

MS MATTERS

mssociety.org.uk

DOES MS MAKE YOU FEEL INVISIBLE?

People from our community talk about what helps them feel seen and heard



RESEARCH

Why I take part in MS research

NEWS

Speaking up about disability benefits

COMMUNITY

How local groups help tackle isolation



MS Society

Step aboard for a fresh take on Spring in 2026



The MS Society will receive a donation worth 10% of the value of your Riviera holiday if you mention them when you book.



River cruise	Departures	Duration	Price from
Bruges, Medieval Flanders, Amsterdam & the Dutch Bulbfields	April 2026	8 days	£2,099PP
Amsterdam, Kinderdijk and the Dutch Bulbfields	April 2026	5 days	£1,299PP
Burgundy, the River Rhône & Provence	April to June 2026	8 days	£1,799PP
Rhine, Strasbourg and Heidelberg	May to June 2026	8 days	£1,899PP
Lyon, Provençal Rhône & the Camargue	April to June 2025	11 days	£2,949PP

Other departures are also available, please check the website for availability

To book, check availability or to request a brochure
Call **01283 893 170** and mention the MS Society
Visit **rivieratravel.co.uk/mssociety**



Donation equivalent to 10% of the total basic cost for all that travel will be made by Riviera Travel to MS Society in the month following that of departure for all bookings where MS Society was mentioned at the point of booking. Riviera Travel retain the right to withdraw this offer at any time. Full details can be found by visiting rivieratravel.co.uk/affinity.





Contents

Cover photography: Anastasia Jobson, Adrian White/MS Society

NEWS

- 6** In Parliament – protecting benefits
- 9** MS and employment report
- 11** Stop MS Appeal update
- 13** Sparking MS conversations

REAL LIFE

- 14** Cover story: Does MS make you feel invisible?
- 19** Tips on navigating isolation
- 20** Archaeologist Cat Jarman shares her story



INSIGHT

- 36** Ask the expert: let's talk about sex
- 39** Befriending service offers a listening ear

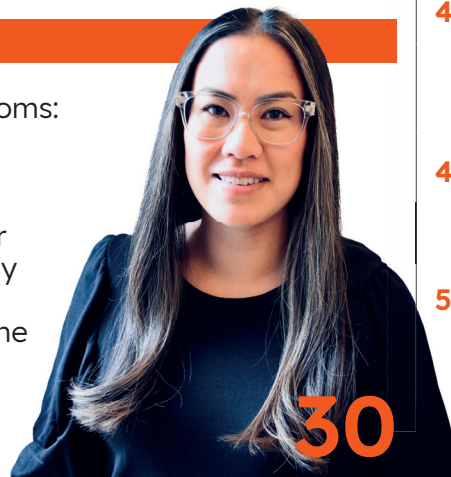
COMMUNITY



- 40** Local groups tackle isolation + Celebrating our volunteers
- 42** Bim's online ballet classes + Belfast centre reopens
- 45** Have your say: local services you value
- 47** Martin's Pennine Way challenge + Relapse warning signs

RESEARCH

- 23** Vitamin D: a new piece to the puzzle
- 25** Monocytes discovery + Northern Ireland research hub
- 26** Why I take part in MS research
- 28** Invisible symptoms: talking about bowel issues
- 30** Making it easier to have your say
- 33** Giving people the tools to stay in work



Articles signed by the authors represent their views rather than those of the MS Society. Mention or advertisement by the MS Society of products or services

is not an endorsement by the MS Society, its officers or staff. The information in MS Matters is not tailored to any specific needs and it's designed for information only. No

information should be taken as direct medical advice. You should assess any activity to decide if it's right for you and make sure you have the right facilities and practical support.



MS Matters is a Multiple Sclerosis Society publication ISSN 2517-6919. © Multiple Sclerosis Society 2025. Individuals or organisations wishing to reproduce, store in

a retrieval system or transmit by electronic, mechanical, facsimile or other means any part of this publication should apply for permission to: MS Matters, MS Society,

Carriage House, 8 City North Place, London N4 3FU. Registered charity nos 1139257/SCO41990. Registered as a company in England and Wales 07451571.



WHEELCHAIR ACCESSIBLE VEHICLES

MOTABILITY | NEW | USED | HIRE

Call our mobility advisors

0800 916 3022 or visit
alliedmobility.com

Follow us    



Motability
Scheme

Latest info

We've reviewed, rebranded and printed our information booklets for:

- **Managing MS relapses**
- **Understanding progressive MS**
- **Diet and MS**



We've also updated the **"I have MS"** card. It's a handy card to fit in a wallet, on a lanyard or keyring. The card mentions wheelchair access or needing the toilet, finding somewhere to sit or that it's hard to talk.



Download or order at mssociety.org.uk/publications or call **0300 500 8084** (select option 4).

All our information about living with MS is on our website too, along with personal blogs, videos and podcasts.

SUMMER 2025 - ISSUE 150

Reading MS Matters, I'm reminded how impressive our community is, especially when we work together.

Our cover feature is inspired by feedback from our community that MS can make people feel invisible and unheard. Jenny, Annie, Nikoma and Stewart talk about their experiences of feeling invisible and what we can do about it.

For some people, managing their MS while staying in work for as long as possible is really important. Our new report on employment (page 9) shows what could be done to better support people with MS in work. And archaeologist Cat Jarman (page 20) reflects how worrying about the impact on her career was one of the reasons she kept her diagnosis a secret.

In our campaigning, our focus is on making sure everyone with MS is heard.



But we saw a lack of understanding about the reality of MS in the government's proposals for disability benefits. Our campaigning as a community put pressure on the government and protected vital support for people with MS (page 6). I'm inspired every day to see how thousands of us speak up. The more of us who raise our voices, the more powerful we are. ^{MS}

Charlotte Gill
Head of Campaigns and Public Affairs

Donate to stop MS

It's the final year of the Stop MS Appeal and, so far, we've raised an incredible £95.7 million. Will you help us cross the finish line and reach our goal of raising £100 million to fund world-leading MS research? Your donations can help turn cutting-edge science into life-changing treatments.

Donate today at mssociety.org.uk/msm-stop



Income from advertising and inserts included within MS Matters goes towards production costs of the magazine, such as printing and postage, leaving more of the charity's money available to help stop MS. Advertisements must conform to the British Code of Advertising Practice. Services offered by advertisers are not endorsed by the MS Society.

MS in Parliament

How we're working with MPs to protect disability benefits

Government proposals

In March, the UK Government proposed changes to disability benefits. They launched a public consultation on some of the proposals, but not on the proposals to cut disability benefits. We worked hard to support our community to make their voices heard. The controversial proposals included:

- Changing some of the criteria to receive Personal Independence Payments (PIP), which could make it harder for people to get PIP.
- Lowering the additional allowances for disabled people who are new Universal Credit (UC) claimants from 2026.

They got it wrong

As soon as the government announced their proposals, we were clear that they'd got it wrong and needed to rethink. Our response hit the front pages. Thousands of us spoke out about the impact of cuts on social media and in messages to our MPs. Since then, we've kept up the pressure in Westminster. And earlier this month, we had a big campaign win when the government announced they were scrapping their harmful plans to change PIP.



Campaigners John Stainton (left), Kerry Riches (centre) and Jane Felstead (right) at the parliamentary event

Putting MS at the heart of UK Parliament

We hosted a parliamentary event on 23 April to raise awareness of what it's like to live with MS. Thousands of us invited our MPs. On the day, many MPs said they were there because they were invited by their constituents. This shows just how powerful our voices can be.

Over 100 MPs joined us to meet our campaigners and celebrity supporters, hearing first-hand stories

from their constituents.

In his speech, Sir Stephen Timms, Minister of State for Social Security and Disability, said "We want to support people to stay in work when they need to." But that "difficult decisions will need to be made."

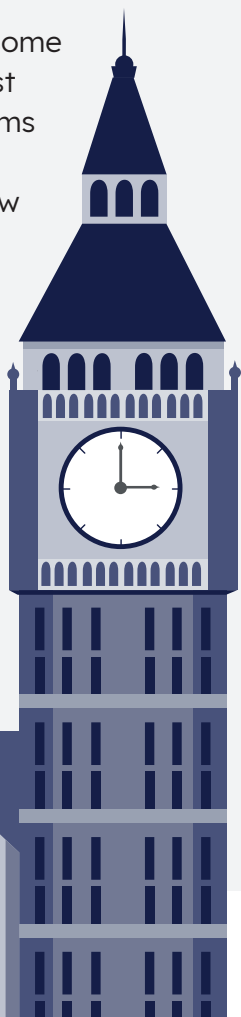
People living with MS expressed their concerns about the impact of the cuts. Phoebe, a campaigner who has MS, spoke at the event.



She said “It honestly feels like having my life jacket ripped off me when I’m already drowning. If PIP is taken away from me, I’ll be forced to work full-time like so many others. This will ultimately push my already declining body into worse health and consequently take me out of work completely.”

With the government’s agenda, there was a strong focus on PIP and cuts to benefits. But we also had conversations about healthcare and treatment. And how important it is to invest in neurology services.

Kerry Riches, who appeared on Big Brother in 2023, said “Today has been massively important. It’s been a long time coming. We’ve been some of the poorest groups in terms of neurology services – now it’s time to put MS on the map.”



Amplifying voices across all UK nations

Scotland

The Independent Review of Adult Disability Payment remains a key priority for our community. The recommendations should be published at the end of July. This means by the time you read this, we’ll be working hard and looking into getting improvements started. In Scotland, we echo our UK-wide call to reverse plans to cut additional disability allowances in Universal Credit. And we’re making sure MS is part of the Scottish Government’s plans to introduce a Long-term Conditions Framework.

Northern Ireland

A consultation was launched as part of the Neurological Review. Together with Northern Ireland Neurological Charities Alliance (niNCA) members, our focus groups gathered views from people with neurological conditions. These included people living with MS. Their views helped shape our joint consultation response.

Wales

We’re looking ahead to the Welsh Parliament/Senedd elections in May 2026. We held a successful Senedd event in May, bringing together health professionals, researchers, local group volunteers, and people living with MS. We aimed to spark conversations with Members of the Senedd. We also attended Welsh party conferences in the spring and summer. We raised awareness of MS and the commitments we need from the next Welsh Government. We want to make sure health and social care services support the MS community to live well across the whole of Wales.

Find out more about... Getting involved

We’ve campaigned to improve PIP and protect disability benefits for over a decade. It’s never been more important. Together, we can make a change. Get involved or find out more about our campaign at mssociety.org.uk/raise-your-voice



medimotion

GET MOVING EVERYDAY...

Enjoy safe exercise at home with MOTomed

Passive/ Active Movement Therapy Devices

Regular MOTomed training can build endurance and strength, improve circulation and increase range of movement.

Popular Interest free hire/buyer plan available

Delivery, setup and training included

Widely used in UK hospitals, rehab centres, stroke clubs, MS therapy centres, leisure centres, schools and colleges.



MUVI



LOOP



Gracile

Discover how MOTomed can work for you:

tel: 01559 384097

sales@medimotion.co.uk www.medimotion.co.uk

RECK
MOTomed®
www.motomed.com



No compromises: Supporting people to thrive in work

Our new report highlights the barriers people with MS face at work and the need for better support.

This year, we asked you about your experiences at work through a survey of over 1,100 people with MS. It's vital evidence at a time when the government is proposing major changes to workers' rights, welfare benefits and employment support.

What our research shows

- **Almost all (96% of)** people with MS say their condition affects their ability to work.
- **Half (50%)** reported they'd left a job because of factors relating to their MS. Often, this is before they want or need to.

- **Half (50%)** of the people who responded said a lack of support and financial pressures led them to stay in a job that compromised their health.

- Benefit reforms pose an extra risk to people with MS in and out of work. **Four in ten (41%)** people with MS in work get PIP and use it to help them stay in work.

Our recommendations

We know that for many people with MS, leaving work is the right thing to do. But others leave work because they don't get enough support.

Based on what you've

Sarah (51)
is a civil
servant
living with
relapsing



remitting MS. She says "My main MS symptoms are intense pain, fatigue, and problems with movement. I had a major relapse a couple of years ago. Since then, I've been claiming PIP to help with my costs. Receiving PIP means that I can afford to work part-time and better manage my symptoms. "Without PIP, I would have to seriously think about increasing my hours at work. This would have a detrimental impact on my health, make my symptoms worse, and would mean more time off sick."

told us, we've developed recommendations for government and employers to:

- make access to flexible working standard practice
- improve employer and government support at work, like the Access to Work and Disability Confident schemes
- make sure everyone with MS has the benefits they need to support them in and out of work. ^{MS}

You can read
our report at
[mssociety.org.uk
/no-compromises](https://mssociety.org.uk/no-compromises)





Designed & Engineered in Great Britain

ENGINEERING TO ENABLE

4.9/5



Independent Service Rating based on 308 verified reviews



Compact Outside Inclusive Inside

easy to drive
4.5m
long



Brotherwood C'arete | Ford Tourneo Connect

✓ In Stock | Short Lead Times

4 Seats + Central Wheelchair Location

Flat, Level Lowered Floor with 56" Internal Headroom

with Android Auto / Apple Carplay, Adaptive Cruise Control, Rear View Camera, Front & Rear Parking Sensors, Navigation & Voice Control

from £10,995

£9,995

Advance Payment



Advance Payment valid Quarter 3 2025. £1,000 Additional Manufacturer Support on selected Ford Tourneo Connect Models only. Offer applies to new customer orders from 20/06/2025.

Brotherwood® Conversion Includes:

- ✓ Comfortable Flat, Level Lowered Floor Conversion
- ✓ Inclusive Central Wheelchair Location - Between Two Second-Row Seats
- ✓ PAWRS Powered Loading System - No Pushing Required
- ✓ Easy-to-Use STORQ Self-Tensioning Wheelchair Restraints
- ✓ Optional 200KG Wheelchair Restraint System Upgrade

Request a brochure or **FREE**, no-obligation home demonstration at Brotherwood.com

FREEPHONE
0330 1747 560



BROTHERWOOD®
ENGINEERING TO ENABLE

Stop MS Appeal hits £95.7 million!

The total reached at the end of May brings us closer to our goal to raise £100 million for MS research.

TARGET
£100 MILLION



Through our matched giving campaign, you raised more than £676,000, with two generous supporters matching each donation. Thank you so much to everyone who donated!

In April, nearly 300 MS Superstars ran the 2025 TCS London Marathon for us, including 21 who ran for the Stop MS Appeal. From the marathon, we hope to raise £900,000, including £117,000 for the Appeal.

Here are some ways you can support the Stop MS Appeal in its final months.

Buy a pair of Monkey Sox

For every pair of Stop MS Classic Crew socks sold, Monkey Sox will donate £7. Wear them while running, cycling or walking. And help spread the



word about Monkey Sox and the Stop MS Appeal wherever you go! Buy them at mssociety.org.uk/monkey-sox

Join an MS Walk

All the money you raise by taking part in an MS Walk this year supports our Appeal. Our Ambassador, Scott Mills, joined us for our Birmingham walk. He said “My mum has MS, and I’ve seen how the condition has affected her over the years. MS Walk is a great way to get outdoors, connect with others in the MS community and raise funds for research.” Sign up for the MS

Walks in Glasgow (13 September), Cardiff (20 September) and London (27 September) at mssociety.org.uk/join-ms-walk

Join My MS Woof

This October, team up with your dog to walk, run, or roll 5k a day – or any distance that suits you and your pup. Visit mssociety.org.uk/my-ms-woof



Have a good laugh

Our Ambassador, Ivo Graham, will host an evening of comedy on 7 October at the Shaw Theatre in London. Ivo will be joined by a lineup of some of the UK’s most celebrated comedians. For more information, email specialevents@mssociety.org.uk

Sing and celebrate

Our Carols by Candlelight concert takes place on 4 December at Central Hall Westminster in London. Expect festive favourites and a joyful atmosphere as we celebrate the end of the Stop MS Appeal. For more information, email specialevents@mssociety.org.uk

Donate to our Stop MS Appeal

Will you help us reach our goal of raising £100 million for MS research? Donate today at mssociety.org.uk/msm-stop

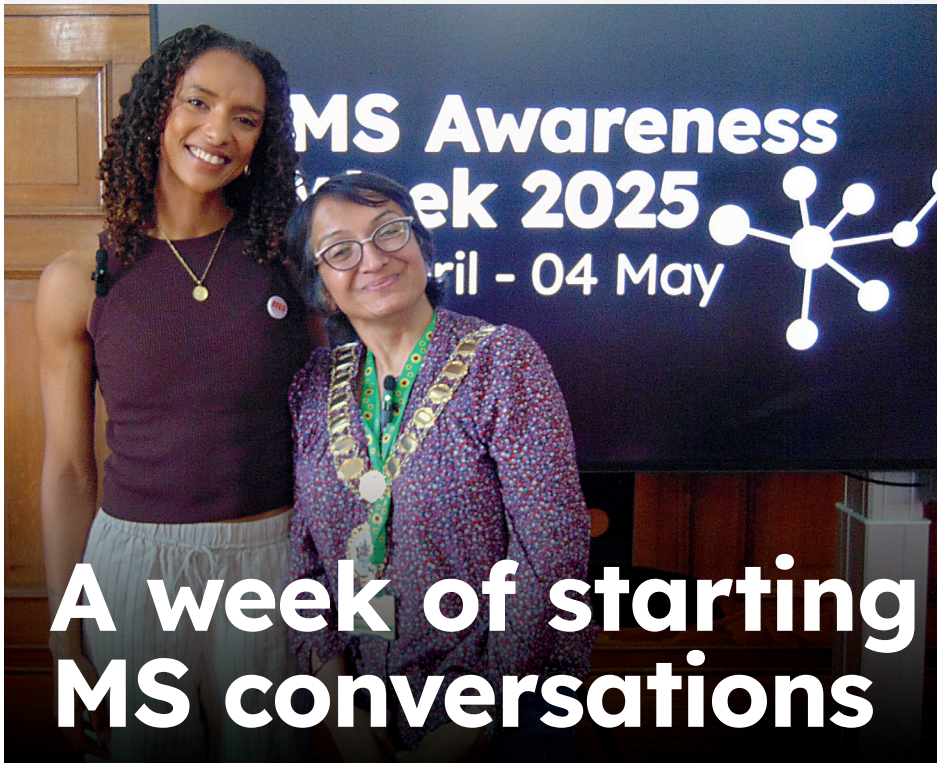




- Specialist in Wheelchairs, Powerchairs, Scooters, Adjustable Beds and Chairs
- Top 10 Approved Dealer on Motability Scheme
- 12-Month at Home Warranty
- Aftercare Support

Book Your Free Home
Demonstration Here





Wider access to cladribine in Scotland

In June, the Scottish Medicines Consortium (SMC) announced that cladribine (brand name Mavenclad) would be available to more people with MS in Scotland.

Cladribine is a disease-modifying therapy (DMT). Until recently, it could only be prescribed on the NHS in Scotland for people with 'highly active' relapsing remitting MS. Now, cladribine will also be available in Scotland for adults who have 'active' relapsing remitting MS.

In some parts of Scotland, cladribine could be available straight away. But other Health Boards might take weeks or months to set things up for it. ^{MS}

You can read more about cladribine at mssociety.org.uk/cladribine



This year's MS Awareness Week was all about finding ways to talk about MS.

Whether it's talking to a family member about their MS diagnosis or asking an employer for support, finding the right words to talk about MS can be hard. But opening up can be empowering.

That's why this year's MS Awareness Week (28 April – 4 May) was all about starting MS conversations. So we teamed up with our friends:

- MS Together
- MS Trust
- MS-UK
- Neuro Therapy Network
- Overcoming MS
- Shift.ms
- Talks with MS

We kicked off the week

with an exciting in-person 'conversation café' event at Islington Town Hall. The Mayor of Islington, Councillor Anjna Khurana, and Olympian Lina Nielsen spoke about their experiences of MS and some of their memorable MS conversations.

Throughout the week, we also created and shared new videos and infographics to help people start MS conversations. We shared people's stories with the media and were covered by outlets like BBC News.

Thank you to everyone who took part and started an MS conversation. ^{MS}

If you'd like to hear about people's most memorable MS conversations, please visit mssociety.org.uk/msaw-2025



Does MS make you feel invisible?

Four people from our community talk about how MS can sometimes make them feel invisible and not listened to. And what we can do about this.

Jenny has primary progressive MS and Nikoma has been diagnosed with relapsing remitting MS. They discuss how using a wheelchair and feeling unrepresented have affected their experiences.

Has your MS ever made you feel invisible?

Nikoma: There have been times at the shops when I've been struggling, and it's taken a while before someone has offered to help. Maybe when people look at me, they see I'm young and think I'm OK. But I'll think "Did you not see me struggling?" Sometimes, that's made me feel a bit invisible.

“ In the Black community, we're not so vocal about our issues. But it makes it worse if people don't speak about things

Nikoma

Jenny: I can relate to that, Nikoma. Do you use a wheelchair?

Nikoma: No, but my walking and balance have been really bad recently.

Jenny: If anything, I found people were less judgmental once I started using a wheelchair. Before, people often thought I was drunk. Oh, how wrong they were. But people can overlook you when you're in a wheelchair. I don't get distressed. I'm assertive but never aggressive.

Sometimes, when I'm out with a carer, I'll ask someone a question and they'll answer the carer instead of me. I'll say "Could you speak to me, please?" And my carers give people visual cues to encourage them to communicate with me.

Nikoma: What needs to be done to help you feel seen as someone in a wheelchair?

Jenny: I think it's important to keep turning up. If something's not accessible, you have to say "How can we get around this"? I take a ramp with me when I go out. If a shop doesn't have one, I'll say breezily, "I'd like to come in, but I need a ramp. Here's one. Can you help me with it, please?"

Do you feel represented?

Nikoma: When I was first diagnosed, I was handed lots of information booklets. I didn't see any people with MS who were Black. When I went to an MS group, everyone was white. There wasn't anyone who looked like me. It started off being quite an isolating experience.

Since then, I've set up an online support hub for Black people with MS with areas where people can get information and support, and just talk. In the Black community, we're not so vocal about our issues. But it makes it worse if people don't speak about things. ➤

“ I think it's important to keep turning up. If something's not accessible, you have to say "How can we get around this"?”

Jenny



What helps you feel supported at home?

Nikoma: My six-year-old daughter's only ever known me the way I am. We try to be as open as we can with her. She can say "multiple sclerosis" and knows what it means. My wife, Simone, has thrown herself into understanding MS. We've co-written a book about our experiences.

Jenny: My husband's got myalgic encephalomyelitis (ME). We know if we don't manage the combination of ME and MS, things will go to pot immediately. So I try to keep my husband off caring duties and be as independent as I can. I've hired carers to help with things like getting to bed. I use direct payments, so I can pay them more. A good carer is worth their weight in gold!

How important is creativity to feeling seen?

Nikoma: I used to travel the world as a sound engineer. I also play the keyboard, so the creative element is part of who I am. My left hand is super numb, but I still try to play because I know it's helpful for me. And it felt good to write the book with Simone and give people a view into our lives.

Jenny: I started painting out of desperation. It's helped me cope in so many ways. It's true that you get better with practice and I surprise myself regularly. I exhibit my work locally. As an artist, you've got to be brazen and say "My work is good enough."

Paying for care

Jenny mentioned how she uses 'direct payments' to pay for carers. You can find out more about getting social care at mssociety.org.uk/paying-for-care

“ A lot of my friends have health issues, so they have a good understanding. And my dog, Milly, always listens and understands!

Annie



Annie and Stewart, who both have progressive MS, talk about social barriers, health services, and coping with loss and grief.

What social barriers can make you feel invisible?

Annie: Things like a lack of blue badge spaces and accessible public toilets. Before the pandemic, I used to know where every public loo in Bolton was. But now they mostly don't exist, which limits me from going out.

Stewart: Most people have little or no understanding of the problems. For example, the disabled toilet in our village hall has the wash basin and hand dryer on opposite sides of the room. That's difficult if you have mobility issues.

Samaritans offer emotional support during difficult times. Call them for free on **116 123** or email jo@samaritans.org

What about people's attitudes?

Annie: I think people intend to be kind. But they often don't know what to say or how to be. It's like when you experience bereavement. My son died by suicide nine years ago. People don't know what to say, so they either say nothing or say the wrong thing.

Stewart: Yes, I experienced that when my daughter died in a road accident. People visibly crossed the street to avoid me because they didn't know what to say. The pain is still raw on occasions, even after 30 years. Somebody once said, "The load

Access to health services

We're working with the NHS to improve access to MS nurses and neurologists, including calling for proper investment in services. We want people with MS to have the support they need for self-management and to be involved when services change. Everyone should have regular, meaningful contact with the right specialists.

doesn't get any lighter, you just get better at carrying it." I think that's true of MS as well.

Annie: Yes, loss is loss, whether it's a bereavement, or you lose your health, or you get made redundant. My grief for my son won't change. But life grows around the loss if you allow it to. It's similar to MS.

I don't refuse to think about it, but I don't dwell on it. And I enjoy finding ways around things and thinking, "If I can't do this, I can do that instead."

Stewart: You've just got to keep doing things. My hobby is keeping bees. Physically, it's quite hard work. But it's joyous when you open a hive and see the bees doing their work. It calms me down completely.

Do you feel listened to by healthcare professionals?

Stewart: My first MS nurse was wonderful. She realised I had prostate cancer and got me an urgent >


appointment with a urologist, which saved my life. But then she retired. My current MS nurse will see me if I'm in the diary, but that's as far as it goes.

Annie: The MS nurse I had when I was first diagnosed was also brilliant. But things have changed locally. I do wonder if it's because I'm older, with progressive MS.

I haven't had a neurologist appointment for 15 years. And since the pandemic, my MS nurse appointments have been on the phone or a video call. Recently, I received a letter saying that the MS nursing service is moving to patient-initiated follow-up. That means we won't get regular appointments. It's up to us to contact them.

What about friends and family?

Stewart: When I was first diagnosed, I didn't want people to know I had MS. I wish I'd had the guts to open up from the beginning. I feel happier being honest about it now. And most of my friends and family are very understanding.

Annie: I think I'm quite good at making myself heard. I do pick who I tell things to. Some people are uncomfortable talking about illness, so I don't force information on them unless it's necessary. A lot of my friends have health issues, so they have a good understanding. And my dog, Milly, always listens and understands! 

If you'd like to talk about any of the topics in this article, please call our free MS Helpline on **0808 800 8000** or email helpline@mssociety.org.uk We're here to support you.

“ I wish I'd had the guts to open up from the beginning. I feel happier being honest about it now

Stewart



Learning to navigate isolation

Aileen talks about how she rebuilt her confidence during a difficult time.



Aileen's tips

- **Background music,** audiobooks and podcasts help to shape quieter days
- **Go virtual** - increasing my technical know-how was a game-changer
- **Keep a 'social diary'** of everything fun I'm looking forward to
- **Learn more!** Many courses are free and combine virtual and face-to-face. I've met lovely people with shared interests this way
- **Find your tribe** through online and face-to-face forums. MS-specific forums are great, but you can also search for groups that match your interests or location
- **Volunteer** for services such as Age UK's 'Silverline' phone initiative or the MS Society's telephone befriending service. Visit mssociety.org.uk/befriending-service 

After an MS diagnosis in 2002, I went several years almost symptom-free. Then, four years ago, things began to change. It felt like my body had a new, unwelcome sitting tenant, which was throwing wild parties. In reality, I'd developed secondary progressive MS.

I'd moved to a new area, so my friends weren't nearby. Then a bad fall led to long periods at home on my own. I felt trapped. With such narrowed horizons, it was little wonder health challenges were taking over from socialising. The fun version of me was ebbing away, which was especially hard on my family. I'd moved so we could share more quality time. But this newfound isolation was affecting everyone.

It was time to take myself

in hand, rebuild some confidence, and find my tribe.

Try anything once

One lockdown legacy was an increase in virtual activities, so I began researching local options. My mantra was "be open-minded, try anything at least once and avoid making assumptions".

The first opportunity came through a U3A book group, which was welcoming and fun. We met online initially, then face-to-face gatherings came later. Through a shared love of reading, I learned how others navigated isolation. And being busy made me think less about MS.

I've now got some great friends, but I still try new things. Living with MS isn't easy, but these things work for me.



MSMATTERS

If you're feeling isolated, our MS Helpline can offer emotional support and a listening ear. Call for free on

0808 800 8000 or email helpline@mssociety.org.uk

We're all unique

Professor Cat Jarman is a bioarchaeologist, writer and broadcaster. She was diagnosed with relapsing remitting MS in 2016. Cat presents a history podcast, *The Rabbit Hole Detectives*, with Charles Spencer and author Richard Coles.



What is bioarchaeology?

Bioarchaeology is looking at evidence from the bones of people who lived in the past. Bones contain chemical traces that show what people ate, and where they lived and travelled. This helps us understand what their everyday lives were like.

What's been your most interesting discovery?

One of my most interesting discoveries was about women in the Viking Age. Historians used to think that Viking women stayed at home while men went on raids. Using bioarchaeology, I proved Viking women also travelled and were part of the migration process.

What led to your MS diagnosis?

I had an optician's appointment where he noticed I had double vision. A few weeks later, I woke up with pins and needles in my hands. By the afternoon, it had spread up my arm. Within a few days, it was my entire right-hand side. A week later, I couldn't pick up a cup of tea, put my key in the door, or write my name. The pain on my right side was quite intense. It was very, very hard.



I hope sharing my story can help other people

But I was lucky in that I was diagnosed quite quickly, within about three months. I was put on Tecfidera (dimethyl fumarate) and then Kesimpta (ofatumumab). Fortunately, I've not had a relapse since then.

How did you feel when you were diagnosed?

My career was a huge part of my life, so the uncertainty was frightening. In the science I was doing, you need fine motor skills because you're constantly doing stuff with your hands. After nine months, I'd recovered the use of my hand. But I thought "I don't know if this will happen again. A career where I'm using my hands all the time is too much of a risk."

I decided to try to change my career and focus on writing and broadcasting. Since then, I've written two books, *River Kings* and *The Bone Chests*, and worked on TV programmes and podcasts. ➤

You kept your diagnosis secret until recently. Why is that?

When I was first diagnosed, I told a few people extremely close to me. The reaction of some people in my professional life, who I had to share it with, made me decide to keep it to myself. Some of the comments made me feel like people were discounting me.

Archaeology is a physically demanding job. I've done field work where you camp in the middle of nowhere and work 12-hour days in the sun. The same is the case for broadcasting, where you're required to work long hours and be 100% physically reliable every day. I worried that if people knew I had MS, they'd hesitate to pick me.

If it's a choice between five people who would all be brilliant, and one person has MS, they'd be unlikely to choose that person.

How do you feel about talking about MS now?

I'd just begun a new relationship. Charles Spencer and I met at a dig at his Althorp Estate. We were friends for a few years before we got together. Then suddenly, because of who my boyfriend is, my MS is global news. It wasn't my choice to share it, and it felt devastating.


Now, I hope sharing my story can help other people.



When I was diagnosed, it felt like my life was over. Since then, my career has taken a different path. I'm not doing what I wanted to do originally, but I've been lucky.

Is there anything you've learned from your work that can apply to MS?

In archaeology, you have to remember that people are unique. People have had different experiences. And just because you've got one

bit of evidence doesn't mean it applies to everyone. It's similar when you're dealing with a medical condition. We're all unique, and MS impacts us in different ways. 

If you're worried about how MS might affect your work, we have information and tools to help. Visit mssociety.org.uk/ms-and-work



Vitamin D

A new piece to the puzzle

We know there's a link between low vitamin D levels and a higher risk of developing MS. But previous research has found that vitamin D supplements don't seem to be effective as a treatment for MS. This new research could suggest otherwise.

In the D-Lay study, researchers looked at the use of high-dose vitamin D in 303 people with clinically isolated syndrome (CIS). CIS can be an early sign of MS. They wanted to see if vitamin D supplementation had an impact on relapses or new lesions on MRI scans.

Half of the participants took high-dose vitamin D. The other half took a placebo (dummy drug).

What did they find?

Researchers found:

- people who took high-dose vitamin D had a 34% lower risk of relapses or new lesions, compared to the placebo
- relapses and new lesions were seen less frequently in people who took high-dose vitamin D (60.3% compared to 74.1% of participants on the placebo)
- people who took high-dose vitamin D had a longer average time to a relapse or new lesions (224 days compared to 432 days in the placebo group).

How does this fit with other research?

The results of D-Lay MS seem to contrast with what we've learned from other trials. This could be because of differences in who took part in the trial. Or how the trials were designed.

The people in the D-Lay study had lower vitamin D levels. So supplementation might have more of an impact on people who are deficient in vitamin D. And the D-Lay study was longer than previous trials, so may have given more time for the effects of the treatment to be observed.

The results of this study suggest that vitamin D supplementation may have some benefit for some people with early MS. But the dose of vitamin D tested in the D-Lay MS study was much higher than the recommended dose. And participants were monitored closely for safety purposes.

We know vitamin D is important in other ways, including bone health. If you're concerned about your vitamin D levels, speak to your health care professional. They can help you find out what supplementation dose is right for you. ^{MS}

You can find out more about the D-Lay study at mssociety.org.uk/vitamin-d-study



Freedom and Independence for Drivers and Passengers



Ford Connect Rear Passenger

- Rear entry with manual, anti-slip ramp
- Flexible seating with two ISOFIX in mid-row
- Class leading quality and headroom (145cm)



Award-winning



Dacia Jogger Rear Passenger

- UK's only wheelchair accessible car - space for six people
- Extreme SE model - premium ambiance
- Latest infotainment systems including Apple CarPlay



Ford Connect Upfront

- Travel upfront next to the driver - space for five people
- Side entry, ISOFIX in mid-row & spacious boot
- Front & rear parking aids, air conditioning, alloy wheels



Ford Connect Drive/Upfront

- Drive from your wheelchair/ switch to upfront passenger
- Automated tailgate and ramp - no assistance required
- Space for up to four people - two rear fold down seats

Stock available immediately

Book a free home demonstration

W sirusautomotive.co.uk T 0121 505 7777





The role of monocytes in myelin repair

Myelin is the protective coating around nerves that's damaged in MS. And researchers recently discovered a type of immune cell called a monocyte might be stopping the brain from repairing myelin.

Monocytes release a protein called Wnt (pronounced "wint"). When researchers

blocked this protein in mice, myelin repair improved. They think this could be because Wnt stops the full development of the cells that make new myelin.

This shows us that targeting monocytes and Wnt may be a promising approach for developing new treatments for myelin repair. The researchers

say they hope we could also use these findings to develop a blood test that helps predict who's at higher risk for MS. This could guide earlier, more personalised treatment.

Read more at mssociety.org.uk/monocytes



New research hub launches in Northern Ireland

A new research hub dedicated to MS research has launched at Queen's University Belfast. In partnership with investment from Queen's, our funding has made the Hub possible.

Northern Ireland has one of the highest rates of MS in the world, with more than 5,300 people living with the condition. The Northern Ireland MS

Research Hub will bring together neurologists, immunologists, ophthalmologists, and neuroscientists to speed up progress in MS research. Previous findings show that the retina (the back of the eye) can become inflamed and lose nerve cells in MS. Research at the Hub will build on these findings. The team will use

cutting-edge technology to scan the retina in more detail than ever before. This could provide faster, simpler ways to monitor how MS progresses, and how people with MS respond to treatments.

Read more at mssociety.org.uk/ni-research-hub



Why I take part in MS research

The benefits of being in a study

We fund a broad range of research projects. They work to improve diagnosis, treatments and support for people living with MS. Taking part in research is a big part of that process — Lauren Forrester and Paul Griffin told us what it was like for them.

Paul Griffin is taking part in ChariotMS. This is a clinical trial testing whether a drug called cladribine (Mavenclad) can help people with MS maintain the use of their arms and hands.

Paying it forward

In the early days of my MS I was able to take Rebif, which someone would've been on a trial for 20-plus years ago. I think it's only fair I pay it forward — and that's why I decided to take part in clinical trials myself. While it may be too late for me, it'll hopefully benefit the next generation of people living with progressive MS.

Personal benefits

But there are also personal benefits to taking part. I get regular, dedicated time with a neurologist and MS nurse. These appointments are often far more thorough than regular clinical appointments. And

“While it may be too late for me, it will hopefully benefit the next generation of people living with progressive MS



Paul Griffin

was diagnosed with relapsing remitting MS in 1996. Then secondary progressive MS in 2017

they often include tests you wouldn't normally do — especially when you have progressive MS. These include physical and cognitive tests, and additional MRIs. For example, through the trial, I found out I have high blood pressure. And now I can tackle this with my GP.

And it's all at no extra cost to me. The trial team pays for fuel to get to the appointment.

I'd say give it a go

If you're considering taking part in research, I'd recommend giving it a go. It's important to remember you're not signing your life away. If you change your mind, you can withdraw from the trial at any time.

Lauren Forrester took part in a research project that tests if virtual reality games can help people with MS rehabilitate their upper limbs.

Taking back control

When I was diagnosed with MS in 2021, I spent six months in hospital. I was completely paralysed on my left side and couldn't get out of bed. I don't remember most of my time in hospital, and my partner had to make most of the decisions for me.

Taking part in research helped me take back some of that control. It's a way of taking back agency.

It was such fun

Before taking part in this trial, I'd never used virtual reality. But it was so much fun and really engaging. Instead of rehabilitation exercises, it felt like a light-hearted game. But, at the end, there's the bonus of it potentially being beneficial for you!

“ Research doesn't have to feel clinical or scary, but it can be very fascinating and fun



Lauren Forrester has been living with highly active relapsing remitting MS since 2021

It's the small wins

For me, it's the seemingly mundane things I've regained. My biggest win recently is that I can now carry two cups of tea at the same time again. And it feels great doing something positive. Because how can we expect progress if we don't make it happen ourselves?

I can't recommend it enough

If you're considering taking part in research, I recommend you go for it! Research doesn't have to feel clinical or scary, but it can be very fascinating and fun. ^{MS}



Find out more about... taking part

Would you like to take part in research? Find out more on our webpage mssociety.org.uk/take-part



We all need to poo!

New study aims to help people discuss their bowels

We're funding a research project to find ways to support people with MS to self-manage bowel symptoms. Research Network member Pat Poole found out more from nurse and PhD student Jessica Parkhouse.

I'm Pat. I've had primary progressive MS officially for about 10 years. And, unofficially, much longer than that. I'm part of the MS Society's Research Network, which helps researchers consider the real-life needs of people with MS when designing their projects.

I live in a small Yorkshire village with my two cats and my husband. I have children and grandchildren I like to spend time with. And I enjoy crocheting, knitting, and working in my garden.



Pat Poole
Research
Network
member

Jess's story

I met PhD researcher Jessica Parkhouse. She told me about her new study, which aims to develop a programme to help people with MS discuss their bowel symptoms with clinicians and self-manage their bowel problems.

Jess is a nurse by background. She became interested in MS because her auntie has MS. When she worked at University College London Hospitals, she did a stint on a specialist ward, where she made the connection between neurological conditions and digestive issues. Jess told me "It's everything I'm interested in, medicine, neurology, therapeutic treatments and self-managing chronic illnesses."



Jessica Parkhouse
RN, MRes
PhD student
in Nursing
Research at
King's College
London

A difficult subject

When I was talking with Jess, the comical phrase "we all need to poo" came up quite often. And it's true, everyone from the King downwards has this amazingly efficient waste management system within our bodies.

Jess told me most people with MS will experience constipation and incontinence (loss of control of your bowels or bladder). It's the third most difficult symptom to manage, after fatigue and pain. But we don't talk about it. We might chat briefly with our friends, but we find it difficult to raise the subject with our medical professionals.

Raising awareness

Jess wants her programme to raise awareness among medical staff around why they should initiate conversations about bowel management. If clinic time is short, doctors should know how to signpost patients to the proper support.

She's passionate about giving people with MS the tools to raise the subject themselves. And play a significant part in these discussions. She also wants to remove the stigma that can be associated with talking about our poo.



Empowering us to feel in command of our condition can have a beneficial effect on our quality of life

Taking back control

We talked about the problem that many people still live with MS symptoms silently. Lots of us are treating our symptoms with a mix of trial and error.

Taking control and managing chronic symptoms ourselves works well, and it's what Jess is aiming for. But we need help to set off along the right road. We need the knowledge and strategies to discuss our bowel problems with our clinical team and pursue treatment.

Impact on quality of life

Empowering us to feel in command of our condition can have a beneficial effect on our quality of life. This is why Jess is so passionate about the project. MS care varies countrywide. In certain

regions, it can amount to as little as half an hour with an MS nurse twice a year. Self-management can help address that gap.

Jess's programme will give people with MS the language to use, knowledge of who to go to, and how to quantify issues for health professionals. Opening dialogues and raising awareness with clinicians can only lead to better outcomes for people's quality of life.

Watch this space

Jess's project is just starting out. She's developing it with the help of people living with MS. And she needs to decide what form the programme will take.

She told me she hopes to do a good job and do the project justice. I can't wait to see the finished product. ^{MS}

Find out more about... bowel problems

If you experience bowel problems, our website provides information that could help you manage them. Visit mssociety.org.uk/bowel



Making it easier to have your say

How your voice can help shape MS research

Heather Mah is a PhD student looking at how people are involved in MS research. She won our writing competition for researchers with this article about her work.

It's important to involve patients and the public in shaping research. It can help make sure studies meet the needs of people who benefit from the research. For people affected by MS, this means sharing their experiences so researchers can understand more about what it's like to have MS. This is known as 'patient and public involvement' (PPI).

While PPI can help make research better, I've found it can be hard for people with MS to take part. So I'm doing a PhD looking at PPI in MS research. I want to know what the experience of doing PPI is like for people with MS, research staff, and PPI coordinators.

The challenges of doing PPI

Accessibility isn't just about physical spaces. People with MS told me about a range of things that made PPI hard to do. First was finding out about the opportunities. Many were not widely advertised, as researchers often asked the same people they'd already worked with or recruited on social media. This means the experiences

of some people with MS may not be reflected in research.

People with MS said their invisible symptoms, like fatigue, brain fog, and difficulty remembering words, could make it hard to talk at meetings. Sometimes meetings were long, used complicated scientific language, or were held at the end of the day.

Researchers told me how difficult it was to find accessible spaces for meetings, especially with small budgets. Rooms needed to be close to public transport, with accessible toilets, a lift and big enough to fit everyone and their mobility aids. Online meetings have made it easier for people to come together and talk about research without having to travel. But people with MS and research staff said they missed seeing each other in person. Chatting before and after meetings helped them to get to know each other better.

The emotional impact


Both people with MS and researchers found doing PPI could sometimes be emotionally difficult. For some people with MS, it took several years to accept

their diagnosis. They didn't feel ready to get involved in research when they were first diagnosed. Others spoke about how some discussions could be upsetting. For example, how MS can get worse, because this reminded them about their own health. Staff delivering PPI found discussing certain topics difficult and worried about the wellbeing of their PPI advisers. We need to recognise how it can be emotionally and physically demanding for everyone involved.

Why this research matters

PPI has the potential to improve MS research by involving people with MS in its design. But we need to address the access challenges that can limit how people can get involved.

PPI activities need to be flexible, understandable, and responsive to people's needs. For example, including people new to PPI, providing breaks and support around difficult topics. This way, people with MS can feel comfortable sharing their experiences and research can reflect the true needs of the MS community.

I'd like to thank all the participants who shared their experiences and the Horne Family Charitable Foundation for funding this PhD. 

“

PPI has the potential to improve MS research by involving people with MS in its design

Interested in shaping MS research?

Our Research Network is a group of people affected by MS who use their lived experience of MS to influence and shape research. Find out more about joining our network at

mssociety.org.uk/take-part



MS Society

MS
Weekly

Lottery

Enter our
weekly lottery
and you could win

£10,000!

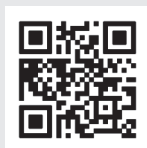
Play today!

By phone

01628 820 116
(Mon-Fri 9am-5pm)

Online

mssociety.org.uk/play-lottery
or by scanning the QR code



GambleAware

18+

Multiple Sclerosis Society. Registered charity numbers 1139257 / SC041990. Registered as a limited company in England and Wales 07451571. Multiple Sclerosis Society is licensed and regulated in Great Britain by the Gambling Commission under account number 4989. Licence holder: Edward Tait, MS Society, 8 City North Place, London N4 3FU.



Giving people the tools to stay in work

and overcome employment challenges

We spoke to Professor Helen Ford about her team's work to empower people with MS with the psychological tools to stay and thrive in their careers.

Can you tell us about the background of your work?

We've spent over a decade researching employment challenges faced by people living with MS. We saw that people with MS were leaving work much earlier than others with similar long-term conditions. And we wanted to understand why.

At first, we assumed mental health factors like anxiety and depression would be the main psychological causes. But we found resilience and a concept called 'self-efficacy' – the belief you can succeed in a certain setting – played a much stronger role.

So we focused on how we could help people with MS build resilience. And gain confidence navigating challenging situations in the workplace.

You're using Acceptance and Commitment Therapy (ACT). Can you explain what that is?

ACT is about accepting your situation and developing strategies to manage

the challenges. Techniques include mindfulness, and something called 'defusion' which allows you to step back from unhelpful thoughts. ACT has been shown to help people with MS in other contexts.

Tell us about the READY programme and how it inspired your work.

READY is an ACT-based group programme developed for people with MS in Australia. We'd heard positive feedback about it. So we thought about how we could adapt it for our NHS teams. That led us to create a digital version of the READY programme to offer resilience training to healthcare professionals and people with MS. ➤



Professor Helen Ford

Consultant Neurologist and Professor of Neurology at the University of Leeds.



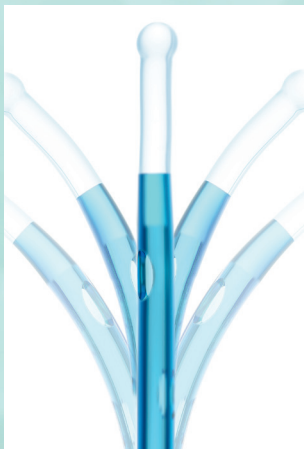
Unique male and paediatric single use catheter that's ready to use immediately



iQ CATH

4-6 times a day, 150 times a month, 1,800 times a year. This is how often an average user of intermittent self-catheterisation inserts a catheter. This is why the quality and application safety of the catheter are crucial.

Advantages of using the iQ CATH with sleeve



Sleeve

The sleeve is a thin film that covers the catheter completely and permits a no-touch insertion, assisting with a clean intermittent self-catheterisation technique.

Unique soft and flexible rounded tip

This combination allows the catheter to smoothly follow the path of the urethra.



For convenience, the catheter is immersed in saline for immediate use



iQ CATH female catheter also available

 MANFRED SAUER UK

For more information or sample requests, please contact the helpline on:

01604 595 696 quoting **MSM/July**
helpline@manfred-sauer.co.uk
www.manfred-sauer.co.uk

 MANFRED SAUER CARE
NHS Prescription Dispensing Services

We also offer a **FREE HOME DELIVERY SERVICE** providing a personal service from a professional team. Please contact the helpline for more details.



What were the results of your initial pilot study?

MS-PROACTIVE was a pilot study with 90 participants across three centres. We wanted to test if our programme was helpful for people with MS and identify areas for improvement.

We saw improvements in self-efficacy (believing in your ability to reach your goal) and, interestingly, a reduction in work instability. This is the risk of a person losing their job, which can be influenced by many external factors.

What does the programme involve?

It's structured around weekly 30-minute online sessions for seven weeks with a booster session at 12 weeks. Many people revisit certain exercises multiple times. We co-produced the programme with people living with MS. They helped shape the content and the design of the platform to make sure it was suitable.

What barriers do people with MS face in accessing psychological or work-related support?

The biggest barrier is the shortage of neuropsychologists. People who took

part in our study made it clear they needed a flexible option. Something they could manage in their own time without multiple hospital appointments. That is why we focused on the digital format.

What's the next step to make it widely accessible?

We believe healthcare professionals can also benefit from building their resilience and self-efficacy. It also better prepares them to support people with MS.

So far in our study, INTERACT-MS, six NHS sites are involved, each training five team members. These team members will then support people with MS through the programme. We're collecting data at the start, after eight weeks, and after six months. We're also gathering real-time user feedback to improve the programme.

What do you hope the long-term impact will be?

Work offers so many benefits beyond financial stability. It's also tied to identity and self-worth. We've already seen how powerful this programme can be. We hope that it helps people with MS to manage the ongoing challenges they face in the workplace and beyond. ^{MS}

Find out more about... work and MS

In partnership with the Work Foundation at Lancaster University, we asked 1,125 people about their experiences of living and working with MS. We recently published our findings in a joint report 'No compromises: supporting people with MS to thrive in and out of work.' Read the full report at mssociety.org.uk/no-compromises



Ask the experts

Let's talk about sex

Research Network member Tony Sibley lives with secondary progressive MS. He asks Emily White, PhD student at King's College London, and Dr Ashley Brown, her supervisor, about their research into sex and MS.



I'm Tony. I'm currently enrolled in a study about a topic many people struggle to talk about: sex and MS. I had the pleasure of interviewing Emily and Ashley about their study. They're developing an app to help people with MS who experience sexual difficulties.

After the interview, I found myself sitting and reflecting on what these two professionals have achieved so far. And how this could be a huge leap forward for many MS patients. I hope that, when the time comes, they can take the study to the next level.

Q What's your research about?

Emily: Sexual difficulties are often an invisible symptom of MS many people find hard to talk about or seek help for. Our research is focused on developing a digital app that delivers a self-guided psychosexual intervention for people with MS.

Ashley: It's about

creating a safe, accessible resource that can address sexual wellbeing in a condition as complex as MS.

Q What made you want to tackle the subject of sex and MS?

Ashley: I've been working in the field of sex and wellbeing since 2017. In 2020, my focus shifted towards people with long-term

conditions. I connected with Professor Rona Moss-Morris, who'd done a lot of work around MS. We know that 60-80% of people with MS experience sexual difficulties. So we saw it as an important area to focus on.

Emily: It was the human element that drew me in. Sex is a subject many people feel uncomfortable discussing. But it's vital for people's overall quality of life and their relationships.

Q So how could an app help people with MS?

Ashley: Many people are diagnosed with MS when they're considering starting families and relationships. So early intervention and self-management of sex and intimacy issues are incredibly important.

Moving to a digital format is a big leap forward, especially with limited NHS resources. NICE guidelines are moving more towards self-management strategies. That's where the app fits in. It provides structured support people can use at their own pace.

“ Sexual difficulties are often an invisible symptom of MS that many people find hard to talk about

Q What have you learnt so far?

Emily: One of the most valuable things I've learnt is how important it is to stay connected to the people we're designing the app for.

We learned some features of the app, like automatically turning pages, weren't helpful for people with MS. They wanted to be in control. It was a powerful early lesson – the small things mattered. Based on feedback, we're also working to make the app relevant to people with and without partners.

The MS community has taught me so much already – from the emotional impact of intimacy to communication challenges as MS progresses.

Q What are the next steps in your research?

Emily: Right now, our goals are to understand how to best measure sexual difficulties in people with MS. And finalise the app's content. After that, we'll start user testing and set up a small trial of the app.

Ashley: We should have a better idea of the outcomes from our small feasibility trial in the next two to three years. Then we'll be looking at funding to help us run large-scale trials and implementation work. Long-term, we want to get this into the hands of people with MS to transform how sexual wellbeing is supported. Eventually, we hope the lessons we learn can be applied to other long-term neurological conditions. ^{MS}

MEET THE EXPERTS



Dr Ashley Brown



Emily White

Emily and Ashley's work is part of our Doctoral Training Centre at King's College London. Find out more at mssociety.org.uk/dtc-kings-college



CONTACT US FOR A FREE HOME DEMO



TRAVELSCOOT ESCAPE THE WORLD'S LIGHTEST MOBILITY SCOOTER

only 14.8 kg

including battery



RE-MOBILISE YOUR LIFE!

The TravelScoot is the world's lightest and most compact electric mobility scooter. It can be used indoor and outdoor on varying terrain enabling people to engage in daily activities or life's bigger adventures.

The scooter folds up and down in less than a minute, and fits into any car boot. At only 14.8kg it is easy to lift in and out. All purchases include a TravelScoot travel bag. Additional accessories are also available.

Use code 'ms matters' at the checkout

£200 off*

Now £2,395

Was £2,595

*This promotion expires on the 30th September 2025

For more information please visit our website or call us on 01923 510350, www.travelscoot.co.uk

Get in and out of bed independently with the award-winning, original and trusted...

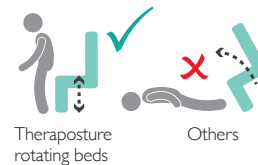
Rotating bed range from Theraposture



- New Orbit bed – revolutionary design for ultimate personalised support and comfort
- Saving £27,000+ a year in care costs*
- Proven to help with MS
- Widest range of singles and doubles
- Buy, rent, new or refurbished
- Buy back options – lowering the price you pay
- 14-day Suitability Assurance



Rotoflex®



In partnership with



10% OFF ALL THERAPOSTURE PRODUCTS IF YOU HAVE MS, IN ASSOCIATION WITH THE MS SOCIETY**



Freephone: 0800 834654

Email: info@theraposture.co.uk www.theraposture.co.uk



Open: Mon-Fri 08:30-17:30, answerphone messages can be left at other times. Kingdom Avenue, Northacre Industrial Park, Westbury, Wiltshire, BA13 4WE. * Based on example County Council care costs. ** T&C's apply. Goods sold to privately purchasing clients living with MS, shall receive a 10% discount (excluding special offers) on their orders and the MS Society will receive a contribution of 7.5% of the net value of each sale.

MSMATTERS

How a friendly phone call can reduce isolation



Ahra An manages our telephone befriending service, which is part of the MS Helpline.

The befriending service was set up in 2020 during the pandemic. We were getting a lot of calls on our MS Helpline because people were feeling lonely and socially isolated.

Five years on, there's still a huge need for the befriending service. People sign up because they want to speak to someone regularly. They can talk about anything they want, whether that's their MS or the movie they watched that week. Just connecting with someone is so valuable.

How does the service work?

When you sign up for the service, we'll match you with a volunteer, so you'll always



Ahra An manages our telephone befriending service

speak to the same person. Then your volunteer will phone you at the same time every week for 12 weeks. The calls last for an hour. Our befriending volunteers are very diverse. Some have MS, some have

family members who live with it. Some volunteers don't have any connection to MS. They just want to support the community. ^{MS}

Befriender feedback

98% of people who've used the service say they'd recommend it to others. Here are some of their comments.

"I loved my calls with my volunteer. It just felt like I had another friend, one who could understand me and my illness more than my other friends."

"My volunteer was a great listener, and it was healing and encouraging to experience their empathy."

"My volunteer is a truly amazing person. Their care, compassion, friendship and laughs have helped me through an extremely difficult time. I think their support adds tremendous value to anyone going through the struggles of MS."

Find out more about... the befriending service

You can register for the befriending service by calling the MS Helpline on **0808 800 8000** or filling out a form on our website. Visit mssociety.org.uk/befriending-sign-up

If you're interested in volunteering for the service, please email ahra.an@mssociety.org.uk or call her on **020 8438 0704**.





How our groups bring people together

Our UK-wide network of local groups provides friendship, activities and support. Members talk about the difference local support can make.

Rueben and Rachel are members of the Nottingham and District MS Society Group and value the social opportunities it offers. The group runs regular coffee mornings and day trips, and provides information and emotional support.

“It’s like a big family”



Rueben was diagnosed with highly active relapsing remitting MS in September 2023. He had five major relapses within nine months, which have left him with

constant pain and limited mobility.

He says “It’s nice meeting people with the same condition and hearing them talk about their experiences. And how they deal with everyday situations. I’ve made amazing friends among people I wouldn’t normally mix with.

“Without the group, life would be a broken record. Every day would be the same – just being there with your own thoughts.

“We’ve got a WhatsApp group to include people who don’t make it to the coffee mornings. We chat about everything, not just about MS. It’s like a big family.”

“Understanding and acceptance”



Rachel was diagnosed with relapsing remitting MS 18 years ago. Her MS was initially highly active, but she’s been relapse-free for 14 years since being prescribed

Tysabri. She uses two crutches and a mobility car to get about.

She says “I’ve been going to the coffee mornings for about a year. There’s disabled parking and we’ve got a little bit of the pub to ourselves. So we can speak freely without worrying people will overhear.

“We have a range of different abilities – anybody’s welcome. It’s so nice to sit and talk about your symptoms and not have to try and explain them. People automatically understand what you mean. It’s the understanding and acceptance.”

Vivienne is a member of the South and West Cornwall MS Society Group. The group was revived by Fiona Salamone in 2021 after a few years of inactivity. Fiona now has nine fellow volunteers who support her in running the group.

Their partnership with Age UK Cornwall provides vehicles and volunteer drivers. This helps make sure members of the group aren't excluded because of poor travel links across the region.

“Valued from the start”




Vivienne, 54, from Camborne was diagnosed with relapsing remitting MS in 2017. Her main symptoms are extreme fatigue and cognition issues. And her mobility has been

impacted, reducing how far she can walk.

She says “I moved to Cornwall four years ago from Manchester. When we moved, I became quite isolated as I didn't have a friendship group down here. I was worried about joining other groups because you often get seen as the unreliable one. Or difficult because of having MS.

“I randomly spoke to a lady through Facebook Marketplace who also had MS. She recommended the local MS Society group. I'm really into my crafts and I've been able to join arts and crafts activities run by the local group. We've even been sailing! The group were so welcoming and understanding of my MS. They make an effort to sit you with similar people to get to know. You just feel so valued from the very start.

“There's nothing to lose by joining a local group and I recommend trying out all the different activities on offer!” 

Find out more about... MS Society groups

Find a local MS Society group near you by searching on our website at mssociety.org.uk/near-you



Celebrating our volunteers

During Volunteers' Week (2-8 June), we took the opportunity to say a big thank you to our volunteers and highlight the difference they make. We hope you saw some of our stories on social media, like our volunteer blogs and video shout-outs from our Ambassadors.

These highlighted the breadth of the roles our volunteers do. For example, our local groups and befriending volunteers help people affected by MS to stay connected. Our National Council members and campaigns volunteers advocate for change. All our volunteers play a vital role in providing services and support to the MS community.

We appreciate our volunteers all year round! Thank you to everyone who gives their time and skills to the MS Society. Together, we do what we do for the MS community.

If you'd like to find out more about volunteering with us, visit mssociety.org.uk/volunteering



Bim's ballet class for people living with MS

In March 2020, choreographer Bim Malcomson and a group of people with MS were rehearsing for a special ballet performance. The show was meant to be the culmination of a partnership between the MS Society and the Royal Opera House.

When COVID cancelled the show, Bim wanted to keep offering classes for people with MS. So she went online. Her pay-what-you-want Zoom group is still going strong today.

Bim explains “I wanted to give the group a sense of continuity, an opportunity to move, dance and keep a feeling of connection. This was during a time that, for many, was very challenging. After six months, it became clear to me that the class was here to stay. So I opened it out to the wider MS community.”

Mario Mattia has been part of the Zoom classes since the start. He was diagnosed with MS in 2007. He says “Sharing these Zoom ballet classes with others who are also living with MS is a fun way to work out. And to feel part of a community. It reminds you you're not alone in facing the challenges that come with the condition. Together, we find strength, not only in movement, but in each other.”

To find out more about the classes, contact Bim through her website bimmalcomson.com



Belfast Resource Centre opens its doors

Our Northern Ireland team were delighted to return to the Belfast Resource Centre in June, following its refurbishment.

Work began in June 2024, and we now share the premises on Annadale Avenue with the disability charity Sense, who own the building.

Ann Wilson, Northern Ireland Resource Centre Manager, said “It's been so lovely to welcome our MS community back to the Resource Centre. To be able to bring all our services and activities back under the same (newly replaced) roof has been wonderful. The Centre is looking fantastic, and we're all delighted to be back.”

If you'd like to find out more about the services we offer, please drop us an email at nireception@mssociety.org.uk



Wheelchaircars.co.uk



FREE NO OBLIGATION HOME DEMONSTRATIONS



USED VEHICLES FROM £2995

Tel: 0161 793 5934

Full details on our website,
www.wheelchaircars.co.uk



Croft Bungalow

Peak District self-catering Accessible Bungalow

- Award winning accessible bungalow - featured on the BBC
- Sleeps up to 4 people (twin/double room, single room, bed/settee)
- Hoist, profiling bed, wetroom, 2 riser-recliners, showerchair/commode
- Great location, 15 mins from Chatsworth, 10 mins from Bakewell
- Level access throughout and private adjacent offroad parking
- Virtual tour, videos and photos on our website
- Two local foodie pubs within 100meters - for those non cooking nights

Website: www.croftbungalow.co.uk

E-mail: enquiries@croftbungalow.co.uk . Phone: 01629 650979

Treworgans

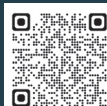
ACCESSIBLE HOLIDAY COTTAGES IN CORNWALL



Fully wheelchair accessible with a wide range of mobility aids available.



01726 883240 / 07762 173860
www.treworgans.co.uk



rollz motion performance

rollz

Enjoy a smooth and safe ride on all terrain!

Helps people living with MS experience comfortable walks even on rough terrain

- The Rollz Motion Performance is a 2-in-1 rollator and wheelchair with pneumatic tyres.
- Transforms from rollator to wheelchair in seconds, without any tools.
- Modern design and eye-catching colors to encourage walking.
- Includes the world's first activity sensor for rollators - the Rollz Fit.
- Measures distance, speed and time traveled with the rollator.

Scan to get 10% discount with code MS10 until August 31st.



0333 207 2080
info@rollzmobility.co.uk
www.rollzmobility.co.uk

Designed in the Netherlands

Looking to become more independent and confident by reducing falls and trips and making walking less of an effort while living with the effects of multiple sclerosis (MS)?

*84% of FES users report a reduction in the incidence of falls after using FES**

**OML FES user survey 2024*



Functional Electrical Stimulation (FES) restores and improves movement to assist with walking, grasping, shoulder or bowel function leading to improvements in daily living activities, quality of life and reduced pain.

FES is a treatment which involves applying small electrical pulses to the nerve, activating the muscle which has become weakened due to a neurological condition.

Odstock Medical Ltd (OML) is the leading provider of FES treatment and equipment to the NHS.

What our FES patients say...

“ I do wear it (FES device) quite a lot and it's the difference for me of just shuffling to the shops and back versus regaining my life and going for walks and having really fulfilling family holidays. I like being outside a lot and it helps me to do that as well ”

Email: enquiries@odstockmedical.com

Call: 01722 439 540

Website: www.odstockmedical.com

Videos:  Odstock Medical Ltd

Follow us:  @OdstockMedicalLimited  @OdstockMedical

11-005-0026 v6



Have your say



We asked you what local services and support help you manage your MS. Here are some services you told us you value.

Local peer support with Hampshire MS Support and Dorset MS Support. Also, great local support, exercise classes and more from the MS Society Lymington and New Forest Group.

Tracy Noel

Being a volunteer with the MS Society in South East Kent has changed my life. I think I found 'me' again. Local friends are giving each other support.

Yolanda Barker

The Chilterns Neuro Centre is fantastic. Exercise classes, physio, social groups, OT support and complementary therapies including hyperbaric oxygen. I attend most weeks around my work commitments, and the support definitely keeps me going.

Amanda Readhead

I'd strongly recommend Ability Bow, my local rehabilitation gym in East London. This charity helps disabled people to make the best of themselves, often with remarkable results. If exercise were a pill, everyone would be taking it.

Alf Ladder

Living with MS has really changed my life. And the Hampshire MS Society Group has been good for me to help make that change. I feel I'm a better person as a result. Thank you, everyone.

John Stainton

T.E.A.MS Essex in Brentwood is an amazing group. There's exercise, massage and a great social club. Most importantly, it's a happy group. So, when you're feeling low, just pop along there. When you come out, you're on top of the world.

Tina Hinchon

MS Research and Relief Fund (MSRRF) is a gem of a charity based in North East England. It's free for people with MS and their carers.

Eileen Campbell

The charity Samson Centre for MS in Guildford, Surrey offers Pilates classes and support from physios, and, of course, from my fellow MSers!

Louise Whyte

Wessex MS Therapy Centre. It's filled with people who are simply incredible.

southalljoy



For our Autumn/Winter issue we're asking...

How do you best manage your MS symptoms in the winter?

Send your thoughts to msmatters@mssociety.org.uk

We'll also post the question on our social media at [facebook.com/mssocietyuk](https://www.facebook.com/mssocietyuk) and [instagram.com/mssocietyuk](https://www.instagram.com/mssocietyuk)

Turning Bed With 'Tilt' function

NEW lifting foot-section for Lymphoedema

See demonstration Videos at www.laybrook.com

- ✓ RISING & TILTING ROTATING BED FOR EASIER ACCESS
- ✓ DYNAMIC AIR MATTRESS OPTION AVAILABLE
- ✓ ANTI-ENTRAPMENT BARRIER ON SCISSOR MECHANISM
- ✓ PLUS - HIGH RISK MATTRESS, DEEPER & MORE COMFORTABLE MATTRESS AS STANDARD, SIMPLE REMOTE (WIRELESS AVAILABLE)

MSMTBHP-2

Laybrook.com
motion furniture

✂️ INSTALLATION INCLUDED
🏠 FREE HOME ASSESSMENT
£ FINANCE AVAILABLE



Call for a **FREE** brochure
or visit www.laybrook.com for more information
0808 250 2102

From a world with MS, to a future free from its effects

A gift in your will could take us there.

We've never been so close to stopping MS. And it's support from gifts in wills that makes our vital research and support possible. Will you remember us in your will and help stop MS for future generations?

▶ For more information or to write your will for free today, visit mssociety.org.uk/msm-wills or call 020 8438 0828



Multiple Sclerosis Society is a registered charity in England and Wales (1139257) and Scotland (SC041990), and a company limited by guarantee (07451571). Registered office address: 8 City North Place, London N4 3FU.

MSMATTERS

Your thoughts



Sharing achievements and being aware of 'early warning signs'.



Martin's Pennine Way triumph

In November 2024, my husband, Martin Koppany, achieved an extraordinary milestone – completing all 268 miles of the Pennine Way. Martin lives with relapsing remitting MS. He started walking the Pennine Way post-lockdown after a heart attack and discovered he could tackle short sections. Encouraged by this progress, he set a bold goal: to walk the entire route. Around the same time, he started taking Ocrevus (ocrelizumab).

With support from me, the

children and friends Sally and Tony, Martin gradually conquered the trail through a series of circular walks. He eventually walked over 500 miles. His balance steadied, and his right leg, which used to fail after 30 minutes, grew stronger. Walking in nature became both a physical and mental boost. We joined him for the final stretch to Kirk Yetholm, where we celebrated with a pint and signed the official Pennine Way book.

Now, Martin has set his sights on a new adventure: the Northumberland Coastal Path.

Amanda Stevenson

You are your own early warning system

With all the uncertainty that comes with MS, it's good to have someone who knows your personal health as well as you do. That's you! With relapsing remitting MS, it's not possible to predict the next relapse. But changes in how you feel should not be ignored. I did, and I had my worst relapses.

My 'early warning signs' are waking up feeling dizzy, nose bleeds and incessant yawning. Some other neurological conditions use early warning signs to help warn patients of an upcoming episode. Realising you're feeling them, whatever they might be for you, could empower you to get the clinical help you need. Or to slow routine activities down and rest.

Christine

Do you have something to share?

Please get in touch and let us know your views.

@msmatters@mssociety.org.uk

fb.com/MSSociety

@mssocietyuk

@mssocietyuk

Disability benefits are a lifeline. Not a luxury.

Protect disability benefits



Show your support and raise your voice
at www.mssociety.org.uk/raise-your-voice



Volunteer spotlight

Sam's Source to Sea challenge

Sam Perrett, 35, from Worcester, is about to start the first of five 'Source to Sea' river triathlons (hiking, kayaking, cycling). He hopes to raise £500,000 for the MS Society.




Nikki (left) and Sam

raising £500,000 for the MS Society. It's a huge target, but something I'd be so proud to achieve.

Starting in September, my first challenge will be the River Severn. The route is around 385km, starting with a 55km hike in the Welsh mountains over two days. After that, it's five days of kayaking and an 80km cycle from Gloucester to Portishead. I've only casually cycled or kayaked before, so this isn't something I'm used to.

Over the coming years, I'll take on four more rivers:

the Rhone (2026), the Tagus (2027), and the Rhine (2028). Each is progressively longer and more challenging. I've yet to decide on the

final river, but it'll be the biggest of them all to finish off the five years. With what I have in mind, it will be BIG! 

Follow Sam's journey at

source2sea.uk
or on Instagram
with the handle
[@Source2sea.uk](https://www.instagram.com/Source2sea.uk)



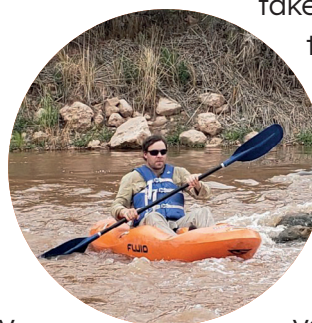
My wife Nikki was diagnosed with MS in January 2023. She had symptoms for a long time before that and overcame cervical cancer when our nine-year-old daughter was 18 months old. We now have a three-year-old daughter too. Information and support from the MS Society really helped us in those months after the diagnosis.

After Nikki was diagnosed, I decided I wanted to get fitter. I quit smoking, started going to the gym and got a personal trainer (PT). The PT suggested

I had a goal to work towards – a weight goal or something similar. I responded that I wanted to get from the source to the sea of the River Severn. It's safe to say my PT was a little confused!

Five expeditions

Since then I've set myself the goal of completing a series of expeditions along five rivers over the next five years. I'll use a combination of hiking, kayaking and cycling. I've also given myself the target of



What motivated you to get involved with the MS Society?

Tracey: I'd worked with local charities as a consultant. I could see their impact on helping people connected to their cause.

Leann: I'd watched my cousins navigate their MS diagnosis. I know how important information and support are, not only to people living with MS but also to their families.

How does LivingWell help people feel seen and heard?

Tracey: People tell us it feels like being part of something again. The spaces we create aren't about fixing anyone. They're about listening, sharing and feeling understood.

Leann: Our peer groups create a



GETTING TO KNOW YOU

Tracey Harrison and Leann Kelly

Tracey and Leann manage our LivingWell programme. This helps people affected by MS build resilience and connections through webinars, courses and sessions led by people living with MS.

safe space for people to share their experiences – groups led by people affected by MS. For example, our Progressive Forms of MS Peer Group connects people who can't access local support. They can chat to other people

who understand what it's like living with MS, from the comfort of their home.

Why are you passionate about this issue?


Tracey: I've seen firsthand how important it is to feel connected and empowered when you're navigating

an MS diagnosis. LivingWell isn't just a programme – it's a community. It's an honour to help people discover their strength.

Leann: An MS diagnosis can feel isolating and lonely, but it doesn't have to be that way. I get to see the power in someone sharing their experience of MS. And the ripple effect it can have on others.

What gives you hope?

Tracey: The people we meet every day. Their honesty, humour and resilience are a constant reminder of what's possible.

Leann: MS has been a huge part of my life for 30 years. I've watched DMTs increase during that time through research. This gives me hope for people like my cousin, who can enjoy the things he loves without MS stopping him. 



See our full LivingWell programme and sign up for our webinars, information events and peer groups at mssociety.org.uk/living-well-events



Regular Exercise at a Low Price



tigo

**MADE IN
GERMANY**

THERA-Trainer tigo

- ✓ Active and passive movement (with or without motor support)
- ✓ Increases mobility
- ✓ Strengthens the muscles
- ✓ Improves levels of stamina and flexibility
- ✓ Encourages cardiovascular system
- ✓ Exercising of legs and/or arms is possible
- ✓ Improves metabolism and vitality
- ✓ Exercising is possible from a chair or a wheel chair

Payment plan available to suit all budgets

We have moved to new premises
Come and visit our showroom
By appointment only - call 01908 564100

Call our friendly team in Milton Keynes on 01908 564100 to arrange a **FREE**, no-obligation demonstration in your home



Simply scan the QR-Code for more information about the THERA-Trainer tigo.

Visit our website for future updates, new products and much more – www.thera-trainer.co.uk

THERA-Trainer UK Ltd.

T. 01908 564100 | info.uk@thera-trainer.com | www.thera-trainer.co.uk



**MS Matters
readers get
10% off**
All TGA Mobility
scooters,
powerchairs and
wheelchairs*



10% off with MS Society

At TGA, we believe that when it gets harder to move, you needn't stop living. We provide scooters and wheelchairs tailored to suit all kinds of people with all kinds of needs. Which is why we are supporting MS Society so that MS Matters readers can receive a 10% discount on mobility scooters, powerchairs and wheelchairs. As an extra thank you, we will make a donation to the MS Society for every product purchased.

To ensure you find the ideal product, TGA offers a free home demonstration appointment with a qualified regional advisor so you can try our products with no pressure or obligation in the comfort of your own home and surroundings – making sure you get the right product for you.

tgamobility.co.uk | info@tgamobility.co.uk | 0800 058 4145

*T&Cs apply. See website for details.

