

May 2021

# Open Door

Quarterly magazine of the MS Trust

Multiple  
Sclerosis  
Trust

MS

**What got you  
through  
lockdown?**

We share your photos  
and stories

## **Get involved**

Why Charlie chose to get on his bike to raise money

## **Walking difficulties**

Getting your walking back on track after months in lockdown

## **Stem cell transplantation**

We speak to an expert for answers to common questions on this treatment

# Welcome to the May issue of Open Door



Hello and welcome to the May issue of Open Door. It's been a busy few months at the MS Trust. We've been hard at work keeping you updated on all of the latest Covid-19 vaccine news as the rollout continued across the country. We've also

successfully run our first virtual conference and shared the stories of dozens of people with MS and how they have coped over the last year as part of our *'Me, MySelf and I'* campaign for MS Awareness Week. We've collated some of these stories for you to view on pages 12 and 13.

Also in this issue we take a look at some recent research on the delay between taking a DMD and actually noticing an impact, known as therapeutic lag (page 7), plus we look at the relationship between MS and ethnicity (pages 8 and 9). We also speak to Professor Basil Sharrack, a consultant neurologist whose work focuses on stem cell transplantation in people with MS (pages 18 and 19).

While I have this space, I'd also like to take a moment to thank all of our wonderful and loyal supporters who have supported the MS Trust over the last 12 months. Without you, the charity might not have survived as it's no secret that the last year has

been extremely challenging for many charities. From virtual quizzes, to running around your local park, we've been so impressed with the ways you have found to continue to raise money to support people with MS.

Just one example of many, is our long time collection tin supporter Allison and her friend Rachel from West Street Newsagents in Chipping Norton. Inspired to do more, Rachel added a selection of second hand books next to the collection box and has raised a whopping £908.55 since the start of the pandemic. What a fantastic result! You have all stepped up magnificently to the challenge and the whole team here at the MS Trust would like to say a huge thank you.

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

**David Martin, Chief Executive, MS Trust**



**To donate £3 to cover the costs of Open Door text OPEN25 to 70331**

Texts charged at standard network rate. For T&Cs, see [www.easydonate.org](http://www.easydonate.org)

## What's inside?

### 3. Latest MS news

Virtual conference, our information services and latest drugs news.

### 6. Research updates

Do medicines improve fatigue and how long does it take for an MS drug to work?

### 8. Who gets MS and why?

A look at research on who actually gets MS and what role ethnicity may play.

### 10. Talking to health professionals

What has it been like to work as an MS health professional during the pandemic?

### 12. What got you through lockdown?

A look at the charming and inventive ways many of you managed to cope over the last 12 months.

### 14. Walking difficulties

Advice on getting your walking back on track after months of lockdown.

### 16. Mindfulness

We talk to Paula about how her mindfulness practise has helped to ease her MS symptoms and support her mental health.

### 18. Stem cell transplantation

We pose common questions to stem cell expert Professor Basil Sharrack.

### 20. Meet the fundraising team

A quick introduction to the team who guide you through your fundraising activities.

### 21. Get involved

Meet Charlie an inspiring young man who chose to raise money for his Aunt.

### 22. 15 minutes with...

Sam is a Friend of the MS Trust who recently completed Miles for MS.



Multiple Sclerosis Trust, Spirella Building,  
Bridge Road, Letchworth Garden City, Hertfordshire SG6 4ET  
T 01462 476700 E [hello@mstrust.org.uk](mailto:hello@mstrust.org.uk) W [mstrust.org.uk](http://mstrust.org.uk)  
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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](https://mstrust.org.uk/keepintouch)

# Latest MS news

## New podcasts launched as part of MS Awareness Week

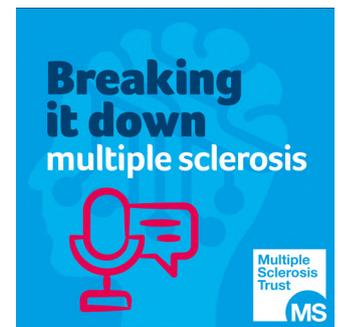
**The last 12 months have been unlike any other. This MS Awareness Week we highlighted the stories of people with MS who have dealt with so much uncertainty over the last year.**

On top of the restrictions, worries about jobs and the health of family and friends; people with MS have also had to contend with delays to the MS services they rely on. This MS Awareness Week we wanted to tell the stories of the people behind the statistics and highlight the urgent need to get MS services back on track.

During the week itself we launched a new podcast series called *'Me, MySelf and I'*, where we talk to people from the MS community about their experiences with MS and how the last 12 months have impacted on them. From being diagnosed during lockdown, to starting a new job remotely.

All of the MS Trust podcasts can be found by searching *'Breaking it down – A multiple sclerosis podcast'* on any of the major podcast streaming platforms, Spotify, Apple, Google podcasts and Amazon music. You can also access all of the MS Trust's podcasts at [mstrust.org.uk/ms-podcasts](https://mstrust.org.uk/ms-podcasts)

They cover a wide range of subjects including mental health in the *'It's all in your head'* series, and there are also episodes on bowel habits and sleep problems.



## New disease modifying drugs approved for RRMS

**At the end of April, Novartis announced that their new drug for relapsing remitting MS had been approved by NICE for use on the NHS in England and Wales.**

Kesimpta (ofatumumab) has been shown to be more effective in clinical trials compared with Aubagio (teriflunomide). You take Kesimpta with a self-injecting pen once a month, once a health professional has trained you. The drug binds to and destroys selected white blood cells (B-cells) that are involved in MS.

David Martin, MS Trust CEO, said *"We're delighted that ofatumumab has been approved by NICE. People with MS need access to a range of treatments so that they can work with their consultant to find the one that suits them the best. Ofatumumab offers access to an effective treatment which doesn't require regular hospital visits."*

April also saw the MHRA (Medicines and Healthcare products Regulatory Agency) and European Commission grant marketing authorisation for an under-the-skin (subcutaneous) injection of Tysabri.

Clinical trials have shown that monthly subcutaneous injections of Tysabri are as effective as monthly infusions at reducing relapses and lesions seen on MRI scans.

It currently takes several hours to have a Tysabri infusion in a hospital clinic and some people have to travel a long distance to get to their infusion clinic. However, subcutaneous injections will take considerably less time and could be given monthly by a health professional in a clinic closer to home, such as at a local hospital or health centre.

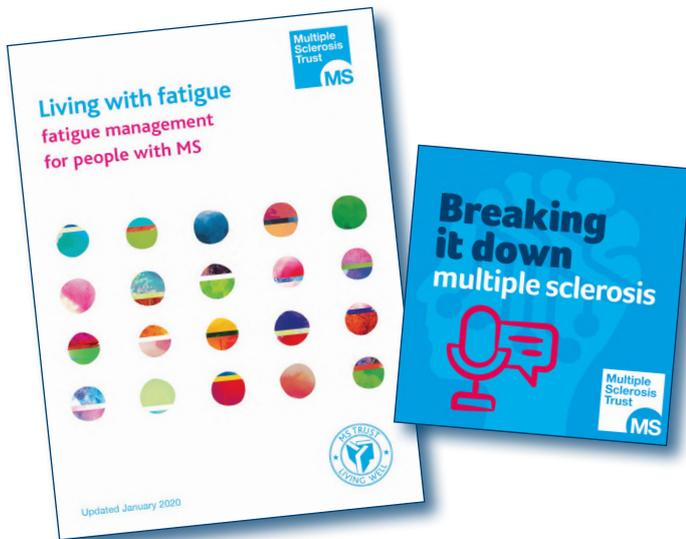
To read more about the drugs currently in development for all types of MS you can visit [mstrust.org.uk/drugs-development](https://mstrust.org.uk/drugs-development)

# Information Services at the MS Trust

We hope you're enjoying this spring edition of **Open Door**, and find it a useful source of information. Do you know about all the other information and support services we offer?

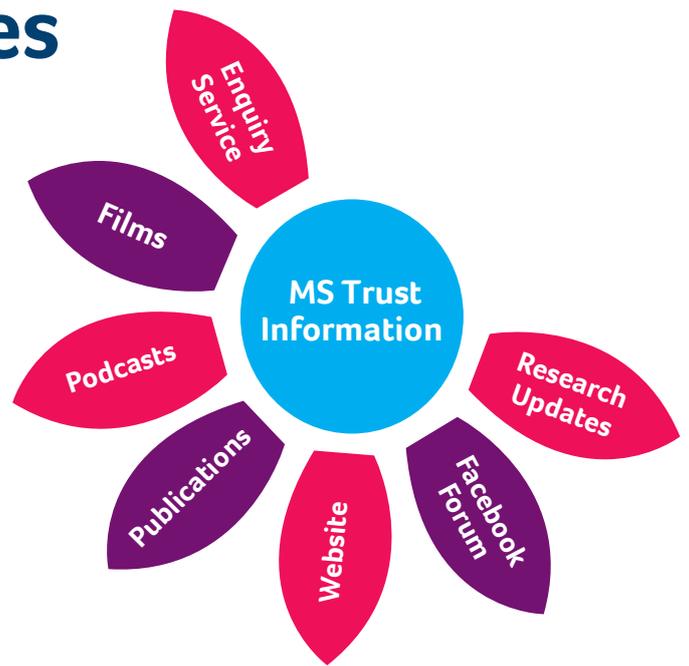
The MS Trust Information Team consult people with MS and work closely with expert health professionals to create evidence-based guidance tailored for the MS community in the UK. You can read, listen to and watch our information online, in print, and on the go.

Perhaps the first place to start is our extensive website. You can look up details on specific topics in the A-Z, as well as browsing for general knowledge on how to live well with MS. If you prefer to have printed books and leaflets, you can order them for free through our shop, although you can also get a digital copy sent to your inbox to keep and share as you need. [shop.mstrust.org.uk](http://shop.mstrust.org.uk)



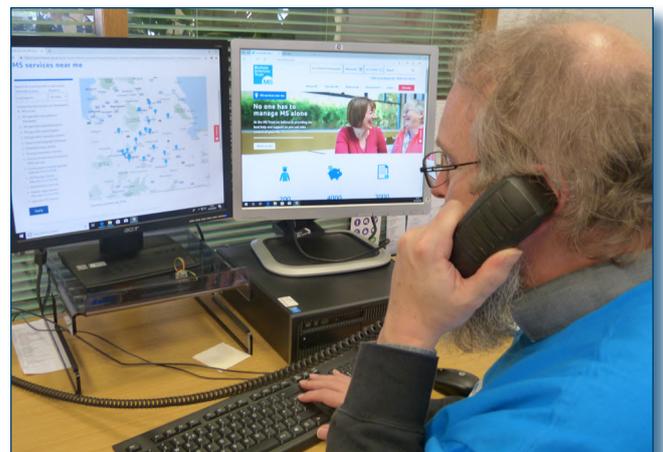
Our mobile app holds all the publications as well, so you can have them with you on the go. If you prefer to absorb information through film or audio, you might like to check out the MS Trust podcast: *Breaking it down*, or see what's on our two dedicated YouTube channels, MS Trust and MSTV for children and young people affected by MS.

Thousands of you already subscribe to the Research Update, where we sift the newest scientific research and explain how it could be relevant to you. And if you're looking for other people with MS to share ideas and support with, then our Facebook forum could be just what you are looking for [facebook.com/groups/multiplesclerosisistrust](https://www.facebook.com/groups/multiplesclerosisistrust).



If you have a specific question about MS, then you can ask the friendly and knowledgeable Enquiry Service. We aim to make sure you have the information you need to make informed decisions, and can talk you through the options open to you, or send you a detailed email or letter with the details you need [ask@mstrust.org.uk](mailto:ask@mstrust.org.uk).

All of these services are absolutely free to use, as much or as little as you need. If we've helped you make sense of MS in the past, we'd love you to consider a donation to allow us to carry on helping other people in the future [mstrust.org.uk/donate](http://mstrust.org.uk/donate).



# The first virtual MS Trust Conference

**Earlier this year the MS Trust were excited to hold our annual conference virtually for the first time. We were delighted to welcome nearly 500 MS specialists and delegates, who came together over three days to learn about the latest developments in the MS sector and how they can make a difference to people with MS.**

Despite being virtual, the programme boasted a whole host of MS experts including leading neurologists Professor Gavin Giovannoni, Professor Alasdair Coles and patient advocate Caroline Wyatt (BBC journalist), to name just three. The subjects discussed were hugely varied, from respiratory function, management of spasticity, paediatric MS and relapse management, through to mindfulness, acceptance and commitment therapy (ACT) and self-care. The main focus throughout each of these sessions was commitment to improving the care and treatment for people living with MS.

During a discussion with leading MS professionals and neurologists, the stark reality of the impact of Covid-19 on MS services was highlighted. Referrals from GPs to neurologists were down by 20% over the previous 12 months, there was also a reduction of between 20%-40% (depending on region) in the prescription of DMDs. The pandemic exacerbated existing socio-economic discrepancies, for example for some people with MS,

the need to work from home provided a welcome relief from the daily commute, however others in lower paid jobs weren't afforded that luxury.

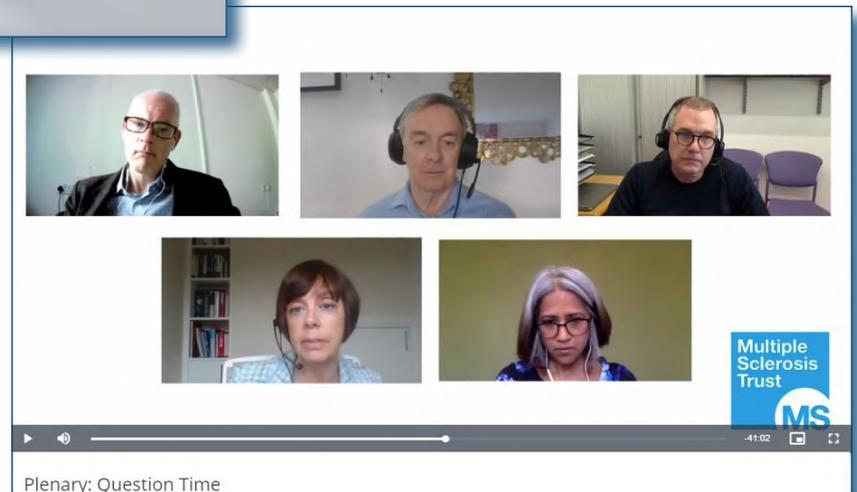
It was widely agreed that changes in service provision will be needed to address the impact that Covid-19 has had on already stretched MS services. Future services could include more phone appointments, the development of online resources to support people with MS and examine the use of more self-management tools. A report on the current challenges facing MS services was launched at the conference, 'NHS reset and reform' a link to it can be found at [mstrust.org.uk/reset-and-reform](https://mstrust.org.uk/reset-and-reform)

Following the conference we had some really positive feedback that despite the challenges of using a virtual platform, so much knowledge was still shared, which will ultimately be used to improve the lives of people living with multiple sclerosis across the United Kingdom.



*"I really enjoyed the conference and came away inspired and excited about caring for people with MS, it was just what I needed after the last 12 months. I found the virtual platform brilliant and felt I could concentrate on the lectures better as there were fewer distractions." – Conference attendee*

*Just an excellent and informative conference. Really enjoyed it! Thank you. Great to have patient's perspectives on therapy/treatments. I found Caroline's presentation particularly moving and so well delivered! Well done. – Conference attendee*



# Do medicines improve fatigue in MS?

**Fatigue is one of the most common symptoms of MS and can have a major impact on people's lives. Clinical trials of medications for fatigue have given mixed results. The aim of this study was to compare the effectiveness, safety, and acceptability of amantadine, modafinil, methylphenidate and placebo in people with MS-related fatigue.**



## The study

Two MS clinics in the United States recruited 141 participants with MS who were affected by fatigue and had low to moderate disability.

Participants were assigned to take each of the medications or placebo in one of four sequences. They started taking one medicine and took it for six weeks, followed by a two-week washout period and repeated this process for all four treatments. Neither participants nor the researchers knew which medication they were currently taking.

Methylphenidate, also known as Ritalin, is a central nervous system stimulant used to treat narcolepsy and attention deficit hyperactivity disorder. In the UK it is rarely used to treat MS fatigue, but it is sometimes used in the United States.

Fatigue was measured at the beginning of the study using the Modified Fatigue Impact Scale (MFIS) and again during week five of each treatment period. MFIS is a questionnaire which you complete yourself. It assesses the impact of fatigue on different aspects of daily life: physical activity, thinking processes and taking part in social activities. People were included in the study if their MFIS was 33 or more out of a maximum score of 84. Participants also completed the Epworth Sleepiness Scale (ESS) which measures daytime sleepiness and a questionnaire which assessed the impact of fatigue on quality of life.

## The results

At the beginning of the study the MFIS score was 51.3 out of a maximum possible score of 84 for the worst fatigue. MFIS scores improved with all treatments, including placebo:

- 51.3 at baseline
- 40.6 with placebo
- 41.3 with amantadine
- 39.0 with modafinil
- 38.6 with methylphenidate

There was no significant difference between any of the treatments.

For more information visit: [mstrust.org.uk/fatigue](https://mstrust.org.uk/fatigue)



When the data was analysed more closely, those people who had excessive daytime sleepiness at the start of the study (ESS greater than 10) had improved fatigue levels while taking modafinil and methylphenidate, compared to placebo. In people with no excessive daytime sleepiness, there was no significant difference in fatigue levels between any of the treatments and placebo.

Side effects were more common with the three medications than with placebo, affecting 39% of participants on amantadine and 40% on modafinil and methylphenidate, compared with 31% on placebo.

## What does it mean?

The design of the study reduced the likelihood that participants could guess which drug they were currently taking; in studies which compare a single fatigue drug with placebo, side effects can allow participants to recognise when they are taking the active treatment, and this can influence the results.

Overall, the results of this study suggest that none of the medications is more effective than placebo at reducing fatigue levels. However, there was some indication that modafinil and methylphenidate could be beneficial if daytime sleepiness contributes to fatigue levels.

The researchers concluded that the lack of effect on fatigue levels compared to placebo, and the increased risk of side effects, do not support the routine use of amantadine, modafinil or methylphenidate for treating fatigue in MS.

## Find out more...

You can learn more about techniques for managing fatigue in our A-Z [mstrust.org.uk/fatigue](https://mstrust.org.uk/fatigue) or in our book [shop.mstrust.org.uk/living-with-fatigue/](https://shop.mstrust.org.uk/living-with-fatigue/) which you can read online, download or order as a printed version.

Authors: Nourbakhsh B, et al.

Title: **Safety and efficacy of amantadine, modafinil, and methylphenidate for fatigue in multiple sclerosis: a randomised, crossover, double-blind trial.**

Journal: **Lancet Neurol.** 2021 Jan;20(1):38-48.

Read the full study: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7772747/>

## RESEARCH UPDATE

# How long does it take for an MS drug to be fully effective?

In relapsing remitting MS, disease modifying drugs (DMDs) work with different parts of the immune system to reduce the inflammation caused by MS to nerve cells in the brain and spinal cord. This helps reduce the number and severity of relapses and the build-up of disability which can occur if you don't recover completely from relapses.

It's known that there is a delay between starting a DMD and getting full benefit, described as 'therapeutic lag', but how long this is for individual DMDs is not clear. Two recent studies have investigated how long it takes for a DMD to be fully effective and the factors that might affect therapeutic lag.

### The study

This large study combined data from the multinational registry, MSBase, with a French MS registry and one UK MS clinic. Medical records up to the end of 2018 were selected for people with at least three years of clinical data prior to treatment and one or more years of data while taking a DMD. Relapse rate and disability levels in the three years before treatment and during at least one year of treatment (for the effect on relapses) or at least five years of treatment (for the effect on disability levels) were compared. The researchers analysed the data to estimate therapeutic lag for each of the DMDs – the point at which relapse rates and disability levels became stable after a new treatment was started.

### The results

Researchers identified records with the required data from just over 9,000 people. These provided 11,180 treatment periods for analysis of relapse therapeutic lag and 4,088 treatment periods for analysis of disability level therapeutic lag. There was not sufficient data to calculate therapeutic lag for two recently introduced DMDs, Mavenclad and Ocrevus.

Overall, therapeutic lag for relapses was three to seven months. Copaxone and Gilenya had the shortest therapeutic lag, while Tecfidera had the longest. Therapeutic lag for disability was longer, ranging from seven to 16 months.

Pre-treatment relapse activity and disability level appeared to have the greatest impact on therapeutic lag. For relapse activity, a longer therapeutic lag was associated with women, higher initial EDSS and lower initial relapse rate. For disability, a longer therapeutic lag was associated with men, higher EDSS and higher initial relapse rate.

### What does it mean?

The results confirm that there is a therapeutic lag for all the DMDs and this should be taken into account when assessing MS activity, particularly during the first few months after starting a DMD. If you have a relapse during the first six months of treatment it does not necessarily mean that your DMD is not working, and most neurologists will recommend that you continue with the treatment for at least one year.

More importantly, the results have implications for the design of clinical trials for new MS treatments, particularly those for progressive MS where disability levels are the main measure of success. These two studies have shown that it can take up to 16 months for a DMD to have a full effect on disability progression; people with higher initial disability levels may also take longer to respond to treatment. Clinical trials longer than the standard two years may be needed to fully assess the potential of a new treatment to slow down, stop or reverse disability progression.

### Find out more...

You can read more about the disease modifying drugs for relapsing remitting MS in MS Decisions [mstrust.org.uk/ms-decisions](https://mstrust.org.uk/ms-decisions) or our booklet Disease modifying drugs which you can read online, download or order as a printed version from our shop at [shop.mstrust.org.uk/disease-modifying-drugs](https://shop.mstrust.org.uk/disease-modifying-drugs)

Authors: Roos I, et al.

Title: Delay from treatment start to full effect of immunotherapies for multiple sclerosis.

Journal: *Brain* 2020; 143(9): 2742-2756.

Read the full study: [https://www.medscape.com/viewarticle/940343\\_1](https://www.medscape.com/viewarticle/940343_1)

Authors: Roos I, et al.

Title: Determinants of therapeutic lag in multiple sclerosis.

Journal: *Multiple Sclerosis Journal* 2021:1352458520981300.

[Epub ahead of print]

Read the summary: <https://pubmed.ncbi.nlm.nih.gov/33423618/>

# Who gets MS and why?

**The number of people being diagnosed with multiple sclerosis around the world is increasing.**

**In this article we take a look at recent research which investigates who might be more susceptible to multiple sclerosis and why that might be.**



Around the world, MS diagnoses are on the increase. Multiple sclerosis is most common in Northern Europe, North America, Australia and New Zealand. These countries have majority populations of Nordic and European heritage, leading to suggestions that there is a link between MS prevalence and 'Viking genes'. However, these countries share other factors, such as similar diets, lifestyle, obesity rates and industrialisation. Countries in the Middle East and South Asia have reported rising MS prevalence alongside increasing adoption of 'Western lifestyles', and there are similar demyelinating conditions that are common in East Asia and South America.

It's easy to forget that genetic diversity in humans doesn't just mean skin colour. Most genetic diversity is not something you can see when you look at a person - it's the highly variable pattern of proteins on the surface of your cells, known as your haplotype. Researchers have identified dozens of haplotypes that are associated with a higher risk of developing MS. Many of these are more common in Europe and Scandinavia than elsewhere, but they are not restricted to people of European or Scandinavian ethnicity.

Of course, genetic susceptibility is only part of the picture. Most people with susceptible haplotypes never develop MS. Researchers think that there is likely to be a trigger that sets off the chain of events in your body that leads to multiple sclerosis. The most likely triggers are some kind of environmental factor, like your diet, smoking, vitamin D levels, viral infection or local air quality.

For environmental triggers, your personal risk is based on where you grew up, not your ethnicity. People who move between countries as adults retain the risk profile of the place they lived as children. Their children and grandchildren take the risk profile of the place that they grow up, irrespective of their ethnic heritage. So, if there is a link between MS and countries with 'Western' lifestyles, then it is shared by everyone who lives there, whatever their ethnic heritage.

## **Does MS affect ethnic groups differently?**

Researchers have been concerned for some time that MS affects people differently, which might lead to inequalities of health care. A recent study in London showed that there was a higher prevalence and incidence of MS in White people than Black and South Asian people. However, once diagnosed, other studies have shown that Black people in both the UK and US are likely to notice their MS progress faster and become more disabled at a younger age than White people.

The Marmot Review published last year reported on the impact of social inequality on health in the last decade. As the report makes clear 'Inequalities in health arise because of inequalities in society – in the conditions in which people are born, grow, live, work and age'.

Social inequalities can affect people's trust and engagement with medicine, and the quality of the care they get. We have seen this during the pandemic where people from some ethnic groups have been more at risk of

severe disease, but also less likely to take up vaccines. A lack of awareness of MS within some ethnic groups, coupled with delays in seeking medical advice or delays in referral to specialists could result in a delay in diagnosis. This may explain the worse outcomes for Black people with MS – they are further along their MS journey when they reach the neurologist.

Different MS symptoms are more common in different groups of people too. Cognition problems are seen more often in Black people with MS than other people with MS. Although rates of optic neuritis are similar in Black and White people with MS, for Black people it tends to be more severe and cause greater visual disability.

And then there is the overall impact of MS on employment and everyday life. Unemployment rates in the US are higher in Black people with MS than in White people with MS. People in some ethnic groups, both here and in the US, may be more likely to be employed in physically demanding jobs such as hospitality, health, or social care. As a result, if they are affected by disability in MS, they are more likely to have to retire or leave work.

Someone who is able to pay for exercise classes, and can afford additional medicines and healthy food is less likely to experience disability progression in MS. Where people have a reduced income due to unemployment, this has a direct impact on how well they can live with MS. Although financial inequality can affect everyone, people from Black and other ethnic groups may be more likely to be pushed into poverty by MS.

### Should MS be treated differently in different ethnic groups?

A recent study from the US found that Black people with MS were more likely to have adverse reactions to beta interferon DMDs, and they were less likely to do well on tablet based DMDs. The same study showed that White people tend to find that

glatiramer acetate is less effective for them than it is for Black or Asian people.

MS is an unpredictable condition. When you and your neurologist discuss the best disease modifying drug (DMD) for you, you are both trying to balance the risks of the DMD against the risk of you experiencing severe MS related disability. 'Watch and wait' has been a fairly common approach to MS treatment in the past, but if your ethnicity means you are more likely to progress faster, then you might prefer to move to more effective treatment options sooner.

### What next?

MS affects everyone differently, making it harder to spot these trends. However, the good news is that researchers are now looking directly at health inequality among people with MS across the UK, aiming to ensure that everyone gets the health services and support that they need. The aim is to ensure that every health professional working in MS understands the impact of inequality in MS and how to combat it. We are doing our part to shine a light on inequalities in MS care, and to ensure that the voices of all people with MS are heard.

### Further reading

You can find the complete list of research used in writing this article in the online version.

- Harding KH, et al. **Socioeconomic status and disability progression in multiple sclerosis.** *Neurology* 2019;92(13):e1497–e1506.
- Professor Sir Michael Marmot, et al. **Institute of Health Inequity: London; February 2020:** The Marmot Review 10 Years On.
- Romanelli RJ, et al. **Multiple sclerosis in a multi-ethnic population from Northern California: a retrospective analysis.** *BMC Neurology* 2020;20:163.
- Albor C, et al. **Ethnicity and prevalence of multiple sclerosis in East London.** *Multiple Sclerosis* 2017;23(1): 36–42.

*“There are lots of factors that can influence someone’s overall chances of better outcomes following a diagnosis of MS and we can’t ignore that someone’s ethnicity might be one of them. Whether that’s because of genetics, cultural influences that can make it harder to manage the disease, and/or socio-economic factors that are more prevalent in certain ethnic groups.*

*As a British Asian living with MS, I think it’s really important that research is being conducted so we can unpick these various threads and optimise personalised and holistic support for everyone living with the condition. One of the questions I asked when I was diagnosed was simply “How many other Asians in the UK live with MS”? Nobody could tell me. Even now there is limited data available. Let’s continue this conversation so we can find out the answers!”*

**Trishna, person living with MS.**



# Talking to Health Professionals

**Gowri Saravanan**

**Gowri Saravanan** is the only Neurology Specialist Nurse for NHS Shetland. We caught up with Gowri to find out what the past year has been like and how NHS services in Shetland were affected by the global pandemic.

## Hi Gowri, it's great to speak with you! Can you share with us a bit about when you first become an MS health professional and what made you want to become one?

I have been an MS Specialist Nurse since October 2019. When I started my training to become a Neurology Specialist Nurse, I developed a passion towards understanding MS diagnosis and the impact it has on a person's daily life, and how we can support them.

## What's your favourite thing about your job?

Working with people with MS. To be a part of their journey and see what support we can offer to improve their daily life. Our service is provided by the Consultant Neurologists from NHS Grampian and I feel very much supported by the Neurology team.

## How has your role changed over the last year, due to the pandemic?

I am the only Neurology Specialist Nurse in Shetland and was redeployed briefly during the pandemic. However, I was able to continue to provide support to people with MS by telephone, emails, and the 'near me' secure video call system to make sure services were continued and patient's needs were met.

## What were your initial thoughts and feelings on these changes?

We did not know what impact Covid-19 would have in Shetland initially and the numbers of cases have been low in comparison to mainland Scotland. However, we knew there would be a big

impact on people who were vulnerable but we managed to make sure that there was continuity of care for existing patients and those newly diagnosed.

## What are some of the biggest changes you've faced over the past year?

The biggest challenge for me has been managing MS services remotely for the majority of patients as they could not come into the hospital due to Covid restrictions and shielding.

## Looking to the future, what are you hoping for regarding MS services?

Through the MS Trust, I have recently managed to complete my MS development module which helped me to acquire new knowledge on MS diagnosis, management and planning the service development to fulfil patient needs.

I am planning to support the Neurology Consultant and the wider multi-disciplinary team in implementing new services available for the benefit of people with MS. For example, fampridine and siponimod have been approved to be used within Scotland and it's proposed to have them available for NHS Shetland patients in the near future. I am keen to provide support towards this for the benefit of MS patients in NHS Shetland.



# Talking to Health Professionals

*Mavis Ayer*

**Mavis Ayer** is an MS Lead Nurse at University Hospital Southampton NHS Foundation Trust. We spoke with Mavis about her experiences as a health professional and how the last year has seen MS services challenged in a way never seen before.

## Hi Mavis, lovely to speak with you! Can you tell us about when you first became an MS health professional and why it was a role that appealed to you?

Yes. I was first drawn to multiple sclerosis because of my interest in neuroscience and I became an MS health professional six years ago. I also wanted a role which offered a better work-life balance than the job I was in at the time.

## How has your role changed over the last year, due to the pandemic?

My role over the past 12 months has changed massively! The services we offer all became virtual and we had to adapt very quickly with new technology, constantly changing advice and the ever evolving uncertainties that came with the pandemic. All this while considering how it would affect our patients.

## Were you or any of your team redeployed to help out in other areas of the NHS?

Although I was not personally redeployed, some of my nurses were in the first wave of the pandemic. I actually volunteered to be redeployed during that time but it wasn't practical as I was leading a team in charge of managing MS services. In the second wave, I was unfortunately affected by Covid-19 myself, which meant that I couldn't be redeployed.

## What are some of the biggest challenges you've faced over the past year?

As I mentioned previously, managing the uncertainty of the situation, facing our own fears while trying to manage our patients' fears and worries.

The ever changing advice on DMDs, vaccinations and shielding have all been huge challenges for myself and the team around me.

## Looking to the future, what are you hoping for regarding MS services?

Although it has been a challenging year, I think it's important to reflect on what we have learned and to keep going with those things that have worked well, such as virtual consultations, for example.

It's also important to remember to look after ourselves as clinicians, take care of our mental health, wellbeing and building resilience so that we can be at our best, both for our patients and ourselves.

**The MS Trust believe strongly that everyone with MS in the UK should have access to MS specialists regardless of where they live, or the type of MS they have.**

We are pleased to have recently been able to restart our Specialist Nurse Programme, which was paused last year due to the pandemic. We are now working closely with NHS organisations around the UK to improve access to MS specialist nurses and to support MS service improvement as a part of the programme.

We are also pleased to announce that we are currently recruiting for an additional MS nurse to be based at The Walton Centre in Liverpool to support across the North Wales area.

**For more information on the Specialist Nurse Programme visit**

[mstrust.org.uk/specialist-nurse-programme](https://mstrust.org.uk/specialist-nurse-programme)

# What got you through lockdown?

As talk turns to a possible end to social distancing restrictions and a return to some form of normality, we reflect upon a year of challenges which saw us take part in more virtual catch ups, home baking and outdoor exercise than ever before. Here's what you had to say about what helped you through the last year...



"I decided to take this time and reflect on my life and what I could change to help myself. I started upcycling furniture which I've really enjoyed and has boosted my wellbeing."

**Ella**

"I took up outdoor swimming. I've met some great people and it has helped improve my mood and the inflammation in my legs." **Cheryl**

"Learning Italian on Duolingo, just for the fun of it! It's keeping my brain busy and I'm definitely sleeping better. Will have to go to Italy post lockdown!" **Wendy**

"Myself and three friends ran 60 miles each and we raised a few quid for Open Door. I also drank a lot of wine, but not at the same time." **Ann**

"Being in lockdown I had to try and keep active, so I decided to build a pizza oven from scratch for my garden. A big challenge, but I am determined I WILL get this up and running before spring this year." **Stefano**



"Poetry is what got me through being diagnosed with secondary progressive MS during the second lockdown as well as my wonderful family, friends, partner and MS nurses."

**Carly**

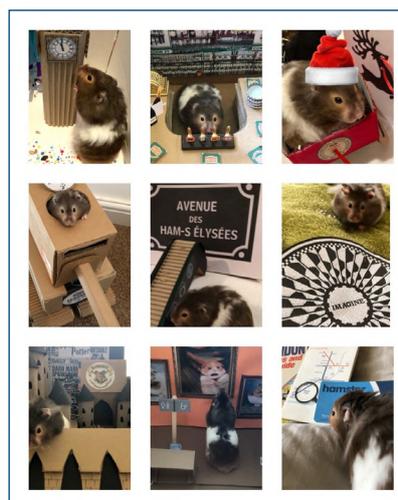
Live in my garden,  
They've sun bathed and slithered all over the Arden!  
A magical place where trees and creatures survive  
and mythical dreams which come alive!  
Shakespeare once wrote in his time,  
But my magical snails they sleep all the time  
dreaming of midsummer when it is their time,  
So then they will slither until it is night writing their  
message this is their plight!  
And one day will come that will see them in flight  
But for now my magical snails can sleep  
Peacefully tonight.

—C.J.



"Horses have been my life, and though MS is limiting the amount of horse care work I can do, during lockdown I have been developing my training. My horse has been out of work, but having been given the all clear from the vet I am now getting back in the saddle myself." **Ros**

"Good friends, family and a hobby got me through lockdown. I am part of a wargames club so set up a WhatsApp group together with some fellow gamers in Manchester which was a great help. I assembled a huge number of plastic figures and painted some up, which is great therapy. We are all looking forward to meeting up again to pursue our gaming activities in the near future." **Dave**



"While most of us haven't left the house, Spud the hamster, has had many, many adventures. Being a self-employed pet sitter, battling with my MS as it progressively got worse, my work dried up and I worried about my future. Spud kept me going and sane during this period. Creating these adventures has enabled me to remain

focused and given me a reason to keep going and not give up! I owe that boy so much. During lockdown, Spud has been to the art gallery, Coronation Squeak, wizard school 'Hamwarts', London, into space, on a staycation, Hammywood, New York, joined the Army, then to Hong Kong, Paris (as Hamkys), Ham-waii (when the snow here got too much) and Hamsterdam." **Lisa**

"I was working at home through the lockdown and still am as I work in a primary school and am high risk. To keep me busy I continued to cross stitch - one of my favourite hobbies. One of my work colleagues and dear friends, Pauline loves cross stitch too so I roped her in to help! I made the boy, Pauline made the girl. To us they represented our school children, their bubbles and the tree of life and hope." **Dawn**



"I painted almost everyday during lockdown. The BBC said that we should place our most recent paintings in the windows of our front room at home which I did. The one on the top left was done many years ago when I was able to go sailing. Underneath that is my youngest daughter, Sophie, with the baby Emilie she had just given birth to. We have six grandchildren now." **Mike**



"I was diagnosed with MS in the first lockdown and I have managed to get through this last year with the support of my husband, children, friends, colleagues and dogs! I have many hobbies including knitting, crocheting and sewing and have made many face masks for my friends and colleagues who have made donations to the MS Trust raising £197.00 so far. I have a classic car, Doris the Morris, who my husband completely refurbished, who I love and I am looking forward to being able to drive her this summer." **Jill**

**We know that lockdown hasn't been easy. If you've found it particularly difficult, there are plenty of charities and resources out there who can help.**

- MS Trust enquiry service - **email:** [ask@mstrust.org.uk](mailto:ask@mstrust.org.uk) **phone:** 0800 032 3839
- Samaritans - **website:** [samaritans.org.uk](http://samaritans.org.uk) **phone:** 116 123 **email:** [jo@samaritans.org](mailto:jo@samaritans.org) for a reply within 24 hours
- **Text "SHOUT"** to 85258 to contact the Shout Crisis Text Line, or text "YM" if you're under 19
- If you're under 19, you can also call 0800 1111 to talk to Childline.
- NHS Every Mind Matters [nhs.uk/oneyou/every-mind-matters/](http://nhs.uk/oneyou/every-mind-matters/)



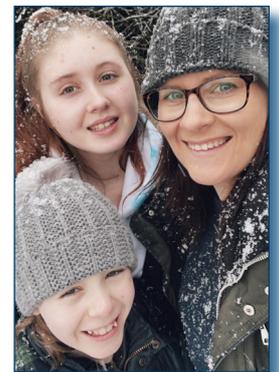
"This little bundle of fun has helped us through lockdown and she doesn't even know it. Molly was born on the 9 August and it's been a whirlwind ever since! Lockdown will end before we know it and we will look back and wonder whatever did happen to 2020!" **Wes**

"Friends and family have got me through lockdown, plus my love of art. I paint and have been invited to many virtual exhibitions!" **Carol**



"Finding out the wonderful news that my husband and I are expecting our first baby in July. I was amazed to learn that MS symptoms are suppressed during pregnancy. Due to this, I am the most active I have been since my diagnosis two and a half years ago. With this new found energy, I have been able to enjoy pre-natal yoga sessions online, go on daily walks, meditate and read." **Jo**

"My girls, Beth and Abbie got me through lockdown, walking our little dog, Shelby in the sunshine and the snow too of course. They keep me smiling; I'm very lucky." **Clair**



"In 2020 I spent a lot of time making masks and bookmarkers for the MS Trust and the NHS. I also made a few MS bunting." **Stephen**

"I got back into crocheting. I'm trying to learn a new pattern every week and enjoying it enormously." **Lesley**



## WALKING DIFFICULTIES

# Getting your walking back on track after lockdown

Staying active may have felt more difficult over the last year. With fitness centres closed, limitations on leaving the house and multiple lockdowns affecting our motivation, many people may not have been as physically active as they'd usually be. If MS affects your walking and you haven't been as active over the last year, you may have noticed some changes in your walking ability. To help you start to get back to where you were, we spoke to neuro physiotherapist, **Rebecca Farrington** who shares her tips for keeping moving and improving your walking.



### How MS can affect your walking

There are lots of MS symptoms that can affect how you walk. Some people with MS may experience reduced sensation or strange sensations in their legs and feet, like numbness or pins and needles. These symptoms can make it difficult for you to tell whether you've placed your foot correctly on the floor.

Other problems that can affect walking include muscle tightness (also known as spasticity), muscle spasms, an increase or decrease in muscle tone, muscle weakness, problems with coordination (ataxia), balance issues, dizziness, fatigue and visual problems. Some people may experience more than one of these symptoms at the same time. These symptoms can all impact how your muscles work for you meaning that walking can become difficult. This can make people feel less confident when walking, particularly if they've had a fall before. Sometimes people might also be using their walking aids wrongly or overusing them. This can impact your posture and the way you walk.

### How a neuro physiotherapist can help

A neuro physiotherapist can help you maintain and maximise your function and movement. We understand how muscles and nerves work, and we have an understanding of MS. We would initially carry out a full assessment to identify the problems you're having with your walking. This would include looking at your range of movement, muscle strength, whether you have any issues with tone or spasms, your coordination and balance, how your sensation is and your core strength. We would assess how you move – that might start by looking at how you move from a seated to standing position and how you get into bed. Then we'll look at how you're moving when you're walking and how far you can walk.

Once we've done a full assessment, we'll give you an individual treatment plan tailored to suit you. This may include a range of specific exercises to help you improve your muscle strength, balance and your core strength. We'll also explain whether we think you'd benefit from using a walking aid or a splint.

Physiotherapists work with you to keep you as motivated and as active as you can be. We may push you to get the most out of you – that's how you make improvements and get your gains.

## WALKING DIFFICULTIES

### What you can do if you've noticed a change in your walking

#### **Ask for help**

If you notice a change in your walking, the most important thing is to ask for help from a health professional. Speak to your consultant or your MS nurse. If you already know your neuro physiotherapist, give them a ring. They may be able to do a virtual call and set you up with some simple exercises to get you started. Services may be running differently at the moment, but they are still there to support you.

#### **Set realistic goals**

Set yourself achievable goals. Be realistic about what you can do in a day. Your goal might be to go for a walk in the garden or down the driveway. Then go a bit further and walk to the next lamppost and then to the end of the road. Set small, achievable goals that you can do daily.

#### **Break it down**

Everyone should aim to be doing 150 minutes of activity each week. This sounds a lot but it can help to break it down. Aim to do 30 minutes of activity a day. You can break it up into short 5 or 10 minute bouts through the day.

#### **Work with your physiotherapist**

Be honest with your physiotherapist about how your treatment plan is going. Are you managing to keep up with your exercises? Are you finding them too easy? Work with your physiotherapist to get the balance right.

#### **Consider your posture**

Be aware of your posture throughout the day. Try standing in the corner for a few minutes every day. Bring your shoulders back and stand up straight and tall. This simple activity activates so many muscles and is a welcome relief from sitting down all day.

#### **Keep moving**

Maintenance is so important when it comes to walking – if you don't use it, you lose it! Do something you enjoy and try to build exercise into your routine so you're more likely to keep it up. Think about what you enjoy doing – whether that's chair-based exercises, an online yoga class or walking up and down the garden – and keep doing it! It's about giving yourself the opportunity to be active and trying to do something that interests you so you can maintain that motivation.

#### **Motivate yourself**

Think about why you want to be active. It's not just about keeping you strong. Is there an end goal you're working towards? Maybe you'd like to be able to walk a certain distance. You can also use tools like step counters to help keep you motivated.

#### **Don't be afraid of using a walking aid**

Don't be afraid to use an aid if your physiotherapist suggests one. Walking can be difficult and it can require an awful lot of concentration. Some people feel like they're giving in to their MS by using a walking aid. But if you use an aid correctly, it can open the world up to you and enable you to go for that walk or do all those activities that you enjoy and do them for a little bit longer.

#### **Find activities to do at home**

Think about activities you could do while doing tasks around the house, for instance, walk around the kitchen table a few times while you're waiting for the kettle to boil. Take the opportunity to do an exercise while your carers are with you. Simply standing up can count as exercise. Why not try moving from a seated position to a standing one five times? If you're safe using stairs, go up and down a few times.

#### **Set some reminders**

If you're a little bit forgetful, perhaps set an alarm a couple of times throughout the day and whenever it goes off, that's your prompt to get up and do an activity.

#### **Be kind to yourself – there will be tough days**

Be realistic and be kind yourself – everybody has bad days. It's about accepting that this may be an off day but there may still be small tasks you have achieved. Have some rest and start again tomorrow.

#### **Don't compare yourself to before**

Don't think about the past and what you were able to do before this pandemic started. You've decided that you want to be more active. Take that positive note and move forward. Make realistic goals that you can achieve each week and celebrate even the small successes.

For more information visit:

[mstrust.org.uk/a-z/walking-difficulties](https://mstrust.org.uk/a-z/walking-difficulties)

**Rebecca Farrington is a neuro physiotherapist who works in a neurology rehabilitation unit at Belfast Health and Social Care Trust.**

# Mindfulness

Paula was diagnosed with relapsing remitting MS 10 years ago, after years of experiencing strange symptoms and trying to be taken seriously by her doctor. She tells us how she has turned to mindfulness over the years to help her manage both her symptoms and her anxiety.

## What is mindfulness?

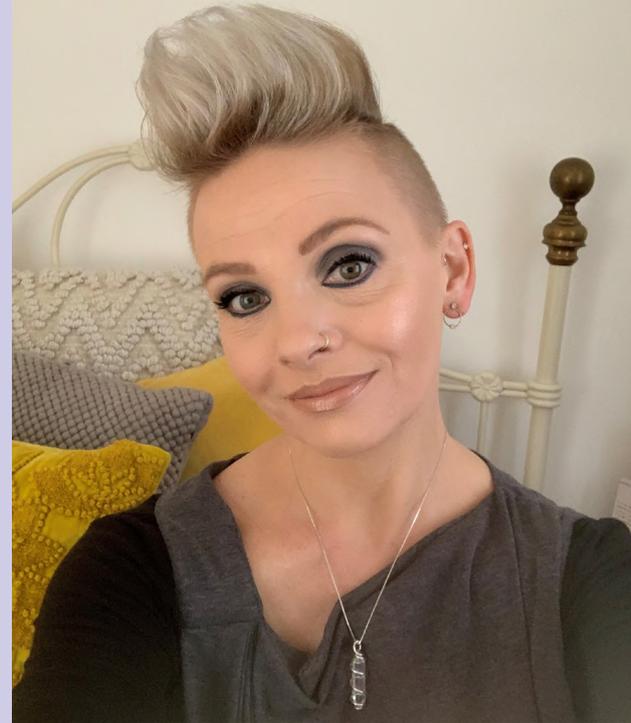
- Mindfulness is a well-established therapy, with considerable research based evidence for its effects on people with MS. Getting the most out of mindfulness will involve a commitment to regular practice, but you may find significant improvements as a result.
- Mindfulness is a meditative technique that involves learning to focus attention on emotions, sensations and thoughts in an accepting and non-judgemental way. By focussing fully on the present moment rather than on regret for the past or worries about the future, mindfulness helps to break the cycle of negative thoughts and emotions. Some people with MS have suggested that mindfulness helps them to be kind to themselves and put MS into context.

*Paula has produced two mindfulness videos for the MS Trust which can be found on [MSTV youtube.com/MSTVUK/](https://www.youtube.com/MSTVUK/)*

*For more information on mindfulness visit [mstrust.org.uk/a-z/mindfulness](https://www.mstrust.org.uk/a-z/mindfulness)*

Looking back, I think my first symptoms started just after my daughter was born. That must have been around 14 years before my actual diagnosis as my daughter is 24 now. After having both my daughter and my son I had periods when I couldn't lift my arms and my husband had to help me get dressed and undressed. I also had strange sensations such as burning, electric shocks, numbness, the list goes on and on. When I was finally diagnosed I was almost happy and relieved that it wasn't all in my mind, my experiences were real!

There is a history of autoimmune diseases in my family such as lupus, Sjogrens and arthritis, so in a way multiple sclerosis was just another one to add to the family list.



My husband and children were obviously concerned but I felt that they didn't really understand what it meant to me to have this diagnosis. I remember feeling quite angry towards them for their lack of understanding.

Following my diagnosis I felt quite alone. I had to make choices about medication or no medication, which felt really huge. Initially I tried Avonex and also Copaxone but neither agreed with me. I was in a dark place. I had become 'Paula with MS'. My whole life was about the disease, what symptoms I was experiencing, was I having a relapse and what medication should I be taking. It was a bad time for me. My mood dropped and I was consumed with my diagnosis. I wanted to try a more holistic route, but felt there was very little support available for that type of approach, which made me feel more alone.

I realised I had to take matters into my own hands, that this was no way to be living, I actually felt like I wasn't living at all. I went back to my meditation practice, which had dropped away following my diagnosis. I started taking it very seriously, almost like it was a medication to be taken daily. I also improved my diet, and made sure I could get out and about more by walking in nature.

## Discovering mindfulness

I first discovered mindfulness 19 years ago when my doctor suggested I look into it for my depression. I was very resistant to the idea but in the end I think I hit such a low point I thought I would give it a go, even if it was just to shut my GP up (in the nicest possible way!). Mindfulness gave me the insight to really be aware of my body and what was going on with it. It's the main reason I started to notice all the strange goings on in my body.

I dipped in and out of the practice until a year after my MS diagnosis when I decided I really needed to find a way of living with this disease instead of it consuming me.

Mindfulness has helped me to get my life back. It's allowed me to identify when my mind is over thinking things and I've got myself caught up making stories up about the future. It also offers me a way to be with my symptoms and pain. I realise I cannot change my diagnosis and what could happen in the future, but I can recognise how I'm responding to these thoughts and come back into the present moment. I am much calmer these days; I have learnt that things are not always how I want them to be, but how I meet those moments is really important. MS is a difficult disease to live with, especially as the symptoms are hidden. I still have down days but I definitely surf these moments much more skilfully now. My increased calmness also has the benefit of rippling out to those around me.

### Mindfulness and coping with lockdown

I moved to Norfolk after the first lockdown. My husband lost his job so we decided to take a leap of faith and start a new more relaxed way of life. Just before I moved I spoke with my MS consultant who said, when you move just ask your GP to refer you to a new consultant. Well it hasn't been as easy as that. I have now been here since October and still have no MS consultant or MS nurse, and only the GP for help.

My mental health has been up and down over the last 12 months, like so many others, but my practice has held and supported me through the harder days. I had a relapse just after Christmas, from which I'm still having some symptoms from. I had no access to help other than from my GP, who was amazing. When I feel my mind getting out of control, I take to my meditation stool, which I feel is more like my medication stool. After I sit I'm aware of the impact it has on de-stressing my body and slowing down the whirlwind of thoughts. It doesn't make them go away, but it allows me to calm them down. I liken it to putting a snow globe down and watching the snow settle.

Mindfulness has helped me become more resilient. Through my practice, I can sit and clearly observe the content of my mind. I feel I have much more insight into the helpful thoughts and the not so helpful, offering me the choice of which ones I'm going to run with. Mindfulness has literally saved me from my overthinking mind.

The practice offers me a technique that I can call upon, I find that what I learn on the cushion is definitely taken out into my everyday life. Through awareness I am able to identify my sabotaging behaviours. Mindfulness has offered me the ability to see the silver linings in situations and a real sense of gratitude for my life and my body. However ill or broken it may seem, my body is still trying to do its best for me.

### Paula's top tips for beginning mindfulness practice

- 1) Start with small micro moments and build up to a longer practice. Scatter these moments throughout your day with small mindful activities, which is about doing an everyday task with awareness so we learn to step out from autopilot.
- 2) Mindfulness can be as simple as one breath in and one breath out, but with awareness, try this with a smile on your face as this helps release dopamine and serotonin (happy chemicals).
- 3) When practising use the breath as your support. Be aware of the feelings and senses around you. As the body relaxes, the mind can then be open to letting go and allowing thoughts the space to settle.
- 4) Research mindfulness to get a deeper understanding of what it actually is, otherwise you can become disheartened.

*"I liken it to putting a snow globe down and watching the snow settle. Mindfulness has literally saved me from my overthinking mind."*



## ASK THE EXPERT

# Stem cell transplantation

Stem cell transplantation is increasingly in the news. We take a look behind the headlines and find out what the treatment actually entails.

In this article we discuss a type of stem cell treatment called autologous haematopoietic stem cell transplantation (AHSCT) which is offered to a small number of people on the NHS each year. Professor Basil Sharrack, a consultant neurologist who's involved in researching AHSCT in MS, answers some frequently asked questions.

For more information visit:  
[mstrust.org.uk/stemcells](https://mstrust.org.uk/stemcells)



## Q What is stem cell transplantation?

In conditions where the immune system is responsible for causing an illness, like MS, then changing the faulty immune system with a fresh one can help stop the damage the immune system is causing. This is the aim of stem cell transplantation.

The process involves harvesting your own stem cells, which live deep in the bone marrow, and storing them. Then we give individuals a high dose of chemotherapy which reduces the number of immune cells in the body, good and bad, and then we reintroduce the stem cells which we harvested back into the blood. These stem cells are very clever. They find their way around the body and back to the bone marrow and start producing new immune cells.

By doing this, you're giving the body a fresh start in terms of providing a new immune system which has not been exposed to whatever caused MS in the first instance. Stem cell transplantation can, therefore, stop MS in its tracks.

## Q Who is stem cell transplantation suitable for?

Neurologists will look at what's causing the problem in a particular phase of somebody's MS. Stem cell transplantation is a very powerful anti-inflammation treatment. If inflammation is the main cause of the problem at a particular stage in somebody's MS, then this treatment will hopefully stop that and help that person. When we talk about active inflammation, we're talking about people who are having relapses and show signs of disease activity on an MRI scan.

If there's no evidence of active inflammation in a particular individual, then this treatment might not be that helpful.

Unfortunately, the stem cells we use can't repair damaged parts of the brain and spinal cord. They can only modify and rectify a faulty immune system.

That isn't to say that stem cell transplantation isn't effective in people with progressive MS. People who have a significant element of inflammation but have progressive disease will probably gain some benefit from stem cell transplantation. However, the benefit will probably be limited compared to people with relapsing remitting MS (RRMS).

We select who we treat very carefully because it's a really tough treatment and we need to make sure that the people who receive this treatment are fully aware of what's involved and the implications both in the short and long run. For instance, the treatment will have an effect on fertility, both for women and men, so it's important to discuss that upfront and mitigate for any risks by storing sperm and eggs.

## Q How long does the treatment take? How quickly do people recover?

The treatment starts with you coming into hospital where we harvest your stem cells. We do that by giving certain drugs which move the stem cells from the bone marrow into the bloodstream. Then we harvest the cells from the bloodstream, taking them from a large vein.

At the same time, because the drug we normally use to activate the stem cells can cause inflammation, we give individuals a small dose of chemotherapy.

Once we've harvested the stem cells, we allow a bit of time for you to recover. We'd then bring you back into the hospital a few weeks later to give you a very large dose of chemotherapy. This wipes out the faulty immune cells. This leaves you with no effective immune system so you have to be kept in isolation for, on average, about four weeks.

Once you've received the chemotherapy, we inject the stem cells back into the body through a vein. These stem cells make their way to the bone marrow and start producing immune cells. We monitor people very carefully as this is a very critical period. You will be very prone to infections at this stage and the large dose of chemotherapy will make you feel unwell. You may get a sore mouth, experience loose stools and generally feel unwell to various degrees.

There is a risk of death with this treatment due to infections, however this risk is gradually reducing as procedures improve. Looking at transplants carried out since 2005, the risk of death has fallen over that time.

Once your white cell count has recovered, which means you're not as at risk of getting infections, you're allowed to leave the hospital but will be monitored very carefully on a weekly basis with repeated blood counts.

In terms of recovery, people often need physiotherapy as well as psychological support. The whole process takes about three months for people to feel back to their normal selves. It is a long process.

### Q How does this treatment compare to disease modifying drugs (DMDs) in terms of how effective it is?

We think it is far more effective than the DMDs we have at the moment, although we don't have trial evidence to support this statement 100%. We have trial evidence to suggest this treatment is far more effective than some first line DMDs, in particular the beta interferons, Copaxone, Tecfidera, Aubagio, but also some of the stronger therapies like Gilenya and Tysabri.

We don't have head-to-head comparison between stem cell treatment and Ocrevus, Lemtrada and Mavenclad. Individual studies suggest stem cell treatment is far more effective, but we need to confirm this by doing a head-to-head comparison. This is what we hope to achieve from the StarMS study which will hopefully begin in the UK in the next few months.

### Q Can you tell us more about the StarMS study? How can people get involved?

The StarMS study will compare the effectiveness of Lemtrada and Ocrevus (and possibly Mavenclad) against stem cell treatment in people with RRMS.

We're creating a website for the study where you can access and read about the nature of the trial, the inclusion criteria and the participating sites.

We're hoping to have 19 sites around the UK where people can take part. If you're interested in the trial, you can read more about it here: [sheffield.ac.uk/scharr/research/centres/ctrustarms](http://sheffield.ac.uk/scharr/research/centres/ctrustarms)

Unfortunately we're dealing with uncertainty in relation to Covid-19, but we hope that the StarMS study will start in the late spring, providing the vaccine rollout has been successful.

### Q Are there are other types of stem cell treatment currently being researched that might be suitable for people with progressive MS?

Mesenchymal stem cells are currently being trialled in progressive MS. They are a different type of stem cell that we all have in our body. Mesenchymal stem cells are not responsible for building the immune system but they provide support to nerves in the brain and spinal cord.

There is very encouraging evidence from phase one and phase two studies suggesting that it will be effective in progressive MS, but it's not currently a standard treatment.

### Q We often see articles in the media promoting the benefits of stem cell transplantation in MS, sometimes it's even claimed to be a cure, but what exactly does the research say?

The evidence suggests that it is far more effective than anything we have at the moment, but in the right patient group. This means in people with MS who have active inflammatory disease despite the use of standard therapy. The benefit they will gain from stem cell transplantation is far more than receiving the majority of the drugs we can offer them otherwise.

Despite all of this, it's not a cure and not everyone who receives the treatment will remain without MS activity later on. In the first few years, the majority of people who've had stem cell transplantation will experience no further evidence of disease activity. That means no evidence of relapses, no evidence of MRI scan disease activity and no progression of their disability. There are unfortunately a small proportion of people, probably about 20%, where MS activity will emerge again, but even in those people it will not be as aggressive as before and they usually respond to treatment a little bit better. So, stem cell transplantation is very effective, but it's not a miracle cure.

### Q Can people with MS access this treatment on the NHS?

Yes, there are hospitals offering the treatment on the NHS in Sheffield and in London. If you think you might be eligible, the best thing to do would be to discuss the treatment with your neurologist. If they think stem cell transplantation would be right for you, they'd be able to refer you to one of the sites offering this treatment on the NHS.

Once the StarMS study is running, there will be more sites around the UK offering the treatment through this clinical trial.

**Professor Basil Sharrack is a consultant neurologist at Royal Hallamshire Hospital, Sheffield. His main research area is autologous haematopoietic stem cell transplantation in MS.**

# Meet the Fundraising Team

From running the London Marathon to purchasing our Christmas cards, the MS Trust offers many different activities and opportunities to get involved. In this edition of Open Door, we speak to the Fundraising Team to find out more about the people behind some of our much loved campaigns.

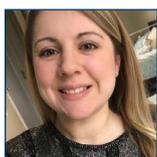


## Rob, Director of Fundraising & Marketing

**What does your role at the MS Trust involve?**

I oversee all of the Trust's fundraising and marketing activities and I'm a director for our trading company. It's a cliché I know, but no two days are the same. One day, I'll be discussing business planning with the rest of the senior management team; the next I'll be reviewing an exciting new fundraising initiative.

**What's your favourite thing about your role?** Meeting our incredible supporters and fundraisers is always a highlight – everyone's story is different, but their generosity and commitment is a constant.



## Marissa, Individual Giving and Legacies Manager

**What does your role at the MS Trust involve?**

I manage donations which aren't raised through events or community fundraising. This includes regular donations, in-memory donations and legacies. I have managed the MS Doesn't Stop and 'MS Trust...in us' campaigns, and the current 'Promise today, change tomorrow' campaign.

**Why did you decide to work for the MS Trust?** I was diagnosed with MS in August 2018 and it is amazing to work for a charity which does so much for the MS community in the UK.



## Jason, Trusts and Corporate Fundraising Manager

**What does your role at the MS Trust involve?** I work with the wonderful grantmaking trusts and businesses who support us.

I write funding requests to trusts who might be interested in a project, and provide stewardship and reporting back to those who send us a grant. I also handle charity of the year partnerships with businesses of all sizes.

**Why did you decide to work for the MS Trust?** I wanted to work somewhere I could help improve people's lives. Even if I have a tough day at the office, I go home knowing I helped make a positive change to the world.



## Claire, Fundraising Officer

**What does your role at the MS Trust involve?**

I look after people taking on active challenges such as trekking or cycling.

This could be cycling in their local village, climbing Ben Nevis, or even Mt Kilimanjaro! I also look after skydiving, the MS:Play gaming challenge and our MS Trust Christmas cards, helping to pick the designs each year and overseeing the Christmas trading season.

**How long have you worked at the MS Trust?** Over 13 years!

**What's your favourite thing about your role?** I love speaking to our supporters and hearing about their ideas for challenges and fundraising they can do. I am always so impressed with their creativity and enthusiasm. Without our supporters and people fundraising for us we simply couldn't achieve what we do at the MS Trust. So a big thank you!



## Erika & Louise, Events and Community Fundraisers

**What does your role at the MS Trust involve?**

Between us we look after a large number of different fundraising events including London Marathon, the Great North Run, Ride London, skydiving, the London Asics 10k and The Vitality Big Half teams as well as the MS Trust Running Club, which covers anyone taking on their own running challenge. We also offer support for fundraisers within schools and universities, help monitor our collection boxes across the UK and send out wedding favours. We're also excited to get back to hosting this year's My Garden campaign.

**What's your favourite thing about your role?** **Erika:** I've been fortunate to get to know many amazingly passionate people who have huge enthusiasm to play their part in making a difference for people with MS. I find our fundraisers hugely inspiring and I'm so pleased that I can see their hard work going to such great resources and support.

**Louise:** A highlight was supporting the Vitality Big Half Team in 2020 as this was one of the last big running events to take place before the pandemic. All our runners were amazing!



## Phoebe, Community Fundraiser

**What does your role at the MS Trust involve?**

I look after Miles for MS, Mission:100, Friends of the MS Trust and Be Bold In Blue. I also support our fabulous fundraisers who support us at work.

**What's your favourite thing about your role?** I've worked at the MS Trust for two years and I especially enjoy getting out and about and meeting our wonderful supporters (I'm looking forward to when we can do that again!)

# 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](https://mstrust.org.uk/fundraising) (N.B. All of these events were going ahead at the time of writing. Please check with us or the event organisers for latest updates)



“Hi, my name is Charlie, and during the most recent lockdown, I decided to raise money for the MS Trust. I chose to raise money for the MS Trust because my Auntie has MS. She is very special to me because she's not only my Auntie, she's my Godmother too.

I love cycling, so I set myself the challenge to cycle 250km around my village over 31 days with the aim of raising £250. During this time, I have cycled almost every day, after finishing online schoolwork, in snow, rain, wind and sunshine!

I have been overwhelmed with the generosity of everyone who has donated and have smashed my target, raising just over £4,000 for the MS Trust! I'd like to say a massive thank you to everyone who has donated and supported me.”

We can't thank Charlie enough for all his hard work during this challenge. He really did go out in all weathers, with his Dad even falling off his bike in icy conditions. Thanks Charlie (and Dad!) – what a superstar you are.

If Charlie has inspired you to get on your bike, or perhaps take on another challenge, we would love to hear from you. Our Fundraising Team can provide top fundraising tips, advice and more!

Email the team on [fundraising@mstrust.org.uk](mailto:fundraising@mstrust.org.uk) or visit [mstrust.org.uk/events](https://mstrust.org.uk/events)

After so many cancellations last year, it's lovely to be able share a selection of running challenges which have been planned in for the summer months.

## 5K May for World MS Day

Sunday 30 May is World MS Day, so get your running shoes ready to run 5k, donate £5 and nominate 5 others to take up the challenge. Let's run together to fly the flag for our MS Heroes

[mstrust.org.uk/may-5k](https://mstrust.org.uk/may-5k)

## London Asics 10K

This summer festival run through our capital is a great way to get back out there and run with the masses on Sunday 25 July. Don your blue MS Trust tee and join the team to take on a 10k. Limited places this year so don't hesitate to sign up!

[mstrust.org.uk/asics-10k](https://mstrust.org.uk/asics-10k)

## Vitality Big Half

New date of Sunday 22 August 2021, a route based on the London Marathon gives you a great opportunity to take in the sights of London whilst completing a half marathon and raising vital funds for the MS Trust. Take up the challenge and join our team!

[mstrust.org.uk/big-half](https://mstrust.org.uk/big-half)

If running isn't for you, we've got a fun selection of alternative ways to raise money this summer, take a look.

## My Garden Party

There are many ways to support the MS Trust from your garden. Whether it's selling plants or produce, organising a garden party or hosting a virtual tour. Get your green fingers ready to raise funds for the MS Trust – we will be rooting for you!

[mstrust.org.uk/mygarden](https://mstrust.org.uk/mygarden)

## It's game on with MS:Play!

Join us for our next MS:Play gaming weekend on 26-27 June, where you pick the console, games and length of your gaming marathon. We will help you turn your gaming hobby into a fantastic fundraiser. Play your way to help us ensure no one has to manage MS alone.

[mstrust.org.uk/msplay](https://mstrust.org.uk/msplay)

## London to Brighton cycle

Leave the buzz of the city behind on the 19 September. Cycle along idyllic country lanes and take on the challenge of Ditchling Beacon, before reaching the bustling Brighton seafront. Water stops and an amazing buffet lunch are provided en route! Perfect for both experienced riders and those new to cycling.

[mstrust.org.uk/londontobrighton](https://mstrust.org.uk/londontobrighton)

Discover more fun fundraising ideas at [mstrust.org.uk/fundraising](https://mstrust.org.uk/fundraising)



15 MINUTES WITH...

# Sam Bromfield

**Sam Bromfield is a Friend of the MS Trust based in Norfolk. Our Friends network is dedicated supporters who are the face and voice of the MS Trust in their local community. We caught up with Sam to find out a bit more about her and why she wanted to take part in Miles for MS last summer.**



## Can you tell us about your diagnosis and how you felt at the time?

I was diagnosed with MS just after the summer in 2015. The diagnosis followed a bad relapse that left me in hospital unable to walk and very scared and confused. I had struggled on and off for a few years prior to this with my mobility and numbness, so when I was given a diagnosis I felt relief more than anything that I finally had an answer and I had options to help me.

## Do you feel that being diagnosed with MS changed your outlook on life?

100%. I think it's easy to get lost in a 'what if' mindset and wonder what life would be like without MS, but for me it gave me that nudge to step back and really look at what I valued in life and what I wanted.

## What are the main symptoms you experience day to day?

Sensations. I know that seems very broad but for me daily I experience different sensations across my body that can really vary from numbness to tingles. I struggle with mobility issues daily too, the extent of this can also vary.

## What made you decide to take part in Miles for MS?

I love taking part in fundraising events and prior to Covid my favourite thing to do was cake sales, because who doesn't love cake! I would also really enjoy hosting busy quiz nights. As both of these were taken out of the equation last year, I started to look for other fun ways I could support the MS Trust. That's when I found Miles for MS. It was perfect as there was no pressure for what had to be accomplished or even how it was completed. This meant that, although at the time I wasn't able to walk miles on end or run, I could use my exercise bike. I made a team with some of my friends and we set ourselves a goal, then we all completed the miles in our own ways.

## How did you feel once you'd completed your challenge?

I felt great! For two reasons really, one being that it really helped me prioritise movement and made it fun but also because it was the first time I had taken part in a physical challenge since being

diagnosed. I had always assumed these events were aimed at people that could run for hours on end, so it made me so happy to learn how inclusive Miles for MS was. You can literally plan around what works for you and what you can manage.

*"I think it's important to note that any movement is good movement and staying active can look so different for everyone."*

## Do you find staying active helps with your MS?

Definitely. I think it's important to note that any movement is good movement and staying active can look so different for everyone. I try not to put pressure on myself to complete a specific thing each day and instead have adopted a more mindful approach to what movement my body can manage. For example, some days I may feel stiff and have sat at my work computer a lot, so yoga or Pilates stretches help. Other days walks outside help me feel good.

## What would you say to others who are thinking of taking part?

Don't overthink it and have fun with it. If you are hesitant at taking part in a physical challenge, as I was, I want to reassure you that there is no pressure behind this and anybody can take part no matter what your ability.

## For more information on how to get involved in this year's Miles for MS challenge visit

[mstrust.org.uk/event/miles-ms](https://mstrust.org.uk/event/miles-ms)

**Sam has also filmed a number of video diaries which you can view on MSTV, our YouTube channel aimed at younger people.**

[youtube.com/MSTVUK](https://youtube.com/MSTVUK)



**SIGN UP  
NOW!**

# SKYDIVE IN SUMMER 2021

Take part in a sponsored skydive at an airfield near you.  
Make sure that no one has to manage MS alone.

**To find out more, visit:  
[mstrust.org.uk/skydive](https://mstrust.org.uk/skydive)**

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Am I having a relapse? (IF513)

How can I live well with MS? (IF512)

Managing Spasticity (IF400)

Living with Fatigue (IF204)



Disease modifying drugs (DG442)  
(Download only)

Primary progressive MS (IF352)

Secondary progressive MS (IF458)

Making sense of MS (IF448)



#### Delivery details

Title	First name	Last name
Job title (if health professional)		Email address
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Please return to MS Trust, Spirella Building, Bridge Road, Letchworth Garden City, Herts SG6 4ET

Remember, if you have any questions about MS you can call our free Enquiry Service: 0800 032 38 39

All our information is free, but we can only continue to offer our services thanks to donations.

If you'd like to support our work, visit [mstrust.org.uk/donate](http://mstrust.org.uk/donate) or text to donate £5 via text, text MSTR01 to 70970.

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