

August 2021

Open Door

Quarterly magazine of the MS Trust

Multiple
Sclerosis
Trust

MS



We grab
15 minutes
with '*wonky and
wonderful*' cabaret
performer, Diva
Hollywood

Personal treatment stories

Two people discuss
their experiences with
different DMDs

Can't stand the heat?

Tips to stay well in the
summer

Welcome to the August issue of Open Door



Hello and welcome to the August issue of Open Door. As we all know the last year and a half has been incredibly difficult. So back in April, I was delighted to be able to announce, that the MS Trust is now in a position to restart both our specialist nurse

and advanced MS champion programmes. We know that, now more than ever, people with MS need the support of their MS health professionals and our programmes aim to ensure there are more available across the UK. Read more about this on page 7. We are also thrilled to be able to introduce our latest MS Nurse, Michelle Cole, who will work out of the Walton Centre and cover the North Wales area which has been in desperate need of more MS nurse support for some time now. Michelle started her new position on 12 July.

When we think of MS health professionals, we often think of neurologists or nurses, however in this issue we've spoken with two pharmacists who specialise in MS. They have huge experience with DMD monitoring, managing side effects and ensuring new drugs are available to be prescribed. Take a look at page 10 to learn more.

We also talk to Jenna and Regan about their journey with DMDs. Jenna discusses experiences with Mavenclad and Regan tells us what it was like to receive a Lemtrada infusion (page 8). Choosing a DMD can be a confusing time, so we're grateful to them for sharing their story with us.

As this issue of Open Door lands right in the middle of August, we want to take a moment to congratulate the incredible Stephanie Millward, Kadeena Cox and David Phillips, all of whom are living with MS and taking part in the Tokyo Paralympics this year. From all of us at the MS Trust we wish you the best of luck.

Finally we loved grabbing 15 minutes with the fabulous Diva Hollywood earlier this year (page 22). She tells us all about how an MS diagnosis inspired her to take up the art of burlesque!

As always we welcome any feedback you have on Open Door, so do get in touch at opendoor@mstrust.co.uk

David Martin, Chief Executive, MS Trust



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For T&Cs, see www.easydonate.org

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Keep up to date with the latest MS news by signing up for our regular email round-up mstrust.org.uk/keepintouch

Latest MS news

Pregnancy Register

Are you pregnant and have MS? Then Queen Mary University of London are keen to hear from you. They are conducting a study to look at women who have MS and are pregnant, to find out more about the use of newer treatments in pregnancy. The aim is to improve the care of women with MS who are considering pregnancy in the future.

They would like to invite you to join the UK MS Pregnancy Register. By signing up and answering a series of questionnaires throughout your pregnancy and after the birth of your child, you can improve the understanding of what it is like to be pregnant with MS in the UK. The findings from this study could influence how pregnant women with MS are treated in the UK.



They will also ask for the details of your GP and MS team, and any other doctors who may be involved in your care or the care of your baby in the first year of its life (for example obstetricians, paediatricians). All information is strictly confidential.

If you'd like to find out more information about the study or to join the MS Register take a look at this link ukmsregister.org/Account/Register or email: contact@ukmsregister.org

Mission 100 – Orkney vs Shetland

Between April and August this year, the inhabitants of Orkney and Shetland went head-to-head in an epic fundraising challenge! Mission:100 is a regular fundraising event in the MS Trust calendar, where we ask our supporters to raise £100 in 100 days. This helps us to ensure that the 100+ people diagnosed with MS each week have access to our Making Sense of MS publication.

This fundraising event caught the eye of long-term supporter, Hayley Budge, who suggested the inter-island fundraising battle. Hayley led the Orkney Team, while Amy Uren headed up Team Shetland. Both of these incredible supporters have links to multiple sclerosis and have done a fantastic job promoting the event, recruiting over 500 members to join the dedicated Facebook group, with around 200 people taking part. At the time of writing, this challenge has raised over £30,000 for the MS Trust, which goes a long way to helping us keep our vital services running.



Photo credit Ken Amer

This event has been truly inspiring, with people of all ages taking part, the community spirit is incredible. Supporters have been running, baking, painting and selling plants to raise their £100. It has been a fun event for all involved, while never losing sight of the reason for doing it. We would like to take this opportunity to thank everyone who has fundraised, with special thanks going to Hayley Budge and Amy Uren, without whom, the event would not have happened.

Improve your wellbeing with MS-UK online

MS-UK online offers a range of activities for people living with multiple sclerosis. Their aim is to help people manage their wellbeing independently through exercise, information and connecting with others.

The activities offered online have been chosen by the MS community and future activities are guided by the feedback they receive. Below is a quick look at the activities available.



Exercise classes

The exercise classes are held twice a week and consist of three levels for different abilities to help improve your daily function and achieve your optimum mobility ms-uk.org/ms-uk-online-exercise

Masterclasses

The masterclasses are held once a month and focus on exercise topics such as balance, stretching, foot drop, walking and core exercises ms-uk.org/exercise-masterclass

Mindfulness

A nine-week Mindfulness Based Stress Reduction (MBSR) course, this is a standardised course and has been developed specifically for people with MS. MS-UK have also just piloted a shorter, four-week course ms-uk.org/mindfulness-courses

Chair yoga

Chair yoga classes are held once a week and consist of two levels for different abilities. It is the practice of simple exercises to help

move, strengthen and stretch your body while expanding your breath and calming your mind, free from the everyday “chitter-chatter” ms-uk.org/chair-yoga-sessions

Information sessions

Information sessions are held each month and are delivered by Dr Gretchen Hawley, a physiotherapist based in the US specialising in MS. Previous topics have included neuroplasticity, regular vs functional exercise, spasticity management, fatigue management and hand therapy ms-uk.org/sessions-dr-gretchen-hawley

Peer pods

This is the social aspect of the service to enable people to connect with others in a safe space and share experiences on topics of interest, or if they wish to, to discuss their MS. There are currently five peer pods running weekly via Zoom with three more launching soon. Each pod is volunteer-led. ms-uk.org/peer-support-service

To get involved, visit ms-uk.org/ms-uk-online or email register@ms-uk.org

My Neuro Survey is coming: Get involved and make your voice heard

We are delighted to be supporting My Neuro Survey, the national neurological patient experience survey run every two years by the Neurological Alliance. The Neurological Alliance is a coalition of over 70 organisations, including the MS Trust, working together to make the voices of people with neurological conditions heard.

The survey is the only one of its kind and plays an important role in improving services for people living with neurological conditions, including MS. This year, given the impact of the Covid-19 pandemic with many neurological services grinding to a halt, the survey is more important than ever.

The survey is set to launch at the end of September and will be promoted through the MS Trust, other patient organisations and within some neurology clinics. For the first time, this year's survey is UK-wide and includes a version specifically for children and young people.

Data from previous surveys has been used to improve neurology services and spark debate in Parliament. It will be available online and as a paper survey and we would love for you to take part! Keep an eye out for more information on our social channels or visit neural.org.uk/myneurosurvey and when the time comes, make your voice heard.

Research Update

The impact of DMDs on childhood MS

There is increasing evidence that for adults with relapsing MS, a combination of earlier diagnosis, more effective disease modifying drugs (DMDs) and a proactive approach to treatment switching has increased the time people remain free of long term, permanent disability. Researchers wanted to find out if this was also the case for people whose MS symptoms begin in childhood (before 18 years old).

The study

Researchers examined data in the Italian MS Registry. They selected medical records for people who had relapsing MS which had begun before they were 18 years old and had been diagnosed for at least three years. These records were split into four time periods: children with onset of MS before 1993, from 1993 to 1999, from 2000 to 2006 and from 2007 to 2013. The time periods were chosen because they roughly correspond with the approval of disease modifying drugs (DMDs) in Italy – beta interferons in 1996–1998; Copaxone in 2002; and Tysabri in 2007.

The time to reach two disability milestones, EDSS 4 (some difficulties with walking) and EDSS 6 (needing to use a walking aid) was compared for each time period. The researchers also captured details of disease modifying drug treatment and disease activity.

The results

A total of 3,198 people with onset of MS before they were 18 years old were identified. Compared to those with onset of MS before 1993, the risk of reaching EDSS 4 and 6 dropped for each of the subsequent time periods:

EDSS score of 4:

- 1993 to 1999 risk of 0.70
- 2000 to 2006 risk of 0.48
- 2007 to 2013 risk of 0.44

EDSS score of 6:

- 1993 to 1999 risk of 0.72
- 2000 to 2006 risk of 0.44
- 2007 to 2013 risk of 0.30

In later time periods, a greater number of people with childhood onset MS took DMDs, especially highly effective drugs. These drugs were also taken at an earlier age and for longer periods; in the 2007 to 2013 time period, people were diagnosed and started DMDs nearly at same time. Other aspects such as disease activity at onset did not change significantly between the time periods.

For more information
visit: [mstrust.org.uk/
talk-to-us](https://mstrust.org.uk/talk-to-us)

For the full set, 69% were women; average age at onset of MS was 15.2 years; age at diagnosis was 22.1 years; time from onset to diagnosis was 3.2 years; follow-up period was 21.8 years; average time to reach EDSS 4 was 31.7 years; average time to reach EDSS 6 was 40.5 years.

What does it mean?

Overall, the risk of reaching disability milestones EDSS 4 and EDSS 6 has fallen by 50% to 70% in the most recent time periods, similar to that reported for people with adult onset of MS. The researchers suggest that the gradual decrease in disability risk was due to the increased use of DMDs, especially more effective ones (Gilenya and Tysabri), starting treatment earlier and for a longer time compared with the past.

The authors conclude that increased availability of more effective DMDs approved for under 18s and improvements to managing treatment will lead to better prospects for people with childhood onset of MS.

Find out more...

Read more about childhood MS, how it's diagnosed and treated, ways to help you cope with school and much on our website. MSTV is our dedicated YouTube channel for young people affected by MS and features young people talking about living with MS, whether they or their parents have the condition. Videos cover a range of different topics – everything from symptoms to how MS makes you feel.

Authors: Baroncini D et al.

Title: Risk of persistent disability in patients with pediatric-onset multiple sclerosis.

Journal: JAMA Neurology 2021 May 3:e211008.

Read the summary: pubmed.ncbi.nlm.nih.gov/33938921/

If you're aged 11 to 17 and have experience of MS, visit mstrust.org.uk/talk-to-us to suggest topics you'd like us to cover or volunteer to become an MSTV young reporter yourself.

Research Update

Machine learning identifies new subtypes of MS from MRI scans

MS is divided into four subtypes: clinically isolated syndrome, relapsing remitting, primary and secondary progressive MS. These are used to guide the timing and choice of treatments. However, these subtypes are based on observed symptoms, such as relapses and disability which can be difficult to measure and may not reflect the underlying biology driving the course of someone's MS.

Researchers wanted to find out if there are hidden patterns in data from MRI brain scans taken over time that would give a better indication of biological differences in MS activity and detect progression earlier.

The study

The international team which included researchers from University College London, used MRI scans previously taken in clinical trials involving 6,322 people with MS. These included scans from four primary progressive, five secondary progressive and three relapsing remitting studies. Data was extracted from the scans and machine learning (artificial intelligence) used to identify subgroups with similar patterns of change in brain structures over time.

Results from the initial findings were tested against a second set of MRI scans from 3,068 people with MS. These included scans from one primary progressive, two secondary progressive and two relapsing remitting studies.

The results

The researchers found they could classify people into three subtypes, based on early changes seen on MRI scans:

- Cortex-led subtype showed early signs of tissue shrinkage in the outer layer of the brain
- Normal-appearing white matter-led subtype began with diffuse tissue changes in the middle of the brain
- Lesion-led subtype started with widespread build-up of lesions, followed by early and severe shrinkage of brain tissues in several areas.

The cortex-led subtype was most common in both sets of MRIs. The lesion-led subtype had the highest relapse rates and risk of disability progression but was also the subtype most likely to show a response to treatments for both relapsing and progressive participants in clinical trials.

Combining MRI-based data with clinical assessments taken at the start of clinical trials (EDSS, timed walking and upper limb function) gave a more reliable prediction of future disability progression.

What does it mean?

The researchers conclude that the three new MRI-based subtypes do a better job of predicting MS activity, disability progression and treatment response than the standard relapsing and progressive subtypes.

This study used MRIs previously taken for clinical trials so the next step will be to confirm the results in studies where participants are selected from the outset based on their MRI subtypes. The data did not include scans of the spinal cord as these are not routinely collected in clinical trials; future studies could investigate the effect of adding spinal cord measures to MRI subtypes.

The findings have the potential to open up research into new, more effective treatments by enabling researchers to select clinical trial participants based on the biology which is driving the course of their MS.

Further research will need to translate the results into practical guidelines that can be used in the clinic to help predict those who are more likely to have disease progression and support treatment choices for those who would best respond to a particular therapy.

Find out more about MRIs

Magnetic resonance imaging (MRI) is a scanning technique used on the brain and/or spinal cord to support MS diagnosis and to monitor on-going MS activity. You can read more about the technology mstrust.org.uk/a-z/magnetic-resonance-imaging-mri and what it's like to have an MRI scan mstrust.org.uk/mri-scan.

Authors: Eshaghi A et al.

Title: Identifying multiple sclerosis subtypes using unsupervised machine learning and MRI data.

Journal: Nature Communications 2021; 12(1): 2078.

Read the full study: nature.com/articles/s41467-021-22265-2



Health Professionals

Restarting our specialist nurse and advanced MS champion programmes

The impact of Covid-19 on MS services and indeed, the whole NHS, has been unparalleled. Whilst we know that MS nurses and therapists have worked incredibly hard to adapt to these challenges and provide a service for people with MS, we also know that many more resources are urgently required. So earlier this year we were delighted to restart our specialist nurse and advanced MS champion programmes.

The aim of the programmes, which had to be paused during the pandemic, is to support the recruitment of additional nurses and therapists in the areas with the greatest need. We work with NHS organisations across the UK, to promote the importance of MS specialist health carers. The specialist nurse programme operates by offering the NHS a support package which includes funding for 80% of the nurses role for their initial 15 months in post, at which point it is possible to prove the value of the new role. The programme also includes accredited training courses run by the MS Trust to educate all MS health professionals. The objective is to ensure that everyone living with MS has access to the support they need.

We restarted the specialist nurse programme in April and were delighted to finalise an agreement to support the Walton Centre NHS Foundation Trust in Liverpool, with an additional MS nurse who started this July. Michelle Cole will work with the existing MS team covering the North Wales region.

The MS Trust is also pleased to have restarted the advanced MS champion programme following a very successful pilot of six sites. An advanced MS champion helps people living with advanced MS to navigate a system that can be very complicated. They provide specialist knowledge, bridge the gap between health and social services and provide continuous, stable access to health services. Our recent campaign on Advancing MS Care provides more information on ways you can support this initiative mstrust.org.uk/get-involved/advancing-ms-care. With more than 40,000 people living with advanced MS in the UK, this lack of access to healthcare cannot continue.

Everyone with MS should have access to specialist nurses and therapists to help manage their personal treatment plans, receive regular reviews, for general support and advice. We plan to place two more MS nurses during 2021, we also plan to undertake our biannual mapping of MS services across the United Kingdom. This enables us to support our Enquiry Service with an up-to-date map of where the services are and who works there. The data collected helps us prioritise the areas of highest unmet need, so when we plan our programmes we can be sure that we are starting with those areas where there is currently little or no access to nurses and therapists.

We are acutely aware that the path to addressing overstretched nurses and therapists, along with increasing waiting lists, is a long one. We are endeavouring to support the centres we work with to implement more sustainable solutions which will tackle these issues over the long term. Through our education programmes we will continue to train, support and mentor nurses and therapists in multiple sclerosis to support every person with MS, whichever stage of their journey they are on.

To find MS services near you visit:
mstrust.org.uk/about-ms/ms-services-near-me





Personal stories on DMD use

Mavenclad: Jenna's story

Jenna, 29, was diagnosed with relapsing remitting MS in 2017, just two weeks before Christmas. After three years on one of the injectable disease modifying drugs, Jenna was forced to consider changing her treatment following a relapse shortly after the birth of her baby. Here, Jenna talks about why she chose to switch to Mavenclad and how she's found the treatment so far.

Choosing Mavenclad

Originally after my MS diagnosis I started on Plegridy in February 2018 and I was on it for about three years. At the end of August last year I had a baby. Unfortunately about four months after that I had a relapse. That's when my MS team suggested I try a stronger disease modifying drug (DMD). They gave me five options, which I narrowed down to either Mavenclad or Ocrevus. I decided on Mavenclad because it felt a little less invasive than having an infusion and I wouldn't have to take time off work going into hospital for infusions.

How I take Mavenclad

Before I started treatment, I had to have blood tests to check my white blood cell count, plus a urine test to make sure I wasn't pregnant. I also had to have a chest x-ray as well.

There isn't a regular treatment plan with Mavenclad. It's taken as a tablet. How many tablets you take is based on your body weight. For me, I had six tablets per week. I took six tablets for one week in April and six for one week in May. Then you don't take anything for a year. The following year you repeat the course. If it works, that treatment cycle should hopefully cover me for about four years.

There is some ongoing monitoring involved with this treatment. I'll have my first set of bloods since my treatment course in the next few weeks. Fingers crossed everything is on track and I can continue with the next treatment course.

*Find out more about
your DMD options at*
**[mstrust.org.uk/about-
ms/ms-treatments/
ms-decisions-aid](https://mstrust.org.uk/about-ms/ms-treatments/ms-decisions-aid)**



How it's fitted in with my lifestyle

I've found Mavenclad to be quite a convenient treatment to be on. It's nice to do a course of tablets and then not have to worry and not have to remember to take anything else. It felt easier than having an infusion because the tablets get delivered to your door, you can take them at home and you don't have to travel to hospital to take it. I'm now working four days a week since having my baby and I really didn't want to have to go into hospital on the day that I was meant to be spending with him, so Mavenclad has helped me to avoid that.

The side effects

I've been quite lucky that I haven't noticed any side effects. The one that I was most worried about was hair loss, but because I had postpartum hair loss anyway, if Mavenclad has impacted that too I've not really noticed! Before I started the treatment I was having visions that my hair was going to be coming out in clumps – thankfully, it hasn't.

My advice for others

When choosing a DMD I would definitely say make use of all the materials out there and do your research to make sure it fits in with your lifestyle. I don't think I would have chosen Mavenclad if I was considering having a child, but given that I'd already had one, it's worked out fine for me.



Lemtrada: Regan's story

Regan, 22, was diagnosed with MS when she was just 16. Whilst navigating school life and completing important exams, she started her treatment with Lemtrada – one of the strongest disease modifying drugs available for RRMS. Here she sheds some light on her experience with the drug and discusses what infusion clinics are like, the side effects she experienced and the ongoing monitoring after treatment.



Switching to Lemtrada

Initially I was given Copaxone for my MS. Unfortunately I ended up having anaphylaxis and swelling on the brain with that drug so I came off it. It was quite hard to deal with because I was trying to go to school and I was trying to hide my MS a lot. I'd only told my friends at that point. In school I ended up using a crutch, so people were noticing more and more that there was actually something wrong.

After trying Copaxone, my MS team thought it was best to go for a harder hitting drug – the only issue was my age, being under 18 at the time. It took a while, but eventually I was given the okay to start treatment with Lemtrada. It was quite intimidating going from the Copaxone injection to this big IV drip given in hospital.

The treatment courses

In the first year, you have five days of the treatment. It's given as an infusion in hospital. You also have your pre-treatments, like antihistamines, steroids and I had anti-sickness medication too as I don't tolerate medications well. You get those for the five days.

Then the second year, it was a three-day treatment course. Again, you have the pre-treatments like steroids. You get a whole load of aftercare for each treatment, such as antifungal and anti-virus medications because of your weakened immune system.

Following both treatment courses, you have ongoing monitoring. I had my bloods done every month for four years after my second treatment course. I've only just finished the monitoring.

Infusion days

The infusion itself takes quite a while. You go into hospital in the morning and you usually leave late afternoon. Sometimes they are faster or slower depending on how you react to the infusion. When you get there, you get all the pre-treatments I mentioned before. You can move around with your drip – it's okay to do that. You're not really stuck in the chair at all. Just take a book or something with you because it can get quite boring when you're there for eight hours. It is a long day. I had my infusions in the summer and my hospital would get really warm. It's handy to wear a t-shirt and shorts or light bottoms so you don't get too hot. The nurses regularly monitored my temperature and vitals.

Tricky timing

Unfortunately, my infusion ended up landing two weeks before my exams. I was trying to revise, plus trying to take in all this information about this drug I was being given.

I had to be really careful with my immune system at that point so we had to arrange a private room for my exams. It just made the whole thing more stressful. You have this big treatment and you have exams that you're told are going to decide what you do when you leave school – both at the same time.

The second treatment course was tough too. Again, it fell right before my exams and my 18th birthday. I couldn't go out or do anything because of my weakened immune system. It was quite disheartening too because the first treatment course hadn't worked as well as hoped. I felt like what's the point of doing it again? Looking back, the timing could have been so much better.

Side effects

The first few days the infusion went a bit too fast and I ended up with migraines and sickness. After that they slowed things down. It does get easier the more your body gets used to it.

My joints felt a bit achy and I felt more fatigued following the treatment. I think the stress of having the treatment affected my body too – it's quite exhausting. Other than that, I didn't have many side effects, personally, I was quite lucky that way.

The outcome

Unfortunately, Lemtrada didn't entirely work for me. The first year, it did give me a bit of a boost and it did hold off a lot of the physical symptoms of my MS. Now I'm looking to start a new treatment. I've had Tecfidera over the last year because of Covid-19, but I'll be starting Ocrevus soon.

Every drug doesn't always work for everybody, but it was a great opportunity to have Lemtrada.



MS Pharmacists

Another vital role which makes up an MS team is a pharmacist. In this article we spoke to two MS pharmacists, Brina and Aoife, to find out more about their role within an MS service and to hear the latest developments on drugs in the pipeline.

They have expertise in the prescribing and dispensing of MS medications, as well as ongoing monitoring, managing side effects, advising on interactions and ensuring newly available drugs are ready to be prescribed.



Q

What is the role of a pharmacist within an MS team?

Aoife says: Our role as MS pharmacists is quite varied – we have patient-facing and non-patient facing roles. Our typical day involves screening, checking prescriptions and running a monitoring clinic, where we oversee blood monitoring for people on disease modifying drugs (DMDs) who require extra monitoring. With the MS nurses, we run DMD education and screening clinics, where we talk through the medication that a person is about to begin. We also provide an MS medicines information service to doctors, nurses, and people with MS.

The non-patient facing role involves contributing to service development and improvement. For example, we will contribute to audits and clinical guidelines which are discussed at our clinical governance meetings. We work with our colleagues across London and nationally, for example, contributing to NICE guidelines. We also network with other pharmacists to share good practice and discuss challenges to try and improve the care provided to people with MS.

Q

Can people with MS talk to you directly?

Brina says: Pharmacists working in a hospital role are often in the background, providing a supporting role to the nurses and doctors. Unfortunately, sometimes we don't get to meet all of our patients face to face in a traditional clinic setting. However, we are in contact with people with MS on a daily basis, and available to speak to them if they need us.

Usually our contact is related to DMDs. It may also be related to blood monitoring or interactions with other medications or dietary supplements.

We provide advice on symptomatic medications as well, not just to people with MS but to GPs too if they have any queries. We commonly receive questions around vaccines. For instance, if someone's going travelling, whether the vaccines they need are safe for them to take. We also answer queries about contraception or if medication is safe in pregnancy and breastfeeding.

Q

What work do you have to do behind the scenes when a new drug gets approved for use on the NHS?

Aoife says: When a new drug is approved for use on the NHS, we must inform our Use of Medicines Committee that we are intending to use it at our NHS Trust. The drug is added to our formulary (a list of approved drugs that may be prescribed at our Trust) to be used in line with national guidance. If the medication is a new DMD, usually a new pathway and a clinical guideline will be agreed by our MS service.

We must ensure that we have resource to support the prescribing, administration, delivery and long-term monitoring thereafter. We also need to give an indication of how many people are likely to need the drug, and whether it will replace existing treatment or if it is a new line of treatment. We must make sure that there is funding available for that treatment.

We also communicate and collaborate with our peers, locally and nationally, to share how they're delivering the same service so that we can agree and share good practice, but also discuss how we get around different challenges. MS treatment is a rapidly evolving landscape. We are always thinking months and years ahead, so that we are aware of what's coming next and so that we can try to plan in advance.

Q

Can you talk through some of the DMDs that are in the pipeline, or starting to become available, for relapsing remitting MS (RRMS)?

Brina says: In terms of medications coming through in the pipeline, we have Kesimpta (ofatumumab) for RRMS which is an under-the-skin injection that can be administered at home after the first dose. This will be a convenient home-based, high efficacy medication, especially if people with MS don't want to come into hospital for their treatment.

Tysabri (natalizumab) is a high efficacy option now available as an under-the-skin injection. Currently, it is given as an infusion into a vein over one hour. The frequency of administration will still be the same. It will still need to be given in a medical setting, but it will speed up the time spent in hospital as it won't need to be given as an infusion over one hour and observation time can be reduced if the treatment is tolerated.

On the horizon, there's ponesimod which is undergoing NICE consultation for RRMS. There's also diroximel fumarate which has just been submitted to the EMA for licensing. The trials have shown that it has fewer gastrointestinal side effects than Tecfidera (dimethyl fumarate) which can sometimes cause stomach upset, constipation and diarrhoea when people first start it.

Q

What does the landscape look like for people with progressive MS in terms of treatments?

Brina says: More research is happening in progressive and advanced MS now. We're optimistic that new treatments, or repurposed drugs, will become available for this group of people. There are a number of studies currently ongoing.

- **ChariotMS trial** – looking at whether Mavenclad (cladribine) can slow down the worsening of hand and arm function in people with advanced MS.
- **Oratorio-Hand trial** – examining the effect of Ocrevus on upper limb disability progression.
- **MS-STAT2 trial** – investigating whether simvastatin can slow down progression in MS by protecting the nerves from damage.

We're watching these trials closely to see if they have positive results.

Q

How can you support people with progressive MS who aren't on a DMD, but are using a range of symptomatic treatments?

Aoife says: This is an area that we are keen to develop. Up until now, people with progressive MS have predominantly received community-based care, and therefore any interaction with a specialist MS pharmacist would be more reactive, for example, if they're admitted to hospital for an ailment.

However, as more treatment options become available which require specialist input and monitoring, for example DMDs and symptomatic medication, we are meeting and learning more about this group of people.

Our potential here is to proactively decrease preventable harm, mainly caused by problematic polypharmacy – so being on too many medications. As pharmacists, we can perform medication reviews which involves going through all the medication someone may be on and assessing whether they're working, and if they're having any adverse effects that are causing them to feel unwell. We can look at all of their medications and ensure that they're getting the best from each one and, if necessary, switch or stop the medications that aren't working or are causing unpleasant side effects. Our priority is to make sure that people get the right medication at the right time.

Q

Can you provide some clarity on whether people with MS have to pay prescription charges for their medications?

Brina says: Having MS is not a prescription payment exemption, although if someone is exempt for other reasons they would not need to pay, eg because of their age or other medical conditions.

All medications that are delivered by home delivery, eg home care companies such as Healthcare at Home or Lloyds Pharmacy, don't need to be paid for. If a medication is administered during a hospital admission, for example, a Tysabri infusion, it wouldn't need to be paid for. This is the same for medication which is given to go home with if it's linked to a hospital admission. For example, people that come in for Lemtrada (alemtuzumab) treatment may take home antibiotics or antivirals – they don't need to pay for those.

However, if a medication is dispensed using an outpatient prescription, for example after a clinic visit or if they collect their medication from the hospital pharmacy, then they will be charged an NHS prescription fee.

People can always discuss prescription charges with their pharmacist to see if there's a better way we can provide the medication for them. The majority of our medications are provided by home delivery as, for most people, it's more convenient.

Brina Bharkhada is an MS specialist pharmacist at the National Hospital for Neurology and Neurosurgery, Queen's Square, London. Aoife Shields is also based at the National Hospital and is the principal MS pharmacist.



Personal story

Scooting adventures with Sally

While some people say that the use of a mobility aid gives them a new lease of life, for others it can seem more daunting. We spoke with Sally who opened our eyes to a new way of getting around, reminding us that there are a number of options available to suit all levels of ability.



Can you start off by telling us a little bit about your diagnosis?

It was way back, around 15 years ago, I had numbness in the right side of my face. I left it for a couple of days before I decided that I needed to go and make an appointment with a GP. She suggested cerebral palsy and referred me to see a neurologist. I then had an MRI. From there, I got my diagnosis.

When you were first diagnosed with MS, what were some of the initial thoughts and feelings you had?

The thing with MS was that I didn't know very much about it. All you tended to hear back then were not very positive stories; you didn't hear about people's journeys, it was just the ending. I told a very, very small number of people and their reaction was even bigger than mine. They were supportive, but I kept it very close probably because of what I've explained in terms of how people just see the end as opposed to the journey.

It took you a while to feel comfortable talking about your MS diagnosis. What was it that prevented you from telling people? What made you feel like now was the right time?

I managed to keep my diagnosis to quite a small group and I didn't feel that there was a need to talk about it more widely. I didn't want to be defined by it and I definitely didn't want to be the friend with MS. I wanted to still be the same me, I wanted to be Sally. The reason for speaking out now is that my MS has become more obvious. There are also real benefits to talking about it. If I don't talk about what I've found

useful, then it's a missed opportunity. People who are going through a similar journey might find things that I have to say helpful, such as my experience using scooters. Everyone has their own MS journey, and I'm going through mine.

When did you start using scooters and what was it that opened your eyes to them?

It's not something that I would ever have associated with somebody who's got a mobility challenge. Everyone's MS is different and my challenge is mobility. I have foot drop with my right leg, which makes me trip and look strange when I'm walking.

I have a friend who uses skateboards and also has a micro scooter. One day in either 2012 or 2013 we were talking about holidays and she offered to lend her scooter to me. I took it to Greece. I didn't scoot through the airport but used it to help carry my bags. I think people still associated scooters with kids at that time.

I bought my own scooter in 2015. It has bigger wheels which means you can get further quicker, plus for me, the bigger wheels make it easier to balance. It's brilliant and when I first got it I would get scooter envy from kids.

If you'd have asked me at the beginning, there was no way I thought I was going to be able to balance on a two wheeled scooter. I thought I was going to need a three wheeler but that's really not the case. The key thing is to try it while you're still able. Don't wait until you're at a more challenging stage with your MS.

"If you'd have asked me at the beginning, there was no way I thought I was going to be able to balance on a two wheeled scooter."



What are some of the things you enjoy about using a scooter?

Number one, I can cover greater distances with little effort. Without a stick, I can walk around 100m but with my manual scooter, more like 1km. I can keep up with friends more easily and effectively walk with them. It makes me feel part of something, as opposed to being separate from everybody else. For me, that is a really big deal.

Number two, they look cool. Just because you've got a disability it doesn't mean you don't want to look cool anymore. You don't have to look different or be different, you can be the friend who scoots as opposed to the friend who has MS.

Number three, I can take my smaller scooter abroad. I was very fortunate at the end of last summer to go away. That was the first time I had scooted from check in through to the plane and then I even took my scooter on board with me as it's tiny. It made such an enormous difference.

What changes would you like to see to help make these types of scooters more accessible?

There's been so much change over the last 15 years, including the introduction of electric scooters. I'm hoping that scooters in general will become a more popular way of getting around. I did write to my MP to tell her about my use of electric scooters. I want to make it legal to use one in a bike lane so others can see that you don't have to go straight from being able to walk to a sitting mobility aid. It's a long, long journey and there are many stages in between where you can still use other things.

I'd like to make scooters more accepted in shops and airports so people understand that I'm not just going to scoot around and be annoying. It's my mobility aid and I think there's the potential for them to be other people's mobility aids too.

That's a big challenge as well; if you were to talk to people about mobility, it does not conjure up a cool image. I really hope that over the coming years, people come up with ability aids that aren't just something that you have to use and look older than you may be. Let's get people coming out with cooler mobility aids and making them a fashion accessory. If you've got to use it in everyday life, why not allow people to choose it in the same way you do a haircut or what clothes you wear?

What are some of the challenges that you have faced when using scooters in places such as supermarkets or airports?

I've been in shops and been challenged or asked if they can take my scooter to store it somewhere. The response is always a polite "No, thank you, as I need it." The whole piece around invisible disability has been much more talked about over the last couple of years so I don't get challenged as much now as I did. Although my scooter looks different than the classic mobility aids that people are used to seeing in airports and in shops, it isn't just for fun, and I'm not doing it to be disruptive.

Looking back on the time since your diagnosis, is there anything that you would tell yourself if you could go back?

I think you need to focus on celebrating. There will be lots of things that you can't do but skip the commiserating and don't be afraid to try new things. Just because you can't do something that you could once do, it doesn't mean to say that you won't be able to do something you haven't yet tried.



"Without a stick, I can walk around 100m but with my manual scooter, more like 1km."



What advice would you give to others who are in a similar position, including those who are perhaps thinking about what they can do to improve their mobility?

1. Try someone else's scooter out first as a starting point. I'm sure you'll have a friend or a relative who has got one you can borrow.
2. Don't assume that because your standing or walking isn't great that you won't be able to balance on a scooter.
3. Always wear a helmet just in case!



Can't take the heat?

For people with multiple sclerosis, staying well in summer isn't always as simple as applying the right SPF or remembering your antihistamines to avoid hayfever. In this article, we look at how you can make the most of summer.

Temperature sensitivity

Between 60% and 80% of people with MS find that heat can cause their symptoms to worsen. This is known as temperature sensitivity and might include a build up of fatigue, blurred vision, loss of balance or a worsening of cognitive symptoms such as concentration or memory.

If you have MS, just a small rise in core body temperature has the potential to make a difference. Summer weather, excessive central heating, vigorous exercise or having a fever can all raise your core body temperature. You might also find environments with lots of people crowded together uncomfortable. During warmer months, you may feel that this influences the activities you want to do.

Here are some useful tips to help you manage temperature sensitivity:

- **keep a cold, hydrating drink nearby**
- **head out earlier or later in the day, when temperatures are generally cooler**
- **invest in a fan for your home and maybe a handheld one for when you are on the go**
- **wear garments made from natural fabrics such as cotton and linen which are more breathable**
- **fill a spray bottle with cool water and use it to mist your face**
- **opt for lighter meals such as salad**
- **take a cool bath or shower.**

Exercise

The NHS recommends that adults should undertake some form of physical activity every day. This may seem like a daunting task especially when it's warm in the summer, but it's good to remember that there are a whole range of options when it comes to exercise.

With the nature of MS and things such as mobility, visual problems, heat sensitivity, bladder or bowel issues, you might feel that you have to be more conscious of your limits when undertaking exercise. That doesn't mean missing out though. If you try an activity and it does not make your symptoms worse, then it is most likely fine for you.

Summer typically brings drier weather and longer daylight hours, making it the perfect time of year to take up something new. Some good activities to try at this time of year include:

- swimming
- cycling
- yoga or Pilates
- rambling or walking
- archery
- sailing, kayaking, canoeing or rowing
- seated exercise classes
- bowling.

If you attend group classes or work with a personal trainer, it is important that they are aware of any adjustments you may need, such as taking regular breaks or adapting some routines.

Sun exposure has been shown to reduce the severity and progression of MS and also lift depression.

If you have any concerns about certain physical activities, make sure you talk to a health professional beforehand. Physiotherapists will also be able to give you some tips as to which exercises best suit your needs.

Vitamin D

Vitamin D plays a key part in regulating the amount of calcium and phosphate in your body. These are essential for keeping bones, teeth, muscles and the immune system healthy.

There are several ways that you can ensure you give yourself enough vitamin D including eating foods such as oily fish, red meat, liver, egg yolks or by taking supplements. These are available as tablets, capsules or drops.

During sunnier months (late March/early April to the end of September), most people should be able to get enough vitamin D purely through sunlight hitting their skin. The sun does not have to feel hot for it to be providing vitamin D so it's important to remember to cover up or protect your skin if you are out in it for long periods. Excessive sun exposure carries a risk of skin damage and cancer so make sure you aren't risking allowing your skin to redden or burn.

Medical conditions such as osteoporosis, heart disease, diabetes, cancer and multiple sclerosis have all been linked with low levels of vitamin D. If you are a person with established MS, you may find that low vitamin D levels make you more prone to relapses and faster disease progression. This has been shown in studies through measures of disability (EDSS), brain volume and brain and spinal cord lesions. So it's important to try and take advantage of sunnier days and spend some time outdoors if you can.

Healthy eating

As the sun comes out so too do the barbecues, summer drinks and ice creams. While this time of year often brings food to the forefront of our minds, having a balanced diet is a key part of maintaining good health, all year round.

For people with MS, there is no specific diet proven to help everyone but you may notice certain things help with symptoms or reduce the impact of MS on your life. Eating a healthy and varied array of foods is a simple step to help you feel at your best. This means eating a wide variety of foods in the right proportions and consuming enough for your body.

You should try to base your meals around carbohydrates like bread, pasta or rice, adding in plenty of fruit and vegetables. Protein is another important part of your diet and can come from animal or plant sources. Fatty, sugary and salty foods should be occasional treats and kept to a minimum. Aim to have between six and eight drinks a day. Water, squash or tea and coffee are good options.

Figuring out what works for you may take some patience and people often find that starting a food diary helps. You could make notes on how different changes to your diet make you feel, and what impact they have on your MS, if any.

You should always discuss big dietary changes with a doctor, MS nurse or dietitian beforehand and be careful not to exclude essential nutrients.

Accessible holidays

Holidays in 2021 may look a bit different but there are still plenty of options when it comes to booking a break. Whether you are planning a summer staycation or travelling abroad, make sure you think about these things for a stress free trip.

- **Check the latest government guidance** – Make sure that you're aware of the latest rules for any region you're planning to visit.
- **Find the right holiday for you** – Do plenty of research and check the fine print for things like cancellation policies or flexible options.
- **Remember to pre-book assistance if you need it** – If you plan to travel via public transport, make sure you let the operators know of any additional assistance you may need beforehand.
- **Taking medication?** – If you are, consider how many days you will be gone for, what the regulations are for any countries you will be visiting and whether your medication needs to be stored at a certain temperature.
- **Don't forget travel insurance** – No one likes to think about what could go wrong but once your trip is booked, it's important to arrange travel insurance as soon as possible.

Visit mstrust.org.uk/stress-free-summer-holiday for more tips on accessible travel



What led Trishna Bharadia to become a health and disability advocate?

Hi Trishna, thanks for chatting to us today. For those that don't already know you, can you tell us a little bit about yourself and the work you do?

I was diagnosed with RRMS in 2008, aged 28. My diagnosis wasn't a good experience, I wasn't given any information or directed towards any of the right kind of support. It's that negative experience which took me into my advocacy work. I thought, people shouldn't have to go through this, let's see if I can make a change.

Initially I started volunteering with various MS charities like the MS Trust and that led me to working with other clinicians, patient associations and patient groups. I also work across different disease areas, looking at the overarching issues that affect lots of different patient communities, like diversity and health care, digital health, health literacy and good patient engagement practices.

Were you involved in volunteer work before or was it your MS diagnosis which spurred you on?

As a family, we've always been taught to give back to the community, so I did do charity work before my diagnosis. I did hospital radio for a long time and various things like tin-shakes for lots of different charities. However, I think the MS diagnosis really focused my attention on health care.

Once you start volunteering, you realise that there's such an array of different opportunities out there, it's not just about running the London Marathon. It really shows you how much you can develop personally. My initial foray into it was through Asian MS, I attended an event with my mum and happened to be sat next to the person who was the lead of Asian MS and we got chatting. It all started from there. I then got involved with the MS Society and the MS Trust. There was never really a plan to become an advocate, it just happened.

You've often spoken about how much you love to dance. How does dance help you with your MS symptoms?

I was always a hockey player, we're a hockey family. I always say I was born with a hockey stick in my hand. I played for about six years after my diagnosis, but it became increasingly difficult with my fatigue, my reactions were slowing, and I found I was getting injured more frequently.



That's not a good thing when you have hockey balls flying all over the place, I ended up in A&E a number of times.

By the time I gave up hockey I'd already started doing some Zumba. I loved it and thought it was the perfect replacement to hockey. For me, dance has been very much a way of being able to express myself. It really helps my fatigue, which sounds counterintuitive, to exercise to help fatigue, but it does help.

It makes me happy. You're enjoying the music and you're keeping fit at the same time. It's also a truly inclusive form of exercise. I've met a lot of people through dance that have taken away the fear from the future. One of the things that always worried me about my MS was the possibility of needing to use a wheelchair, but through these classes, I've met lots of wheelchair users and seeing what they're achieving and doing, made me realise there's nothing to be scared of.

How have the last 18 months or so been for you? What kind of impact do you think the pandemic has had on people with MS?

It's been hard. I live in a shielding household. I'm obviously clinically vulnerable, because of my MS. Both my parents have got health conditions and they're over 70, plus my younger sister is clinically extremely vulnerable due to medication she takes for a long term condition. I've left home three times since last March 2020. The first time was to get my flu jab in September last year and then I went out to get both of my Covid vaccines. So it's been difficult. I've missed having the social connections, but the thing I missed the most, is having to watch my niece grow up over FaceTime. That's been really difficult. I've also not seen my twin sister in that period either.



I think what it has done, is shine a light on a lot of the issues that people with MS and other conditions have faced for a long time. People have started to understand what it's like to not be able to go out. I have a really busy life; I get the weekend off and I'm just too tired to socialise. So very quickly you can become isolated and lonely.

What would you say are the main priorities for the MS community over the next few months and coming out of the pandemic?

Making sure that some of the positive measures that have been put in place over the last year or so are here to stay. For example, flexible working, working from home and telemedicine. Also, what lessons can we learn from the vaccine development? Where can we implement things that could speed things up in MS research?

Moving into the future I think that mental health is going to become increasingly important. We need to make sure that the community has got the support that it needs, because even as we're moving out of lockdown, there is still a lot of anxiety. Everybody's had different challenges, so we need to make sure that they feel supported.

Can you tell us about your work with Asian MS? And why it's so important to have a group specifically focused on Asian people with MS.

I've been involved in Asian MS for over 10 years, and it was already running way before I joined. It falls under the umbrella of the MS Society. We are a national support group which is there to provide culturally sensitive support and information to people in the Asian community who are affected by MS. We aim to raise awareness about the condition, and in doing so we try and help reduce some of the stigma and the prejudice that is attached to living with a long term condition and/or disability.

To find out more visit:
mssociety.org.uk/care-and-support/emotional-support/national-ms-support-groups/asian-ms



People have said to me 'Why do the Asians need their own support group?' It's because there are some very culturally specific issues that have to be addressed. For example, we need information in various languages. How do you explain to somebody whose first language isn't English what MS is? I don't know if there is a word for myelin in Punjabi, so how do I explain that to my relatives?

Then there's other culturally specific things that can impact the reaction within the wider community when somebody is diagnosed. People often question whether it means that you won't be able to get married or have children. People have said to me 'You have MS because of karma. You must have done something bad.'

You need to have a group that is tackling these issues from within, because whilst it's very hurtful, I understand why they're saying that. I understand the importance of religion, the importance of marriage and family. I also understand that there is a lack of education and awareness around MS. MS isn't like diabetes and heart disease which is very prevalent in the Asian community. At one point MS was called a Caucasian disease, I know people who were told that it can't be MS because you are Asian.

I spoke to a GP who's black herself, she said that during medical school, when they were learning about MS, they were told to look out for young, white females presenting with eye symptoms.

It needs to be understood by people outside of the Asian community, that it's not about us having a special group, it's about us being able to provide support in a way that a non-Asian group wouldn't be able to, because they don't fully understand the issues that are in play. We don't exclude non-Asians. All we say is if you want to be involved with Asian MS and our work, then you need to understand why we exist. We're not some exclusive club, it's not that at all.

One final question. What are your hopes for the future?

The way that treatment development is going is providing exciting prospects for the MS community. I really want there to be more and better awareness about what MS is, how it affects people, particularly the hidden symptoms. I believe that unless people fully understand what you're going through, they won't be able to offer the right kind of support.

I've been diagnosed now for 13 years, and in just those 13 years, I've seen huge progress. I'd like to think, that over the next 13 years, who knows what progress might be made?

You can find out more about Trishna and her work on her social media channels.

Instagram: [@TrishnaBharadia](https://www.instagram.com/TrishnaBharadia)

Twitter: [@TrishnaBharadia](https://twitter.com/TrishnaBharadia)

Facebook: facebook.com/trishnabharadia2015

LinkedIn: linkedin.com/in/trishnabharadia/

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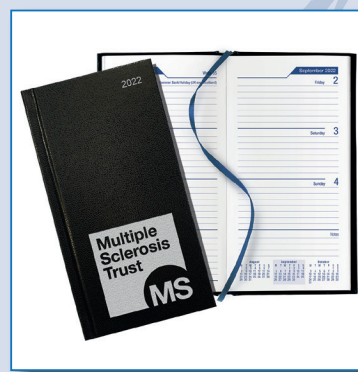
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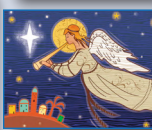
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XCBS007

Bargain Selection

£5.99 | 25 assorted cards, designs
may vary

All of our new designs
for 2021 are packaged
in compostable bags
and can be recycled with
food and garden waste!



Fundraising

Miles for MS

Miles for MS ran from May to July this year with people all over the UK taking part. From Aberdeenshire to Cornwall people have been donning their MS Trust tops and trainers to rack up the miles in aid of the Multiple Sclerosis Trust. At the time of going to press they have raised an incredible £63,000 and covered an astonishing 14,800 miles, which from our Letchworth office would take us over half way around the world, past New Zealand and on route to South America!

People taking part could personalise their challenge to suit them. From a short daily walk to a marathon a day, with up to three months to complete their fundraiser this event has been accessible to many. We have had so many lovely supporters taking part that we asked a few people to share their stories. This is Joanna's story:

"I was diagnosed with relapsing remitting MS in October 2015 when I was 26. This was only six months after getting married and was a very difficult diagnosis to come to terms with when my husband and I were just starting our life together. I had so many questions about everything, particularly about starting a family and medication. My neurologist suggested that I contact the MS Trust and that was my first introduction to the charity. I received a huge amount of information and support which led to us making the decision to start a family. I had had so much anxiety about this before speaking to the MS Trust, but they put my mind at ease, and I felt like we could make an informed decision. This was the first time in my life I felt like I had been helped directly by a charity and that led to me wanting to do some fundraising for them.

I have now fundraised for the charity on several occasions, and I felt this year it was particularly important because of the impact of Covid-19. Two years ago, I ran 5k a day in May to raise money so I felt like I wanted to up my game in the hope I could raise a little more than I did last time. For some reason I decided to run 10k a day (maybe I should have just done 6k!). I found the first three runs pretty tough and wondered whether I had maybe taken on too much, but once the first week was done and the donations were coming in, I started getting into the swing of it and really enjoyed the hour to myself every day in the fresh air.

There were days which were harder than others, I have a full-time job and two small girls so one of the hardest things was finding the time but thanks to my incredibly supportive husband I always managed to squeeze it in.

Miles for MS
2021



Miles for MS is a great way of getting involved in fundraising as you can choose your own distance in your own way.

For me, running is something I have always done, pre and post diagnosis, however I have never run 10k every day for 31 days. My main motivation was to raise money, but a big part of it was also to prove to myself that I could still do things like this. I have always enjoyed the fundraising I have done, whether that's been eating cake at a coffee morning or pushing myself in Miles for MS. If you are thinking of doing something it will give you so much joy seeing the donations coming in and a great sense of personal achievement."

We also spoke with Andrew, who cycled the equivalent of 31 marathons over the month of May. He had these words of encouragement to anyone thinking of fundraising.

"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! Keep going, every individual's challenge is their own mountain to climb. Keep fit, keep well!"

On behalf of everyone here at the MS Trust, we would like to thank everybody who took part in Miles for MS this year.

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

My Garden Party

Get the bunting up and drinks in ice, bask in the summer sun with friends and family whilst hosting a garden party. Get baking and open your garden to your local community. Perhaps a plant and produce sale on the front lawn or an afternoon tea in the grounds of your village hall. So many ways to have fun and fundraise for a cause close to your heart. mstrust.org.uk/mygarden



Skydiving is back!

This summer or autumn, experience the thrill of skydiving from 10,000ft and freefalling at around 120mph before parachuting back to the ground. This is a once in a lifetime adventure in the skies! Find out how you can take part at mstrust.org.uk/skydive

MS Play - calling all gamers!

Have you got into gaming over the past year or perhaps you have a family member or friend who loves gaming? Take part in our MS:Play gaming challenge where you pick the console, games and length of your gaming marathon. Play solo, hold a family challenge or perhaps take on friends online, the choice is yours! We will provide you with everything you need to turn your gaming into a fantastic fundraiser. Find out more at mstrust.org.uk/msplay

Ultra Challenge Series

Which one will you pick? Choose from a variety of events and distances and you will be rewarded with some breathtaking scenery along the way! Will it be the Isle of Wight, the Jurassic Coast, the Chilterns, the Lake District or, perhaps one of the other amazing locations on offer? Find out more at mstrust.org.uk/ultra

Supporting the MS Trust on your special day

Whether it's an intimate gathering of your nearest and dearest or a large-scale celebration, add a notable touch to your wedding or civil partnership with MS Trust wedding favours for your guests.

A lapel pin and place card supporting the MS Trust is a thoughtful gesture at a poignant moment in the lives of our supporters, and for the MS Trust to feature at such an event it really is an honour.

"Our favours were the MS Trust badges, which all our guests loved and wore throughout the celebrations. We know that charities like the MS Trust can make a huge difference to people affected by MS. We want to support in any way we can, and I hope this may encourage others to do the same and give a little back on their special day." – Lisa, MS Trust supporter



Give your guests one more reminder of your special day with an MS Trust wedding favour and have your loved ones generate awareness of the charity with a lapel pin they can wear proudly for years to come.

Order yours now shop.mstrust.org.uk/merchandise

For more ideas of how to support the MS Trust on your special day email fundraising@mstrust.org.uk

MS health professionals go the extra mile and more to support the MS Trust

We always knew our MS health professionals were dedicated and inspirational, but the latest recruits have really set the bar high. Every year, the MS Trust holds two, week-long foundation training courses for MS health professionals. Newly appointed MS specialist nurses, therapists and other health professionals who specialise in supporting people with MS can enrol. This year a dedicated team of 15 health professionals not only took on the training but decided to give something back by taking on another challenge. Led by Laura, an MS support nurse, they aimed to cover, on foot, the miles between Lands' End and John O'Groats collectively from their respective locations across the UK. They set to work on fundraising, excelling themselves in every respect by smashing their target in miles and raising over £1,250.

"The best part is seeing the money we have raised as a team and hopefully it has offset some of the cost for our education," said Laura.

A big congratulations and thank you to Laura and the team on passing their training and for their wonderful fundraising.

15 minutes with...

Diva Hollywood

Diva Hollywood is a cabaret performer and this issue's cover star who has been performing on stages across the world since 2005, around the same time she was diagnosed with MS. We caught up with Diva to find out about her diagnosis, how she got into performing arts and why it appeals to her.



Hi Diva, would you like to tell us a little bit about yourself? When did you start performing and how did you come up with your alter ego?

I've been aware that I'm an artist for pretty much my whole life as I'd always been into visual arts, animation, painting and that sort of thing. I was aware of burlesque and cabaret because I had done acting in the past but I didn't feel like I was the right size. I wasn't a size eight or a super coordinated dancer because I'm also dyslexic and dyspraxic.

In the same year as I got my MS diagnosis, a friend of mine's partner was making a play about a circus performer whose female partner runs off to become a burlesque dancer. The girl that was supposed to do it dropped out and so I ended up in the play completely by chance, but I loved it.

Later that year, I was in New York with an incredible theatre company and we went to this burlesque lounge called the Slipper Room. While we were there, I asked the promoter if I could perform in one of the shows. He agreed that I could in a couple of weeks' time, luckily I was there for three so I just grabbed what I could and made a costume. At this point, I'd never actually performed live.

After that, I got hooked and thought, instead of hiding my body when I became disabled, why not show it off? For the first three years, I was performing with a walking stick a lot of the time because my balance was so off. My left side was spasming and I couldn't see out of my left eye a lot of the time but I could still perform.

Can you share a bit more about your MS diagnosis? What were some of your initial symptoms?

It was almost like going into Alice in Wonderland. I was having issues with my eyesight and my vision was woozy to the point that I woke up one morning thinking I was hungover. I had also begun fainting but put that down to overworking or having too much coffee.

Luckily, living in Liverpool means we have the St Paul's Eye Hospital and they booked me in for an MRI. Initially I was told that I had either a brain tumour or MS, which was terrifying. I did a lot of research that week. When I got my MRI results they confirmed it was MS but at that point there wasn't enough scarring to be diagnosed officially or to get any medication. I had to wait for over a year until I could be officially diagnosed.

How did the diagnosis affect your work?

I was a workaholic and I suppose that my diagnosis helped in some ways. I used to be a digital artist and I would be on the computer for 15 or 16 hours a day, smoking cigarettes, drinking way too much coffee, sleeping for only six hours and then getting straight back onto the computer again. I realised I couldn't be on a computer for this long anymore and that's when I decided that cabaret and burlesque was something I could actually do.

"For the first three years, I was performing with a walking stick a lot of the time because my balance was so off. My left side was spasming but I could still perform."

Have you been learning any new skills recently?

My plan for life is to live like I have four and a half years to live. If you live like you only have a day then you would get arrested, but if you live like you've got four and a half years, then there is still time for naps.

With that in mind, I've been keeping as busy as possible through lockdown and making the most of the time. I've been trying new songs on my ukulele and I'm also learning guitar which is really good for my brain. When I'm having really bad brain fog I feel better after I sing and play. I have been learning ventriloquism as well.

What have you learnt about yourself over the past year and what are you hoping to take forward?

I think I realised that I'm actually an introvert who's only an extrovert when they get paid for it. I really enjoy wearing no make up with my hair up in a scrunchie and comfortable clothing on.

Because for me, Diva Hollywood is so associated with when I got sick, I do talk about my illness and invisible disability when on stage. I think I've missed being able to be the most super version of myself and forgetting about how I feel or my illness because you're always working towards something. I call myself wonky and wonderful. I'm always working on new acts and I host shows as well. I've been working with an amazing performer in Brighton who has helped me to write an Arts Council bid because I want to take my art practice further and use all of the skills I've mentioned.

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