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RESEARCH

Keeping
your brain
flexible

NEWS

Our message
to the Prime
Minister

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MSM004 • SUMMER 2024 • ISSUE 147



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Contents

30

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NEWS

- 7** Our message to the Prime Minister
- 9** New data: more people living with MS
- 11** My MS Woof: our dog walking challenge
- 13** Losing the filter on embarrassing symptoms
- 15** Community events and LivingWell webinars

REAL LIFE

- 17** Kadeena Cox on the Paralympics
- 18** Why I take part in research



RESEARCH

- 21** Latest research news
- 24** Cover story: Getting inspired at MS Frontiers 2024
- 30** Keeping your brain flexible
- 32** Science and superheroes with Dr Rana Fetit
- 34** Can MS be prevented?



INSIGHT

- 36** Professor Anna Williams answers your questions
- 38** Snapshot of UK MS Register
- 40** Meet your brain cells

COMMUNITY

- 43** What research means to you
- 45** Your thoughts: feeling forgotten
- 47** Our retail heroes
- 49** Volunteer spotlight: Trishna and Dean on influencing research
- 50** Meet researcher Clara Stein

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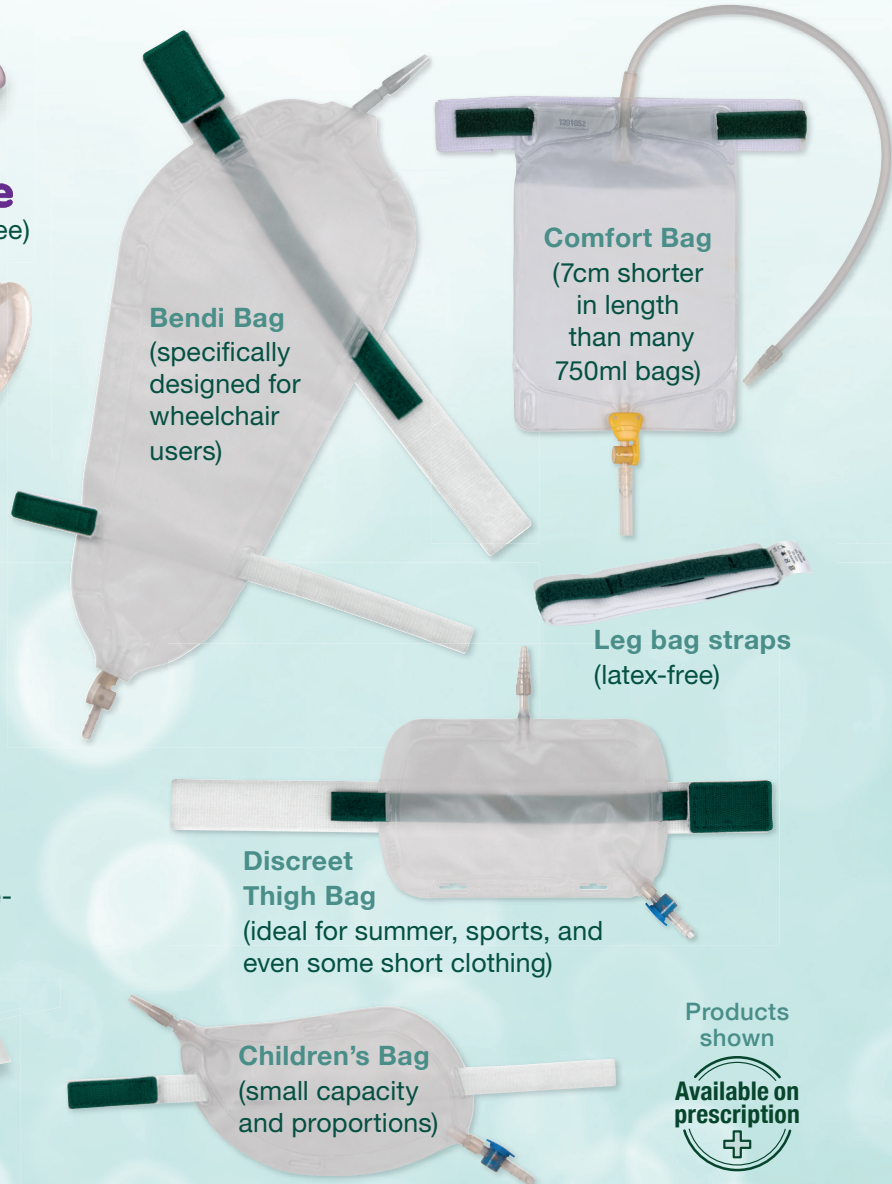
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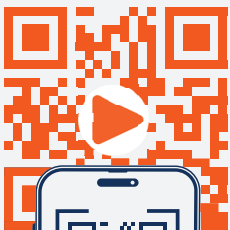
You may notice while reading this issue we've introduced QR codes on some of the pages. For people who aren't familiar with them, here's some more information.

What's a QR code?

It's a type of barcode that can be easily scanned by a digital device, like a smartphone or tablet, to open a website. Most modern devices have built-in QR scanners in the camera.

How to use a QR code

1. Open the camera app on your device.
2. Point your device at the QR code as if you're taking a photo.
3. Once your device recognises the QR code, a notification will pop up on your screen.
4. Tap the notification to be directed to the web page linked to the QR code.



SUMMER 2024 - ISSUE 147

Since joining the MS Society I've been inspired every day by researchers and people living with or affected by MS. Without them the huge research breakthroughs we've seen in the past few decades wouldn't be possible. But together we're still fighting to find new treatments, and better ways for people to manage their MS. Especially for those with limited treatment options.

In this edition we'll find out more about the latest research into stopping MS. Turn to page 24 for exclusive access to our biennial research conference, where you'll hear updates from leading researchers. Is it farfetched to think we can prevent people getting MS in the future? Find out on page 34. Or jump to page 40 to learn all about key brain cells involved in MS.

We hope reading about the



latest research and personal stories from people with MS will inspire you and offer hope for the future. If you'd like to share your story, please email msmatters@mssociety.org.uk We're always looking for new people to feature. And if you'd like to talk about any of the topics in this issue, call our MS Helpline for free on **0808 800 8000**. We're here to support you. 📞

Hannah Boam

Research Communications Officer

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Our message to the new Prime Minister

Earlier this year, we launched our MS manifesto. Thousands of us across the UK signed our open letter to the new Government and got in touch with our local candidates. Together, we made our voices heard.

What do we want to see?

We're calling on the Labour government to make sure people with MS have the support they need. We'll continue to campaign until we see these changes happen.

- Setting up a neurological taskforce to address staff shortages and poor access to treatment.
- Improving mental health support. That includes introducing an NHS talking therapies pathway for people with neurological conditions.
- Supporting people with MS to move into and stay in good quality employment.
- Improving the Access to Work and Disability Confident schemes, and Statutory Sick Pay.
- Fixing benefits systems to take into account fluctuating

conditions like MS. We want to scrap the PIP 20m rule and change the 50% rule to be more flexible.

If you want to read our full manifesto or find out more about what we did during the general

election, check out mssociety.org.uk/general-election

What happens now?

As new MPs take up their positions and returning MPs get back to the job, we'll continue to campaign

for change. We won't stop until everyone living with MS has the right support and healthcare to live well. Now is the ideal time to make sure our MPs know our priorities.

Campaigning for change

Keep track of our latest campaigns by signing up to receive updates at mssociety.org.uk/support-our-campaigns and don't forget to follow us on social media. 



FIND OUT MORE ABOUT... CAMPAIGNING

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More than 150,000 people in the UK live with MS

There are around 20,000 more people living with MS in the UK than we previously thought, according to new data.



Our latest research shows the number of people living with MS at any one time is now estimated to be over 150,000. The previous figure, based on data from 2019, was more than 130,000. That's an increase of nearly 13%.

The new data

also estimates that, in the UK:

- more than **7,100** people are **diagnosed every year**, an average of **135 each week**
- **71% (108,614)** of people with MS **are women**
- **68% (103,390)** of people with MS are **aged over 50**

What does the data mean?


The data shows there are more people living with MS than we thought. The sharp rise is thought to be due to a combination of factors, including a better diagnosis process and people

with MS living longer. It doesn't necessarily mean there's an increase in the risk of developing MS.

But the figures do show there's a much greater need for support. Our figures show there's an average of 18 people living with MS for each GP practice in the UK.

How will this help people with MS?

The data is important

to help us support people living with MS. The way it's been collected means we can break it down by nation and region. By working with other MS charities, we'll be able to see where health services don't meet the needs of the local population. This means we could run targeted campaigns to improve services in those areas. 

FIND OUT MORE ABOUT... MS FIGURES

Do you want to learn more about the research? Visit mssociety.org.uk/new-prevalence or use the QR code.





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Have a paw-some time with My MS Woof


Get the pack together and join our charity dog walking challenge this October.

There are now more than 150,000 people living with MS in the UK, according to new research (see page 9). So, in October 2024, we're challenging you to walk, run, roll or stroll 150km. That's just under 5k a day. But if this seems too far, you can set a distance that suits you and your dog.

Millie held a My MS Woof group walk with Buddy and Barker, her two beagles, last year.

She says:

"I was diagnosed with relapsing remitting MS in 2016. The MS Society has been my go-to ever since for information, help and support. Because of this, I set myself a goal to do one event a year to help raise money for them. It's for all the support they've given me and my family over the years. We raised £1,750 for My MS Woof! We're blown away as our original target was £200.

"We sold 170 bars of fudge, 30 lamb dough pups and 30 tuna pup cakes. And we had so many laughs at our dog show with categories like the dog with the waggiest tail. It was a magical day I'll never forget!" 



NICOLA AND DORA LEND A PAW

Some famous friends and their dogs will feature on our social media this summer, including actor Nicola Walker. She says "Me and my labrador Dora love to get out into the fresh air. So the My MS Woof challenge is the perfect way to get outdoors and help fund life-changing research."

FIND OUT MORE ABOUT... MY MS WOOF

Do you want to raise money for MS research like Millie? If so, please collar your friends and family and sign up for My MS Woof at mssociety.org.uk/ms-woof -2024 or use the QR code.



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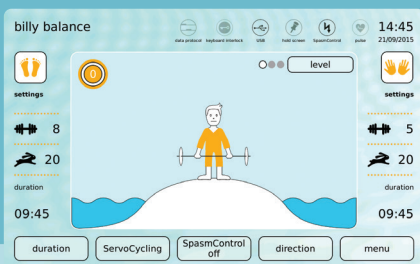
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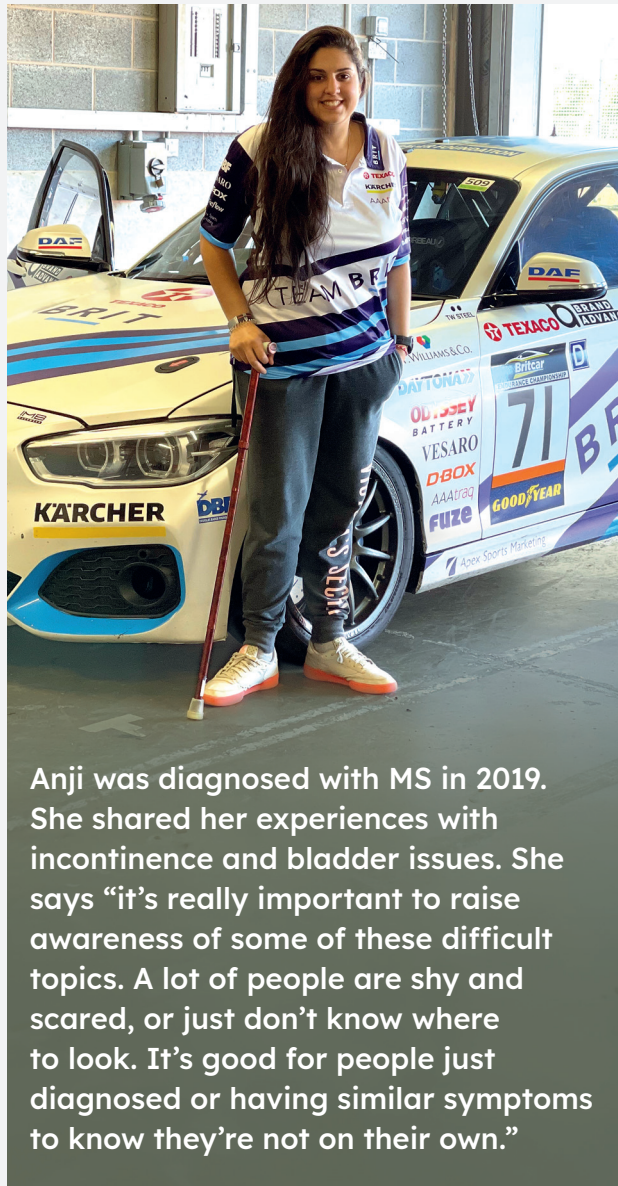
Losing the filter

This year's MS Awareness Week was all about symptoms many of us find hard to talk about or embarrassing.

For the second year running we partnered with six MS charities, including the MS Trust and MS Together. Our joint campaign was called MS Unfiltered. The idea came from members of the MS community, who wanted to break the silence on taboo symptoms like sexual dysfunction and bladder issues.

We surveyed the MS community and over 1,400 people responded. Over a third told us they've avoided seeking medical help due to embarrassing symptoms. 85% of people were embarrassed by at least one of their symptoms.

We shared many stories throughout the week in the media, and on our website and social media. We created five videos with community members discussing difficult symptoms. And three videos with healthcare professionals offering tips on how to talk about embarrassing symptoms. 



Anji was diagnosed with MS in 2019. She shared her experiences with incontinence and bladder issues. She says "it's really important to raise awareness of some of these difficult topics. A lot of people are shy and scared, or just don't know where to look. It's good for people just diagnosed or having similar symptoms to know they're not on their own."

CAMPAIGN HIGHLIGHTS

- News stories appeared in over 250 newspapers and broadcast channels, reaching a potential audience of 42.8 million people
- Our videos were viewed over 238,000 times on social media
- Our social media posts appeared on 1,775,390 screens
- We appeared on Sky News and Channel 5
- Charlotte Nichols MP, Chair of the All Party Parliamentary Group for MS, tabled a parliamentary motion recognising MS Awareness Week. It was signed by MPs from five parties.

FIND OUT MORE ABOUT... MS UNFILTERED

Watch our videos with an MS nurse and a GP for tips on dealing with embarrassing symptoms on our YouTube channel [youtube.com/@mssociety](https://www.youtube.com/@mssociety)
Visit mssociety.org.uk/msaw-survey or use the QR code for more on our MS Unfiltered campaign.



Multiple sclerosis on your mind?

Freephone:
0808 800 8000



Our MS Helpline offers emotional support and information to anyone worried about MS.

We're here Monday to Friday, 9am to 7pm except bank holidays.

MS Society

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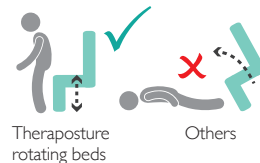
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Knowledge is power

Nicole Saunders first attended one of our LivingWell webinars in 2020, after being diagnosed with relapsing remitting MS.

“There’s such a wealth of knowledge, experience and information in the MS community. The webinars do really well at bringing it together and sharing it.

“I always come away with a little gem. Something to follow up on, another thing

to apply for. I always take something useful away that later helps me.

“For example, the webinar on MS and work has given me more confidence to have conversations with my employer. I’ve become a more confident advocate for myself because of the things I’ve learned from the webinars.” ^{MS}



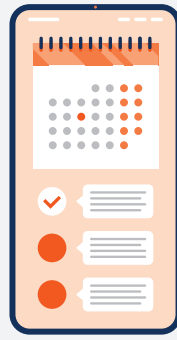
Nicole Saunders is a wellbeing volunteer with LivingWell

FIND OUT MORE ABOUT... LIVINGWELL

LivingWell runs virtual wellbeing courses, sessions and webinars for everyone affected by MS in the UK. Topics include managing symptoms, exercise and work.

In 2023, the team delivered 86 virtual sessions.

To find out what’s on this year, use the QR code or the weblink in the column to the right.



DIARY DATES

WEBINARS

22 AUGUST, 6.30PM

Being active with MS

Personal Trainer Dom Thorpe provides fitness coaching for people with a disability or chronic illness. He’ll share his tips on being physically active with MS.

mssociety.org.uk/being-active-webinar

19 SEPTEMBER, 6.30PM

Planning ahead with MS

Jenny Watt, from NHS Greater Glasgow & Clyde Health Board, will share information on topics like wills, Power of Attorney and health plans.

mssociety.org.uk/planning-webinar

See our programme of webinars and information events at mssociety.org.uk/virtual-support-events

ACTIVITIES

7 SEPTEMBER

Zip it to stop MS

Take on an exhilarating zip wire ride across the Clyde in Glasgow or at Penrhyn Quarry, Bethesda, North Wales.

mssociety.org.uk/zipline-events

SEPTEMBER

MS Walk

There’s still time to join an MS Walk in London (14 September), Cardiff (21 September) and Glasgow (28 September). Walk, roll or stroll to stop MS!

mssociety.org.uk/events-ms-walk

13 OCTOBER

Run Bournemouth

Enjoy stunning coastal scenery at one of the UK’s largest running events. Choose your distance from 5k, 10k or a half marathon.

mssociety.org.uk/events-run-bournemouth

Find out about all these fundraising events and more at mssociety.org.uk/get-fundraising

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Our Ambassador Kadeena Cox OBE, a parasport athlete and cyclist with MS, is training for the Paris 2024 Paralympics in August. We asked her how it's going.

How are you preparing for the Paralympics?

I'm training in Loughborough and Manchester, crossing all my t's and dotting all my i's as I try to build my fitness.

As an athlete with MS, is there anything you do differently from other athletes?

I probably take more rest than most athletes. I don't train the day before a race. On race day, we have a plan for what I'm going to do. I get spasms, so we have a plan to get me off the track and get me to medical. I need quite a lot of support after the event.

I have to adapt my training because of tiredness and fatigue. If my spasms are bad, I just have to not do a session.



Apart from your own events, what are you most looking forward to?

I'm looking forward to the Athletes' Village. Just being around other athletes, getting to know sportsmen and women from our country and other countries. Coming together as athletes is so nice. The village is an absolute vibe.

Why is it important to raise awareness of MS?

Number one, we want to try and find a cure for MS. But also lots of people don't know what MS is. They don't know the signs to look

for and they don't know how to support people. I think it's important so we can support people with MS and so people who could end up with a diagnosis are aware of the signs. 🗣️

Keep an eye on our social pages for updates on Kadeena at the Paralympics.
facebook.com/mssociety or instagram.com/mssocietyuk

WHY I GET INVOLVED IN RESEARCH

Two people with MS share their experiences.

Tony Sibley is part of the Octopus trial.

I was first diagnosed with relapsing remitting MS in 1990, and I was diagnosed with progressive MS in 2019. My life completely changed on that day. I had to give up the successful business I ran with my wife. Unfortunately, because of the COVID-19 pandemic, it was tough to get the help I needed.

I was originally on the MS-STAT2 trial and I've been on the Octopus trial since October. It takes less than five minutes to take the tablets and fill out a chart. Every 10-12 weeks I come up to Coventry Hospital for tests. It's a big ask as I get up at four to be there for eight in the morning. But it's worth the effort as I talk to the team about anything that concerns me and my wife can be involved too. The team is very supportive and the extra care is reassuring.

The benefits

The team monitor whether or not your MS is changing and check for any drug side effects. So I have an insight into whether my MS is getting worse or stabilising. Being on the trial and having an MRI every year is comforting, not only for

myself but for my wife too.

I've always wanted to be involved in these trials. Even though I may be on the placebo, or the drug may not benefit me, I'm full of hope that my MS will stabilise. The alternative is possibly progressing at a faster rate. At least I'm part





The team is very supportive and the extra care is reassuring

of a trial that's trying to make my situation better.

I feel extremely grateful to the team at Coventry and to the MS Society. Without them, I wouldn't be on this journey.



Rabiah is a member of our Research Network.

Since my MS diagnosis 25 years ago, I've contacted MS charities everywhere I've lived. At first, I was seeking support. Later, I was looking for ways to contribute. It's led me to various activities - from running a support group for young people with MS, to fundraising and walking or cycling for MS. And my most recent work as part of the MS Society Research Network.


The opportunities I've been given as part of the Research Network have been rewarding. They've had the very welcome and unexpected side effect of increasing my level of hope.

Recently I had the opportunity to speak to a pharmaceutical company about my experiences of living with MS. I've also had a chance to attend the MS Frontiers research conference. I teamed up with a neurologist to debate against another team about whether we should

use labels to describe MS. It was a great chance to learn more about others' experiences with MS and take in some talks.

The tasks

Usually, Research Network tasks are centred around reviewing and providing guidance on research funding proposals. This is useful to researchers because they get direct feedback on their proposal and can make changes before submitting. This makes sure the research is relevant to and involves people living with MS.

I most enjoy getting to see what new research is being considered. There are so many people in the science community dedicated to improving the lives of people with MS or preventing people from getting MS at all. The potential for better disease modifying therapies alone is incredible. Being part of the Research Network is truly rewarding. In some way, it helps me feel like I'm taking a little control back from my MS. 

Are you interested in joining our Research Network like Rabiah or taking part in a trial like Tony? Visit mssociety.org.uk/take-part-research or use the QR code.



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THE LATEST UPDATES IN MS RESEARCH

Training the next generation of MS researchers to improve drug-free symptom management

In 2024, we launched two new Doctoral Training Centres. They'll focus on finding effective ways to manage MS symptoms without drugs. The Centres are based at Glasgow Caledonian University and King's College London. They'll provide high-quality research training for 12 PhD students.

The King's College London Centre will focus on digital health interventions to treat MS symptoms. These will aim to treat symptoms including pain, sexual difficulties and psychological distress (for example, low mood or anxiety). They'll be part of a single digital platform called 'My MS Digital Symptom Toolkit'. This will allow people with MS to get support for different symptoms in one place and allow a smooth referral process for healthcare professionals.

The Glasgow Caledonian University Centre will research how exercise and physical activity can help people with moderate to severe MS. As well as more traditional forms of exercise, they'll look at newer approaches like dance and virtual reality. They'll see if these improve fatigue, mobility and cognition. ^{MS}



Professor Lorna Paul is the lead researcher at the Glasgow Caledonian University Doctoral Training Centre.

We hope to answer the 'what, when and how?' questions around physical activity for people with MS with more advanced disability.

Although some of the studies will be laboratory-based, we'll particularly focus on applying physical activity and exercise programmes in the 'real world'. The students will work closely together. And we hope a number of them will go on to be the MS symptom management research leaders of the future.



You can read more at mssociety.org.uk/training-centres or use the QR code.



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MSMATTERS



New research suggests infections contribute to progression

Research we've funded found inflammation caused by infections, like colds and viruses, could contribute to MS progression.

Professor Ian Galea and his team studied 50 people with primary and secondary progressive MS over two and a half years. A urine sample was taken each week to check for signs of infection and inflammation in the body. And they measured changes in the brain and spinal cord with MRI scans.

They found inflammation from infections was linked to the loss of nerve cells in the spinal cord. This can contribute to progression.

What does this mean for people with MS?

This highlights the importance of seeking early treatment for infections and getting vaccinations you're eligible for. Bladder infections are very common in MS and were a big cause of inflammation in the study. People with MS should discuss urinary symptoms with their MS team, who can suggest ways to reduce infections.

These findings could also offer new treatment strategies to slow down progression. For example, the brain and spinal cord are usually protected from inflammation elsewhere in the body. Researchers can look into why this protective barrier is failing in progressive MS and find ways to stop it.

You can learn more at mssociety.org.uk/latest-research-infections or use the QR code.



RESEARCH NEWS IN BRIEF

New research reveals the power of microglia in smouldering MS

Brain immune cells called microglia are in overdrive in MS, causing damage to nerves. Researchers found a way to switch them off by targeting their energy source.

This work opens up new ways we might slow or stop the progression of MS. Researchers could look for drugs that switch active microglia off in MS lesions, protecting the nerves.

Read more at
mssociety.org.uk/microglia

Fatigue management app gets government support

The UK Government has selected REFUEL-MS for fast-track into the NHS. This is a fatigue management app being developed with some funding from us.

We hope this means people with MS will be able to access the app through the NHS as quickly as possible once the study ends in 2028.

Find out more
mssociety.org.uk/refuel 



MSFrontiers²⁰²⁴

GETTING INSPIRED BY RESEARCH



MS Frontiers is our research conference, bringing together scientists, clinicians and healthcare professionals to share the latest advances in MS research.

Speakers from the UK and across the world came together earlier this month to discuss the hot topics in MS research. The conference gave researchers the opportunity to share information, spark collaborations and find out more about work happening across different fields.

Over two days we heard from over 50 speakers, from PhD students beginning their career in MS research to world-leading experts. We've picked out a few of our highlights. And you can visit our social media channels and website to hear more about what happened at the conference.

Shutterstock/Simon Ayre

THURSDAY

10am Putting the puzzle pieces together



Sasha Leigh lives with MS. She opened MS Frontiers 2024, welcoming researchers to Liverpool.

I've worked in and around research for over 20 years. So, when I was diagnosed with MS, I was already aware of the role the MS Society plays in funding research. Being part of the Research Strategy Committee allows me to bring those different elements of my life together – research, research strategy, and my experiences of MS. And MS Frontiers has been an exciting opportunity to see the research in action.

It can often feel like your work is just a small piece of the puzzle. But conferences like Frontiers help researchers bring those pieces together to see the big picture. As someone living with MS it gives me a feeling of hope for the future. It's always inspiring to meet the wider community of engaged and motivated people, all working to make a difference to the lives of people with MS. ➤

10.20am A new use for old medicines



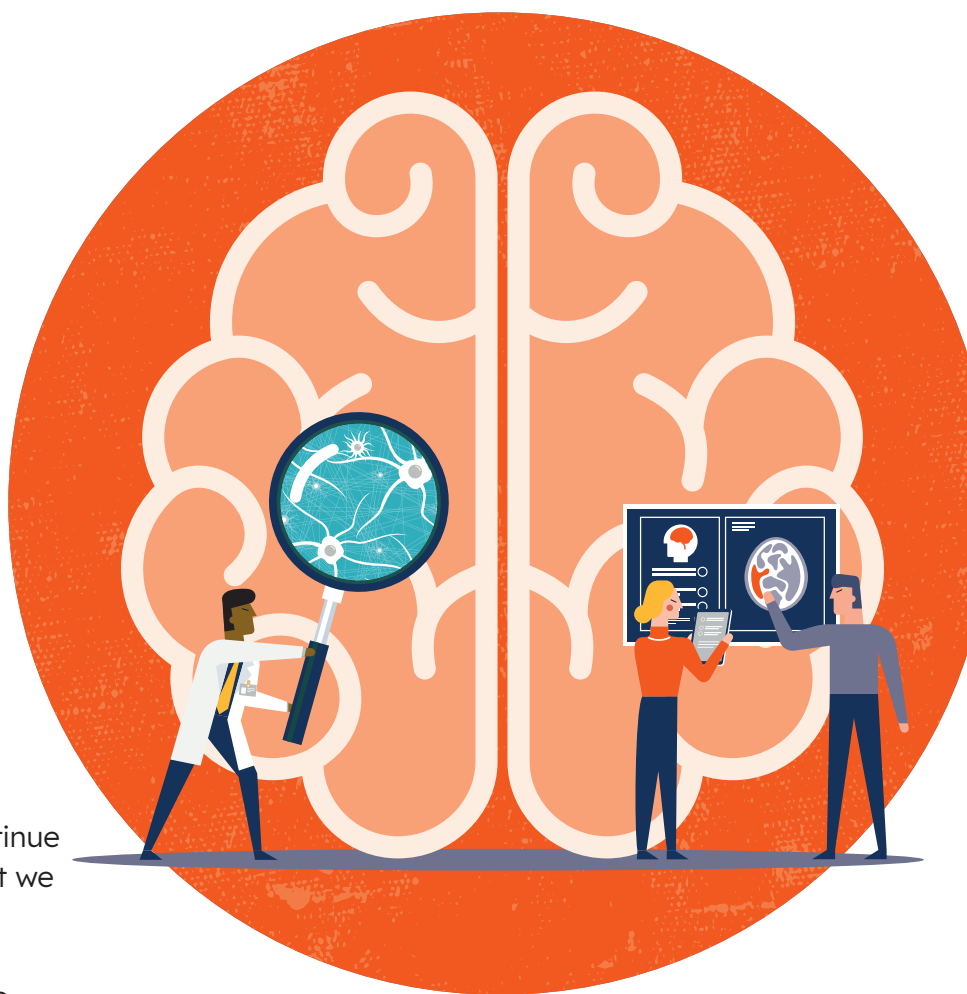
Professor Anna Williams is based at the University of Edinburgh. Her research focuses on understanding how

oligodendrocytes work – they're the cells that make myelin. She joined us at MS Frontiers to talk about finding new ways to use existing drugs.

Anna spoke about the progress we've made so far in controlling relapsing MS. We now have treatments that can reduce inflammation and myelin damage in the brain and spinal cord. But to continue to make progress, Anna stressed that we need to think differently.

Many trials for people with MS are testing repurposed drugs. This means finding a new use for existing medicines. Anna's work focuses on gathering and assessing as much information as possible about the biology of MS. From this, we can choose existing therapies that look promising. And test them in clinical trials to get effective treatments to people with MS as fast as we can.

Anna answers your questions on [page 36](#).



1.15pm What does MS look like in 2034?



Professor Alasdair Coles is a researcher and consultant neurologist at the University of Cambridge. He teamed up with **Helena Jidborg Alexander, who lives with MS.** Together, they delivered an interactive session about what MS care and research might look like in 2034.



Before the conference, they asked people with MS about topics including artificial intelligence (AI), symptom management and advanced disability. They posed the same questions to researchers at Frontiers to compare their responses.





3.45pm Making progress towards prevention

Researchers highlighted how important research into prevention is, and what steps we're taking. We're leading this work by setting up an MS Prevention Taskforce.

Read all about this work on [page 34](#).

5.30pm Let's debate

Researchers debated whether AI is ready to personalise care for people with MS.

You can read about what happened at mssociety.org.uk/frontiers-debate

WEDNESDAY - PRE-CONFERENCE

Supporting early career researchers

Early career researchers will become the leading researchers of the future.

And we want to support them to get there.

So we gathered early career researchers from across the UK to meet their peers and learn more about how the MS Society can support them. They also benefitted from workshops about how to best communicate their research. And practical tips for working with people with MS to help shape their research. ➤

**FRIDAY****9am Understanding ageing and MS**

Professor Jennifer Graves is based at the University of California, San Diego.

Her work focuses on the impact of ageing in MS. She presented her research in our keynote session.

We know that MS doesn't suddenly change because of age. But people with MS tend to have more symptoms as time goes on. And we know that as we age, our bodies become less effective at repairing the protective myelin coating that's damaged in MS.

In her talk, Jennifer highlighted the importance of understanding more about the role biological age plays in MS. This knowledge could help us design better treatments for MS. Particularly for people who might not be eligible for any treatments at the moment.

You can read more about ageing and MS on our website
mssociety.org.uk/ageing-ms

12pm Thinking about cognition

Professor Maria Pia Amato is based at the University of Florence.

Her research spans multiple research areas, including the cognitive impact of MS in both children and adults.

Maria received the Ian McDonald Memorial Award this year. This award is presented to researchers whose work has had a major impact on our understanding of the diagnosis, cause or treatment of MS. The Award recognises Professor McDonald's outstanding contribution to the MS research field. The recipient of the award is invited to present their research at MS Frontiers.

Trouble with memory and thinking is something that many people with MS experience and it can have a big impact on day-to-day life. But it can also be a neglected symptom. In her Award Lecture, Maria outlined ways to measure cognition in the clinic using simple tests. And highlighted the importance of doing research to understand this common and frustrating MS symptom.



TANGIBLE BENEFITS

Throughout the conference we heard about the importance of translating research findings into tangible benefits for people with MS. It's clear that this is high on the agenda for MS researchers.

1pm Wrapping up - a chance to get inspired



Dr Emma Tallantyre and Dr Yvonne Dombrowski are the co-chairs of the scientific committee – the team of researchers who help make MS Frontiers possible. They reflected on their conference experience.



Emma says “MS

Frontiers is a real celebration of UK MS research and expertise. It's a think-tank for the next big project and gives us a chance to get inspired by everything going on. This year we've had a real focus on the impact that research can have for people with MS. It's been wonderful to have that in the forefront of our minds.”

Yvonne says “When I joined my first MS Frontiers as a junior researcher many years ago, I was blown away by the community feel. As a newbie to the field and the UK, I felt very welcome and made connections that still last. Conferences like MS Frontiers bring together new ideas, strengthen networks, and support upcoming new talent who will carry MS research into the future.” ^{MS}

We're excited to see how the research we learned about at the conference will go on to have an impact for our community.

Visit our research blog to read more about our MS Frontiers 2024 highlights at mssociety.org.uk/frontiers-roundup or use the QR code.



COGNITIVE RESERVE

HOW IT KEEPS YOUR BRAIN FLEXIBLE

Clara Stein won our writing competition for researchers with this article about her work.



Clara Stein is a PhD student at University College Dublin

Learn more about Clara on page 50

Do you read books, socialise with friends or clean your home? Maybe you exercise, work or play a musical instrument? If so, congratulations! You're helping your brain to adapt to MS.

Brain changes and cognitive difficulties

MS can lead to changes in the brain, which may be associated with cognitive difficulty. Around six in ten people with MS experience some level of cognitive difficulty. This might be difficulty with thinking quickly, following a conversation, or



WHAT IS COGNITIVE RESERVE?

Cognitive reserve describes your brain's ability to adapt to changes. Someone with greater cognitive reserve may experience less cognitive difficulty due to brain changes.

We currently can't measure cognitive reserve directly. Instead, researchers try to estimate it through your experiences in education and work. And whether you do certain activities for leisure which require focus.



remembering a shopping list.

However, brain changes alone can't fully explain why some people with MS experience more cognitive problems than others. Two people with similar MS brain changes don't necessarily experience the same level of cognitive difficulty. It seems as though some people with MS may have a more flexible brain, better able to adapt to brain changes. This may be in part due to cognitive reserve.

What does it mean to have a flexible brain with cognitive reserve?

Imagine that your brain uses a complex network to follow a conversation. Think of this network like the streets of a busy city. You may be used to driving home from school or work using street A. But, today, that street is blocked. Fortunately, you know there are other ways to get home.

It might take a bit longer, but you'll get there safely.

By engaging in enriching everyday activities, we may be able to help our brains be more flexible.

Taking part in any focused, complex activities can train our brains to think of alternative routes. These activities could include education, work, exercising, socialising, reading or playing a musical instrument. Evidence shows people with MS who engage more frequently in these enriching activities have less cognitive difficulty.

This doesn't mean cognitive reserve

can always protect you. Using the same analogy, if most roads in your city are blocked, it can still be tricky to get home. But the more alternative routes you know, the higher the chance of finding a way.

Road to the future

I think the idea of cognitive reserve is really good news. It means many of the everyday activities we do also help our brains. But there's still a lot more we need to learn about how this works in MS.

At this stage, we don't know much about how common MS symptoms influence cognitive reserve. Many people with MS experience fatigue, depression and anxiety. Experiencing any of these so-called 'invisible symptoms' may impact a person's ability to do enriching activities. Unfortunately, invisible symptoms are still often overlooked, both in clinical practice and in research.

At the moment, we're trying to address this gap in our research. Instead of just collecting data on cognitive reserve and cognitive outcomes, we're also asking participants about their experience of invisible symptoms. And self-reported cognitive difficulty.

Our goal is to gain a better understanding of how cognitive reserve is developed in MS. And how we might use this knowledge to achieve a better quality of life and care for people with MS. ^{MS}

Read our tips for dealing with memory and thinking problems at mssociety.org.uk/memory-thinking-tips or use the QR code.



SCIENCE AND SUPERHEROES

MEET RESEARCHER DR RANA FETIT

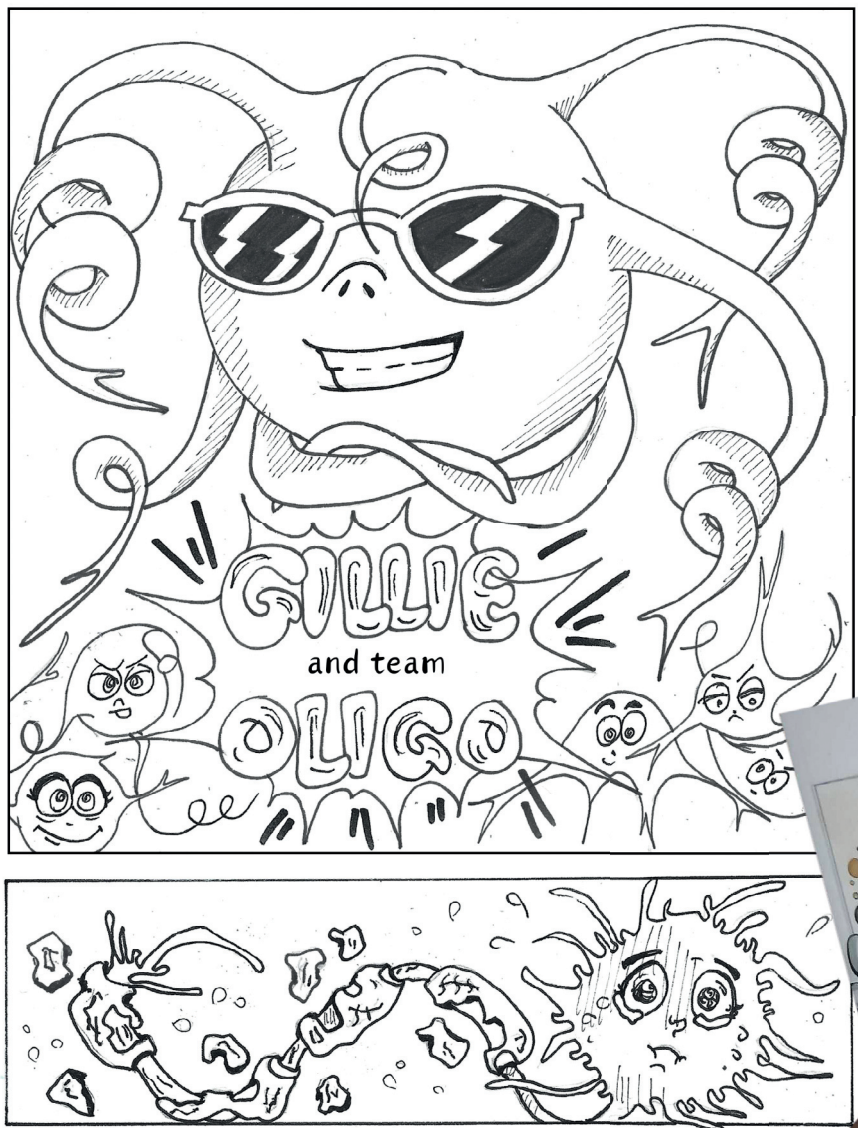
Dr Rana Fetit is a postdoctoral researcher at the MS Society Edinburgh Centre for MS Research. She works in Professor Anna Williams' lab. We asked Rana about her research and her comic book 'The Flickering Message'.

Can you tell us a bit about yourself?

I've always had a passion for science, but also loved art and sketching. When choosing a career path, I was torn between studying science or fine art, but ultimately science took the lead. I'm from Egypt and did a pharmacy and biotechnology degree in Cairo. Then a master's degree in cancer biology, and a neuroscience PhD in Edinburgh. I've always enjoyed working with stem cells and I started working with Anna in 2023 to try and repair the myelin lost in MS.

Can you give us an overview of your current research?

Our bodies have an incredible natural ability to repair myelin. Special cells can travel to the damaged area and turn into myelin-making cells called 'oligodendrocytes'. I'm particularly interested in these



cells. Recent studies in our lab have shown there are different types of oligodendrocytes, each with distinct characteristics. And different types appear in different parts of the brain and spinal cord. The mix of oligodendrocytes also differs between people with and without MS.

My work focuses on transforming human stem cells in a dish into each of these oligodendrocyte types. My aim is to identify a type that's particularly good at repairing damaged myelin. Then it might be possible to develop a targeted therapy for MS.

Can you tell us about the comic you've designed?

I was inspired by the sheer curiosity of my kids. I have two wee ones and we're really into science at home. I was trying to think of how I could explain MS and my work to them. I developed the idea of a comic

about these neurons that are trying to send a message. The immune patrol is attacking them and making it hard to get the message through. It evolved into 'The Flickering Message' which I've now self-published.



Many children are affected by MS. Tools like this could really help them to understand what their loved ones living with MS are going through and why

Did anyone inspire the characters in your comic?

It's mostly based on my wee ones - they're very expressive and funny. Every time I thought of a character, I'd imagine what their faces would look like. The research pages of the MS Society website were also helpful to guide the story.

Why do you think it's important to communicate science to children and why are your comics a powerful tool?

It's something I've always found very fulfilling and important. I love doing voluntary work communicating science in schools and at public science days. Kids have so much potential, and they are so smart. If you can give them the knowledge and help them to understand the world then they can go on to explore and find solutions. Also, many children are affected by MS. Tools like this could really help them to understand what their loved ones living with MS are going through and why. It also helps us as researchers to remind ourselves of the impact our work can have.

Do you plan on telling the story of your specific research through comics?

I hope so! The dream story I'd love to tell would be of a weary nomad neuron who's tired of not finding the help he needs. He eventually comes across a dream oligodendrocyte that can help him recover and find himself and his purpose! ^{MS}

Read more about our Edinburgh Centre for MS Research at mssociety.org.uk/edinburgh-centre or use the QR code.



NOT SO FARFETCHED?

THE SEARCH FOR WAYS TO PREVENT MS

We still don't have a good understanding of why some people develop MS. This might make the idea of being able to prevent MS seem farfetched. But in other conditions without a known cause, researchers are already finding preventative treatments.

The MS Society has set up the UK MS Prevention Taskforce to learn from these conditions and drive progress towards preventing MS.



**Professor
Parth
Narendran**

Preventing juvenile diabetes

Like MS, type 1 diabetes is an autoimmune condition caused by a combination of factors. Parth Narendran is a Professor of Diabetes Medicine at the University of Birmingham and is chairing the UK MS Prevention Taskforce.

“The first drug to prevent type 1 diabetes in children at high risk was approved in 2022” explains Parth.

“Research with siblings of children with diabetes was critical to this success. We described what happens in the years prior to developing diabetes. And found blood markers that show if a child is at very high risk. Importantly, this offers a window of opportunity in which to take action to delay or

WHO'S MOST AT RISK OF MS?

No single gene or environmental exposure is enough to cause MS. Instead we think it's a mix of different risk factors that work together. These include:

- the genes you inherit from your parents
- environment factors like infection with the glandular fever virus
- some lifestyle factors, such as smoking



prevent the onset of diabetes.

“That early research to understand the biology before people get diabetes helped us to get where we are in our field. A similar process may also help in MS.”

Starting up the UK MS Prevention Taskforce

In December 2023 we held a workshop to discuss what research avenues we should explore to make progress towards MS prevention. Researchers and clinicians from MS and other diseases and people affected by MS came together to brainstorm.

Three key themes were identified that are now being considered.

1 What do people at risk of developing MS think and feel about MS and research?

In rheumatoid arthritis, research into the attitudes of people ‘at risk’ has been instrumental in designing prevention studies. This knowledge will help us better communicate the lifestyle changes people can make to reduce their risk of MS. And it will also help to recruit and keep those at risk engaged in future prevention trials.

Shutterstock



2 Studying people at risk of MS

This research will help us understand more about MS risk factors and the earliest biological changes that take place before MS has taken hold. The Taskforce will consider how we can do these studies using existing registries such as the UK Biobank. But also how to design our own studies of higher-risk people. For example, family members of people with MS.

3 Looking over the fence

It was clear in the workshop that there’s so much more we could learn from other conditions about prevention. Not just other autoimmune conditions, like diabetes and rheumatoid arthritis, but also from other neurological conditions like Alzheimer’s and Parkinson’s. The Taskforce will continue to look across the fence at these areas to bring innovation to MS research. ^{MS}

WHAT IT MEANS TO ME



Beth Grimsey, who lives with relapsing MS, is a member of the UK MS Prevention Taskforce.

Research into preventing MS isn’t going to change what having MS means for my own life. But it does inspire hope for generations to come. I’m optimistic that every breakthrough in prevention research will bring us closer to a future where MS is a chapter of the past. A time where my future children and grandchildren can live without fear of the uncertainties and challenges that come with an MS diagnosis.

If you’d like to read more about areas of research we’re prioritising go to mssociety.org.uk/our-research-priorities or use the QR code.



Ask the expert

Professor Anna Williams is a consultant neurologist and professor of regenerative neurology. We put your questions to her.

Q Is stem cell therapy the only real solution to stop MS?

There are different types of stem cell therapy. But people with MS are often referring to haematopoietic stem cell transplantation (HSCT). This is an intensive treatment that works by resetting the immune system to stop it causing damage.

HSCT can be an effective treatment for some people with MS. But there are other treatments that work by targeting the immune system. And there's an ongoing trial comparing HSCT with other MS treatments to find out which are most effective and safest.

Stem cell therapy certainly isn't the only way to stop MS. And it

won't be suitable for everyone. Ultimately, we'll need to approach MS treatments from all angles.

Q I have progressive MS – could myelin repair treatments help me?

Myelin is the protective fatty coating that surrounds the nerves. It's damaged in MS. Researchers are trying to find ways to repair myelin.

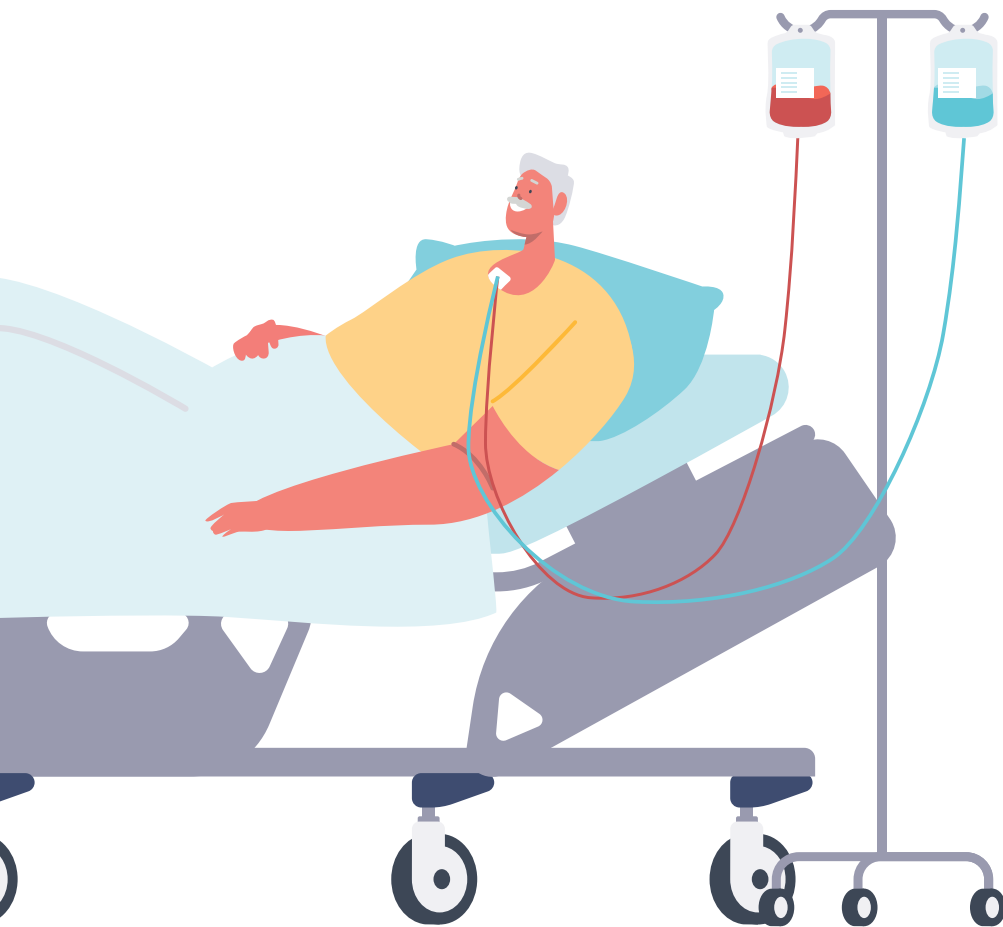
We know that in progressive MS, nerves die and are lost. And we can only put myelin back on to nerves that are still there. So we won't be able to help nerves that have gone. But for nerves that are vulnerable to damage but still there, we should be able to put myelin back on them. If we



can slow down MS progression and stop people getting worse first, then we could give myelin repair treatments.

Q Is there a connection between stress and MS?

When I speak to people with MS in the clinic, they often ask me if physical and mental stress could have an impact on their relapses. When someone has a relapse, they want to be able to explain why it happened. It's a very human way of looking at



life. My instinctive feeling is that too much stress isn't good for MS. But it's really difficult to prove and the actual evidence base is quite thin.

Q How can you tell if drugs are repairing myelin?

Measuring whether a drug can repair myelin is very difficult. We can't look into the brain to see what's happening! We can use different types of scans – including MRI scans. But these aren't always suitable and don't give us all the information we need. For

example, it can be hard to tell the difference between the old myelin and new myelin. Myelin repair trials are also using 'visual evoked potential' (VEP) tests. These test how fast the brain responds to messages from the eye. Myelin helps to speed up messages in the brain. If myelin is being

repaired, researchers would expect to see an improvement in the VEP.

Q Could gene therapy help people with MS?

This is an interesting question! It's something that researchers are thinking about. Gene therapy has been incredible for conditions where a single gene is affected – for example, spinal muscular atrophy. It allows us to correct that one faulty gene. But we know that in MS there isn't just one gene affected. There are over 200 genes linked to MS. So it's more difficult.

But it's possible we could use gene therapy in MS. For example, to alter cells in the brain, so they're better at promoting myelin repair or keeping nerves alive.

Researchers are exploring this in the lab at the moment. It's a long way off from being used as a treatment for MS. But it does have the potential to help people with MS in the future. ^{MS}

MEET THE EXPERT



Professor Anna Williams

FIND OUT MORE ABOUT... MS RESEARCH

You can find out more at mssociety.org.uk/emerging-research or use the QR code.



UK MS Register at a glance

The UK MS Register helps us understand what it's like to live with MS. We share a snapshot of its data (correct at the end of 2023).

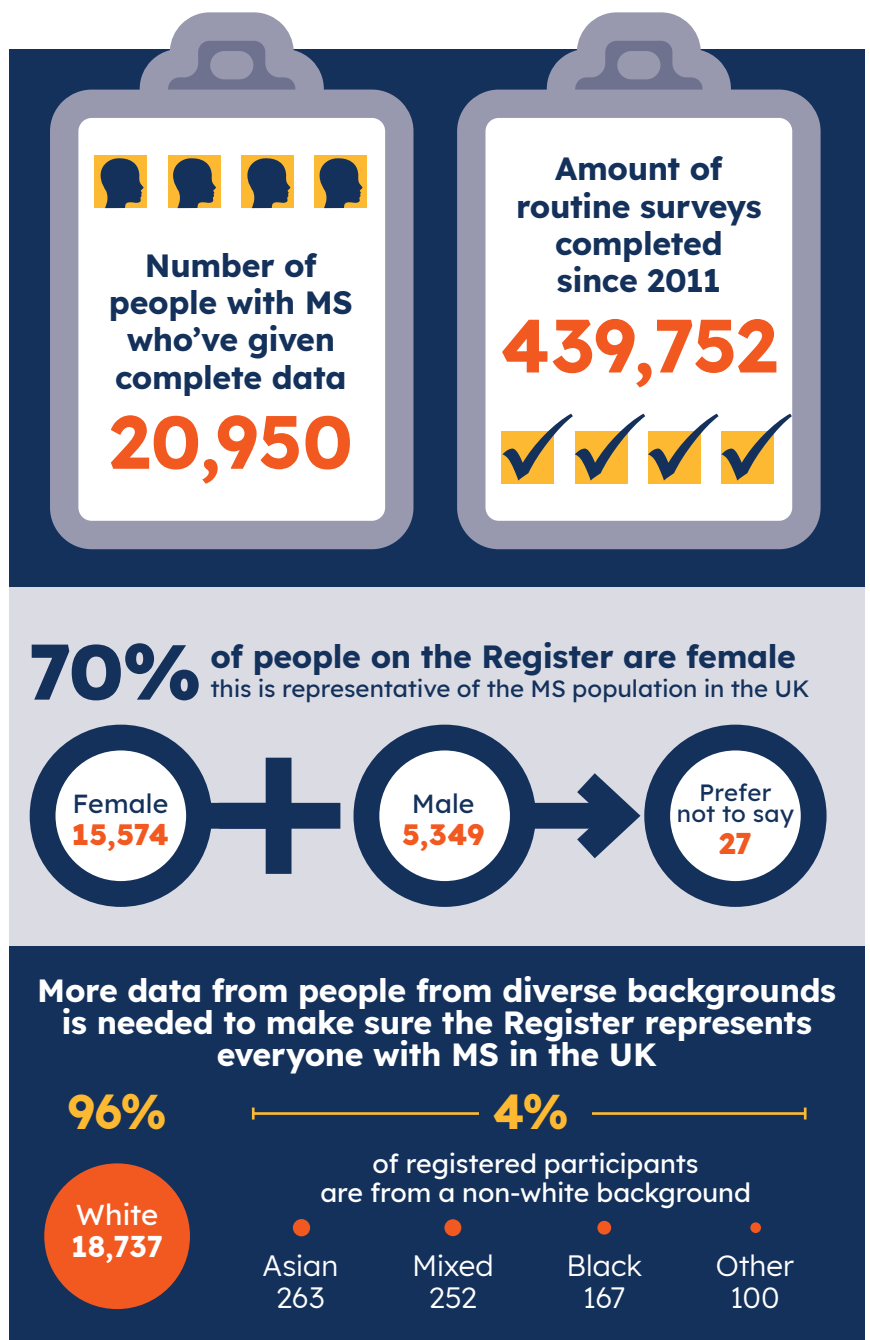
People who've joined the Register are invited to complete online surveys about their MS. If they want to, they can also opt-in to contribute their clinical records. This allows the Register to create the most complete picture of MS in the UK.

Providing researchers with this data helps answer key questions on crucial aspects of MS. These include prevention, diagnosis, treatment, or how to best manage MS. It also provides us with the evidence we need to drive vital MS research and campaign for more support.

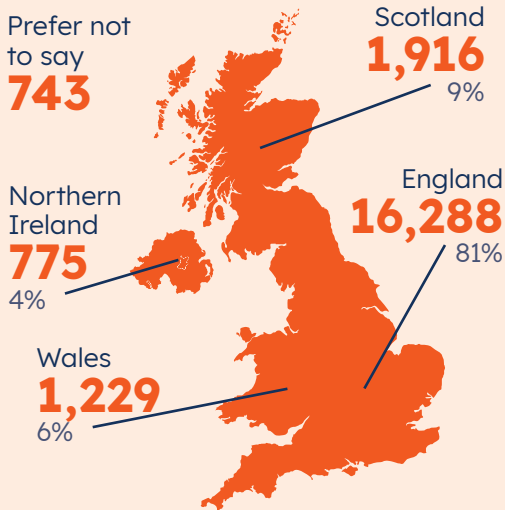
The Register is always open for recruitment. In particular, they'd like to involve even more people from diverse backgrounds, so the data better represents everyone with MS across the UK. 🌍

Interested in joining?

You can find out more and sign up at mssociety.org.uk/join-ms-register or use the QR code.



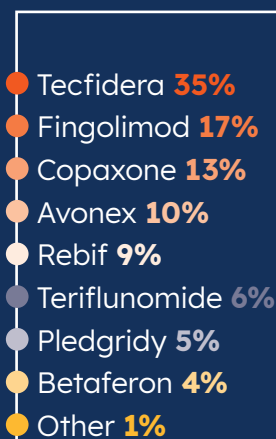
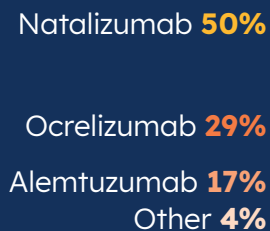
Number of people taking part in each nation



Average age at diagnosis **39.5**



Percentage of people on each type of highly active disease modifying therapy (DMT)*



*Data collected from people who've shared their clinical records

Percentage of people who are on a highly active DMT compared to a moderately active DMT

2019 **32%** 2023 **51%**

The number of people with each type of MS

Benign	448
Primary progressive	2,337
Relapsing remitting	10,967
Secondary progressive	4,889
Unsure	2,309

Percentage of people by disability score

Expanded Disability Status Scale (EDSS) is a way of measuring how much someone is affected by their MS. The greater the level of disability, the higher the score out of 10

EDSS band	%
0-2	6
2-4	27
4-6	21
6-8	43
8-10	3

Most common symptoms reported

SYMPTOM	% OF PEOPLE REPORTED
Fatigue	82
Weakness	66
Gait problems	62
Bladder problems	62
Spasticity	53
Parasthesia	51
Cognitive difficulties	49
Altered sensation	49
Muscle pain	47
Sensory loss	43
Pain	40
Bowel problems	40
Depression	31
Motor control	31
Sexual dysfunction	27

Meet your brain cells

The brain contains billions of cells. We've learned a lot about the cells involved in MS through research. Here's a round-up of five cell types worth knowing about.

MICROGLIA

Pronounced: my-crow-gee-ah

Microglia are the brain's special immune cells with lots of helpful roles. For example, they come to lesions (areas of damage) to tidy up broken myelin.

In MS, microglia seem to be too active at the edges of lesions, which can worsen the damage. But, microglia also produce molecules that promote myelin repair.

So we know microglia are important in MS. But, because they have lots of roles in the brain, scientists need to understand more about how they work.

ENDOTHELIAL CELL

Pronounced: en-do-thee-lee-al cell

The walls of all blood vessels are made of endothelial cells. And the brain is threaded with a network of blood vessels, which supply it with oxygen and nutrients.

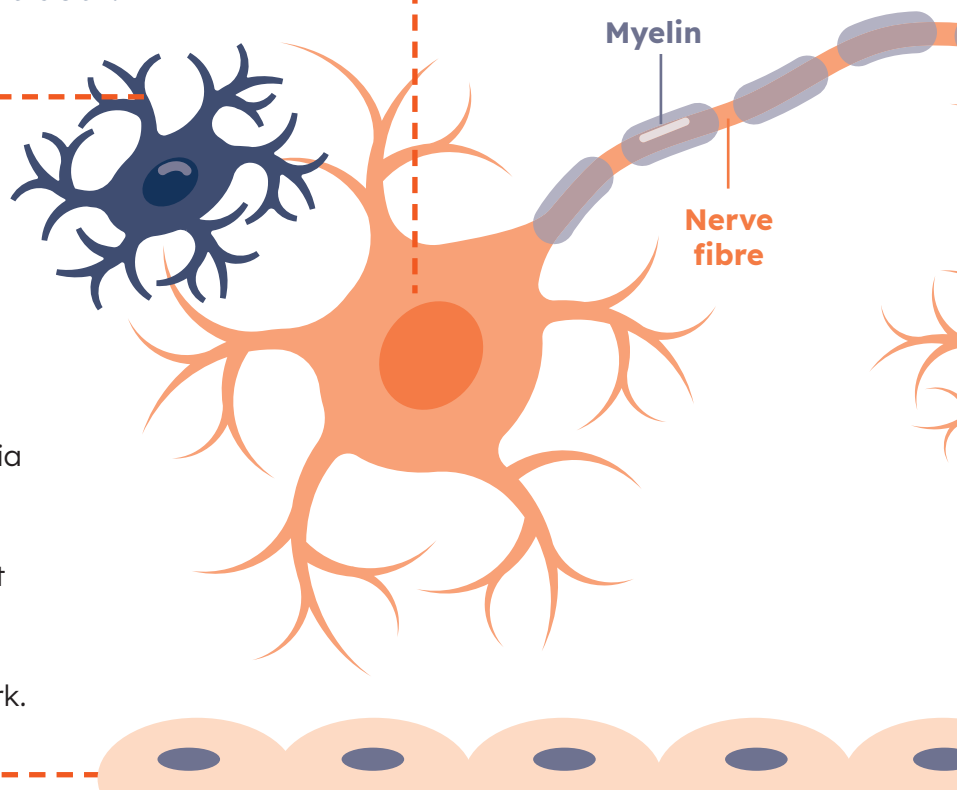
In the brain, endothelial cells have special properties and act as the 'blood-brain barrier'. They form an extra tight seal for the blood vessels and prevent most things in the blood from crossing over into the brain.

Normally they only allow immune cells to cross when there's an infection. But, in MS, immune cells enter the brain where they cause damage. Researchers are currently exploring why immune cells get through the blood-brain barrier in MS.

NEURON

Pronounced: new-ron

There are around 86 billion neurons, or nerve cells, in a network across the brain. They send messages as electrical signals, to pass information across the brain and the body about what you're thinking, feeling or doing. There are lots of



ASTROCYTE

Pronounced: ast-ro-site

Astrocytes cleverly connect lots of different cells. They react to signals from one type of cell and cause another type to respond.

For example, a neuron might need extra energy because it's sending a message. The astrocyte

types which send slightly different messages.

When the immune system damages myelin, it leaves neurons exposed and vulnerable. Without myelin, the nerve can break down and die. Our brains can't replace neurons so this damage is irreversible. Finding ways to protect

neurons before they're permanently destroyed is a key goal of MS research.

Researchers at our Centre of Excellence in Edinburgh showed that, in MS, some neurons are more affected than others. They're using this information to search for treatments to protect the most vulnerable neurons.

OLIGODENDROCYTE

Pronounced:

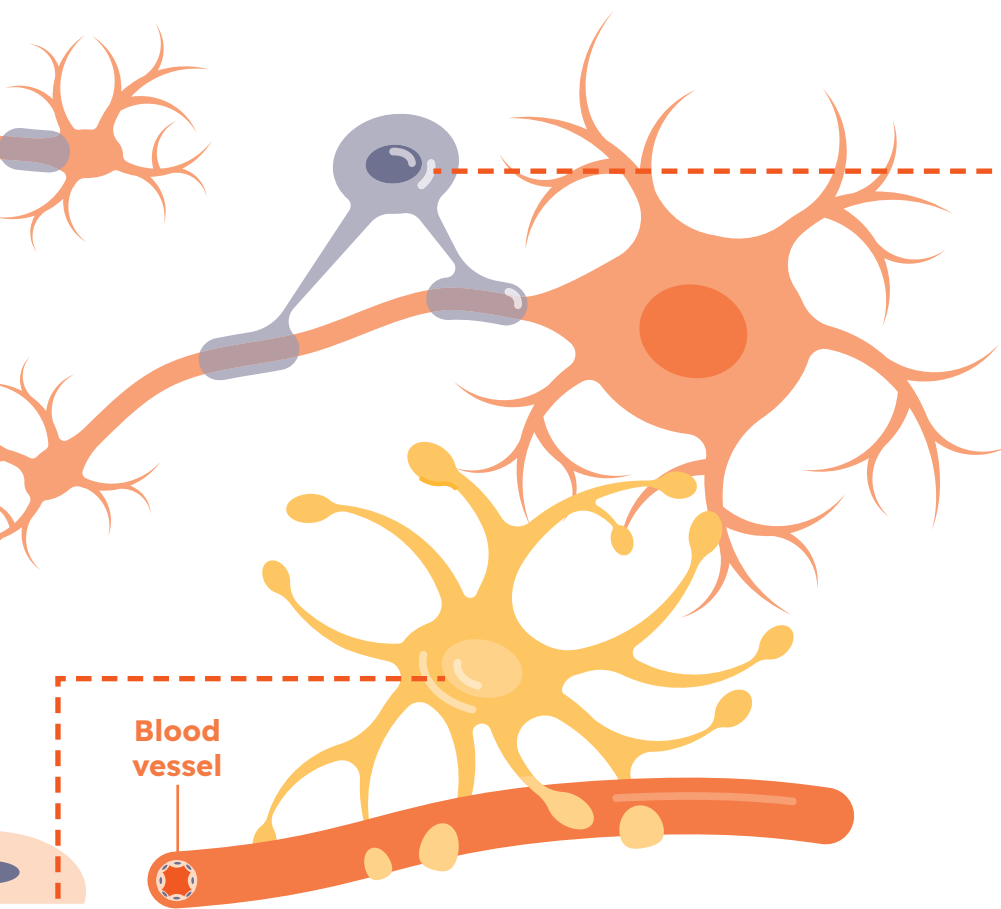
olly-go-den-dro-site

Oligodendrocytes are very important in MS because they make myelin. Myelin protects your nerves from damage and helps messages travel quickly. In MS, the immune system mistakenly attacks and destroys myelin.

Oligodendrocytes reach out arms of myelin to wrap around nerve cells, which are also called neurons (see left). This happens when the brain and spinal cord are developing or repairing.

Researchers hope to find ways to protect and support oligodendrocytes. They'll use this information to find treatments that can help to restore lost myelin.

Our myelin repair clinical trial is looking at two drugs which have shown promise in the lab. Researchers want to find out if the combination is safe and effective for people living with MS.



detects this and tells the endothelial cells to send more oxygen and nutrients to the area.

We're learning that these are very important cells in MS. Recent research with mice who have an MS-like condition showed astrocytes keep oligodendrocytes (see right) alive during

myelin repair. And, just by boosting certain properties of astrocytes with drugs, researchers might be able to improve myelin repair in lesions.

By controlling these connecting astrocyte cells, researchers hope they can increase the effectiveness of myelin repair.

FIND OUT MORE ABOUT... RESEARCH PROJECTS

We fund research investigating all these cell types. Find out more by looking at our research projects at

[mssociety.org.uk/
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HAVE YOUR SAY



We asked what MS research means to you. Here are your answers from Facebook and Instagram.

As a wife of a husband with primary progressive MS, I need research to continue. It's a horrible disease and I just wish for a cure or a way of making it not get worse. For a breakthrough to make life better for my husband and, in turn, our family.

lisahastie77

My mum was diagnosed with MS when I was born and there were no drugs for her to take apart from steroids. Four years ago, I was diagnosed with MS. Because of MS research, I have a fantastic drug. And as a mum of two if – God forbid – they ended up with MS I know the drugs they'd get would be even better because of MS research.

something_profound_sp

I've had primary progressive MS for nearly 40 years and research is the only thing that gives me hope. But I must admit I've been very disappointed over the years. We get promises that things are progressing, but then nothing happens. Everything seems to be either five, 10 or 20 years away.

Andrew Fernandez

Having MS and being a part of MS research gives me the chance to speak on my lived experience and hopefully, in turn, help others.

sincerely5elina

I wish there was more research on natural ways of life to help us. I found that I felt best when I was gluten and dairy free and had no processed foods.

Sian Mann

It means everything.

Treatment evolves and improves because of research, without which I wouldn't be on treatment such as Ocrevus!

seanpaul87

Not all heroes wear capes.

They wear lab coats and give me hope for a brighter future on my darkest MS days.

phoebecharlotteday



FOR OUR NEXT ISSUE WE'RE ASKING...

What treatment or therapy have you found best helps you manage your MS? 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)

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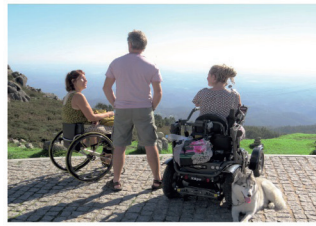
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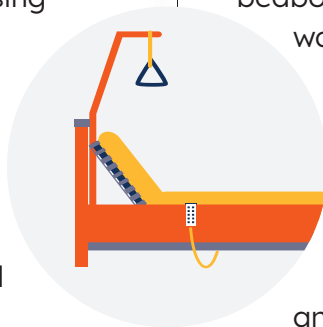
YOUR THOUGHTS



Pamela offers feedback on MS Matters and shares her difficult experiences of living with secondary progressive MS.

I have secondary progressive MS. I find a lot of articles are for people who are newly diagnosed, people with relapsing remitting MS and even primary progressive MS. But secondary progressive MS gets forgotten.

I was diagnosed 30 years ago and told 14 years ago it was



secondary progressive MS. My disease modifying therapy (DMT) was stopped and I've been offered nothing since. I'm now bedbound – I can't stand, walk or move my legs. I can't move my body, so I rely on my adult son to move my legs to make me comfortable. My carers hoist me in and out of bed.

My carers are only here for personal care in the morning and toileting two other times in the day. I've asked a social worker if I can have more hours so I can go out. She said she'd have to take time off what I have and that I didn't want to bankrupt the council.

I feel forgotten. No one offers me help. There isn't a daytime MS group in

my area I could go to as I would need someone with me.

What's somebody like me meant to do? ^{MS}

MS Society If, like Pamela, you're living with secondary progressive MS, we know that help and support is often very limited. We also know that this can leave you feeling extremely isolated.

If you're struggling to get the support you need, please get in touch. Our MS Helpline offers support and information for people living with every type of MS and their loved ones. We're here to listen and help you explore the options for support where you are. Call **0808 800 8000** or email helpline@mssociety.org.uk

Pamela also told us she likes MS Matters' new look. "The magazine layout is clear. The blue background is better to see than orange on a lighter background."



DO YOU HAVE SOMETHING TO SHARE?

Please get in touch and let us know your views.

@ msmatters@mssociety.org.uk

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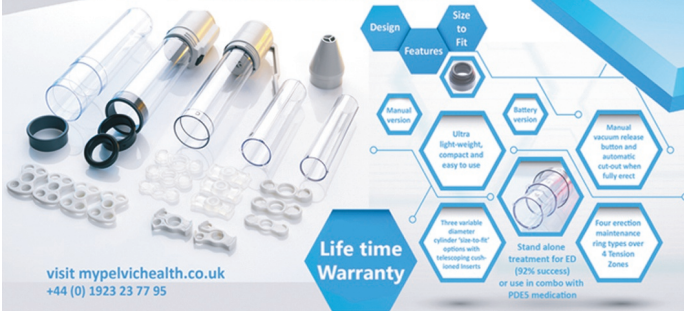
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MSMATTERS



OUR RETAIL HEROES

Did you know we have MS Society charity shops?

Volunteers are the backbone of all our shops, providing essential support to the manager. Donors play another vital role by donating stock. Volunteers and donors are our retail heroes!

We spoke to Mohammed who's just started volunteering at our new shop in Altrincham.

Why did you decide to volunteer in our new shop?

I love to help people and meet new people – and the MS Society is a good cause. I'm learning English and speaking with customers helps me with this. So far, it's been a great experience.

Did you do any training?

We did one day of training at the shop, which was very helpful. Steven, the Shop Manager, also taught me how to use the computer. It was my first time using one.



Mohammed Alfadli

Retail hero in Altrincham

What sort of things do you do as a volunteer?

I volunteer for four hours, one day a week. I help with the organisation of the shop, serve customers and price the goods. The shop sells clothes, shoes and books.

What are you most looking forward to about volunteering?

I'm looking forward to spending my spare time doing something for a good cause and meeting people. I'm considering working in retail, so volunteering will also help me gain work experience.

What are your hopes for the MS community?

I hope to be able to raise awareness about MS and the MS community. 🗣️

OUR SHOPS

We have some other shops around the UK. Some are run by our fabulous local MS groups. You can find them in:

- Exmouth
- Hull
- Shanklin, Isle of Wight
- Stanhope
- Wilmslow

If you're local to one of our shops, please be a retail hero and shop, donate or volunteer.

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MSMATTERS



“None of us are one-dimensional”

Dean and Trishna volunteer with our Equality, Diversity and Inclusion (EDI) Reference Group. They explain why EDI is important and how the group influences our research.



Trishna: EDI is so important when it comes to research. Things like

your age, gender and ethnicity can affect how drugs work in your body. If clinical trials don't take this into account, they might develop drugs that aren't appropriate for everyone.

EDI is also fundamental when it comes to designing studies. For example, people might need information in different languages to be able to take part.

As an Asian woman with MS, EDI has always been

important to me. None of us are one-dimensional.

The EDI Reference group is a safe space where you can make your views heard. We meet twice a month and every other meeting is research-focused. It covers different things, including the MS Society's research strategy and initiatives like the Research Network.



Dean: I got involved in the group because I wanted to help others

and give back to the MS Society.

My role is to make sure we fulfil our requirements as an organisation. It's about sharing best practice and making recommendations on issues like accessibility and reasonable adjustments for disabled people. That goes for staff, volunteers or people using our services. We've made progress, but there's still some way to go.

We're often asked for our views on different aspects of research. For example, recently we gave some feedback on an app that people can use to join the UK MS Register.

I've got MS myself and I'm also a gay man. It's so important we reflect all the communities we serve. Being part of the group is a great opportunity to get some EDI experience. It's fantastic on your CV and you'll meet like-minded people. ^{MS}

The EDI reference group is a group of people affected by MS who help shape all our EDI work. They meet online twice a month. If you're interested in joining the group, email edi@mssociety.org.uk Read our Research EDI Action Plan at mssociety.org.uk/edi-ms-research or use the QR code.



Why did you decide to pursue a career in MS research?

I'm passionate about research with real-life applications. I think psychology can help us to better understand some of the 'invisible symptoms' of MS like fatigue, depression, anxiety and cognitive difficulty. I hope my research contributes to the development of effective interventions to improve the quality of life and care for people with MS.

What's the best thing about your job?

I get to be curious and find answers to research questions I care about. I feel privileged to have the freedom to do this meaningful work.

What's the most exciting thing about your project?

Sharing and discussing the work with people with MS and with the wider community.



GETTING TO KNOW YOU

Clara Stein

Clara is a PhD student and Irish Research Council Scholar at University College Dublin. She's building on her master's in behavioural neuroscience to study cognitive reserve for people with MS.

I love hearing about people's lived experiences and I enjoy advocating for evidence-based research and practice.

What's the best advice you've ever been given?

Probably to be brave enough to put yourself out there and ask



for opportunities. In research, as in many other areas of life, opportunities are rarely handed to you. You need to be willing to ask for support and a chance to participate. The worst that can happen is to receive a 'no'.

What do you like to do outside of work?

I love going on hikes and spending time in nature. I go for lots of walks while listening to German podcasts (I'm from Germany!) And I enjoy reading books – anything from a murder mystery to a rom-com. ^{MS}



Our Research Network volunteers judging panel selected Clara's article as the winner of our writing competition for researchers. [Read it on page 30.](#)

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