to people experiencing difficulties, we often like to break it down into five distinct parts:

- **Respiration** – This is the air from our lungs, without which we'd only be mouthing the words.
- **Phonation** – This happens when air from the lungs vibrates your vocal cords to produce sound. Without this vibration you would be whispering.
- **Articulation** – This is when we shape the air coming through into consonants and vowels depending on the shape of your lips, tongue and opening jaw. Without shape, you'd just be saying 'ahhh'.
- **Resonance** – This is when we can control the nasal tone of each sound by raising or lowering the velum (or soft palate) – this is the soft part of the roof of your mouth, right at the back. Without some nasal tones, you would sound stuffed up or conversely, you would sound hypernasal. This is when air escapes through your nose while speaking when you don't want it to.
- **Prosody** – This helps convey meaning or emotion by changing the stress, intonation (the rise and fall of your voice during speech) or melody of what we say. Without variation in tone, you might sound like a robot.

If one part of this system is disrupted because of MS nerve damage, it can result in a speech impairment or voice disorder. Knowing which one or ones are impaired will help your therapist determine how or what to treat to help improve the problem.

Your speech could also be impaired because of other muscles in your body. For example, if you find it difficult to keep your head upright, this may affect your ability to take in an adequate breath to speak.

Q What type of speech problems do you see in people with MS?

Suzanne: The most common type of difficulty that we see is a motor speech difficulty called dysarthria which can cause speech to sound slurred, too quiet or too fast. By speaking loudly, slowly and clearly, which can be learned and practised, this can help improve how well you're understood by others.

Dysarthria can occur in around 50% of people with MS, but we rarely see it when people are first diagnosed. There are many different types and combinations of dysarthria so it's important that your speech and language therapist explains to you what's happening so that you can focus on the specific aspect of your



speech that is the most unclear. For example, if lingual sounds – the sounds that your tongue makes like ‘l’ or ‘n’ – are reduced in clarity, practising and focusing on those specific sounds and speech movements can make a huge difference.

Q

What can help with problems like speech slurring and reduced voice strength or volume?

Suzanne: Techniques such as speaking slowly, over-exaggerating your speech and good posture can all be hugely beneficial to you being heard and not feeling as though you are endlessly repeating yourself. Often, we tell people to imagine being on stage, giving a performance. By thinking this way, it automatically makes you THINK BIG. You then project your voice through good posture and breath support, and slow your speech down for the best clarity.

It's important, though, that the person you're talking to understands that they too have a role to play. They can help by doing simple things such as facing you, reducing any background noise like the TV or radio, repeating back the bits that they heard so you don't have to repeat from the beginning. These little tweaks can contribute to overall improvements.

Q

What tips do you have for people who have difficulty remembering words?

Suzanne: Difficulty with word finding is more of a cognitive language difficulty rather than a speech difficulty. To explain the difference, speech is HOW you say something, so your physical ability to move, co-ordinate and control movements. Whereas language is WHAT you say, through words or symbols which can be written, spoken or expressed with gestures or body language.

It's not that you've not remembered the word, or that the word is 'lost'; it is more about struggling to retrieve it. It's that tip of the tongue feeling we've all experienced where it's almost there, but something's blocking it from being found.

These difficulties can be hugely frustrating and for some reason it tends to be objects, people or places that are the tricky ones. I often hear people describe how, when they're particularly stressed or under pressure because they're feeling an intense need to get their message out, this has a detrimental effect on finding the right word at the right time.

It's easy for me to say, but by reducing the pressure when you are faced with a situation where a particular word can't be found, you will be better able to manage this. If it has taken more than a few seconds to find the word, your brain has effectively taken you down a path with a brick wall at the end. You need to reverse back up the path and find a different route. This can be done by talking around the word, describing where you might find it, what it looks like, anything that you can do to work around that word block. You may also be lucky and the person you're talking to might be able to help you to find it.



Psychological techniques such as owning what's happening to you and normalising it can help you to feel more in control. By saying with complete and unapologetic transparency, "I sometimes experience difficulties finding the right words because of my MS" will give you ownership of the situation and that will help boost your confidence.

Q

What technology is available to help with speech problems?

Suzanne: There is a wealth of assistive technology out there that can enhance learning, working and day-to-day interactions if you have communication difficulties. If you have more persistent difficulty with face-to-face communication, having a therapist who is skilled in alternative and augmentative communication (AAC) can be a big help. Ask your therapist how confident they are in AAC. If it's an area of specialism that they don't have, there are organisations you can turn to for advice, such as Communication Matters, Ace Centre or the Assistive Technology Industry Association, who are all experts in the field.

For anyone who lives in England and has complex physical difficulties as well as speech difficulties, there are specialised services that are commissioned by NHS England to help you. They can fund high-tech communication devices as well as fund the communication software and the mounting system that you might need (eg, poles that connect a communication device to a wheelchair or a floor mount). If you are eligible for their service, you do not need to pay but you need to be referred by your speech and language therapist. If you aren't eligible, there are other funding routes such as charitable funds or your local NHS services.

If you're noticing problems with your speech, talk to your GP, MS nurse or neurologist – they can refer you to a speech and language therapist for further advice and support.



Swallowing problems

Q How can MS affect swallowing in someone with MS? What can go wrong?

Suzanne: The act of swallowing is a complex one that involves more than 30 muscles and nerves working together to propel food and drink from your mouth to your stomach. These nerves are both motor and sensory so not only do they move the muscles, they also provide the sensory feedback (the size, texture and temperature of food) we need when we swallow. As with the complex speech system, if one component of the swallowing system is disrupted by MS damage, it can result in difficulties with swallowing food or drink or both. A swallowing difficulty is also called dysphagia.

Because MS can affect scattered and diverse areas of the nervous system, problems with swallowing can vary from individual to individual. It's relatively rare in those who are able to walk. If you're experiencing changes or have concerns with your swallowing, it's important that a full clinical swallow assessment is done by a qualified speech and language therapist.

This assessment helps the therapist to pinpoint the difficulty and work out an individualised treatment plan which may include:

- **neuromuscular electrode stimulation or skill training** – electrodes are placed on the neck and provide small electrical currents to activate the nerves and muscles used in swallowing; alternatively, in strength and skill training, the electrodes are used to give you feedback on your muscle activity whilst you swallow (biofeedback), this can be used alongside swallowing exercises to make you more aware of what's happening in your body when you swallow
- **compensatory strategies** – such as holding food or drink in your mouth and when you're ready, swallowing as hard as you can

- **food and drink modifications** – such as different textured foods or thicker drinks
- **swallowing exercises**

If your swallow has been affected by a relapse, it's important to contact your health professional who can refer you for a swallow assessment because the implications of food or drink going down 'the wrong way' can affect your overall health.

Q

Are there any exercises that can help someone who has a swallowing delay and struggles to swallow small tablets?

Suzanne: If someone is experiencing a delay to triggering a swallow, there are compensatory strategies that could be tried, such as a three second preparation. This is a simple strategy of mentally preparing yourself to swallow while counting to three, and when you reach three, you swallow.

Simple sensory tricks to wake up the sensory nerves can really help a delayed swallow trigger. This can be as simple as drinking ice cold or fizzy drinks or strong flavours like sour lemon or ginger as a flavour enhancer – all of these can help to stimulate that sensory reflex.

Difficulty with swallowing tablets is a really common problem. It can be helped by talking to your speech and language therapist or a pharmacist about whether you can, for example, take the tablet with a spoonful of yoghurt instead of washing it down with water. The pharmacist may also be able to provide a liquid form of the medication or could advise you on whether the tablets might be safe to crush into other foods like yoghurt.

Not all problems with swallowing are down to weakness, which can make some exercises redundant. For example, if it's because of a motor planning difficulty, where the swallow movements happen in an uncoordinated way, then muscle strengthening exercises may not be appropriate.

Q

Is posture important when it comes to managing swallowing problems?

Suzanne: Posture is hugely important – this is why commonly, when we see people with complex swallow and physical disabilities, we ensure we see them as part of a multi-disciplinary team. I would see people with my physiotherapy or occupational therapy colleagues who can give me and my patient ideas on how to maximise good posture.

This could be as simple as sitting up at the table with the seat in a good position, up against your back, and making sure that your head is in a nice neutral position and you're not lifting your chin up. All of these things can be a huge help. An occupational therapist and physiotherapist can also look at whether more supportive seating is required, for example moulded cushions.

Q

Are there any foods you should avoid if you have difficulty swallowing?

Suzanne: When people experience difficulties, often the food types that are the first to become difficult are the dry, crumbly textures or the chewy textures like meat. Particularly with dry, crumbly foods, you can accidentally inhale bits before you've prepared for the swallow. We often tell people to avoid the high risk foods like nuts or salads, or foods that have a skin or a husk. Your speech and language therapist will be able to offer you more advice on this.

Q

What would you say to someone who's becoming increasingly worried about choking because of their swallowing difficulties?

Suzanne: It can be a frightening thing and for those who have experienced it, I can imagine it to be something you would never want to happen again. Thankfully, it is extremely rare and if, after having seen your GP or your speech and language therapist, you are still experiencing anxiety around this, then please go back to those same health professionals and talk it through with them. There can be so many things that can be done or explained or advised that can help alleviate those concerns for you.

If you're having problems with your swallowing and you're at all worried, talk to your GP, MS nurse or neurologist – they can refer you to a speech and language therapist for further advice and support.

Suzanne Buckley is a speech and language therapist working in the Neurological Rehabilitation Centre at the Royal Free London NHS Foundation Trust.



For more info on speech and swallowing problems, visit our website:

mstrust.org.uk/a-z/swallowing

mstrust.org.uk/a-z/speech



How to have yourself a merry little Christmas

Christmas is supposed to be a time of comfort and joy but let's not forget all of the worries that come with the festive period too. When you're living with MS, this can add an extra layer of stress to an already busy time so we've put together some useful information and advice to help get you through.

Managing stress

Cooking for large numbers of people, sourcing gifts, making travel arrangements and more... It's completely normal to experience stress or nervousness from time to time, especially when there's a lot going on. However, feeling this way for long periods can have an impact on your health and MS symptoms with some research even suggesting that it can increase the risk of having a relapse.

Learning to manage your stress levels is an important part of managing your condition, all year round. Here are some techniques which might help.

Put things into perspective. Maybe the turkey (or meat-free alternative) didn't turn out as planned, but do your loved ones want to see you or a perfectly cooked dinner on Christmas Day?

Get to know yourself. Learn what your own stress signals are so you can take charge or step back before things get too much.

Try to keep an open mind. If your local supermarket has sold out of Christmas puddings, why not start a new tradition with a different dessert?

Plan ahead. The more organised you are, the less pressure you will feel as the big day approaches.

Ask for help. Christmas is a time for giving and a time for sharing. If you need someone to lend a hand, make sure you ask.

Be kind to yourself. Above all, remember that you are only one person and that you're doing your best.

Find out more about identifying and managing stress: mstrust.org.uk/stress



Fatigue

As one of the most common symptoms of multiple sclerosis, fatigue can sometimes feel like a barrier, affecting things like your short-term memory, concentration or the ability to get things done.

With so many commitments over the festive period, it can be easy to overdo it. Help manage your fatigue by thinking about ways to build up your energy levels, such as getting enough sleep, eating healthily and taking time for yourself when you need to.

It's also worth checking that you're using what energy you do have, as efficiently as possible. Planning and prioritising key jobs, delegating things to others and pacing yourself can all be useful options.

If you're concerned about fatigue and would like more information, our Living With Fatigue book is free to download or order.

mstrust.org.uk/204



Talking to friends and family about MS

If you're newly diagnosed with MS, Christmas may be the first time you've been around friends and family since receiving the news. Even if you're ready to tell others, it can still feel nerve-racking. You might be worried that people will see you differently or change how they behave towards you.

Choosing exactly what and how much you share is a decision that only you can make. You might want to keep it brief or you may prefer to go into more detail, sharing information about MS in general while describing what it's like for you.

If you're looking for some help on how to explain MS to others, you could speak with your MS nurse or look for resources online. Here are some other things you may wish to keep in mind.

Set some ground rules. If you would rather they didn't tell others, voice opinions or anything else, make this clear from the start.

Voice your own concerns. Don't want people to treat you differently? Emphasise this.

Prepare to listen. It's likely that some people will have questions or want to know more.

No right or wrong. How you tell others is your personal choice. There's no right or wrong way to approach sharing an MS diagnosis.

Discussing MS with children can be challenging and it's often hard to know how much they will understand. Our free Kids' Guide To MS is a useful resource designed for 6–10 year olds who have a parent with MS.

mstrust.org.uk/286



Spending Christmas on your own?

The festive season can also be a lonely time of year and it may not always be possible to share Christmas with loved ones. Whether you're spending it alone through personal choice or circumstance, it's important to try and focus on the positives where possible.

Hosting a virtual games night, doing an activity you enjoy or getting outside for some fresh air, if you can, are all great ways to lift your spirits.

It's also good to remember that there are no obligations to celebrate Christmas. Instead, you could try thinking about it as a 'self-care day' and a chance to take some much-deserved time out.

However, if you do struggle with persistent low mood, during any time of year, then you should speak to your GP, MS nurse or neurologist.

Mind, the mental health charity, also have some useful resources on managing your mental health during the Christmas period.

www.mind.org.uk/information-support/tips-for-everyday-living/christmas-and-mental-health/christmas-and-mental-health/

Further information on living with depression and anxiety:

mstrust.org.uk/depression

mstrust.org.uk/anxiety





Personal story

My life with MS

Andy Merry is a Yeoman Warder, commonly known as a Beefeater, at the Tower of London where he lives with his wife Maxine. They have two grown up children. Former Royal Marines commando Andy was diagnosed with multiple sclerosis in 2016, two years after noticing his first symptoms and has since gone on to scale the highest mountain in Western Europe.

In the beginning

My MS journey started in 2014 when I suddenly suffered severe pain in my right eye. I took myself to A&E and was eventually referred to the Moorfields Eye Hospital in London. They found nothing wrong with my eyes and the mystery deepened.

Around the same time, I started to trip over quite regularly, much to the amusement of my family who just assumed that the old man was getting a bit dodderly. While conducting my tours at The Tower, I will often point things out to tourists and found that my right hand wouldn't straighten, remaining curled up as if I was gripping something.

After a referral from our resident doctor and numerous visits to The National Hospital for Neurology and Neurosurgery, I was finally diagnosed in March 2016 with secondary progressive multiple sclerosis. I was on a shift at the Lifeboat Station on the Thames at the time, where I am a volunteer crew member. I informed the rest of the crew about what had happened and was immediately struck by their reaction. It was one of sympathy and I remember thinking that MS didn't seem that bad.

"I had spent 25 years in the Royal Marines and therefore spent my entire adult life pushing myself mentally and physically."

I got on with my life as normal but continued to read as much as I could about the disease to try and understand how it may affect me. It was at this time that I began thinking about what I could do to not only help myself but also show others that MS is not a death sentence. I had spent 25 years in the Royal Marines and therefore spent my entire adult life pushing myself mentally and physically.

Facing the mountain

In September 2016, my wife and I embarked on a road trip around Europe on my motorcycle. One of the places we visited was Chamonix in France where we boarded the cable car that runs up to a mountain called Aiguille du Midi. It was here, through intermittent breaks in the cloud, that I got my first glimpse of the adjacent mountain, Mont Blanc. The answer struck me there and then – I needed to climb this monster and convince people that they should give me money to do so.

My team was very important to the success of the challenge. I asked two people, both of whom I had served with in the Royal Marines and who have the technical and local knowledge that we needed. One had a friend, Rick, who was a local mountain guide. My family are very important and my son Luke was quick to volunteer as was my brother Simon, also a former Royal Marine. The last member of the team was another good friend from the Royal Marines, but also a fellow MSer.

One of the symptoms of my MS will be familiar to many of you – foot drop. This is a real winner when just walking about town, but when faced with rocky, uneven and steep terrain in big mountain boots, it becomes incredibly challenging. Add to this the fatigue and balance problems associated with MS, and it really adds up to a cheeky day out.

Undeterred, we set off for France in June 2017. The climb was long, dangerous and in places extremely scary. We faced a night climb on a 600m rock face and had to dodge a substantial rock fall while doing so. We crossed a narrow and incredibly steep snow field that had claimed the life of someone the night before and all in the knowledge that we would have to come down the same way again in the dark!

“I knew that I could make it to the summit but wasn’t sure if I could get back.”

After two days we reached the bottom of the final 300m before the summit, when Rick, our guide approached me with what turned out to be some very sound advice. He took me to one side and explained that the final approach to the summit was along a thin ridge. To one side was a 1000m sheer drop and to the other a 900m sheer drop. He and I were roped together and if I fell one way or the other, he could do little to save us. I knew that I could make it to the summit but wasn’t sure if I could get back. I was tired and my body wasn’t working in the way I needed it to. I also didn’t want to kill Rick, and if I so much as stumbled I would take him with me to the bottom and Luke would have to watch that!

It took me the best part of an hour to finally come to the very difficult decision that we had come as far as we should... just 300m from the top. Leadership can sometimes be very difficult and this was one of the hardest decisions I have ever made, but I knew it was the right one.

I think it’s important when carrying out any physical challenge that your biggest critic is yourself. You can make excuses to everyone else but in your head, you will always know the truth. I have climbed Ben Nevis once again since Mont Blanc and plan to do it again but this is now much more of a challenge as my MS progresses. My mountains have got a lot bigger.

The MS Trust conference

Earlier this year, I took part in the MS Trust virtual conference. This was my chance to tell my story, albeit electronically, which was a unique experience. I am very comfortable standing in front

of hundreds of people and speaking as I do it almost daily at work and have done so many times during my military career.

For some reason, I found sitting in my front room talking to my iPad slightly more daunting. I’m not sure why. Perhaps with a live audience, it’s possible to gauge the audience’s reaction. When there’s nobody but a small screen and the sound of your own voice, it’s easy to imagine that no one is really listening. I’ve since been told that my presentation went down well so I’m very relieved that someone was there.

“Just like the world though, I remain optimistic about the future.”

The last 18 months

During the global pandemic, I spent the majority of my time on furlough. The Tower was closed and this proved to be a surreal experience when you are used to having thousands of people visiting daily. As I write this, The Tower has fully reopened and we are pretty much back to ‘normal’. Currently, we are welcoming no more than 2,000 visitors a day rather than the 15,000 to 17,000 that we would normally see but I don’t think it will be long before we are back to capacity.

Unlike the world over the last eighteen months or so, my MS hasn’t stood still but has progressed at a pace that I would rather it didn’t. Just like the world though, I remain optimistic about the future.



Big Give Christmas Challenge: one donation, twice the impact



This year, the MS Trust is taking part in our first ever Big Give Christmas Challenge. From 30 November to 7 December 2021, all donations made to our appeal will be doubled thanks to some generous pledges we've already received through the Big Give initiative.

We have £8,600 in pledges waiting to be unlocked by your donations – but we can only unlock these pledges if we receive the same amount in donations during the Big Give week. To help make this campaign a success, register your interest in contributing by visiting mstrust.org.uk/big-give, and we will remind you from 30 Nov–7 Dec to donate!

One of our pledgers, Julie, is a long-time supporter of the MS Trust:

"It was an easy decision making a pledge to support the MS Trust's Christmas appeal," Julie says.

"The MS Trust is a fantastic charity which has helped me so much. It helps fund the MS nurses who have guided me through MS for over 30 years. There's always someone to talk to about new symptoms, ongoing ones, or to direct me to people who can help. It provides information online and in print that is easy to understand and so helpful.

"I wanted to help the MS Trust because of the numerous times it's helped me and pledging my support to the Christmas appeal was the perfect way to say thank you."

All the doubled donations raised through this appeal will be used to support three of our key services: the Advanced MS Champions and MS Specialist Nurses programmes and our free enquiry service which answers thousands of questions every year from people with MS, their friends and families.

So please sign up and register your interest today at mstrust.org.uk/big-give to donate during the week of 30 Nov–7 Dec and see your money doubled in support of our vital services for people with MS.

Together, we can be there for people living with MS every step of their journey.

Be Bold in Blue for the MS Trust

Join the MS Trust and 'Be Bold in Blue' in January 2022. January can be a difficult month, with some claiming 'Blue Monday' is the most depressing day of the year. The MS Trust want to change that trend by bringing the MS community together.

Multiple sclerosis doesn't just affect your physical health, it can also impact your mental health too. Around half of all people with MS experience depression at some point in their life, as well as other mental health problems like anxiety and stress. Symptoms of these mental health problems can include difficulty sleeping, breakdown in relationships and an inability to cope with daily tasks or commitments.

Blue Monday (17 January 2022) is said to be the most depressing day of the year. This Blue Monday join us in making a positive difference for those affected by multiple sclerosis.

Be Bold in Blue will take place the weekend of Blue Monday, Saturday 15 – Monday 17 January 2022. You can Be Bold in Blue however you like! Perhaps you want to take your passion for baking and raise some dough for the MS Trust? Maybe you love to run? Whatever you do, just make it BLUE! Be Bold in Blue your way and support the 130,000 people living with MS in the UK.

"Due to the nature of MS, you do not know what will happen. It makes you value what you can do and it makes you want to make the most of every day. Carpe Diem! Seize the Day!"

– Andrew, MS Trust Fundraiser

If you are interested in taking part, please get in touch

Online: mstrust.org.uk/bbib

Email: fundraising@mstrust.org.uk

Phone: 01462 476707

Fundraising

Get involved!

There are lots of ways you can get involved and support our work. Here are just a few ideas!
To find out more, visit mstrust.org.uk/fundraising

Mission: 100

Your mission, should you choose to accept it, is to raise £100 in 100 days, however you like. Join us now by getting in touch at mstrust.org.uk/m100

Ultra challenge

Choose to walk, jog or run distances of 100km, 50km or 25km. Whether it's along magnificent coastal scenery, or in stunning open countryside, your Ultra Challenge will be unforgettable!
mstrust.org.uk/ultra



TCS London Marathon 2 October 2022

Have you been inspired to take part in the iconic TCS London Marathon 2 October 2022? Now is your chance! Complete our online pledge form to see if you are lucky enough to secure a place on Team MS Trust.

mstrust.org.uk/londonmarathon

Discover more fun fundraising ideas at mstrust.org.uk/fundraising



Festive fundraising

Christmas cards

MS Trust Christmas cards are a fantastic way to spread a little festive cheer. We have a brilliant selection and all of our new designs for 2021 are packed in compostable bags that can be recycled with your food and garden waste. Last year's cards were so popular that many designs sold out, so make sure you place your order today! mstrust.org.uk/christmas



Shop and smile!

Whilst shopping online with Amazon you can support the MS Trust at no extra cost to you. Simply register at Amazon Smile and select 'Multiple Sclerosis Trust' as your charity. Every time you shop via Amazon Smile a percentage of the purchase price will be donated to us. You can support the MS Trust at Christmas and all year round, whilst shopping for gifts and everyday goods. You shop, Amazon gives, we smile!

mstrust.org.uk/shopping

smile.amazon.co.uk

Get your Christmas sox sorted!

We have launched a brand new and exclusive MS Trust sock with our friends at Monkey Sox – the third in our range! This time we have gone for a sports sock with a shorter 2" cuff. They are cushioned on the footbed, so are wonderful for walking, running and cycling, or just if you want some extra comfort. And the best bit? £5 from every pair sold will be donated to the MS Trust. Giving or receiving socks for Christmas just got a whole lot better! Order yours (or perhaps all three designs!) at

mstrust.org.uk/monkeysox

Give the gift of charity

Are you keen to give back rather than receive this Christmas? As lovely as it is to have gifts under the tree, for some, suggesting to family and friends to give to their favourite charity is exactly what they would like for Christmas. A way to say thank you for the support you have received from the MS Trust. Perhaps you are unable to fundraise or donate yourself, but you could ask those generous enough to offer you a gift to pass it on? Your gift could make all the difference for a family impacted by MS and will ensure the MS Trust is here for them, not just at Christmas, but all year round.

mstrust.org.uk/donate

15 minutes with...

Will Berard

Can you tell us about yourself? Before the pandemic you were a stand-up comedian, is that right?

You flatter me. I occasionally performed a bit of standup, but by day I was a software engineer. I'm now training as a computing teacher, which bridges the gap between the tech side and whatever urge was pushing me to the stage to lecture people under the pretence of telling jokes. My sets were always very educational. Preachy, even, at times. Even when I wasn't talking about MS, I had riffs on Buddhism, maths and IT.

Can you tell us a little about when you were diagnosed? How did this impact on your career?

I was diagnosed six years ago. The impact on my career was slow and insidious. I was on the lookout for anxiety, depression (Anx and Dep – the lesser known, much less entertaining duo) and cognitive fatigue which crept up on me – it was those that did my IT career in in the end. Or certainly caused me to take an open-ended break from it.

After a couple of years percolating, the diagnosis precipitated a rather clichéd mid-life reinvention: hammering home the frailty of the flesh, the inevitability of mortality inspired me to do something more meaningful. So, I link the teaching conversion squarely to the diagnosis. But with a squiggly line.

What made you want to volunteer for the MS Trust?

Power, money, influence, the lifestyle. Obviously. Seriously though, I think my very first involvement was the symptoms challenge – I heard about it in Open Door and I submitted a video of a 5-minute bit of stand-up on MS fatigue. I was also signed up to the MS Trust mailing lists and newsletters before starting volunteering. I recall the Trust coming out on top when I went through all the materials I collected at my MS unit – all the helpful booklets. The information mission of the Trust really resonated with me.

What advice would you give to someone thinking of volunteering with the MS Trust?

To do it, of course – what I like about it is that the MS Trust is a small enough entity that the link you get with the charity, as a volunteer, feels more personal. Now I've been working very closely with some of the team, but even before that, there is always a personal touch, which is nice.

What's the most challenging thing about volunteering?

I've ended up doing a huge amount of volunteering, in various capacities, for various charities, MS and not, during the course of my career break. Coming from the private sector, the first thing I noticed was the inefficiencies, especially when you put several volunteers together, because no one feels they have the authority. I was hoping I could say "I have these skills" and someone would give me something to do, but in volunteering,



it doesn't work like that, it has to come from you. Which, with the MS Trust, I eventually did – offering the Ask The Expert podcast, and then that started a collaborative process.

You've helped the MS Trust with eight podcasts over the last few months. How has that been for you?

It was fun. I trained as a sound engineer in my misspent youth, and have always kept a love for tinkering with sound – musical or not. It's always been a hobby and – like the comedy – I always meant to keep it that way, because I'm a dilettante at heart, and if I never actually try anything 'for real' then I can't 'really' fail.

When the pandemic hit, stand-up comedy as we knew it disappeared overnight. I was keen to lend my skillset to a larger, more meaningful project. In the spirit of getting the ball rolling, I sought permission to repurpose some video content of the MS Trust's in audio format. This became the Ask The Expert series, which was then enough for me to get the gig of producer on the podcast – editing, mixing and mastering it.

Even as a person with MS and an MS Trust volunteer, there's a whole side of the MS Trust I did not see or know about. So I floated the idea of a Meet the MS Trust series with interviews with the team, so everyone could hear a bit more about the people behind the scenes and what they do. Most of the recording has been done, some have already come out, and I hope to be able to find the time to put them together over the course of this autumn.

Who were your favourite guests to interview and why?

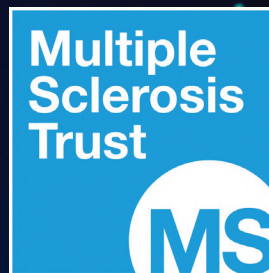
I had a great time with all of them. Obviously. Simon and Janice from the information team stand out, because it was the only time I had two guests on the call. There was a nice dynamic there – and they are my kind of information and research nerds, I'm sure they won't mind me saying!

However, the most interesting were on the health professional side, with Megan and Laura – this is exactly the kind of information that's a bit hidden from people with MS, which is a shame, because the MS Trust does so much fantastic work, it deserves to be publicised!

To listen to Will's podcasts visit
mstrust.org.uk/resources/podcasts-ms-trust

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