MS MATTERS

mssociety.org.uk

MSM005 • AUTUMN/WINTER 2024 • ISSUE 148

RESEARCH
The journey to new treatments

NEWS
HERCULES and MS-STAT2 trial results

INSIGHT
Can mindfulness help with MS symptoms?

ASKING FOR HELP

Your stories on how finding effective treatment for MS symptoms can be life-changing

MS Society

Contents

NEWS

REAL LIFE

Cover photography: Rebecca Cresta

RESEARCH

INSIGHT

COMMUNITY

FSC
www.fsc.org
MIX
Paper | Supporting responsible forestry
FSC® C017177

MS Matters is a Multiple Sclerosis Society publication ISSN 2517-6919. © Multiple Sclerosis Society 2024. 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/SC041990. Registered as a company in England and Wales 07451571.

LATEST INFO

Our printed booklets 'What is MS?' and 'Moving more with MS' have both been updated. 'What is MS?' is available in English and Welsh, and it's our first info booklet in the new-look brand.

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

Have you seen our articles with experts online? They include 'Too hot, too cold: the science behind temperature and MS' and 'Understanding infection, inflammation and MS progression'. And there's lots of research news and interviews with experts across the website with coverage from the Frontiers and ECTRIMS conferences.

AUTUMN/WINTER 2024 - ISSUE 148

If there's one thing I've learned since starting at the MS Society two years ago, it's that everyone's journey is unique. There's no one-size-fits-all solution to treatments and how people manage their MS.

The vast amount of treatment options can be overwhelming and makes it difficult when deciding what to do next. That's why we wanted the latest edition to focus on effective treatments. We want to help you have the knowledge to make informed decisions so you can find the best route for you.

We bring you news on the latest developments with ocrelizumab (page 9) and two drug trial results (pages 23 and 25). And we hear from people who've found treatments that help them manage their symptoms (page 14). On page 36, we look at the role of lifestyle and holistic approaches. We also share practical tips on navigating and finding the right treatment choices.

We know there's a lot of information out there on treatments. So, if you need emotional support and further information, call our MS Helpline for free on **0808 800 8000**. We're here to support you.

Gaynor Kay
Marketing Manager

MAKING HISTORY THIS WINTER!

We're on the cusp of a revolution in how MS is treated. Thirty years ago, there were no treatments for MS. Now there are more than a dozen that can help reduce MS attacks. But these don't work for everyone and they're not enough to stop MS.

This winter we're launching the History Makers appeal to support our research to stop MS. This is history in the making. For research. For science. For people living with MS. Will you make history by helping us stop MS? To find out more use the QR code or go to **mssociety.org.uk/discover-history-makers**

Raising our voices in Parliament

In August, we delivered our call for change for people living with MS to Keir Starmer.

Before the General Election we launched our MS Manifesto. We called on the next Prime Minister to make sure people living with MS have:

- financial security and the chance to succeed in work. That means fixing the PIP process and supporting people to stay in work that fits their skills and experience.
- support and healthcare to stay healthy and live well for longer. We want to improve access to treatments and address shortages in neurologists and MS nurses.

Since Keir Starmer moved into Number 10, we've written to ministers and met with the government. We've also contacted every single MP to make sure they know about MS and the changes we want the government to deliver.

We delivered your signatures to Downing Street

Phoebe, John and Kerry live with MS. In August, we went with them to Downing Street to deliver our open letter. Over 13,000 of us called on Keir Starmer to make real, lasting change for people living with MS.

Phoebe and John were involved in planning our campaigning during the election. And Kerry Riches, who shot to fame on the 2023 series of Big Brother, is a passionate advocate for the MS community. Did you see the video of our hand-in on our social media?

We raised your priorities with MPs

Autumn marks not only falling leaves but also party conference season for our intrepid Public Affairs teams. Over 2,000 MS campaigners told us what priority issues we should raise with MPs. So we've travelled the UK bringing those messages to MPs at the Liberal Democrat, Labour, Conservative and Plaid Cymru party conferences. You might have even spotted our team in some of the videos we shared about our travels.

FIND OUT MORE ABOUT... CAMPAIGNING

If you want to make your voice heard, join our campaigns community at mssociety.org.uk/join-our-campaigns


STYLES FOR MEN & WOMEN
Platinum Trusted Service Award
2024
feefo

Shutterstock

New jab for ocrelizumab

Thousands of people with MS in England, Wales and Northern Ireland will be offered a new 10-minute injection for ocrelizumab (Ocrevus).

Ocrelizumab is a disease modifying therapy (DMT) for active relapsing MS or early primary progressive MS.

At the moment, the drug is usually given in two infusions a year. Each infusion can take up to four hours, or sometimes even longer. We know this can be a really big time commitment for many people.

Shorter appointments

The new injection will still be given by a nurse in a hospital or clinic twice a year. But the appointment time will be much shorter.

Richard was diagnosed with primary progressive MS in 2014.

We spoke to Richard Humpston from Portsmouth, who was diagnosed with primary progressive MS in 2014. His symptoms include bladder issues and difficulty with walking. He now uses a wheelchair to get about.

There were no DMT options when Richard was first diagnosed. But for the past few years, Richard has been taking ocrelizumab via infusion.

Richard says "For me, ocrelizumab has been really positive. I love it and I feel a real benefit from it. My legs are less painful now and I'm becoming less incontinent."

Better experience

"The only issue is that the infusions take so long. I get up really early in the morning and often have to wait around an hour beforehand. Then the process itself takes around five to six hours. My first infusion took eight hours! Being able to take it through an injection will really improve the experience."

Ceri Smith, our Head of Policy, adds "This method will expand the choices available to many people with MS. It'll mean more people can receive this treatment in a way that suits them." MS

FIND OUT MORE ABOUT... OCRELIZUMAB

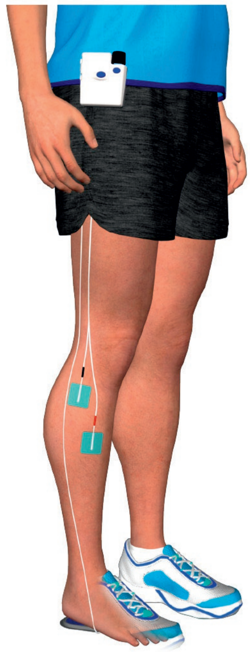
If you're interested in switching to the injection, please speak to your MS team. You can read more about ocrelizumab at mssociety.org.uk/ocrevus or use the QR code.

NHS
Salisbury
NHS Foundation Trust

OML | Leading FES Rehabilitation

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)?
88%* of FES users report a reduction in the incidence of falls after using FES.

**OML Patient Survey 2023*



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.

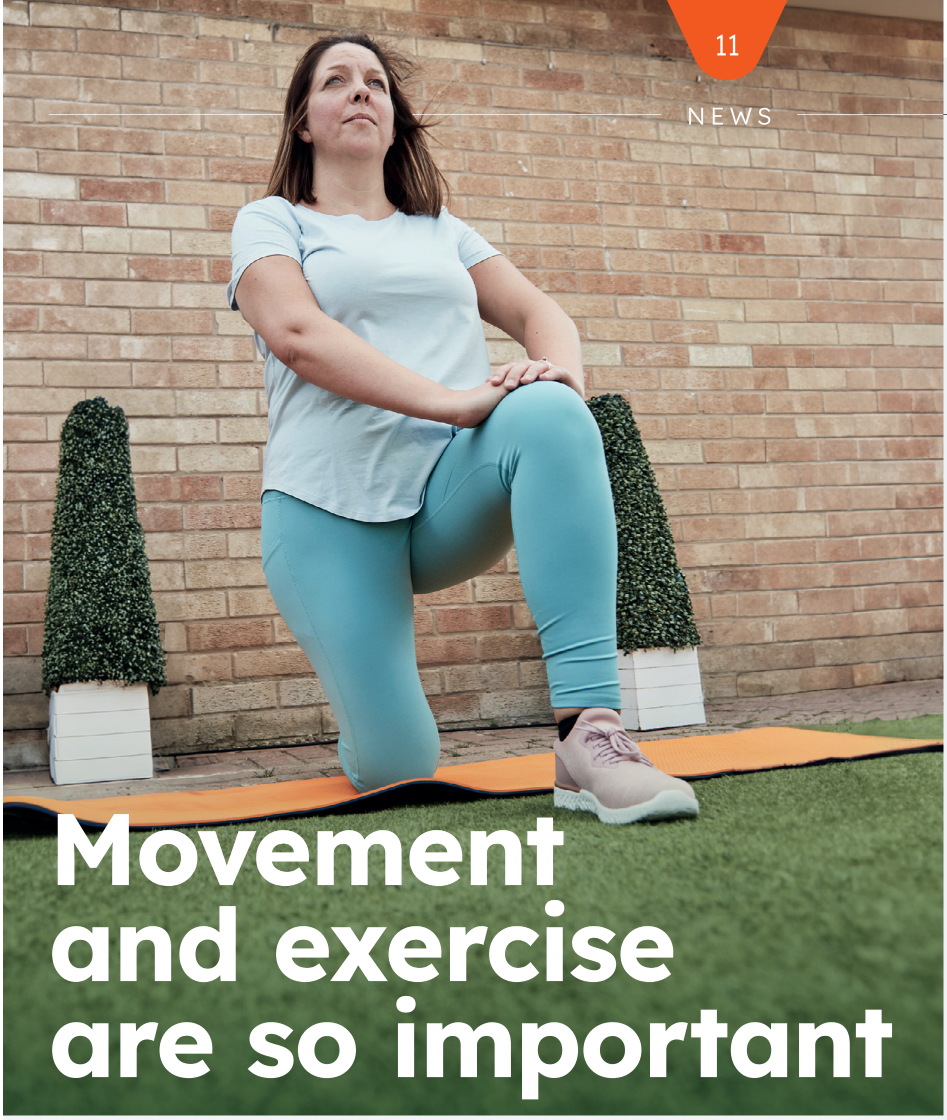
What our FES users say...

> *"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

11-005-0062 v3

Scan here



Movement and exercise are so important

Joanna Mason, one of our Volunteer Group Coordinators, is the face of this year's We Are Undefeatable campaign.

I've always had an active life and career. But when I was diagnosed with MS my symptoms made it hard to exercise and I had to leave my job. This had a knock-on effect on my mental health, my weight and overall wellbeing. When I started volunteering for the MS Society my top priority was to set up exercise classes that were accessible for all MSers.

I trained as an actor many moons ago. So I just had to apply when I saw We Are Undefeatable was looking for people to be part of a new campaign. The process has been so wonderful. I've been able to share how passionate I am about movement and exercise. This has been so important in learning to live well with my MS and my other condition, functional neurologic disorder.

What is We Are Undefeatable?

We Are Undefeatable is a collective of 14 leading health and social care charities, including the MS Society. Together, we're helping to inspire people living with a long-term health condition to move more. We want to show how small amounts of activity can be great for your physical and mental health.

The response to the campaign so far has been incredibly positive and now movement is part of my daily routine.

just swim

The charity Swim England has a new webpage and factsheet about 'Swimming with Parkinson's or multiple sclerosis'. It's written to help you find swimming that suits you. Find it at swimming.org/justswim

FIND OUT MORE ABOUT... WE ARE UNDEFEATABLE

The new website is packed with inspiration and tips to help you find activities you'll enjoy and feel comfortable with. All routines are designed to support people living with long-term health conditions. Find out more at mssociety.org.uk/undefeatable or use the QR code.


Independence

DIARY DATES

WEBINARS

TUESDAY 26 NOVEMBER 2024, 6.30PM

What's next? Newly diagnosed webinar

In this webinar, we'll help you to start making sense of your diagnosis. We'll provide you with information and signposting to further support.

mssociety.org.uk/whats-next-webinar

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

ACTIVITIES

SUNDAY 1 DECEMBER 2024

Santa Zip-it to Stop MS

Join us this December for a fun and festive event on the world's fastest zipline at Penrhyn Quarry, north Wales.

mssociety.org.uk/santa-zip-it

SATURDAY 24 AND SUNDAY 25 MAY 2025

Edinburgh Marathon Festival

Join us for Scotland's biggest running festival. With nine distances open to runners and wheelchair and handbike users, there's an event for everyone!

mssociety.org.uk/edinburgh-2025

SUNDAY 1 JUNE 2025

The Big Leap

Experience the thrill of skydiving from up to 10,000 feet and free-falling at over 120 miles an hour.

mssociety.org.uk/skydive-2025

SATURDAY 21 JUNE 2025

10 in 10 Challenge

Challenge yourself to the walk of a lifetime and climb 10 or five peaks in the beautiful Lake District.

mssociety.org.uk/10-in-10-2025

SATURDAY 5 JULY 2025

Round the Harbours Bike Ride 2025

Enjoy this scenic coastal ride at your own pace in Havant, Southsea, Fareham and Gosport.

mssociety.org.uk/harbours-2025

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

Carols by Candlelight

THURSDAY 12 DECEMBER, 7 – 8.15PM (DOORS OPEN AT 6.30PM)

Our annual Carols by Candlelight concert, sponsored by MetLife, takes place in the beautiful setting of Westminster Chapel, London.

Join us for an uplifting evening with traditional carols and inspiring choral music. There'll also be readings from special celebrity guests. All funds raised from the concert will go to our Stop MS Appeal.

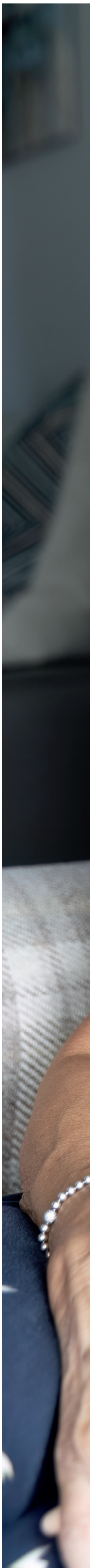
We're offering MS Matters readers a 10% discount. Please use the code XMAS10 when booking tickets.

For more details, email Hettie.tetteh@mssociety.org.uk, visit mssociety.org.uk/carols-2024 or scan the QR code.

Shutterstock / Alamy / Rebecca Cresta

EFFECTIVE TREATMENT CAN BE LIFE CHANGING

Three people with MS explain how they went about getting treatment that's improved their symptoms.


Rebecca Cresta

SEEKING HELP FOR BOWEL ISSUES

Fiona was diagnosed with secondary progressive MS eight years ago. Before that, she had relapsing remitting MS.

I've had problems with my bowels for 15 to 20 years. I'd get severe constipation. Then, when I did need to go, I'd have about a minute to get to the toilet.

Over the years it got worse and worse. I'd not be able to go for six or seven days. Then I'd literally have 10 seconds to get to the toilet. I had so many accidents – it was horrendous.

I'm a very sociable person but it got to the point where I'd stopped going out altogether. This played havoc with my mental health.

Then my MS nurse referred me to an incontinence nurse. She came to my house with a personal irrigation system called Aquaflush for me to try.

During the appointment, I did feel a bit awkward. But the nurse was amazing and put me at ease. I thought, 'I can't go on having accidents in public. That's far more embarrassing'.

That was about five years ago. Now, I use the system daily or every other day, combined with a laxative every 10 days. It doesn't cost me anything – I get it on prescription.

The routine has been life changing for me. I go out every day now and I don't worry about it at all. I can even take it on holiday.

If anything I've said sounds familiar to you, I'd recommend asking your MS nurse or consultant to refer you to an incontinence nurse. Just grab that help.

“I go out every day now and I don’t worry about it at all

RESEARCHING TREATMENT OPTIONS FOR TREMORS

In March, Tobias had Deep Brain Stimulation (DBS) to address tremors caused by MS.

Intention tremors, which started after my last relapse, are the most disabling part of my MS. They make everyday tasks very difficult, forcing me to move very slowly or rely on others. So I researched treatment options.

I read about DBS online and joined a Facebook group for people trying to access it. It's usually used for Parkinson's, but my tremors were so strong I thought it might be suitable.

I spoke to my consultant. Not every neurologist is aware of DBS, but luckily, he offered to put me forward for assessment at Queen Elizabeth University Hospital (QEUH).

The assessment process took a year. It was thorough, involving evaluations by a neuropsychologist and two psychiatrists, a physio examination, and an MRI under general anaesthetic to plan the surgery.

During the 10-hour surgery, two electrodes were implanted in my brain. They're designed to deliver an electrical current that stabilises tremors. They're connected to a pacemaker-like device in my chest, controlling the amount of stimulation.

Recovery took around six weeks. My speech was affected. I had to re-learn how to articulate myself and there are still words I can't say. I have visible scars on my skull, and I'm adjusting

> They haven't found the perfect frequency yet, but my tremors are already 30% better

DBS isn't specifically approved for MS tremor but, on rare occasions, it's used to treat a very serious tremor. How well and how long it works varies a lot and is hard to predict.

to technical aspects. But it's getting better over time.

In May, the device in my chest was switched on. The amount of stimulation needs to be adjusted at the hospital. They haven't found the perfect frequency yet, but my tremors are already 30% better. I have hope for future adjustments. My neurosurgeon Michael Canty and neurologist Ed Newman at QEUH are fantastic.

Have you experienced difficult symptoms like Fiona, Anji and Tobias? If you'd like to talk about accessing treatments, call our MS Helpline on 0808 800 8000. You can ask to speak with one of our MS Helpline nurses. You can also get in touch at helpline@mssociety.org.uk Calls and emails are confidential.

GETTING SUPPORT WITH MENTAL HEALTH

Anji was diagnosed with relapsing remitting MS in May 2023, but she's had symptoms for many years.

I have left side weakness – I lack strength in my arm and my left leg is very wobbly. I get brain fog and spasms. I've had optic neuritis on and off for years.

I'm also permanently in pain – and I've had bad reactions to all the pain meds I've tried. The only thing I can take is a small dose of baclofen. It helps me sleep by reducing the spasms.

I've always been single and I'm very independent. My body was the one thing I felt I could rely on. It hit me hard when it stopped doing what I told it to do.

I felt pure anger and frustration. That's why my MS nurses referred me to the neuropsychology team. I'm so glad they did.

I've talked with my neuropsychologist about what triggers my anger. She's given me different tools to help me step away. These include mindfulness and physical things, like going for a walk.

She's allowed me to admit to myself there's a reason why I'm struggling, and it's called MS. I still have moments of denial, but I'm getting better at accepting my limits.

ASKING FOR HELP

Razia Khan, MS Helpline Nurse

MS affects people in different ways and the symptoms people get can vary greatly. While some symptoms may be more challenging to manage than others, it's important to reach out for support. There are often treatment options available.

Your MS nurse, neurologist and GP will be able to offer advice. Some people find keeping a diary of symptoms gives their MS team and GP a clearer picture of symptoms and the impact they're having.

We have lots of online and printed resources about MS symptoms, as well as treatments and therapies.

THE CREATIVITY FACTOR

Three women share how writing, crafting and singing help them manage their MS.

I get an immediate sense of relief

Becky Haydock, 56, has secondary progressive MS. She's found that writing fiction helps her MS symptoms.

About two years ago, my MS suddenly got worse. I had severe fatigue and my legs stopped working well. I had to give up both my job and my passion for playing music. I was an accomplished violinist and was always out doing gigs. I felt as if my life had come clattering down around me.

Then one day I thought "Why don't I have a go at writing?" It was like a glimmer. I'd had this character in my head for many years. I started writing my first novel, Coming Home.

My second novel, about a young woman who has MS, was a way to write about some of own my experiences through fiction.

My characters and storylines develop in my head in bed at night. As I'm thinking about them, I get an immediate relief, a buzz, an excitement. It's like a huge boost of serotonin. And it helps me fall asleep. The next day, I'll try to write everything down. I'll often dictate notes into my phone.

The process of writing relieves my depression, takes my mind off my unable body, reduces pain and stimulates my brain. I'm convinced that opening up my imagination has helped my whole physical and mental wellbeing.

Shutterstock

Learning new skills is good for your brain

Anita Duffy, 59, has relapsing remitting MS. She's rediscovered her love of crafts through an organisation called Creativity in Care.

As a child, I loved making things. I started doing crafts again after giving up my nursing job and moving from Glasgow to the Highlands. But I lacked motivation.

Then, during the pandemic, a friend introduced me to Creativity in Care. At that time, we were meeting online. The first thing I made was a fabric book. We'd make a new page each week on a different theme. I decided to use it as a way of recording what was happening during COVID.

Being part of the group has changed my life. It's given me an enthusiasm for making stuff again and trying lots of different crafts. Physically, it helps with motor skills, while learning new skills is good for your brain. And the fact that we make things together gives me motivation.

I lead some of the classes now. I love being able to share the things I've learned. It's helped me regain the confidence I'd lost through having MS.

Singing raises your spirits

Christine Milner, 73, who has secondary progressive MS, is a member of the Singing for Wellbeing group in Anglesey.

Making music has always been part of my life. I used to belong to an MS Choir, but that came to an end. So early this year, we got some funding from the MS Society Cymru wellbeing programme for a singing group.

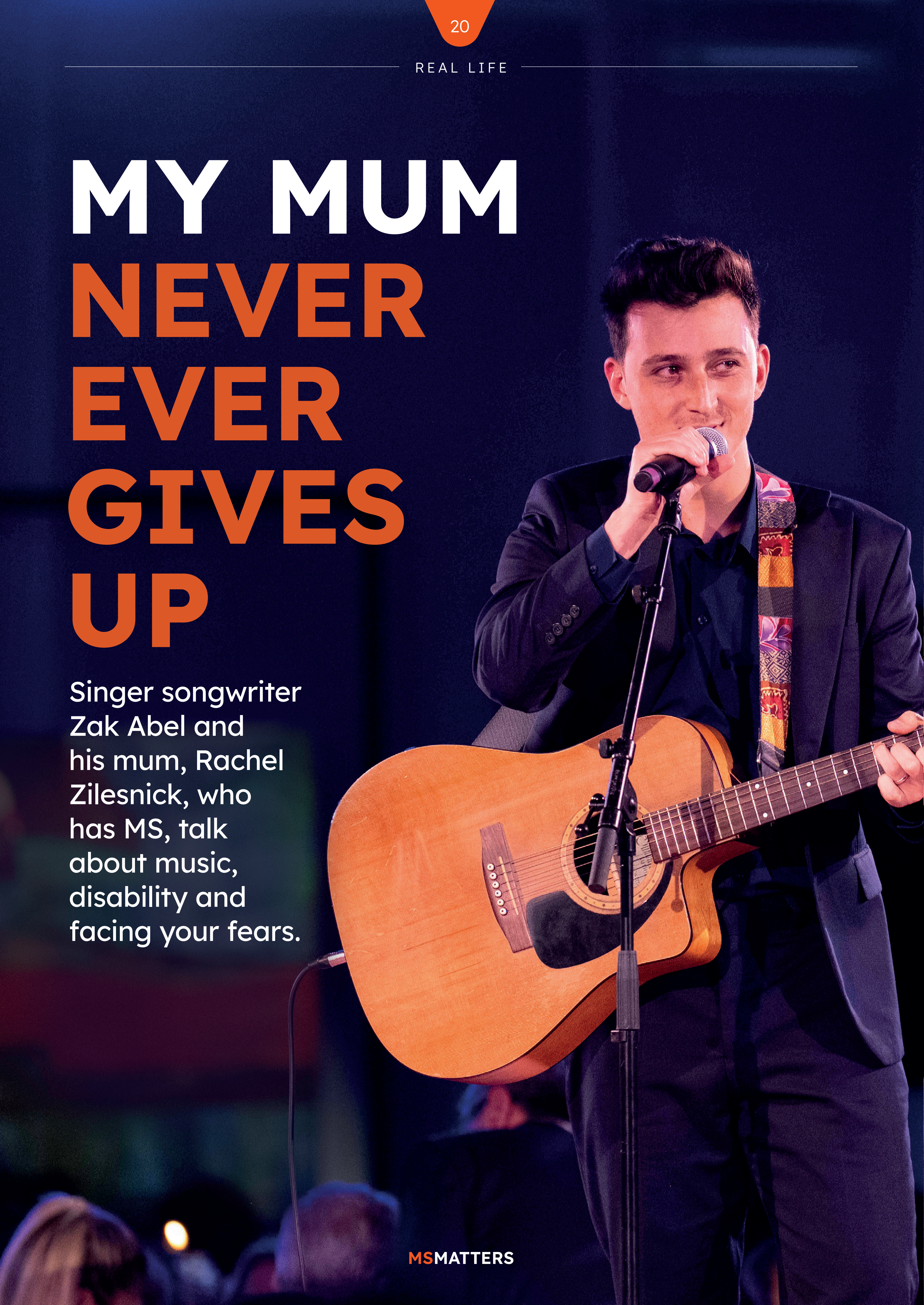
A professional singer leads the sessions and helps us choose the music. The most exciting thing at the minute is that we've been writing our own song. One of the members has written a poem and we've been setting it to a tune.

The group provides focus and mutual support. You're meeting up with others and focusing on the music, breathing, and relaxing.

It raises your spirits and makes you feel better about yourself. It's about being there and interacting with people and the camaraderie. You feel uplifted.

Is there a creative activity that helps you manage your MS? Let us know at msmatters@mssociety.org.uk

Read about other people's creative pastimes and all about life with MS in our community blogs at mssociety.org.uk/community-blog



MY MUM NEVER EVER GIVES UP

Singer songwriter Zak Abel and his mum, Rachel Zilesnick, who has MS, talk about music, disability and facing your fears.

Rachel: When I was 10, I was skipping and my left leg collapsed under me. I was rushed to hospital, but they didn't know what it was. They said I should wear Start Rite shoes.

At 21, my left leg went again. I had an EEG scan and they said I might have some kind of sclerosis – but they didn't say multiple sclerosis. I was diagnosed with benign MS when I was 31. Then when I went to see another neurologist 10 to 15 years ago, they said it was relapsing remitting MS.

I think I've only started to acknowledge my MS in the last 10 years, as my mobility has got worse. I have to use sticks now. I ended up saying "I've got to accept it now."

Managing my MS

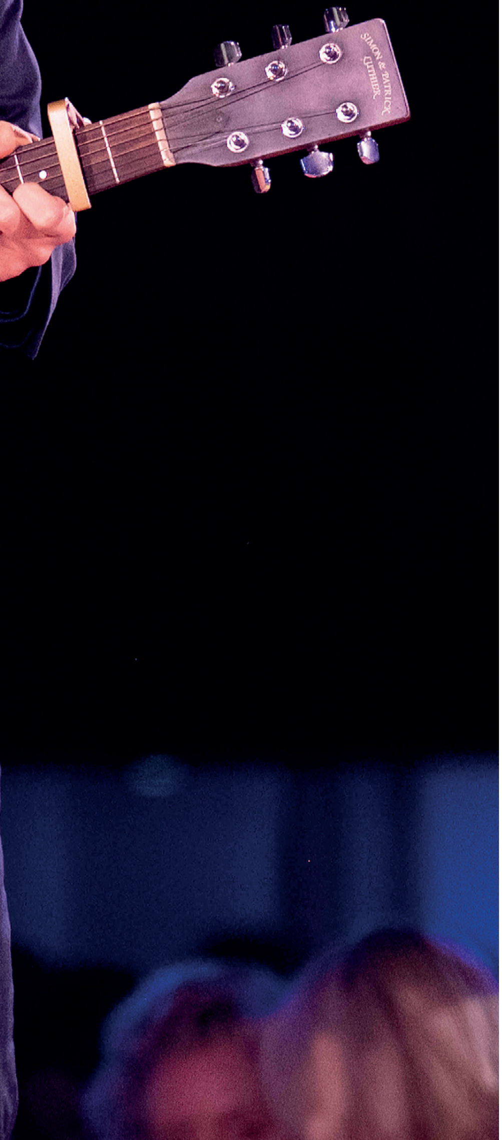
I've always used lots of alternative therapies like meditation, yoga and massage. Recently, I went to see a neurologist to ask if there was a treatment that could help my MS. But I was told I didn't qualify for any treatment. It really upset me.

Zak is very warm and kind. If I'm stressed, he'll say "OK, stop. What do you need? Don't stress. We can sort it out." He keeps me calm.

He never fails to surprise me. I find it amazing that he can get up on stage in front of millions of people, like at the King's Coronation Concert. Each time he sings a song I think "Oh, he did it that way. Oh wow!" He has such energy. He's achieved so much.

WHAT DOES THE TERM BENIGN MS MEAN?

'Benign MS' is sometimes used to describe relapsing remitting MS that's been very mild for 15 years or so. For example, with no attacks and long periods without symptoms. It doesn't guarantee you'll be free of symptoms, and future relapses are possible.



Shutterstock

> The first time I saw Mum as someone who was vulnerable I remember hugging her loads

Zak: The first time I became aware that my mum had MS was when I was 12. We were at Disney World and we were given a pass to skip the queues because my mum was disabled. Before then, I hadn't really thought about it. I remember being overjoyed!

But I was also aware of why we'd been given this pass. I think for the first time I saw Mum as someone who was vulnerable. I remember hugging her loads.

I never felt any lack because of Mum's MS. She gave me every opportunity. And there's no one more resilient than Mum. She never ever gives up. Ever.

Opening up

I have a condition called otosclerosis, which meant I started losing my hearing at 21. Despite the name, it's not related to MS. Like my mum I didn't want to talk about it straight away. Now there's more acceptance of talking about the things we struggle with. Being able to speak about it has helped me fully accept it.

My mum gave me my musical upbringing. She'd play James Brown and dance around. On the way to school, we'd listen to Smooth FM and Magic FM.

And she's always encouraged me. This created a mindset that if you want to do something, you should go for it. It's something that serves me well in my life as a musician.

CAREER HIGHLIGHTS

Zak's music blends soulful vocals with R&B and pop. He's performed for global audiences at King's Coronation Concert and the D-Day 80th Anniversary Concert. His second album, Love Over Fear, is out now.

Zak has created an exclusive playlist on Spotify for MS Matters readers, with songs dedicated to Rachel. To listen visit mssociety.org.uk/zak-playlist or use the QR code.

BREAKING TRIAL NEWS

THE LATEST UPDATES IN MS RESEARCH

Trial shows simvastatin isn't an effective treatment for secondary progressive MS

The phase 3 MS-STAT2 trial has found that simvastatin, commonly used to treat high cholesterol, doesn't slow down disability progression in people with secondary progressive MS. The results were announced by Professor Jeremy Chataway at the ECTRIMS research conference in Copenhagen in September.

MS-STAT2 was part-funded by the MS Society and built on promising results from an earlier phase 2 trial. It tested simvastatin in 964 people with secondary progressive MS. Unfortunately, the results showed that simvastatin can't slow down disability progression.

Simvastatin is a highly effective drug for heart and vascular health. But these results mean it won't be taken forward as a neuroprotective treatment for secondary progressive MS. If you take simvastatin specifically for your MS, speak to a healthcare professional if you have any questions or concerns. MS

Shutterstock

Dr Emma Gray, our Assistant Director of Research

"We're so proud to have funded MS-STAT2. While it isn't the result we desperately wanted, it's shown us we can deliver world-class and well-designed trials that match the scale and quality of big pharma companies. Professor Jeremy Chataway and the trial team made the impossible possible, and we're so grateful to the hundreds of people with MS who took part. Without them, this simply wouldn't have happened.

We'll continue investing in high-quality clinical trials, like Octopus, which is testing promising drugs for progressive MS."

Read more at mssociety.org.uk/ms-stat2-results

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.

It's free to call from landlines and mobiles within the UK. What you tell us is confidential and when you call us, it won't show on your phone bill.

MS Society

mssociety.org.uk

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

Shutterstock

HERCULES trial shows tolebrutinib slows down progression

Read more about tolebrutinib on p43

For the first time, a phase 3 trial has shown a drug can slow down disability progression in people with secondary progressive MS who don't have relapses. The company making the drug (Sanofi) shared the results of the HERCULES trial at the ECTRIMS research conference.

In the trial, tolebrutinib was compared with a placebo (dummy drug).

Tolebrutinib is a Bruton's tyrosine kinase (BTK) inhibitor. BTK inhibitors are a new type of drug being developed for MS. They work by stopping rogue immune cells from attacking myelin. While tolebrutinib showed positive results, it can also have some negative side effects, particularly liver problems. But the team found these problems could be reduced with frequent monitoring.

Two other phase 3 trials also showed tolebrutinib slowed down progression in relapsing MS compared to disease modifying therapy (DMT) teriflunamide (Aubagio). Together, those two trials were called GEMINI.

Before a drug is available on the NHS, it has to be licensed and approved. This process can take several years. But tolebrutinib could become the first DMT for people with secondary progressive MS who don't have relapses.

Read more at
mssociety.org.uk/tolebrutinib

FUNDING NEW RESEARCH

With your support, we've committed to funding several new projects over the past few months. Here's a selection.

When and why does the menstrual cycle worsen MS?

Dr Paul Ansdell from Northumbria University wants to understand the connection between the menstrual cycle and the worsening of MS symptoms. This could lead to better ways to manage symptoms.
Read more at mssociety.org.uk/menstrual-cycle

New MRI markers of MS progression

Dr Rasha Abdel-Fahim and her team from Nottingham University Hospitals Trust are exploring whether two new MRI features can improve how we monitor MS progression.
Read more at mssociety.org.uk/new-mri-markers

Regulation of immune cells in MS

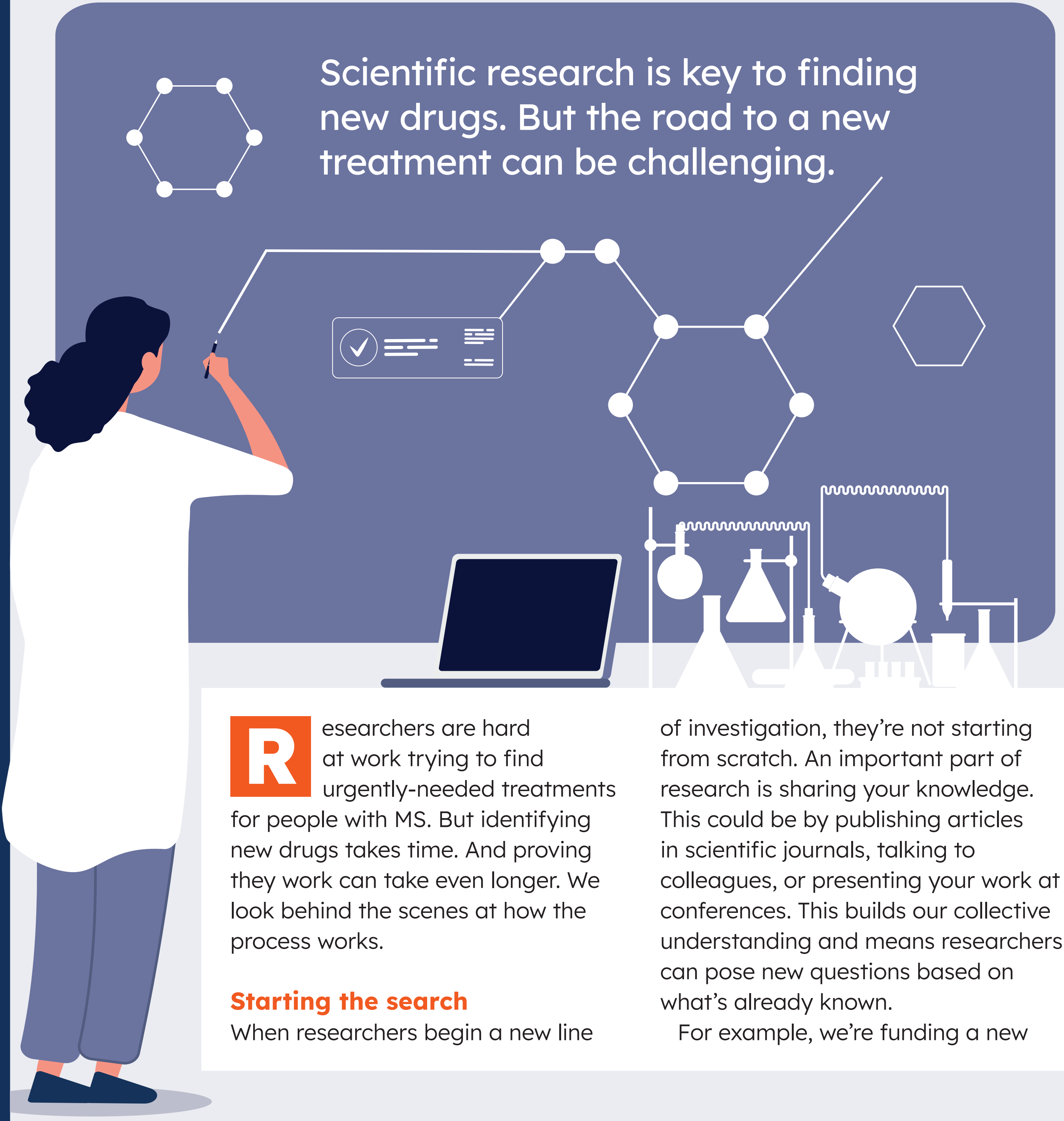
Dr Margarita Dominguez-Villar and her team at Imperial College London are exploring why a special group of immune cells work differently in MS. This could help researchers identify new targets for MS treatments.
Read more at mssociety.org.uk/immune-cells

Our Stop MS Appeal helps fund vital research projects like these. For more information visit mssociety.org.uk/stop-ms-2024

BEHIND THE SCENES

THE JOURNEY TO NEW TREATMENTS

Scientific research is key to finding new drugs. But the road to a new treatment can be challenging.



Researchers are hard at work trying to find urgently-needed treatments for people with MS. But identifying new drugs takes time. And proving they work can take even longer. We look behind the scenes at how the process works.

Starting the search

When researchers begin a new line of investigation, they're not starting from scratch. An important part of research is sharing your knowledge. This could be by publishing articles in scientific journals, talking to colleagues, or presenting your work at conferences. This builds our collective understanding and means researchers can pose new questions based on what's already known.

For example, we're funding a new

> Once researchers have identified a potential drug in the lab, we need to make sure it's safe and effective for people with MS. We do this using clinical trials

project led by Dr Emma Tallantyre. Emma and her team are looking at blood biomarkers – molecules or proteins in the blood that can tell us about a person's health. They want to identify markers to predict if someone with progressive MS will experience worsening symptoms.

Researchers have already identified some promising markers in the blood that could be used in the future to predict MS progression. But they've only been studied one at a time and in people with relapsing remitting MS. So they're building on this knowledge to understand whether they could be used in drug trials for progressive MS.

X marks the spot

Sometimes, researchers apply their knowledge about one area to another. For example, they might suggest a drug they know is used for one condition has the potential to work for people with MS. Our mega-trial Octopus is testing these repurposed drugs. Testing a drug which we already know lots about can speed up research.

There can also be surprising overlaps between different areas of science. For example, we're funding a project by Dr Selinda Orr, who usually works on fungal infection research. After talking with MS researcher colleagues, she wants to find out if the proteins she works on in fungal infections play a role in myelin repair. Collaborations like this can bring in fresh ideas and open new avenues of research.

Confirming the findings

It's important that scientists confirm their findings. Researchers will always repeat experiments more than once. This proves the findings are not a 'one-off'. They'll also make sure their conclusion is accurate by using different techniques to show the same thing.

>

VISUAL EVOKED POTENTIALS (VEP) TEST

What? A doctor places small silver discs (electrodes) at certain points on your head. Then you look at a flashing light or a screen displaying a checkerboard pattern. As the light flashes or the pattern moves, the brain responds. Some people have this test as part of their MS diagnosis.

Why? When eyes are stimulated like this, the optic nerve sends small electrical signals from the eye to the brain. These are called 'evoked potentials' and can be recorded through the scalp. When myelin becomes damaged in MS, it can slow down these signals. Because VEP tests are sensitive and non-invasive, they can quickly and easily indicate if there's damage. Sometimes, even before you notice any symptoms.

Shutterstock

For example, Professor David Lyons and his team at the MS Society Edinburgh Centre for Research study MS using zebrafish. They noticed myelin wraps around the wrong part of nerves after it's lost in a lesion.

To show this was relevant to people with MS they first needed to show it happened in different nerves in lots of different zebrafish. Then they collaborated with other experts who searched for the same phenomenon in brain tissue from people with MS. By showing myelin was misplaced over and over, they realised this was something worth investigating more. Now, they're searching for ways to control it.

MAGNETIC RESONANCE IMAGING (MRI)

What? MRI scans use strong magnetic fields to see inside the brain and spinal cord. During an MRI scan you'll be asked to lie flat on a bed that's then moved inside the scanner. The procedure is painless, but the machine can be very noisy.

Why? MRI scans help diagnose MS. But researchers can also use them in clinical trials to look at changes in the brain. If a treatment slows down how fast changes in your brain are taking place, it's a good sign. It indicates the treatment could also slow down disability progression.

THE 10 METRE WALK TEST

What? On the floor, a walkway of 10 metres is taped out, with an extra two metres at both ends for accelerating and slowing down. Researchers time how quickly you walk the 10 metres.

Why? By looking at walking speed in metres per second over a short distance, doctors can understand more about your mobility and gait.

How do we check they work?

Once researchers have identified a potential drug in the lab, we need to make sure it's safe and effective for people with MS. We do this using clinical trials.

To understand if a drug is effective, researchers carry out tests before, during and after the trial. They can compare the scores to see what the impact of the drug is. A wide range of tests are used in clinical trials. Read about three that are sometimes used in trials for MS in the boxes.

Find out more about the journey from lab to clinic at mssociety.org.uk/lab-to-pharmacy

Thanks to donations to our Stop MS Appeal, we're funding research projects like these. Find out more at mssociety.org.uk/stop-ms-2024

medimotion

GET MOVING EVERYDAY...

Stay active with RECK MOTOmed®

Passive, motor assisted, active movement.
For loosening, strengthening & endurance

NEW

muvi

Train arms & legs together

MOTOmed training can:

Reduce muscle stiffness and increase range of movement.

Improve circulation, walking ability, cardiovascular function.

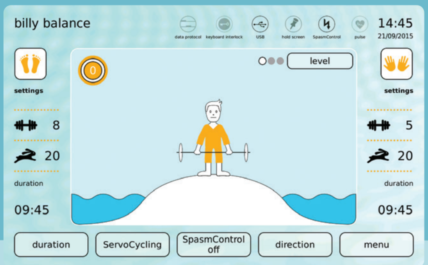
Used extensively in UK hospitals, therapy centres and private homes.

loop

Innovative height adjustment

Interest free hire/buyer plan available.
Call now for a FREE demonstration.

01559 384097



Interactive gaming

Co-ordination training

Children's

Bed Model

Parkinson's

tel: 01559 384097

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

RECK MOTOmed®
www.motomed.com

DRUG-FREE SYMPTOM MANAGEMENT

INNOVATIVE APPS AND DANCE FOR MS

We met three researchers involved in our Doctoral Training Centres (DTCs). They're all researching drug-free solutions to MS symptoms.

Dr Joanna Hudson is a psychologist and researcher co-leading the DTC at King's College London.

Myself and Professor Rona Moss-Morris, my co-lead, have been working on digital health programmes for around nine years.

We've heard the challenges from people with MS in accessing treatments. So our ultimate vision is to generate a one-stop digital app. An app where people with MS can access evidence-based psychological help to manage multiple symptoms.

To start with we're looking at symptoms of distress, pain and sexual dysfunction. Once we've got those three core programmes, we'd like to address more symptoms, like bowel incontinence and menopause.

Increasing access to effective treatments is a real passion that Rona and I share. We're hoping a digital app will become a vehicle that will do just that. We hope this time next year we'll have a version people with MS can test.

Thanks to donations to our Stop MS Appeal, we're funding research projects like these. Find out more at mssociety.org.uk/stop-ms-2024

Shutterstock

Dr Ashley Brown is a sex and psychology researcher, and practicing psychologist. She'll supervise a project developing an app for sexual difficulties at the King's College London DTC.

In MS, the rates of sexual difficulties are high, between 50 and 90%. But most people are quite afraid to talk about it. When asking about quality of life, even if you don't have a long-term condition, healthcare professionals don't tend to ask about sex. Unless they're asking "do you want to have babies?"

I'd like people to easily access education and resources specific to their MS to help them have better sexual and intimate relationships. It's important to consider treatments other than drugs. For example, if you have erectile dysfunction and a pill helps, there may still be psychological or relational problems you want to talk about.

We've already trialled an intervention for sexual difficulties in MS, which had positive feedback. It includes a combination of acceptance and commitment therapy (a type of CBT), sex education and psychosexual therapy. Now, the DTC will refine this and translate it into an app.

I really hope it opens conversations more generally around sexuality, so that health practitioners feel less afraid of asking the questions, less afraid of sending the referral for this kind of platform and ultimately help more people with MS. >

Emily Davis is a researcher and ballerina. She's advising on a project at the Glasgow Caledonian University DTC. It'll investigate how to make dance more accessible for people with moderate to severe MS.

There's a wide body of research on the benefits of dance for Parkinson's disease. It's a global phenomenon, really. And we know that for people with MS exercise and movement bring real benefits, as well as mindfulness and meaningful activities. So I saw an opportunity to look at dance for people with MS.

I've been looking at how a Scottish Ballet programme for MS, called SB Elevate®, can benefit people with MS.

Most people taking part have mild to moderate MS. So there's a real need to see how we can make Elevate® more accessible to people with advanced or severe MS. And that's what this DTC project plans to do. We'll work with Scottish Ballet to evaluate and refine Elevate®, including its in-person, hybrid and remote options.

What are the benefits of dance?

The dancers in my study see it as a long-term way of supporting their health and wellbeing in a meaningful way. Some say it's transformative. Many of them thought dancing was something they wouldn't ever do. But now they get to be a dancer through Elevate®.

What's been so beneficial for people taking part is meeting people who are like them. They can share the experience of dancing and feel the joy. A lot say it's an uplifting experience. Some people even say it's "elevating" which isn't surprising given the name!

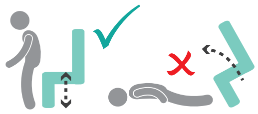
WHAT'S SB ELEVATE®?

On the face of it, a ballet class might seem like something that's very strict and very disciplined. But this is different. Sessions start with mindfulness – breathing, music, eyes are closed. Then it moves into more specific exercises inspired by Scottish Ballet. So maybe Scottish Ballet is doing Swan Lake on stage. The Elevate® class will do movements inspired by that repertoire. Dancers can stay seated, so it's suitable for wheelchair users.

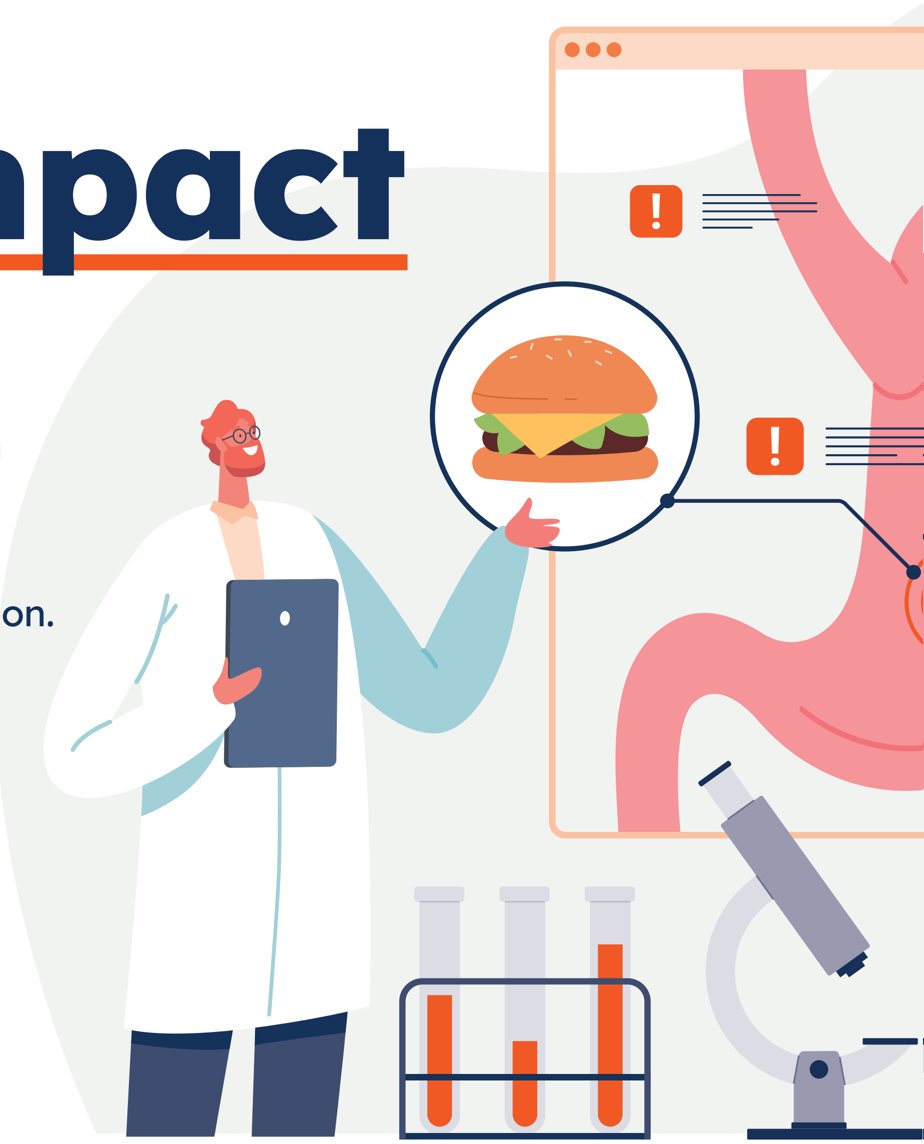
At the end there's a creative task, maybe a poem that inspires different movements. In Orkney, a fiddle comes out which is fun! The social side of dancing, like touch and laughter, makes it unique to other exercise classes.

Find out more about taking part in SB Elevate® in Scotland or remotely at scottishballet.co.uk

Read more about our DTCs at mssociety.org.uk/doctoral-training-centres


Theraposture rotating beds
Others


Unique independent powered foot support



Shutterstock

The impact of diet

Dr Shelly Coe uncovers new connections between diet, inflammation and MS progression.

Dr Shelly Coe is a Senior Lecturer in Nutrition Science at Oxford Brookes University and a registered nutritionist. We spoke with Shelly about her MS Society-funded research uncovering the connection between diet, inflammation and MS progression.

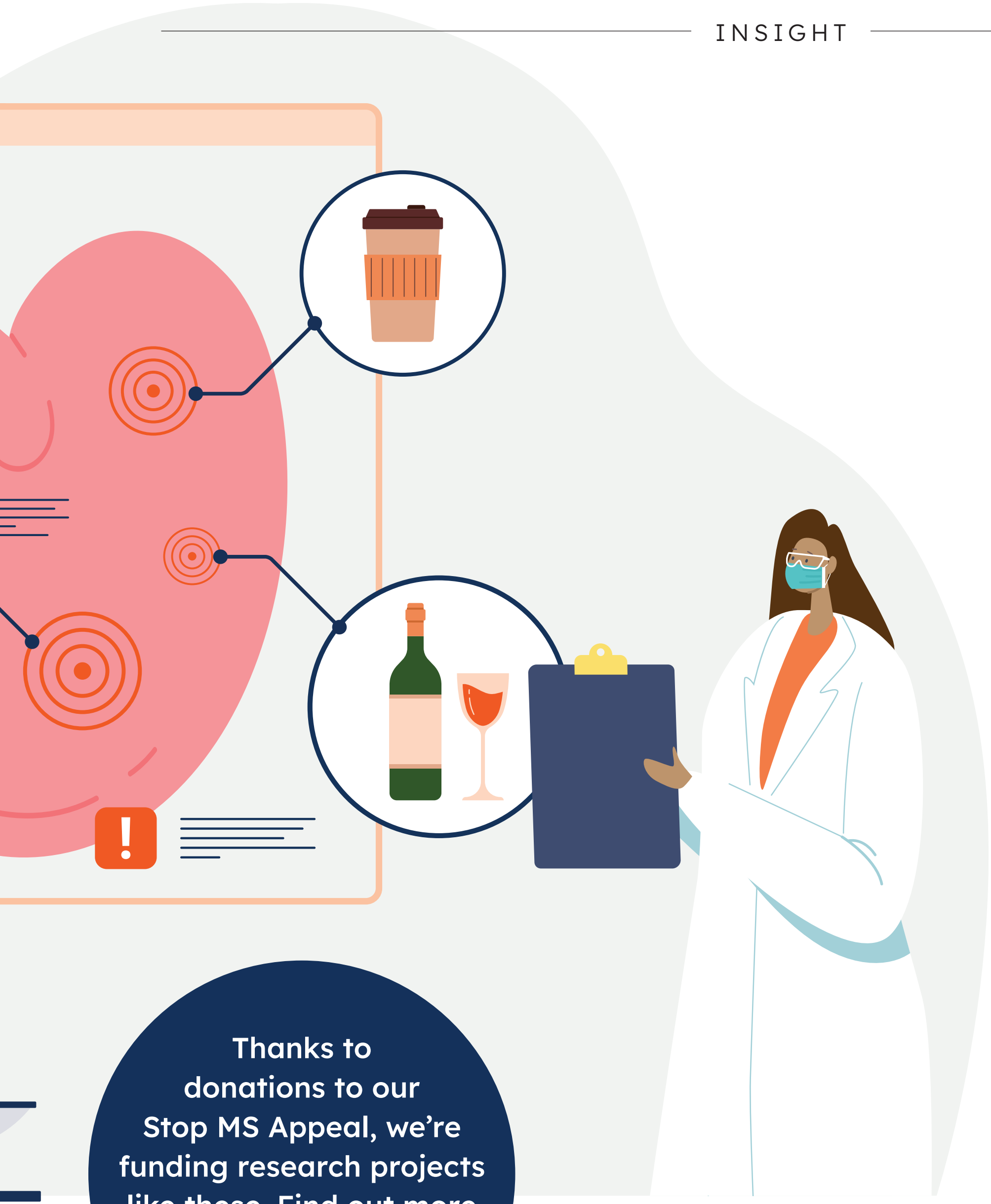
Although many people with MS report benefits from changing their diet, no single diet has been scientifically proven to help. We know some food compounds have inflammatory effects on the body, and these foods can be measured by the Dietary Inflammatory Index (DII). But we don't yet know how this affects MS progression.

Can you tell us about your research into diet and MS progression?

We're using data from the UK MS Register. This is the world's first register to combine information collected directly from people about their MS with clinical data. We're exploring how diet affects quality of life, health, disease severity and symptoms in people with MS. This will be the largest nutrition project from the Register studying how dietary patterns might influence symptom severity over time. We measured diet using a questionnaire from 2016. We'll then look at how these same participants reported their symptom severity in 2022.

What is an inflammatory diet and how does the DII help to measure it?

An inflammatory diet is typically high in saturated fats, sugars and salt. It's also often low in 'anti-inflammatory' nutrients like omega-3 fats and many vitamins and minerals. The DII measures how inflammatory someone's diet is. Previous research has linked higher DII scores with increased relapse risk and more lesions seen on MRI scans in people with MS. We're now looking for any links to how severe people's symptoms



Thanks to donations to our Stop MS Appeal, we're funding research projects like these. Find out more at **mssociety.org.uk/stop-ms-2024**

are. This type of study doesn't prove diet affects MS, but it helps us see where there might be connections.

Why is the UK MS Register such a useful tool for this research?
The Register provides access to a large and diverse group of people with MS. Our team were the first to introduce a diet questionnaire for participants. This lets us use advanced statistical methods to explore the links between diet, quality of life and MS progression.

The insights we gain are only possible thanks to people living with MS who take part in the Register. We're incredibly grateful to everyone who's shared their information.

What are the next steps for this work?
We'll continue to follow up on symptom severity and disease progression in people with MS using data from the Register. There's a growing interest in diet in the field. Research like ours could help provide answers to whether dietary changes can reduce MS progression and improve quality of life. If we find promising results, we could conduct larger studies to test specific diets.

How might your findings change the way people manage their MS?
Much of the current nutrition advice for people with MS echoes the healthy eating guidance given to the general public. However, certain diets, foods or nutrients may be especially important for people with MS. Our goal is to add to the evidence base, ultimately helping to create nutrition guidelines tailored specifically to people with MS. This could work alongside medications in managing symptoms, slowing progression and improving quality of life.

FIND OUT MORE ABOUT... THE UK MS REGISTER

We established the UK MS Register in 2011. It has over 20,000 members who share information about their MS, and the impact it has on their lives. Find out how you can join the Register at mssociety.org.uk/ms-register

Lucy Wilson

“Holistic healthcare is like tending a garden”

Living with MS presents unique challenges that often require a comprehensive approach to treatment.

Disease-modifying therapies (DMTs) are essential for managing MS. But holistic healthcare, which integrates complementary therapies and lifestyle changes, offers a way to address not just the disease but the whole person.

We spoke to Dr Agne Straukiene, Consultant MS Neurologist, certified brain health ambassador and host and founder of the BeeWellWithMS podcast.

What is a holistic approach to healthcare?

Holistic healthcare focuses on treating the whole person, not just their symptoms or disease. For MS patients, this means addressing physical, emotional, mental, and spiritual wellbeing. Factors like diet, sleep, exercise, and stress management are crucial parts of holistic care.

Dr Straukiene likens holistic care to tending a garden. “It’s not just about nurturing the flowers but also considering the soil, water, and light - all the factors that influence how plants grow.” This highlights the importance of taking care of all aspects of life to create a balanced and resilient approach to managing MS.

> Holistic healthcare focuses on treating the whole person, not just their symptoms or disease

Dr. Agne Straukiene

Hosts the podcast, BeeWell with MS. Use this QR code to listen.

How can a holistic approach help manage MS?

A holistic approach offers many benefits for MS management. While DMTs help reduce relapses and potentially slow disease progression, they might not fully control MS symptoms like pain, fatigue or stress. Complementary therapies can enhance the treatment plan and overall wellbeing.

Mindfulness and meditation, practised consistently over eight weeks, have been shown to improve cognitive function, reduce anxiety, and help manage fatigue. Acupuncture may assist in managing chronic pain. Yoga, Pilates, and physiotherapy help improve mobility, flexibility, balance and strength—key factors for maintaining quality of life.

Lifestyle changes such as improving sleep hygiene and following a balanced diet can also support physical and mental well-being. “Changes like quitting smoking, managing stress, and preparing healthier meals can significantly impact MS symptoms and overall health,” says Dr Straukiene.

Is there evidence that holistic care is effective for MS?

Yes, there is growing evidence that holistic care can benefit people with MS. While individual complementary therapies or lifestyle changes may provide small improvements, combining them with conventional treatments can lead to a more significant overall effect.

Mindfulness and meditation have been shown to improve cognitive performance, reduce fatigue, and aid pain management. Acupuncture has shown potential in reducing chronic pain intensity, though more large-scale studies specific to MS are needed. Practices like yoga and physiotherapy have proven benefits, particularly for mobility, balance and strength.

While not all complementary therapies are backed by robust scientific evidence, many people with MS report positive experiences. However, it's crucial to consult a healthcare provider before adding new therapies to ensure they are safe and compatible with existing treatments.

How do I know what information to trust?

In today's digital world, misinformation about MS treatments is widespread, especially regarding so-called 'miracle cures'.

"I often encounter patients who read claims about herbal supplements or alternative therapies that promise to cure MS," says Dr Straukiene. "It's important to rely on trusted sources and consult a healthcare professional before trying any new treatments."

Some herbal supplements can interfere with medications or cause harmful side effects. Dr Straukiene says "I advise patients to critically evaluate treatment options, prioritise peer-reviewed research, and involve their medical team to ensure any complementary therapies are safe and effective."

What should I look for when choosing a complementary therapist?

When considering complementary therapies, it's vital to work with licensed and certified practitioners. Whether it's acupuncture, massage, or herbal remedies, ensure the therapist is registered with a professional body, and any products used are properly regulated. In the UK, look for the Medicines and Healthcare products Regulatory Agency (MHRA) stamp on herbal and medicinal products.

Holistic healthcare, which combines conventional treatments with complementary therapies and lifestyle changes, provides a comprehensive approach to managing MS. By focusing on the whole person - physically, emotionally, and mentally - this approach enhances overall wellbeing.

Dr Straukiene says "I encourage people with MS to remain open to holistic care while relying on evidence-based practices and the guidance of trusted healthcare professionals." MS

> “
> While not all complementary therapies are backed by robust scientific evidence, many people with MS report positive experiences

FIND OUT MORE ABOUT... HOLISTIC HEALTHCARE

Look out for a longer interview with Dr Straukiene on our blog. Just search 'Agne' on our website. Learn more about treatments, diet, exercise and sleep at mssociety.org.uk/therapies-and-treatments or use the QR code.

How I research treatments and therapies

Adeyinka, who was diagnosed with relapsing remitting MS in 2008, has explored both conventional and complementary therapies.

Adeyinka Kilani
lives with relapsing MS

I realised early on that I have to be very proactive with my MS. I've spent a lot of time reading about it. I like to read books because looking on Google gives you the good, the bad and the ugly of MS. It's easy to get overwhelmed.

I used to take lots of supplements, but I don't think they made any significant difference. For me, diet and lifestyle changes have had more impact. I'm on a gluten and dairy-free diet, I started going to the gym and I've tried physio. I've also tried hyperbaric oxygen therapy, which I've found helpful.

Pilates is a 'game changer'

About a year ago, I started doing Pilates through my local MS Society group. I have loss of feeling in the left side of my body and it was almost permanently weak. I've found my left side has improved drastically since starting Pilates. It's been a game changer. Another thing that helped was a six-week cognition clinic. I was so forgetful – I couldn't remember anything. This course equipped me with coping strategies.

Running it by my MS nurse

My MS nurse referred me to the physio, cognition clinic and Pilates. When I'm thinking of trying something new, I like to run it by her. She's open to discussing anything. If there's something she doesn't know about, she'll research it. Sometimes she'll say "maybe there's not enough proof that this works. But if you want to try it, give it a go."

I went on a disease modifying therapy (DMT) in 2018. The hospital ran several information sessions about the different meds available and the pros and cons of each. It gave me a fair idea of which would work best for me.

You can find out more about complementary therapies at mssociety.org.uk/therapies-and-treatments or by using the QR code.


iStock

Could mindfulness help my MS?

We ask retired mindfulness teacher Annie Jones, who has primary progressive MS, and neuropsychologist Dr Emma Burton, from NHS Highland.


Annie Jones


Dr Emma Burton

What is mindfulness?

Annie: Mindfulness is about what you do with your attention and your awareness. So paying attention to what's happening in the present moment without judgement. It's knowing what you're doing while you're doing it.

Emma: I often describe it as focusing on the moment-to-moment changes that are happening within the body. Whether that's noticing your breath or other changes such as an increase in heart rate.

I practise mindfulness with my patients, using a technique called 'the journey of the breath'. We simply notice the breath coming in through the nostrils. Then follow the journey of that breath as it passes through the throat, the chest and the stomach. Then notice the breath as it comes back out of the body.

How can it help with MS symptoms?

Emma: Mindfulness can help with the 'silent' symptoms of MS such as stress, anxiety and fatigue. For example, anxiety can cause the breath to become shallow and speed up. This increases tension in your body and causes increased fatigue. By slowing the breath down, you can start to turn off the body's anxiety systems and reduce tension.

Annie: It can also help with pain. The thing we focus on becomes a bigger part of our experience. If my attention

is solely on the pain in my legs, that pain becomes bigger. I aim to broaden my awareness so that my pain becomes part of my experience rather than the whole. I try to look for what's pleasant. So perhaps the pain in my legs isn't as bad as usual. Or my hands feel warm.

Can it help with MS in other ways?

Annie: I practise bringing mindfulness into daily life. Moving mindfully is important. I don't want to fall because I might hurt myself. I need to look where I'm going and be aware of where I'm putting my feet.

It's also about just doing one thing at a time. If I'm chopping carrots, I'm chopping carrots. I don't want anyone to talk to me. I don't want the radio on. There's a real satisfaction in paying attention to what you're doing.

ANNIE'S MINDFUL BREATHING TIPS

1. Find a comfortable posture – ideally one that helps you feel alert. Make whatever adjustments you need to. Switch off your phone.
2. Notice your body and its contact with the surface you're resting on. You might like to close your eyes.
3. Follow the movement of your breath as it flows in and out of your body. There's no need to try and change it. Just pay attention to your natural breathing rhythm.
4. It might help to place a hand on the body where you most feel the movement of the breath. That's usually the chest or belly.
5. When your mind wanders – which it will – bring it back to the breath. There's no need for self-criticism. Noticing you've lost yourself in thought is mindfulness!
6. Follow the breath for a while. This could be as little as five minutes, three minutes, three breaths or even a single breath.
7. Use the breath as an anchor to bring your mind back to the moment.

Is it easy to learn?

Annie: Mindfulness is a skill, like cooking or knitting. Everybody can learn to do it. It's about sticking with it. And you don't need to sit to meditate. You can do it in any position that's comfortable.

Emma: You can do it in the queue at the supermarket, while waiting for your appointments or on the bus. The more you practise, the better you get. It's a tool you can use at any time.

Are you interested in learning more about how mindfulness can help you manage your MS? Visit mssociety.org.uk/ms-and-mindfulness

There are more disease modifying therapies (DMTs) in trials for progressive MS than ever before. Researchers are testing drugs that could stop immune attacks, boost myelin repair and protect nerves.

We hope a combination of these three things could stop every kind of MS. Read about some of the drugs in trials that could take us there.

METFORMIN

Type of MS: relapsing remitting, primary and secondary progressive MS
Clinical trial: Octopus, CCMR2
Stage: phase 2
Other uses: type 2 diabetes
How it could help MS: repair myelin, protect nerves from damage
What it does: Metformin is an antioxidant. We think it protects nerves from damage by stopping harmful chemicals (oxidants) from attaching to nerve cells.

Studies in mice have shown it encourages nerve cells to produce energy – this could help them stay healthy and support myelin repair. And it encourages myelin-making cells to mature so they're better at repairing myelin.

What's next: We're funding an ongoing mega-trial – Octopus. It'll test whether metformin can slow disability progression compared to a placebo (a dummy treatment). Initial results are expected in 2028. The CCMR2 trial is testing whether metformin and clemastine can help repair myelin in people with relapsing MS. Results are expected in late 2025.

Octopus is recruiting people with primary and secondary progressive MS. Find out more at mssociety.org.uk/octopus

Meet the candidates

DRUGS IN TRIALS FOR PROGRESSIVE MS

CLADRIBINE (MAVENCLAD)

Type of MS: advanced progressive MS
Clinical trial: ChariotMS
Stage: phase 2
Other uses: relapsing remitting MS
How it could help MS: stop immune attacks
What it does: Cladribine targets immune cells called T and B cells. These cells normally attack viruses and bacteria that get into your body. But in MS they attack myelin, the protective coating around our nerves. Cladribine stops these cells from getting into your brain and spinal cord so they can't damage the nerves there. Usually, cladribine isn't prescribed once you have an Expanded Disability Status Scale (EDSS) score above 6.5. But emerging research shows these immune cells could still be driving inflammation after this cut-off. So it could help more people maintain hand and arm function.
What's next: ChariotMS is recruiting people with advanced MS with an EDSS of 6.5-8.5 and has no upper age limit. We hope to see early results in 2027.

Recruitment for the trial is expected to finish at the end of this year. Find out more at mssociety.org.uk/chariot-ms

Shutterstock

TOLEBRUTINIB

Type of MS: relapsing remitting, secondary and primary progressive MS
Clinical trials: HERCULES, PERSEUS
Stage: phase 3
Other uses: none – it's a new drug being developed for MS
How it could help MS: stop immune attacks
What it does: Tolebrutinib is within a new class of drugs called Bruton's tyrosine kinase (BTK) inhibitors. Like existing DMTs, it stops immune cells called B cells from attacking myelin. But it works differently from most DMTs.

It only targets specific B cells known to be involved in MS. This could mean fewer side effects than DMTs which target all B cells.

It can cross the blood-brain barrier. This means it can enter the brain and spinal cord. So it could stop immune cells attacking myelin at the site of damage.

What's next: Results from the HERCULES trial showed tolebrutinib can slow disability progression in people with secondary progressive MS who don't have relapses (see page 25). We hope this could lead to a new treatment for people who currently have no options.

The ongoing PERSEUS trial is investigating whether tolebrutinib can also slow progression in people with primary progressive MS. We hope to see some results next year.

Read more about treatments in trials on our website at mssociety.org.uk/treatments-in-trials or use the QR code.


NEW lifting foot-section for Lymphoedema
See demonstration videos at www.laybrook.com
MSMTBHP-2

HAVE YOUR SAY

We asked what treatments and therapies you've found the most helpful with your MS.

I've tried Tecfidera (dimethyl fumarate) and Mavenclad (cladribine), which sadly didn't work for me. I have my second-half dose of Ocrevus (ocrelizumab) tomorrow and feel optimistic. I've found hyperbaric oxygen therapy and cold water therapy helpful. Talking with professionals, friends and family is also so important.
livingwithms

I have a full body massage once a week. The immediate effect is one of relief and the ability to feel what a relaxed muscle should feel like. It feeds my brain with muscle messages I wouldn't otherwise experience. I'm fortunate to be able to pay for these.
Jane Frappert

After struggling with a wired functional electronic stimulation (FES) device on the NHS for free, I bought a wireless one. When I wear it, I can walk normally without footdrop or getting tired. But it cost £2,800, which most people can't afford. I've used a large part of my life savings.
Fiona McKay

I've been on Copaxone (glatiramer acetate), Gilenya (fingolimod), Avonex (a beta interferon) and now, Tysabri (natalizumab). Tysabri is the only one that has given me stable MRIs and that's been for four years now!
Terrina Bishop

A combination of Ocrevus (ocrelizumab), good nutrition and strength training have massively supported me.
Tracey Jones

EVERYONE'S DIFFERENT

Finding the 'right' treatment or therapy is a personal thing. We know that MS is different for everyone. And so are people's experiences with treatments. Ask your healthcare team to explain the possible benefits, side effects or risks. You can find out more on our website or call our MS Helpline on 0808 800 8000.

Shutterstock

FOR OUR NEXT ISSUE WE'RE ASKING...

If you were the MS Matters editor, what's the most important topic you'd choose to cover and why? Send your thoughts to msmatters@mssociety.org.uk We'll also post the question on our social media at facebook.com/mssocietyuk and instagram.com/mssocietyuk

Treworgans

ACCESSIBLE HOLIDAY COTTAGES IN CORNWALL

Two wheelchair accessible cottages in Cornwall offering

- En suite wet rooms
- Electric profiling beds
- Air/pressure mattresses
- Ceiling & portable hoists

- ★New★Stand - Aids
- ★New★Sara Stedy's
- Shower chairs
- Riser/recliner chairs
- Local care available
- Adapted kitchens

Treworgans is centrally located with easy access to attractions and many wonderful places to eat close by, making it the ideal place to enjoy Cornwall from.

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

rollz

Next level independence

Rollator, transport chair and electric wheelchair combo

- Switches seamlessly between the three mobility-aid options
- Turns on the spot even in narrow spaces
- Easy foldability that allows compact transportation
- Qualifies as VAT exempt

Distributed by Rollz Mobility UK

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

Croft Bungalow

accessible holiday cottage
Peak District
***Sleeps 4**

Croft Bungalow is an award winning adapted self catering cottage. It's level access open plan with a wet roll in wc & shower and an optional pop-up sensory room.

It has a a range of accessible equipment including a hoist, electric profile bed (with removable cotsides), 2 riser/recliners and a wheeled showerchair/commode.

Outside is private parking, an award winning sensory garden & patio (landscaped for wheelchairs & power scooters), all with open country views.

Very near Bakewell & Chatsworth, Carsington Water, Cromford Mills, and multiple accessible Peak District days out. 100 metres from our two village foody & real ale pubs (wheelchairs welcome) too.

CALL US ON 01629 650979
OR EMAIL enquiries@croftbungalow.co.uk
www.croftbungalow.co.uk
*Please feel free to view the *Access statement/3D tour and video on our website*

PEAK DISTRICT & DERBYSHIRE TOURISM AWARDS 2023 ACCESSIBLE & INCLUSIVE TOURISM SILVER AWARD

PEAK DISTRICT & DERBYSHIRE TOURISM AWARDS 2022 ACCESSIBLE & INCLUSIVE TOURISM GOLD AWARD

Restore Intimacy Naturally

Available on NHS Prescription in most CCG areas for men with M.S..

iMEDicare
Pelvic Health Naturally...

Efficient for men with Multiple Sclerosis

SOMAerect Stf
Penile Structural Rehabilitation and erectile dysfunction solution

visit mypelvichealth.co.uk
+44 (0) 1923 23 77 95

Visit www.MyPelvicHealth.co.uk

Or ask your GP for Urology Referral

YOUR THOUGHTS

Jacqueline wrote to tell us about the importance of language when talking about MS research.

I've just finished reading the Summer 2024 issue of MS Matters. How relevant, timely and helpful the article and illustrations used in 'Meet your brain cells' (page 40) are. As are the articles from Professors Anna Williams (Ask the Expert, page 36) and Parth Narendran (Can MS be prevented? page 34).

It's 'lay review time' for the MS Society's Research Network, of which I'm a member. This means it's the time of the year when some of us review research funding applications. We review the 'lay summary', which is written for the general public, rather than researchers and scientists. This summary should be clear and easy to understand.

These mini round-ups in MS Matters certainly help demystify the scientific jargon and focus the mind. The pronunciation descriptors are great too.

It's good to see an article on why it's so important researchers get the lay summary right in funding applications.

Jacqueline Karup, Research Network member

Research Network

34

RESEARCH

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 abl 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.

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.

Professor Parth Narendran

"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 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 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."

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

MSMATTERS

35

RESEARCH

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.

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.

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.

MSMATTERS

WHAT'S THE RESEARCH NETWORK?

It's a group of people affected by MS who make sure the research we fund reflects the needs and interests of people living with MS. They also help us talk about it in a way that's accessible to everyone.

Anyone who lives with MS or cares for someone who does can get involved. It doesn't matter where in the UK you live or how much research experience you have.

Find out more at mssociety.org.uk/join-research-network

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

VOLUNTEER SPOTLIGHT

"I felt heard and respected"

Carla was a member of our General Election co-production group. She shares her experience of being involved in our campaign to get MS on the political agenda.

I was involved with the co-production group to help shape campaigning around the General Election. Previously, I supported the MS Society's work with the All-Party Parliamentary Group for MS. I'm action-oriented, so feeling any kind of loss of control motivates me to do more.

As folk with MS, we sometimes feel we don't have a voice or can't enact change. But people without MS can learn from us as experts. Working toward something with specific goals made it feel tangible and doable.

I really looked forward to our meetings. I felt heard and respected, but I also enjoyed listening to the experiences and ideas of others. This often gave me food for thought long after the meetings ended. I also learned about campaigning as a charity.

Quietly optimistic

It can be easy to fall into being cynical, particularly as change takes time. This is understandable given the demands placed on us as folks with health issues. But I'm quietly and cautiously optimistic, too. Change can be worthwhile and it might need us to push it in the right direction.

If there's something we can do, and we have the energy and time to do it, then why not? It doesn't have to be a consistent commitment. If there was one thing you'd feel brave enough to do, what would it be? Could you write to your local MP? Or sign up to support the MS Society's campaigns?

Want to get involved in our campaigns, like Carla? We're always keen to hear about what matters to you. Visit mssociety.org.uk/join-our-campaigns or use the QR code to find out more.

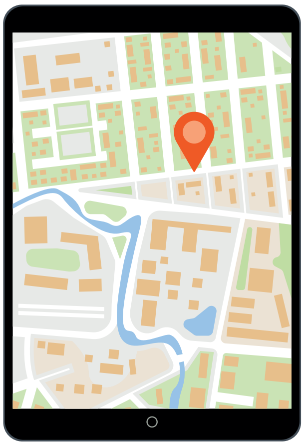
GETTING TO KNOW YOU

Meet our two newest trustees

Leah Mates and Jason Jaspal bring a wealth of experience in fundraising, marketing and partnership building for charities. Leah currently works for the British Heart Foundation and Jason for Samaritans.

What motivated you to get involved with the MS Society?

Leah: I've seen the devastating impact of postcode lotteries on the health of family and friends with neurological conditions. Everyone should have access to the right treatments and support. No one should have a worse outcome just because of where they live.



Jason: Several people close to me live with MS. They each have vastly different experiences of MS – different impacts on their quality of life, long-term outlook and mental health. The importance of treatment, information and access to quality services is paramount.

Tell us one thing you've learned in your work that you'll use to help people with MS.

Leah: There's always so much that could be done, particularly when it comes to saving and improving lives. I'm good at prioritising based on impact and not getting distracted by everything that could be done alongside that.

Jason: The power of personal, authentic storytelling is an incredible weapon when raising funds, driving awareness and influencing people. It keeps our work grounded and human.

What do you feel hopeful about?

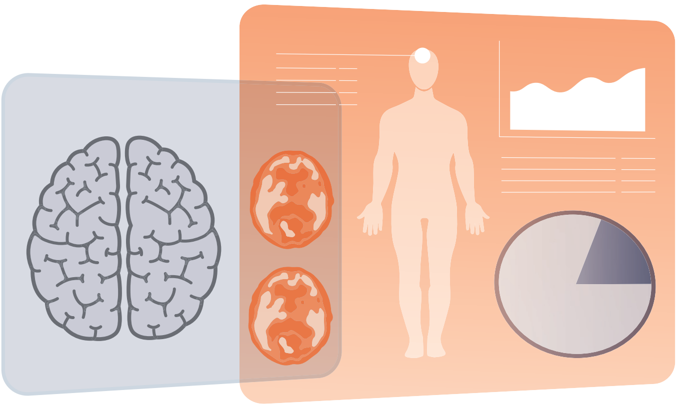
Leah: MS Society research is cutting-edge. With growth in fundraising and partnerships, I'm hopeful we're on the cusp of slowing, stopping and maybe even reversing the effects of MS.

Jason: I'm hopeful that AI, advanced technology and greater collaboration will have a huge and positive effect on future treatments.

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

Leah: My mum has always reminded me that being kind, no matter the situation or how tricky someone is being, is the most important thing.

Jason: Feedback is a gift. It's important we lean into it rather than try to fight against it – even if we don't like what we hear.



Shutterstock


MS Society
10% off
all TGA Mobility scooters, powerchairs and wheelchairs*
Motability
BHTA
tsi
APPROVED CODE
TRADINGSTANDARDS.GOV.UK