

What is MS?

We look at the challenges of describing such a varied condition

Plus

Research studies

What's it like taking part in research?



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Cover photo: Gabriella Gergely-Bartók



14 How is MS portrayed on TV?



16 Who is MS research missing?

NEWS

- 9** New research on Epstein-Barr virus and MS
- 11** Latest research news and updates
- 12** Social care reform and other campaign news
- 13** Spotlight on treatments for MS

- 20** We look at the medical terms for describing MS

RESEARCH

- 16** Who is MS research missing?
- 24** What's it like taking part in research?
- 28** Your questions on taking part answered
- 31** Making people with MS heard

INSIGHT

- 14** How is MS portrayed on TV?



36 Emily and two others share their creative ways of expressing MS



47 Local search and rescue team help Gilby scale Belstone Tor

REAL LIFE

- 35** Martin Baum on the difficulty of explaining MS
- 36 COVER STORY:** Emily, Robert and Elisha share creative ways of expressing MS
- 40** How do you describe your MS?
- 43** Shereena's experience preparing for HSCT

COMMUNITY NEWS

- 7** Your letters
- 45** Introducing our new trustees
- 47** Local search and rescue team help Gilby achieve his dream
- 49** How MS awareness volunteers are helping in Wales
- 50** Join the MS Matters editorial group



Issue 140
Spring 2022

I hope you're all well and enjoying the first signs of spring.

In this issue, we're exploring the different ways of describing MS. From the medical terms used by neurologists (page 20) to the words you use in your everyday life (page 40). MS affects everyone differently, so it's hard to find a one-size-fits-all description. But many of you have found creative ways of getting your message across. Turn to page 36 to read about three people who've used different art forms to express their MS. And see page 14 for your reactions to representations of MS on TV.

Doctors and researchers are highlighting the benefits of listening to people's individual experiences of MS when analysing treatments and care. Read more about this work on page 31. We also take a close look at research studies and what it's like to take part in one on page 24.

Hearing and sharing your stories is so important to our work. You help us to better understand and communicate our community's needs. So if you have a story to share, please contact us at msmatters@mssociety.org.uk.

And also see page 50 for the opportunity to join the new MS Matters editorial group.

Nick Moberly

Nick Moberly
Chief Executive

Your Letters



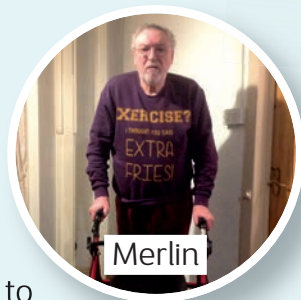
In the summer 2021 edition of MS Matters, we featured Merlin's story. Merlin took his first steps in 28 years with a walking frame after following an exercise programme. Eddy shared his response to Merlin's story:

"I am happy for the gentleman. But such articles reinforce the view that wheelchair users are in their predicament because they can't be bothered to exercise. Please let's not play into the hands of doubters who think our immobility is a life choice.

"Avoiding falls is a life choice and I'm pleased my wheelchair has protected me from their devastating effects. Hopefully the MS Society will highlight the importance of staying fit even if you're in a wheelchair. Looking for a miracle is not the answer. Learning to live with it is."

MS Society: We agree that Merlin's situation was extraordinary. And that the right mobility aids are helpful.

Research tells us exercise can improve your mood, mobility and muscle strength. But we know this will be different for everyone. We support wheelchair users to keep fit too. Find more information at mssociety.org.uk/ms-exercise. And read more about our new exercise videos for wheelchair users on **page 50**.



An anonymous reader wrote to us in response to Bayan's story in the winter edition.

"Bayan refers to 'coming out' as a disabled person, and it really is frightening to do that. I was diagnosed only a few months after I got married. Knowing that many relationships fail when one party is disabled, I was worried I'd lose my husband. He'd said that, while he expected to love me in sickness and health, he didn't expect it to come up so soon. I felt that he felt cheated, and the guilt of 'cheating' him by 'taking away' the vital young woman he married has never left me.

"Fortunately, my marriage is fine. But MS is cruel because it can take far more than your fitness away. It can rob you of your self-esteem."

MS Society: Thank you so much for sharing your experience. We know it will resonate with other readers.



Share your thoughts and feedback at msmatters@mssociety.org.uk. Or use the hashtag **#msmatters** on your social media channels. You can call the MS Helpline for support on **0808 800 8000**

More evidence on EBV infection and MS

A new study has provided the strongest evidence yet that the Epstein-Barr virus (EBV) may play a key role in causing the development of MS.

EBV infects about 95% of people and remains as a

lifelong infection. Most people don't know they've been infected, but for some people, EBV causes glandular fever.

The researchers followed more than 10 million young adults from the US military to track the relationship between new EBV infections and the onset of MS.

They found the risk of developing MS increased 32-fold after EBV infection. And, importantly, results showed EBV infection happens before even very early signs of MS.

What's next?

It'll be many years before we can find out whether preventing EBV infection could stop people developing MS. First we need an effective vaccine to prevent EBV. Excitingly, an early-stage trial into a vaccine began very recently.

And researchers are also looking at whether we could target EBV in people who already have MS. So we're making progress. We need researchers and funders from around the world to come together to drive it forward.

Read more at mssociety.org.uk/EBV

#MSWeek

The uncertainty of living with MS

It's MS Awareness Week from 25 April – 1 May this year. It's a really important time for us to come together, speak out and raise awareness of MS. This year we're asking people to share their stories about dealing with the uncertainty of living with MS. And we're also launching a new fancy dress fundraiser. Find out more at mssociety.org.uk/msweek



Quitting smoking can slow MS progression

Researchers used UK MS Register data to see what effect quitting smoking has on MS symptoms. They looked at how people felt their MS was impacting things like their walking, balance, and ability to carry or grip things over a long period. And they compared the data from people who did or didn't smoke.

It showed when people with MS quit smoking, the rate their disability gets worse slows down, to the same level seen in people who've never smoked.

Read more at mssociety.org.uk/smoking

Over £1M to new MS research

We've recently committed to raise over £1.1 million for nine new research projects. This sees the return of our grant round after a pause due to COVID-19.

We're supporting research that could help find new treatment targets, and advance MRI so we can speed up trials in the future. We're also funding new projects that could improve the quality of life for people living with MS now, like a programme to manage bowel symptoms.

Read more at mssociety.org.uk/research-funding

MS-STAT2 trial completes recruitment

MS-STAT2 is investigating whether the cholesterol-lowering drug simvastatin slows disability progression in secondary progressive MS.

The trial team reached their target after 946 people joined the final stage trial. This brings us close to knowing whether simvastatin could be the first treatment for people with progressive MS to directly protect nerves from damage. We're expecting results in 2025.

Read more at mssociety.org.uk/STAT2-recruitment

STOP MS

We want to say thank you to everyone who's donated to our Stop MS Appeal. This spring, we're raising awareness of amazing MRI research that's giving new insights into how MS progresses and how to stop it. If you can, please donate today to help us make the next major breakthrough. We won't stop until we stop MS. Find out more at mssociety.org.uk/stop-ms

Scan and donate today



Working together to influence social care reform

Late last year, the UK government announced its plans for social care reform in England. We welcome some of the changes to improve care. But they don't go far enough in fixing our broken system.

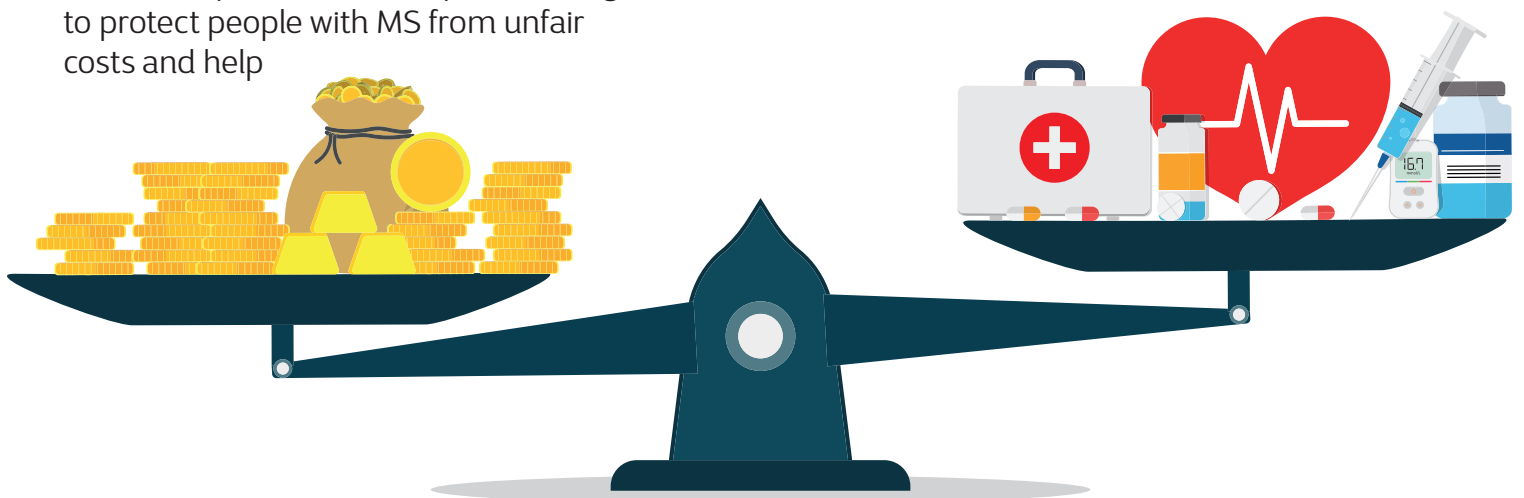
The amount a person will pay for care over their lifetime will be capped at £86,000. And an extra £12 billion a year will be invested in frontline care over the next three years. But the cap isn't enough to protect people with MS from unfair costs and help

them access good quality support.

There's also no plan to improve pay and working conditions for care workers. This ignores the workforce crisis that makes it hard to find care when you need it.

We want the UK government to improve their plans. We're working with other charities to influence the plans as they're debated in parliament.

Find out more at mssociety.org.uk/social-care-reform



Campaigns news

20-metre rule review in Scotland

From August 2022, PIP will be replaced by Adult Disability Payment (ADP) in Scotland. We've been calling for the 20-metre rule to be dropped from ADP. Thanks to your support, the Scottish government has changed its plans. They've committed to an independent review of the mobility criteria for ADP this

year, instead of 2023.

• Read more at mssociety.org.uk/adp-scotland

Northern Ireland Assembly elections

The Northern Ireland Assembly elections will take place in May 2022. In the last term, there's been political instability, changes in party leaderships and a

pandemic. Neurology services that were already struggling are now in crisis. Waiting times are failing our community. We'll be campaigning on these vital issues and fighting for improvement to the benefits system as the election approaches.

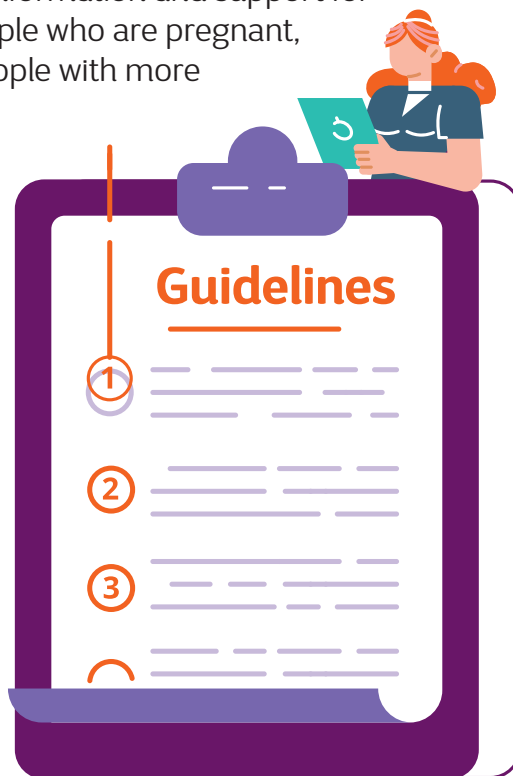
• Read more at mssociety.org.uk/NI-campaigns

New NICE guideline for managing MS

The National Institute for Health and Care Excellence (NICE) is updating its guideline for the management of MS in adults. The guideline sets out the care and services people with MS need and should receive in England and Wales. In December, NICE launched a consultation on the update, releasing it in draft form. We're happy the draft update puts more focus on health professionals to provide tailored information and support for people with MS. This includes people who are pregnant, planning to have children, and people with more advanced MS.

But we're disappointed about its recommendation against the use of fampridine (Fampyra) in England. This is a drug to improve walking in people with MS. And many of you told us about the difference fampridine could make to you. We responded to the consultation, calling for NICE to reconsider their decision.

The final version of the guideline is due in June 2022.



Tell us your needs

Our regular My MS My Needs survey guides our priorities as an organisation. In June we'll be asking for your views again. We understand your needs better when we hear from you, so please fill it out.

- Find out more at mssociety.org.uk/our-evidence

Financial help for those in need

Our community is facing hardship due to the increased cost of living, rising energy prices and the impact of COVID-19. We're here for you.

- Visit mssociety.org.uk/financial-help to find information on financial help that might be available to you.

Spotlight on treatments

New DMT tablet

In December, NICE approved ponesimod (Ponvery) for people with active relapsing MS in England and Wales. This reversed an initial decision to reject the drug. The Scottish Medicines Consortium has also approved ponesimod. And NICE decisions are usually adopted in Northern Ireland after review.

Ponesimod provides another DMT option for people with relapsing MS that they can take as a tablet.

Read more at mssociety.org.uk/ponesimod-news

COVID treatment for people with MS

In December, two COVID-19 treatments became available for people living with MS in the UK. The drugs, molnupiravir and sotrovimab, can help people manage their COVID-19 symptoms and reduce the risk of becoming seriously ill. Read more at mssociety.org.uk/covid-19-support

In the public eye

Three people from our community share their reaction to representations of MS in the media.

We celebrate when films and TV shows feature stories of MS people can recognise. It's even better when those stories help people to better understand the condition. But MS is different for everyone. And sometimes that representation doesn't match up to people's reality, making it harder to feel understood.

TV characters with MS

- Martin Sheen's character, President Bartlet in the West Wing, has relapsing remitting MS, which he hides during his first presidential run.
- In the Netflix show, Sex Education, Ruby's father has MS. The storyline looks at Ruby's experience of being a young carer.
- Neighbours' character Susan Kennedy has been in the show for 28 years. She was diagnosed with MS in 2007.
- Nancy Osborne in Hollyoaks has MS. The writers asked for our help with her diagnosis story.
- Umma in Kim's Convenience, a Canadian sitcom about a Korean family, is diagnosed with MS in season five of the show.



Introducing, Selma Blair

Actor Selma Blair's documentary, *Introducing, Selma Blair*, explores her journey with MS and the disease modifying therapy HSCT.

Natalie Busari said: "I was happy the documentary made it clear that everyone's MS is different and not the same as Selma's. Some of her MS symptoms are very visible. But it didn't take away from the fact that it's not always visible in other people with MS.

"MS and other chronic illnesses aren't always obvious to the naked eye. So it's very

stressful to explain or prove their disability. And it's complex in its nature, so it's hard to explain. I believe Selma's documentary did a lot to help people imagine living with MS. The good, the bad and the ugly."

Read Natalie's full review at mssociety.org.uk/selma-doc



Johnny Connor in Coronation Street

Coronation Street character Johnny Connor was diagnosed with MS in 2017. He later developed hallucinations caused by Charles Bonnet Syndrome (CBS), which the soap linked to MS even though this is very rare.

Martin Baum said: "Filled with clichéd tropes and tired stereotypes, the producers of *Coronation Street* did their best to 'push the envelope' by making the character Johnny Connor an MSer.

"But using this [the hallucinations] to take Johnny's MS to the next level is irresponsible and unnecessary. Worst of all, it makes the audience even more ignorant of what MS really does. And it takes away from the illness I have no choice but to live with."

Read Martin's full review at mssociety.org.uk/johnnys-ms. See more from Martin on page 35.



Kadeena Cox on I'm Celebrity Get Me Out of Here

Paralympic gold medallist Kadeena Cox OBE is an MS Society Ambassador who took part in *I'm a Celebrity Get Me Out of Here* in 2021.

Sheridan Allison said: "Out of all the years I've watched #imaceleb, I've never known a Paralympic champion with MS to go on the show. The year I get diagnosed someone does! Kadeena Cox has honestly inspired me for my future. My MS will not stop me from living my best life."



We'd love to hear your views. Did you see any of these shows and how did they make you feel?

Share your thoughts and opinions at mismatters@mssociety.org.uk or on social media using the hashtag **#mismatters**

Who is MS research missing?

Dr Andrea Stennett is a neuro-physiotherapist and researcher. Research Network member **Richard Eke** spoke to Andrea about the importance of including everyone with MS in research.

MS can affect people of any age or background. But Andrea explained to me that not everyone has been included in research. She's dedicated much of her career to helping people with MS. And she's determined to make research represent the people affected by the condition better.

Andrea said: "You might read a study. You're thinking, great, this is exciting. But you look at who's taken part and you think, this doesn't match the population of people affected by MS in the real world. We



Dr Andrea Stennett

can't confidently know it applies to groups of people that weren't included."

So Andrea wants us all to ask: "Who is missing from MS research, why are we missing them, and what can we do about it?"

Andrea gave some examples. "Some people might not be able to take the time off work to participate – it can cost time and money." She is equally thoughtful about ethnicity, saying: "We're not reaching

some communities. What if patients don't speak English? Or what if they don't have anybody at home to translate all the information we're sending out to them?"

She also thinks researchers are missing older people with MS. Andrea reminds me that traditionally, a lot of research stopped at 65 years old. Why, when we know that people with MS are living much longer now? That also led to Andrea discussing the fewer opportunities for people with higher disability levels. A lot of the studies involving



Richard Eke

people with MS have focused on walking.

Andrea wanted to throw some light on the upper body. So she's been working on the ChariotMS trial, which is testing whether a drug can preserve arm and hand function in people with advanced MS. And the Under & Over study, which is testing a rehab tool for hand and arm function. Neither study has an upper age limit.

Learning from the pandemic

Andrea thinks about who's missing from a clinician's

perspective too. During the pandemic she was concerned about the patients she wasn't hearing from. She said: "We work in East London. It's an economically deprived area. And we have lots of different ethnic minority groups. I was concerned we weren't

reaching everyone."

She added: "Some older people might not have the technical skills to do a video consultation, so as a backup we had the good old telephone."

These are the kind of barriers that exist in research

"The heart of the issue is that we all have a responsibility to make research more inclusive. And that involves widening what we do to reach people of all ethnicities, ages, and socioeconomic groups."



too. Andrea is confident we can reduce them, or make adjustments for people who need it, just like in the pandemic.

Trust and communication

Andrea sees trust as one of the major barriers to participating in research, especially for people from ethnic minorities. She said: “We have to acknowledge that unethical research has been done in the past. It’s understandable people may

not trust the process.”

This led Andrea to question how we heal from that and move on. Andrea thinks all research needs to be open and transparent. And helping people understand what research involves, and what opportunities there are could help too.

Responsibility

Andrea finished by saying: “The heart of the issue is that we all have a responsibility to make research more inclusive. And that involves widening what we do to reach people of all ethnicities, ages and socioeconomic groups.”



As an organisation we’ve launched a new strategy to become more diverse and inclusive. We know research has some unique challenges so we’ve developed a plan to tackle them. Read the plan at mssociety.org.uk/EDI-research. And find out more about what it’s like to take part in research on page 24.



Do MS labels matter?

We take a look at the sometimes mind-boggling medical terms for describing MS and what they might mean for you.

You might've heard your MS described as 'relapsing remitting', 'secondary progressive' or 'primary progressive'. In recent years, doctors and researchers might also describe these different types of MS as 'active' or 'not active'. And 'with progression' or 'without progression'. These labels might not be how you'd describe your MS day to day. But they could help you find the best ways to treat and manage it.

“I’ve now come to terms with having MS and got my head around how unique it is to each of us.”

Active MS

'Active' can be used to describe relapsing MS and progressive MS.

When a neurologist describes MS as 'active' they usually mean the immune system is attacking, or has recently attacked, myelin. Myelin wraps around the outside of the

nerves in the brain or spinal cord. They might see this on an MRI scan, or you may have a relapse, which is a sign too. This is more common with relapsing remitting MS, but it can happen with progressive MS.

If you've had a time without relapses or activity showing on MRI scans, your neurologist

might describe your MS as 'not active'. That doesn't mean there are no symptoms, just that there aren't any signs of new attacks.

Relapsing remitting MS

Relapsing remitting MS is when you have attacks of new or old MS symptoms. That attack is

Sarah, 34

I found the language depressing when I was first diagnosed. I also found the vagueness hard to deal with – this ‘might’ happen, and ‘for some people’ this happened. I wanted something certain to offer some reassurance. I’ve now come to terms with having MS and got my head around how unique it is to each of us. So the language bothers me less.

‘Relapsing and remitting’ is as accurate as possible for such a slippery condition. It indicates that symptoms and flare-ups will come and go, and some days will be worse than others – which is my lived experience of it. I rarely say I have ‘relapsing MS’ to people who don’t have it though. Because most people have no idea what MS is, let alone there being different types!

I tend to explain generally what MS is (what’s going on with the immune system), so they have some background. But I mainly focus on what it means for me. What symptoms I get and how often, and also how I feel on a daily and weekly basis.

the relapse. People often make a good recovery from a relapse. But around half of all relapses will leave some lasting effects.

If you’ve had recent relapses or signs of activity on an MRI scan, your MS might be described as ‘active’. If you’ve had a time without this – maybe one or two years – it

could be called ‘not active’.

Regular appointments with a neurologist can help monitor how active your MS is. And that can help you discuss your options for disease modifying therapies (DMTs) on the NHS. DMTs can reduce the number of relapses and slow down the MS.

Secondary progressive MS

Secondary progressive MS comes after relapsing MS for many people. It’s ‘progressive’ because the effects of MS are gradually getting worse.

A neurologist might describe your MS as ‘with progression’. This progression isn’t caused by relapses, which attack

Mark, 53

When I was diagnosed with MS in 2007, it wasn't explained what type I had. My GP told me almost nothing and said, "good luck old chap". So I went straight to Dr Google and found all the bad news stories because I hadn't been given enough info.

I was later told in writing that I had highly active relapsing remitting MS. It was a really unpleasant way to find out. My subsequent secondary progressive MS diagnosis came as kind of a relief. I felt I'd get a break from the constant attacks and be on a steadier path.

The downside of having progressive MS is I know I'm on the back foot in terms of treatment. Things are starting to get better. But I feel neglected and back to 'see you in a year, can't do much for you'.

I find the language of the main types of MS defines us so separately. I think measures of progression and the impact of symptoms are more important. I've come to use the word 'advanced MS' to describe my own MS. Or 'bad wheelchair rugby player' – that's my other title.



Mark is Head of Comms for Shift.ms

the myelin cover around the nerves. It's because of damage to the nerve fibres inside.

If you also have relapses, or signs of new activity on an MRI scan, it might also be described as 'active'. So neurologists might describe it as 'active MS with progression'.

It's not always easy to be sure if MS has moved from relapsing remitting to secondary progressive. It needs to be clear that changes

over time aren't linked to any relapse you've had. Your neurologist might discuss it with you and monitor your MS for some time before deciding on the right name to use.

It could make a difference to how you treat and manage your MS. There are DMTs available on the NHS for active secondary progressive MS. For secondary progressive MS that's 'not active', treatment could be different. It might

become more about managing symptoms and staying as fit and healthy as possible.

Primary progressive MS

With primary progressive MS, symptoms gradually get worse from the start. But, like other types of MS, people can have different symptoms and experiences of progression.

For example, there can be long periods of time when things don't seem to be



Donna, 36

I was 17 when I was diagnosed. The language the consultant used – with terms like ‘degenerative condition’ – was really unhelpful. I was told I had relapsing remitting MS, but it meant nothing to me because MS meant nothing to me.

My mom only understands basic English, so I had to try and translate a diagnosis that I didn’t understand myself into Panjabi. It was tough. I knew what I was experiencing inside, but my mom couldn’t see most of that.

When I started treatment, I was referred to another consultant who asked me to describe my MS and what it meant to me. He explained everything in a way I could understand. So I knew what treatment meant for me and how it could help me live my life. Understanding things made it seem more positive.

I’m still relapsing remitting. Although my experience of MS has taught me that this may look different for everyone. MS is complex, so I tend to focus on what it means for me.

changing. A neurologist might describe that as ‘stable’ or ‘without progression’. Or, at a time when symptoms are getting worse, it might be described as ‘with progression’.

Some people do have relapses early on, or signs of new activity on an MRI scan. If that happens, it could be described as ‘active’, and you might be offered the DMT ocrelizumab (Ocrevus). An

older name you might hear for ‘active primary progressive MS’ is ‘progressive relapsing MS’.

CIS and RIS

Some people with MS-like symptoms are diagnosed with CIS (clinically isolated syndrome) or RIS (radiologically isolated syndrome). They can be an early sign that someone will later develop MS. But not everyone diagnosed with CIS

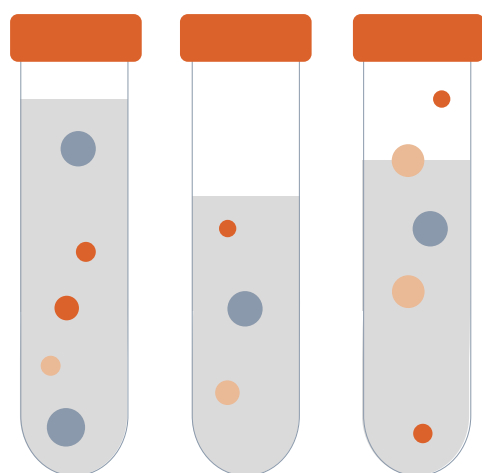
or RIS gets MS. You could be offered treatment with a DMT if you’re diagnosed with CIS and MRI scans show you’re at a higher risk of getting MS.



Find out more at mssociety.org.uk/types-of-ms or you can order our information booklets for free at mssociety.org.uk/online-shop or by calling **0300 500 8084**

What's it like taking part in research?

In this edition we're sharing more about taking part in research. We asked people with MS what motivated them to take part in some of our research studies and what their experience was like. Here's what they said.



Jesse, ADAMS study

The ADAMS study is looking at genes in people from different ancestral backgrounds and how they could contribute to risk of MS.

I was diagnosed with relapsing MS when I was 18. I'm 26 now. A lot of my search in those eight years was trying to find a place where I belonged. I was a young Asian boy with MS, so I was different to most other people diagnosed.



But it's well-known now that MS doesn't just affect people of European descent. So I'm pleased this project is looking at MS genes in people from different backgrounds. I

hope this study will shine more light on understanding MS for everyone – that's why I'm taking part.

The research team posted me a kit to collect my saliva for DNA testing. So it's easy to take part from home.

I want the world to look back on this project in 10, 20, 30 years' time and appreciate how much of a monumental shift in focus it was. If we all participate this could be key to understanding MS.

The ADAMS study is inviting anyone in the UK with MS to take part. Find out more at mssociety.org.uk/ADAMS

Alison, MS-STAT2

MS-STAT2 is a clinical trial for secondary progressive MS. It's testing whether a drug called simvastatin can protect nerves from damage.

I leapt at the chance to join the MS-STAT2 trial. I've lived with MS for over 30 years and until then there'd only been 'hope' there would ever be a treatment that could help me.

Last year I went for what I thought was my final appointment with the trial team. After some rigorous testing, the findings were put into the computer. I cried when I was told I could remain on the trial for another 18 months as I hadn't progressed at all in those three years!

I would encourage anyone to grab any opportunity with both hands to try to slow, stop, prevent or, ultimately, cure this disease. I'm doing this not only for myself, but for my 24-year-old niece. I believe that before she gets this far down her journey with MS a cure WILL be found.

MS-STAT2 has completed recruitment. But there are other trials into progressive MS that are recruiting, like ChariotMS. And soon, Octopus. Find out more on our website: mssociety.org.uk/trials



Mike, Tissue Bank donor

The MS Society Tissue Bank collects donated brain and spinal cord tissue from people with and without MS after they pass away. It's helping researchers across the world understand and develop new treatments for MS.

It's always bothered me that I can't donate blood because of my MS. Being a general organ donor is allowed now, but when I was diagnosed we couldn't even do that.

So I signed up to the Tissue Bank after hearing about it at a support group. I thought this is an opportunity for me to do something positive for the wider community, which doesn't necessarily involve much effort.

Some of the changes I've seen over the last 13 years in MS treatment are a testament to the Tissue Bank.

If you feel passionate about wanting to make a positive change, this is a way you can do it by just filling out some paperwork and carrying a card in your wallet. The Tissue Bank take care of the rest.

Find out more about the Tissue Bank at mssociety.org.uk/our-tissue-bank





Ann, LEAP-MS

LEAP-MS is developing an exercise package for people with progressive MS. It combines online classes with coaching from a physiotherapist.

My secondary progressive MS means I have trouble with walking, and usually use a wheelchair outside. Before being diagnosed, I enjoyed skiing and other types of exercise I've had to give up.

So I was keen to test the LEAP-MS exercise package. I discussed the challenges of my MS with a physiotherapist, specifically my trouble with walking. They then recommended a range of exercises to help me with my walking struggles.

Taking part in LEAP-MS has inspired me to continue online exercise classes for people with MS, namely Mojo Moves – seated comedy aerobic sessions. As with the LEAP-MS exercises, at first I found it difficult. But over time I found myself getting stronger. I've really benefitted from taking part and met lots of lovely people along the way.

LEAP-MS has completed recruitment, but you can read more about Ann's experience and similar studies at mssociety.org.uk/LEAP-MS



A researcher's perspective

Dr Ashley Brown is launching a new study that could help people with MS experiencing sexual difficulties.

We don't talk enough about MS and sex. Intimacy and relationships are a huge part of quality of life that shouldn't be neglected.

Our study will test an intervention to help people with diagnoses like pelvic pain disorders. But I also want to help people who've lost their desire or are struggling with their body image or sexual preferences. Or their medication might be interfering with their sex life.

It'll be a self-directed journey where people can choose what's important to them. And they'll be supported by sessions with a clinician to identify treatment plans and goals.

People with MS have helped us design the research right from the start, and we're hoping to start recruiting people to take part this year.

Ashley hopes recruitment will begin this summer.



Have you thought about joining a research study?

We answer some of your questions about taking part in research.

Q I want to take part in research but I don't want to test a drug. Is there anything else I can do?

Joining a clinical trial is only one way to take part in MS research. Clinical trials usually compare a new treatment with a placebo (a dummy drug), or an existing treatment.

But there are so many other types of research studies you can take part in. You could answer surveys about MS from your home for the UK MS Register. You could try out a new exercise programme or specific diet. Or you could give a sample of your blood or saliva for researchers to look at in the lab.

Q Is there any point in taking part in a clinical trial if I might be given a placebo (dummy drug)?

There are lots of benefits to taking part in research beyond the chance to trial a new drug. Depending on the study, possible benefits might include:

- More contact with MS experts, including physiotherapists, MS nurses or neurologists
- More monitoring of your MS, like regular MRI scans
- Becoming part of a community of like-minded people with MS

Q Why are there so many restrictions on who can take part?

All studies have criteria outlining who can and can't take part. This is so the research is safe, and can test the benefits of a treatment or lifestyle change as quickly and effectively as possible.

Not all, but most include age restrictions and medical





Read other people's experiences of taking part in research studies on pages 24-26

considerations. Older participants can be at a higher risk of experiencing negative effects. And living with multiple conditions could complicate trial analysis.

Even if you're not eligible to take part in a trial, you may still be eligible for the treatment once it's been licenced.

Q Will I have to take time off work?

Some studies might need you to visit a hospital or research site during the day. Usually they'll pay travel expenses to allow for this.

During the pandemic, research teams developed new ways for people to take part in research remotely. And there are lots of studies you can take part in during your own time, like answering questionnaires or online exercise programmes.

Q Is it risky to test something new?

New treatments, activities or lifestyle changes are only trialled after there's a very strong indication they're safe. Participants are closely monitored to look for any side effects throughout all studies.

Many studies we're funding are testing drugs that are already used in other conditions. This means they can be quicker to trial as we already know they're safe.

Q Can I change my mind if I don't want to take part anymore?

Yes, you can withdraw from a study at any time. Just let the research team know. If you're happy to, it's helpful to let the researchers know why you're leaving so they can improve the trial in the future.

Q Where can I find studies?

We know it can be difficult to find studies you're eligible for and how to get involved. Here are a few ways you can find studies to take part in:

- Speak to your neurologist, MS nurse, GP or physiotherapist – they could advise you of local studies or clinical trials you might be eligible for
- Visit the Be Part of Research website. Here you can search for UK studies by location **bepartofresearch.nihr.ac.uk**
- You can search for MS studies recruiting around the world on the website **ClinicalTrials.gov**
- We can't list all recruiting studies on our website, but you can keep an eye on blogs and news about some of the latest studies.

If you find a study you're interested in, sometimes you can contact the researcher directly for more information. But if you want to know more first, or you're unsure a study is right for you, the best thing to do is speak to a healthcare professional.

Making people with MS heard

The global Patient Reported Outcomes for MS (PROMS) initiative is challenging how the effects of MS are measured. **Susanna Van Tonder** spoke to **Dr Giampaolo Brichetto**, a leading researcher on the project, to find out more.



Dr Giampaolo Brichetto

Giampaolo is a doctor and researcher who has worked in the field of MS for over 20 years. He's particularly interested in how patient reported outcomes (PROs) can help us better understand MS.

PROs could help understand invisible effects of MS

PROs can measure what are often the invisible symptoms of MS, like fatigue or pain. They could complement existing

What are PROs?

PROs are a way to understand how someone is affected by MS, from their own perspective. They're usually questionnaires that record your own description of your symptoms and quality of life. They can be done alone, or with a healthcare practitioner.

clinical measures, like MRI or EDSS scores, to give a better all-round understanding of someone's MS.

Giampaolo explained: "Your neurologist might want to measure how well you can walk a certain distance. But that doesn't tell them what you're experiencing – you might feel slow, or uncoordinated compared to normal." This important information could help inform treatment decisions in clinic.

It could also tell us more about the effect of treatments in trials. It can tell us if a treatment is helping in a way that scans or clinical measures don't show.



But they're not widely used yet

I also learned from Giampaolo that PROs aren't used widely or consistently. That's because they're complex to integrate into practice. Few are scientifically validated for MS, which means we can't say for sure they all measure what we think they do. And none have been developed with people affected by MS.

This is where the PROMS initiative comes into play.

What is the PROMS initiative and what is it aiming to achieve?

PROMS is a global initiative involving people with MS, researchers and healthcare professionals. It hopes to overcome some of the barriers to using PROs in research and in clinic, so the experience of people with MS can be heard.

It'll investigate how existing PROs are helping people with MS. And it plans to

develop new, and scientifically validated PROs that could be easily integrated into clinic and research.

The researchers are currently working with people with MS to identify which symptoms are most important to monitor. Then they'll co-develop and validate new PROs with people with MS.

People with MS are co-researchers

A key feature of PROMS is that people with MS have been included, and have shaped the initiative, from the start – not just as an afterthought.

Giampaolo explained: "People with MS act as co-researchers in the PROMS initiative. Their engagement helps us view things from another angle." He notes how crucial our input is because what's relevant for a clinician may not accurately reflect what's important for a person with MS.



Susanna Van Tonder

My involvement

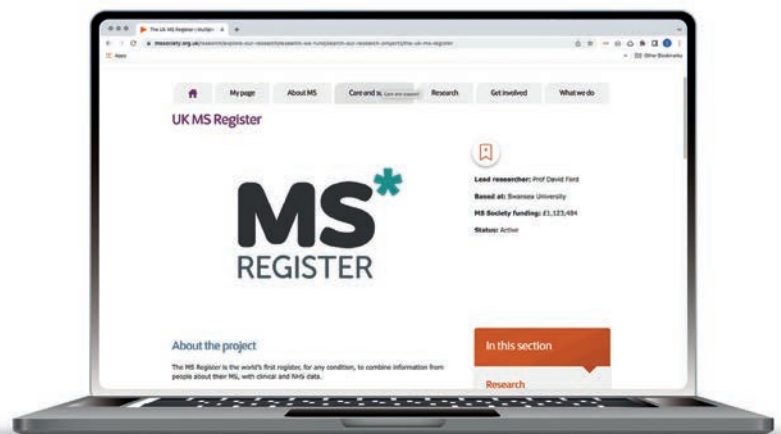
I've been involved in the PROMS initiative as a person with MS and worked with Giampaolo. I feel that PROMS is really bringing forward the patient voice as an integral part of research.

I feel mine and other people's contributions will help challenge the current methods of assessment in MS. So we can move towards a more holistic and accurate picture of what life with MS really means for us.



The UK MS Register uses PROs to provide crucial information to researchers and build a clearer picture of the true impact MS has on people's lives.

The questionnaires allow the 17,000 people who are signed up to track, store, access and then share their own data with their healthcare provider. Find out more at mssociety.org.uk/MSRegister



The difficulties of living with MS

Blogger and influencer **Martin Baum** takes a creative approach to describing his experience of living with progressive MS.



I've been faced with the challenge of describing how much MS has taken over my life for many years. I liken it to a difficult relationship. I'd love to separate myself from it, but MS will not grant me a divorce.

A relationship should be about give and take, but MS is like a sponge. It saps my energy and will to live. It will give no ground.

I'm a 62-year-old man. I didn't know anything about diminishing mobility 40 years ago. I was a medal-winning amateur long-distance runner. Talking was easy and understood by others. I was sociable. Now, because of MS, my life is a challenge. It's filled with glitches that work against me mentally and physically.

But I will not give up on this 'relationship'.

The more obstacles MS throws at me, the more I go with it. What choice do I have? Such is the way of the control freak that MS is – it doesn't know the meaning of the word 'enough'.

After four decades, this relationship is still a work in progress from which I can't escape. I will not give up on it. But the question still remains: will MS ever give up on me?



Free information about MS

All our printed information booklets are free of charge. You can find out what's available in our latest information resources catalogue, which is included in this magazine.

It lists booklets and other resources to explain MS and help with symptoms, treatments, work and money.

There's also a new 'I have MS' card. It's handy for those times when it's easier to explain things without having to speak.

order All our booklets are available at [mssociety.org.uk/online-shop](https://mssociety.org.uk/) or by calling **0300 500 8084**

Creative ways of describing MS

Emily, Elisha and Robert have all found creative and unique ways of expressing life with MS.

Emily Holt uses different art forms to describe her experiences with MS, with support from her creative personal assistants. Emily has progressive MS and was diagnosed in 1999.



Gabriella Gergely-Bartók

I find MS is so unpredictable that I get my ideas from anything and everything that links with what's happening to me at the time. I use my creativity to make good things out of the bad.

I pay a wellbeing PA to help me do creative stuff for a few hours each month. That comes out of the funding I have for my care. It was a bit of a revelation when I discovered I could do that.

I've covered a range of art forms over the past 10 years, including writing projects, graphic design, arts and crafts, and filmmaking.

One of the first images I ever used was an MRI sequence of my brain and eyeballs. We turned it into a short film of tiny, coloured brains forming kaleidoscope patterns. It was in time to The Beatles' song Lucy in the Sky with Diamonds – the girl with kaleidoscope eyes. One of my early sculptures was a finger bowl at a time when I was losing sensation in my hands.

In 2016, I spent a long and stressful time in hospital because of the combined effects of MS, pneumonia and respiratory failure. After that, I decided to start a writing and film project called Enemas at Dawn. It helped me work through all that went on – an induced coma, ventilation, intubation, steroids and sedatives.

I also constructed a small animatronic mermaid lying on a pebble beach, complete with nipple tassels. My sister Polly also has MS. And the mermaid celebrates the first time I persuaded her to wheel me outside the hospital so I could breathe real air. She brought the nipple tassels as I was always having problems with the flapping hospital gown.

I started another project – Enemas at Dawn 2 – after my most recent 64-day stay in hospital with aspiration pneumonia. In the projects, I used lots of different images, videos and even music to help express what it felt like.

One example is an astronaut. The scene in the film Gravity, where Sandra Bullock’s character is spinning through space, is how I felt in ICU with my face covered by an oxygen mask, unable

“Creating art helps me find a way of expressing what I’ve been through. Somehow, I can find the positivity in it, the daft and the dark.”



to wear my glasses, feeling so ill and confused and unable to communicate.

Recently, I’ve worked on a filmmaking project called Virus Diaries. I wanted to share my own experience of isolation as an extremely vulnerable person. I also wanted to encourage people to wear masks and take more care around others who might be more vulnerable.

Creating art helps me find a way of expressing what I’ve been through. Somehow, I can find the positivity in it, the daft and the dark. Verbal communication can be a big challenge for me. Finding other ways of sharing my thoughts and feelings is so therapeutic.

See Emily’s work at mssociety.org.uk/emily-holt-all-videos and watch the Virus Diaries at msociety.org.uk/emily-holt-film



Find out more about arranging support from social and health care services at mssociety.org.uk/social-services-funding

Elisha Samuels, 33, creates videos of conversations between her and her MS. She shares them on her Instagram page [@marksandsparkzqueen](#)

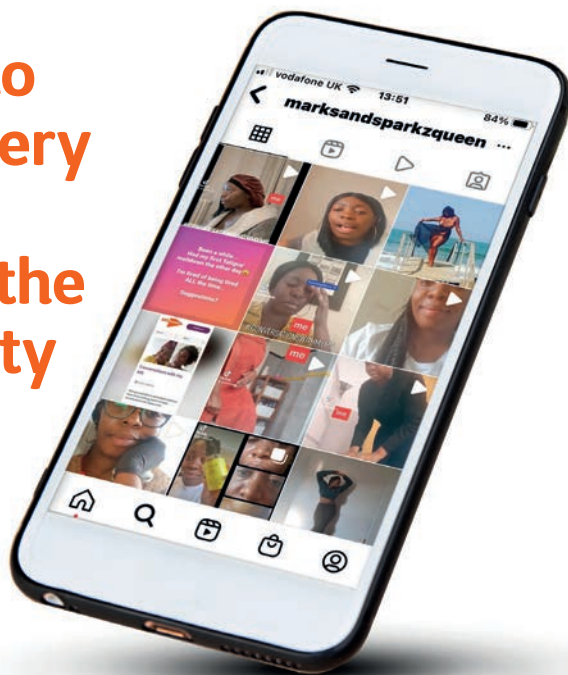
I made my first video after my fourth relapse. I had double vision in both eyes and was spending a lot of time in the house. I'd been having conversations with my MS for a while. So I decided it was the perfect time to set up my Instagram page and share my MS journey.

Most of my friends didn't know about my MS and I wanted to tell them in my own way. I wanted to come out swinging and on my own terms.

I knew I wasn't the only person having conversations with my MS. And sharing my content on social media made me realise I wasn't alone. It acted as a release for me. It was like therapy, and was exactly what I needed.

There are funny days and ugly days

“I want to show every side to combat the negativity online.”



when you live with MS. And I want to show every side to combat the negativity online. I don't want people to dwell on the down days we have. We have them, we talk about them, we cry, and then we move on.

My MS has her own personality and she wears glasses because she's losing her sight. We'll talk about what we can do that day and what we can't. Sometimes my legs and lower body go numb. So we might have a conversation about testing my bath water with a thermometer before getting in. Instead of making her my enemy, she's become my friend.

The videos were just for me and my small following in the beginning. Now I have over 600 followers and I receive positive feedback from people all over the world. And even if I only help one person to have a giggle, that's enough for me.

Robert Gillett, 33, writes poems about his experiences with MS. He shares them on his Facebook page @BeneathTheTracksuit

I started writing poetry in January 2021. I'd been in and out of bouts of depression since I was diagnosed with MS in 2015. I was seeing a counsellor, who'd suggested I write a thought diary. But I felt like it had no context, so I started putting a spin on it that made sense to me.

The first poem just came to me. Writing it down helped me, and it helped my partner Donna, to understand what was going on. I'm not a big talker, so I found this a better way of explaining myself.

I struggle with pain in my legs, arms and face, and I also experience emotional and psychological pain. Writing helps me to process that. I write to the state of mind I'm in, whether I'm sad, confused, upset or in pain. It helps me to be honest with myself.

In one poem, I describe MS as an "invisible thief" because you can't see what you're fighting. I find that being

Extract from Robert's 'The man in the mirror'

The man in the mirror doesn't look like he's struggling,
He looks well,
He isn't feeling my pain.
I need to check back over and over again.
My image really does contradict the way that I feel.
Surely the man looking back at me,
He cannot be real.



aware it's there helps. I know that over-exerting myself will set this invisible thief off.

I like the word "struggle". It's a good way to describe the way it is to live with MS. The MS isn't me – it's something that's with me. I have MS but it doesn't have me.

When Donna suggested sharing my poems, I said no at first. Then I thought maybe it could give people an idea of what it's like. I started my Facebook page in May 2021, and it's grown faster than I ever thought it would. I have 3,200 followers and the page has reached 300,000 people.

I feel happy that I'm helping others. I've had lots of people say to me: "I don't feel so alone anymore. You've managed to put into words exactly how I feel." I'm grateful to hear that. It's a bit like magic.

How do you describe your MS?

There are many medical ways of describing MS and its symptoms. But these aren't always the words people use to describe it in their everyday lives. You told us some of the different ways you like to describe MS to the people around you.

There are ways to help people understand, but I'm not sure anyone ever can unless you have some experience of it. It's a life changing experience. Not just for the person with the diagnosis, but for everyone who loves them. Every day is a new and difficult challenge.

Lisa

I always say my central nervous system is like a faulty wire to a plug. Once that casing on the wire is split, the plug may still work, but not as well as it should do, if at all.

Abi

I say I have MS and point them in the direction of the MS Society website to do the research. And say come back to me with any specific questions. Not many people have asked how it feels to have it. What needs to be understood is how we feel emotionally having this disease. Empathy and patience from the listener are required.

Suzie

Jetlag!

Victoria

Living with relapsing remitting MS for me is like living on a fault line. There's always the threat of a life changing earthquake any day of the week that could wipe out everything you have built. But you love where you live, so you live as if that day will never come.

@thegirlintheorangehat

Brutal

Claire

I'm not sure you could publish the words I'd use to describe it.

Rebecca

For me, my MS is the little old lady that lives inside of me. She gets sleepy, grumpy, likes to sit down with a cuppa. Sometimes she's fit as a fiddle, but sometimes walking too far puts her out. I named her Mavis. I thought it was best to learn to live with her, and carve out that part of me, so I still maintain who I am alongside her.

Shelley

MS is unpredictable and uncontrollable. Even though you might think the person looks well, they'll be experiencing a number of different invisible symptoms. They make life much more difficult and complex.

Clive

My relapsing remitting MS is low and slow impact. Imposter syndrome is a big problem. I describe it as walking under a big black cloud and never knowing if it'll actually rain. But the cloud remains.

Karen

I call it my Cheshire Cat disease, because it fades in and out anywhere and anytime it pleases with no regard for what I'm doing.

Jeanette

I explain fatigue as like when your phone battery is low. You have to think about how you use it. When it's low, you can't waste it on things that will run it down quicker (usually the fun stuff!).

Danielle

share

For our next issue, we're asking: How do you talk to your family about MS? Send in your answers to the MS Matters inbox at msmatters@mssociety.org.uk or keep an eye on our social media ([facebook.com/mssocietyuk](https://www.facebook.com/mssocietyuk) and [instagram.com/mssociety](https://www.instagram.com/mssociety)) where we'll be posting the question later this year.

My journey to HSCT on the NHS



Shereena was diagnosed with MS aged 17 in 2009. She wrote a blog for us about her journey to getting the disease modifying therapy HSCT.

My first neurologist shrugged off every relapse I had. I didn't think anything of it because "the doctor knows best". Little did I know I needed to advocate for myself.

I wasn't on any disease modifying therapy (DMT) until 2019 – 10 years after diagnosis. I tried two different DMTs but my symptoms continued to surface and my mobility got worse.

Ocrevus, Lemtrada or HSCT (haematopoietic stem cell transplantation) were my next options. After making my decision to try HSCT, I was referred to King's College

Hospital. I knew it would be tough.


So far, I've had loads of tests, some chemotherapy and other drugs, and the stem cells collected and stored. I've been shielding to protect myself from infections.


My desire is to walk unaided again. But I worry that my body has experienced too much damage to be rectified.


Read Shereena's full post at mssociety.org.uk/shereena-hsct. For more info on HSCT, visit mssociety.org.uk/dmts-hsct, or call our MS Helpline on **0808 800 8000**

Miles Platt has also written about his experience with HSCT on the blog. He said: "I had quite an enlightened neurologist. He was pretty good, very aware of the treatment, but said it wasn't recommended for use on the NHS in 2017. And he wouldn't be able to get me on a trial because of my age. That's why I went abroad." Read Miles' full post at mssociety.org.uk/miles-hsct

Many of you commented on Shereena's blog on social media.

 **@denise__atkinson**
I found the post-diagnosis silence deafening. I wholeheartedly agree regarding advocating for yourself. Thank God for platforms like these.

 **@mr_tom_and_little_miss**
It seems strange to say this, but I was so pleased to read this. I was beginning to think it was only me that had had that experience. I don't get any support from my neurologist.

 If you'd like to write for our blog, get in touch

at **msmatters@mssociety.org.uk**

Do you have a comment on something you've read in MS Matters or on our website? Let us know!

✉ Email **msmatters@mssociety.org.uk**

📘 Facebook

fb.com/MSSociety

🐦 Twitter **@mssocietyuk**



Getting to know you...

Mohini and **Bayan** are our newest MS Society trustees. For his day job, Bayan works in business development for Reuters. Mohini is Director of Partnerships for UNICEF.



Why did you become a trustee for the MS Society?

Bayan: I've met many fellow young adults with MS since my diagnosis. And I wanted to offer my experience to the charity, and help towards future treatments and care. I'd like every person affected by MS to feel engaged, heard and represented by the charity.

Mohini: I have a close and personal connection with MS, and wanted to contribute towards this brilliant organisation. I'm passionate about social equity and giving everyone a fair and fighting chance for a good and happy existence.

Where's your favourite place you've travelled?

B: Melbourne, Australia. I lived there for a year and it's such a vibrant and multicultural city with great

people, weather, food and nature.

M: When I was a child, my parents took my brothers and me to Kenya for a month-long safari. My dad was born there and it was such a meaningful trip.

If you could have dinner with three people, dead or alive, who would they be?

B: Serena Williams, David Attenborough and Aretha Franklin.

M: David Bowie, Barack Obama and my late father – three of my great loves.

What's the most important lesson life has taught you?

B: Celebrate the good days and use those memories to get through the not-so-good days.

M: Life isn't a level playing field. So it's important for us to use our position and our privilege to help others with less than us. There's always someone else we can help.

Our new council Chairs

Our councils are a voice for the MS community in the nation they represent. We're pleased to welcome our new council Chairs: **Gemma Talbot** in England, **Huw Roberts** in Wales, **Kate Lavery** in Northern Ireland and **Laura Ingram** in Scotland. Find out more at mssociety.org.uk/our-councils

Help shape our future: This year's Board and council recruitment opens soon. For more information, visit mssociety.org.uk/join-our-board or contact our governance team at governance@mssociety.org.uk



MS Society

Help stop MS for future generations

MS research has helped improve diagnosis and develop new treatments that have changed the lives of many people with MS today. A gift left to the MS Society in your will could support tomorrow's generation of crucial research that will help stop MS.

Your legacy gift could fund the researchers who find treatments that mean nobody with MS in the future will have to worry about their symptoms getting worse.

Please consider including a gift to the MS Society in your will today.

Call Sarah on **020 8827 0374**, email **legacies@mssociety.org.uk** or visit **mssociety.org.uk/legacy** to request a free will-writing guide and find out how you can become a force for change.

Multiple Sclerosis Society is a registered charity in England and Wales (1139257) and Scotland (SC041990), and a company limited by guarantee (07451571)



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**FUNDRAISING
REGULATOR**

▶ Let's stop MS together

Dreams of reaching mountaintop come true

Gilby Taylor, who lives with progressive MS, finally fulfilled his dream of scaling Belstone Tor in Dartmoor – thanks to his local mountain rescue team.

Gilby moved to Belstone in Devon three years ago with his wife Jane. He admired the view of Belstone Tor from his garden, and dreamed of reaching the top.

Jane began wracking her brains, determined to make Gilby's dream a reality. Jane knew of someone in the North Dartmoor Search and Rescue Team (NDSART). And a plan started to come together.

On 4 September, the team took Gilby to the peak in a stretcher. Describing the emotional moment, Gilby said: "It was just brilliant. I don't know what more I could ask for." As a thank you, Gilby and Jane have been raising money to support NDSART. They have raised over £7,000 so far.



Dates for your diary

Ready for a challenge? Take part in one of our events and help us get closer to stopping MS.

28-29 May

Edinburgh Marathon Festival

Be part of Scotland's biggest running festival and take part in a 5k, 10k or team relay to help stop MS.

29 May

The Big Leap

Are you brave enough to take the leap of a lifetime? Do the Big Leap skydive at locations across the UK.

2 July

Round the Harbours

Take on this brand new cycling event. The 30-mile route is a unique way to experience the stunning views around the harbours, coastline and countryside of Hampshire.

2 July

My MS Walk: Coombe Abbey

Join us for a walk at Coombe Abbey in Coventry. Walk, jog, stroll or roll and enjoy beautiful woodland, gardens and lakes. Choose from three routes to suit you.

Visit mssociety.org.uk/get-fundraising or call **01382 279378** for up-to-date information and to sign up.

MS Society

Stop MS Appeal Annual Lecture

After two years of being held online only, we're delighted that our seventh Stop MS Appeal Annual Lecture will take place at the Royal College of Physicians in London on **Wednesday 8 June**. We'll still be streaming it live for those unable to attend.

Our annual lecture is a key feature of the Stop MS Appeal, giving donors and

supporters the chance to hear about the latest in MS research from eminent scientists.

This year we'll be hearing from Anna Williams, Professor of Regenerative Neurology and Honorary Consultant Neurologist at the Centre for Regenerative Medicine at the University of Edinburgh.

If you'd like to attend, or need further information, please email Hettie.Tetteh@mssociety.org.uk



Volunteer spotlight:

Louise Nicholas



Louise in Swansea is an MS awareness volunteer with our National Lottery-funded Pontio Project in Wales.

I'm part of a group of volunteers who've designed MS awareness training, which we're delivering to organisations across Wales.

We're all people with lived experience of MS.

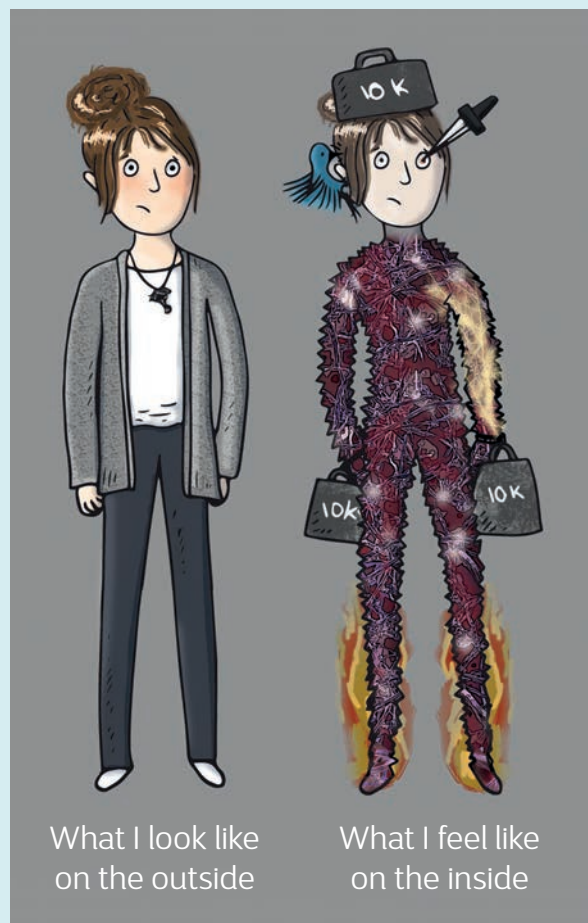
So far, we've delivered sessions for a local authority, charities, major companies and a police force. This has helped to give them a better understanding of what it's like for their employees and colleagues with MS. Especially the invisible symptoms we have.

The feedback we've had has been very positive. Everyone learns a lot about MS and it's great to be a part of that.

I've always had responsible, customer-facing jobs. My last employer and I agreed I could no longer do my job due to the increase in my MS symptoms. I found this difficult. I'm medically retired but still want to feel productive and useful. So I became a volunteer for the MS Society. It's the best decision I've made.

join

The Pontio Project provides emotional, befriending and one-to-one support for people affected by MS in Wales. It also does one-off projects like the MS awareness training. For information about becoming an MS awareness volunteer in Wales, contact sophie.dyment@mssociety.org.uk. Find more volunteering opportunities at mssociety.org.uk/become-a-volunteer



What I look like
on the outside

What I feel like
on the inside

Understanding through images

Jessie Ace is an illustrator and designer who was diagnosed with MS at 22.

Jessie said: "Doing illustrations about MS makes invisible symptoms a real, tangible thing that someone who's never felt these things can relate to. For example, someone who sees barbed wire around a stomach, or a bird pecking at a head, can instantly imagine what that's like. It's more relatable than just saying: 'My MS hug is painful.' It's allowed people to visit my world and understand how it feels to live there."

See more from Jessie at jessieace.com

Make Your Move

Struggling for exercise ideas? As part of We Are Undefeatable, we've helped create a series of exercise videos for people living with long-term health conditions. They help with symptoms including pain, fatigue, stiffness and low moods.

The videos cover exercises like boxing, dance and mindfulness. They demonstrate the exercises in three different ways: sitting

down, using a chair for balance and standing up.

We Are Undefeatable is a movement helping people with long-term health conditions to stay active. It was developed by 16 leading charities including us, Mind and Parkinson's UK.

Watch the videos on YouTube at [mssociety.org.uk/make-your-move-videos](https://www.mssociety.org.uk/make-your-move-videos). Or you can find all of them on the Make Your Move DVD, available



at our online shop [mssociety.org.uk/online-shop](https://www.mssociety.org.uk/online-shop).

Find more videos and support for staying active at [mssociety.org.uk/keeping-active](https://www.mssociety.org.uk/keeping-active)

Shutterstock

Join the MS Matters editorial group

We want MS Matters to be the best it can be. And we need your help.

We're forming an MS Matters editorial group. The group, all living with or affected by MS, will give their time to help shape the magazine and the stories we feature.

We've done this for the research section of MS Matters for years. And it's been so successful, we now want to spread it to the rest of the magazine.

What's involved?

- **Throughout the year, we'll co-create three issues of MS Matters.** You'll have the opportunity to suggest and feedback on themes and articles for the magazine.
- **We'll likely meet online four times a year** for a couple of hours each time. We understand you might not be able to join every meeting, but we'll keep you involved in other ways.
- **We'll also stay in touch via email**, sending magazine features for you to feedback on.

No experience is necessary – just enthusiasm and a passion for creating a great magazine. We'll support you to take part.



If you're interested in joining the group, please contact msmatters@mssociety.org.uk or find out more at [mssociety.org.uk/msmattersgroup](https://www.mssociety.org.uk/msmattersgroup)