MS MATTERS

mssociety.org.uk

MSM008 • AUTUMN/WINTER 2025 • ISSUE 151

RESEARCH
Taking part in research at any age

NEWS
New children's book helps families talk about MS

INSIGHT
What do we know about menopause and MS?

EVERY LETTER TELLS A STORY

Navigating MS at different times of life

MS Society

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Latest info

We've reviewed and updated our website information for people who've been newly diagnosed, including the latest version of the **McDonald criteria for diagnosis**.

We've a new page on **headaches and MS**.

And our information on **several disease modifying drugs** has also been updated:

- **HSCT**
- **Siponimod (Mayzent)**
- **Ozanimod (Zeposia) - only available in Scotland**
- **Cladribine (Mavenclad)**
- **Natalizumab (Tysabri/ Tyruko)**

We've also got information explaining **biosimilars and generic drugs**.

Find all this information and more on our website **mssociety.org.uk** or call our MS Helpline on **0808 800 8000** if you're not online.

AUTUMN/WINTER 2025 - ISSUE 151

Over the last couple of years, I've been lucky to connect with many of our readers who've shared their personal experiences of living with MS. One thing that's always stood out is how MS is different for everyone. People deal with different symptoms and adjust to the effects of MS at different times in their lives.

MS can shape life in unpredictable ways. Whether it's navigating a new diagnosis, starting a family, managing a career, or adapting to getting older. In this issue, we explore how it interacts with the milestones, challenges and transitions that make up our lives.

On page 14, our cover star Penny shares a heartfelt letter to her children about becoming a mum after her diagnosis. On page 40, we look at the connection between ageing and brain reserve. And you can find out more about MS and menopause on page 38.

We're also really excited to share the launch of our new children's book, 'What is MS to Me?' (page 12). And don't miss our interview with Made in Chelsea star Jane Felstead on page 18.

We hope you find this issue insightful. If you'd like to share your thoughts or experiences, please email us at **msmatters@mssociety.org.uk**

Daniella Fisher
Marketing Project Coordinator

Donate to stop MS

For the last 10 years, our Stop MS Appeal has been raising funds to change the MS research landscape. So far, we've raised an incredible £98.5 million. And we're closer than ever to finding treatments for everyone living with MS. Help us stop MS, for good. Donate today at **mssociety.org.uk/msm-stop** or use the QR code.

Campaigning to protect disability benefits across the UK

We're campaigning to make sure people with MS across the UK get access to the benefits they need to live a full and independent life.

Campaigning on PIP

Since last spring, we've been campaigning to stop the UK Government's proposed cuts and protect disability benefits.

We were clear from the start. The UK Government's proposals to cut Personal Independence Payment (PIP) risked pushing people with MS into poverty and worsening health. And, together, we stopped them in their tracks.

Together with our campaigning community, we kept the pressure on MPs to scrap the proposals. We sent thousands of postcards and emails, and made phone calls that reached MPs across the country. Our campaign was featured on TV, radio and newspapers nationwide. We put so much pressure on MPs that over 120 of them challenged their own government – something we don't see every day in politics!

This July, we celebrated protecting PIP. Thanks to our brilliant campaigners, the Government scrapped its proposed harmful changes to PIP.

The Timms review

Our campaigning hasn't stopped there. Minister Stephen Timms has announced there will be a review of the PIP assessment process in the next year.

The Government says this will be 'co-produced' with disabled people and disability organisations. And it will look at making the benefit 'fair and fit for the future'.

Importantly, the Government has promised not to make any changes to PIP until after the review has been completed. The review is expected to end in autumn 2026.

Rob, an MS campaigner, said "We must keep up the pressure on the Government to get PIP right. For me, PIP is vital. It's allowed me to not only pay for the additional costs which come with a diagnosis of MS. It's also taken away a lot of the financial worry and anxiety."

We're clear that this review will only deliver for people living with MS if it's properly independent, fair and includes disabled people. We're keeping up the pressure to make sure the Government delivers on its promise – to include the voices of disabled people in the Timms Review.

Campaigners in Scotland call for the 20-metre rule to be scrapped

Scotland's ADP review

In July, the Scottish Government published the final report from the Independent Review of Adult Disability Payment (ADP). This was a crucial moment for people in Scotland living with MS.

Jo Anderson, our Director for Scotland, said "Nearly half of the 17,000 people in Scotland living with MS claim ADP – and it's vital the system properly reflects their needs."

The proposed changes look promising and are a great opportunity to improve how ADP works for people living with MS. That's especially true when it comes to unfair guidelines such as the 20-metre rule and the 50% rule. Under current guidelines, you won't receive the highest rate of mobility support if you can walk a step over 20 metres. And you aren't entitled to support for your symptoms if they affect you for less than half of the month.

We've been engaging directly with the Scottish Government and Scottish Parliament to review the recommendations. And we're pushing for a Scottish benefits system that understands and supports people living with MS.

Next steps

We're looking for assurance that the recommendations in the ADP review become law. Thousands of campaigners across Scotland have signed our open letter calling on the Scottish Government to implement the recommendations of the Independent Review. And we'll deliver our letter to the Cabinet Secretary later this month. On the PIP review, we're pushing for the review to be meaningfully co-produced and take into account the challenges of living with a fluctuating and unpredictable condition, like MS.

Find out more about... getting involved in our campaigns

We're campaigning for a welfare system that works for people living with MS. Sign up to be the first to hear about opportunities to raise your voice for MS and join our campaigning community today. Visit mssociety.org.uk/sign-up-campaigns


Independence
HORIZON

Carols by Candlelight 2025

We're thrilled to invite you to this year's Carols by Candlelight, taking place on Thursday 4 December at the beautiful Central Hall, Westminster.

The concert promises to be a magical celebration of the season. It'll feature readings from some of our celebrity supporters, including comedian Ivo Graham, actress Nicola Walker and former footballer Ledley King. And performances from our talented choirs.

This year's concert will be extra special as we celebrate the final event of the Stop MS Appeal.

Please join us for an unforgettable evening filled with festive joy, music and community spirit. You can buy tickets at **mssociety.org.uk/carols-2025**

Exclusive VIP dinner

We're also offering a VIP dinner experience after the concert, hosted at Central Hall. Exclusive tables of 10 are extremely limited. If you're interested in securing a place or finding out more, please contact Georgia Cantwell at **specialevents@mssociety.org.uk**

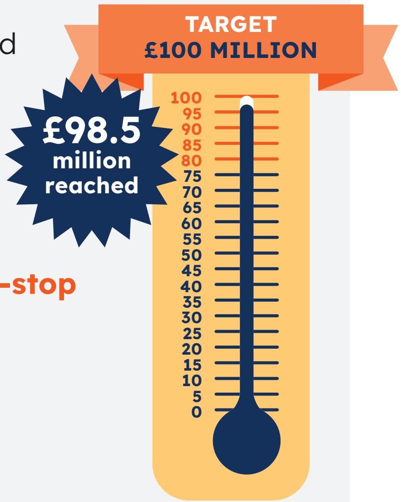
Stop MS Appeal

When we launched the Stop MS Appeal, we set an ambitious goal: to raise £100 million in 10 years to fund groundbreaking research into MS. We're thrilled to share that by October we'd raised £98.5 million. An extraordinary milestone that speaks to the dedication and generosity of our supporters and brings us within touching distance of our goal.

The appeal has allowed us to make bolder, more transformative investments than ever before. We've created a platform for lasting change, from pioneering lab discoveries and building vital research infrastructure to launching world-leading clinical trials.

Now we must make the most of the Stop MS Appeal legacy to drive forward our research. And meet the desperate need for treatments to stop or slow MS progression for everyone. Our new research strategy for 2025-2029 takes us even closer to achieving our vision: a world free from MS.

With your continued support, we're closer than ever to making that vision a reality. If you'd like to donate to the Stop MS Appeal, please visit **mssociety.org.uk/msm-stop**

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Campaigning for better neurology services in Northern Ireland

People living with MS in Northern Ireland have been waiting too long for the Regional Review of Neurology Services. The review is a plan spanning the next 10 to 15 years to tackle waiting lists, increase capacity and improve neurology services overall. Earlier this year, it was finally opened for consultation after a seven-year delay.

We joined colleagues from other neurological charities to gather evidence and submit a response. Using this evidence, we'll be calling for the recommendations within the review to be implemented and fully funded by the Northern Ireland Executive. We held an event in Stormont on 3 November, where we shouted loud and clear that change needs to happen now.

Derek McCambley from Bangor has joined the campaign. He says "Neurology services across Northern Ireland are in dire straits. During a recent relapse, I struggled to access care, and it had a detrimental impact on me. The care we're receiving is well below par, and the review is a chance to change that."

If you live in Northern Ireland and want to join our campaign, email nipress@mssociety.org.uk Read our review response at mssociety.org.uk/ni-review

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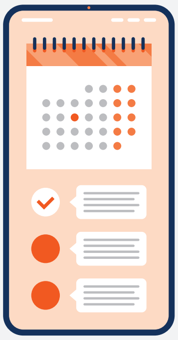


Diary dates

Activities

All these activities can be done at any time.

My MS Walk

Take a step, make a difference! Join My MS Walk and you can walk, roll or stroll anywhere, anytime, to help stop MS. Free sign-up, free t-shirt, and achieve a medal if you raise £100 or more. Let's walk the walk for a future free from MS!

mssociety.org.uk/my-ms-walk

Cake Break

Host a Cake Break and share delicious baked treats while helping fund vital research to stop MS. Grab your apron, set a date and sign up to get our recipes, bunting, and planning guides.

mssociety.org.uk/cake

Tee Off to Stop MS

Swing into action for the MS Society! Host a golf fundraiser to help support people living with MS. For more information or to sign up, email **fundraising@mssociety.org.uk**

Webinars

Thursday 27 November, 6.30 pm

Understanding Your New Diagnosis of MS

We're working in partnership with MS Together to help you start making sense of an MS diagnosis. We'll provide you with information and signposting to further support and guidance.

mssociety.org.uk/new-diagnosis

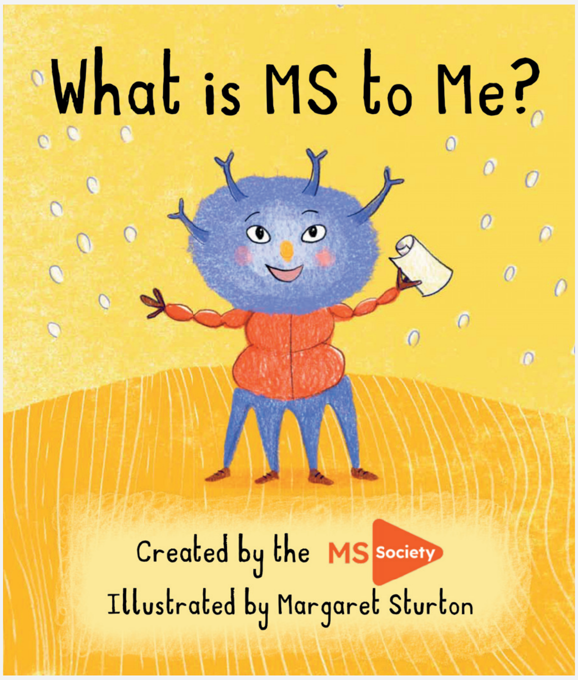
Find out about our programme of webinars and events, including our monthly peer group sessions, at mssociety.org.uk/living-well-events

We co-produced a children's book!

Explaining MS can be hard, especially to children. Describing complex symptoms and invisible changes simply can be frustrating for everyone. That's why we teamed up to create something special to support these moments.

Our new illustrated book, 'What is MS to Me?', was co-produced by people living with relapsing and progressive MS, their children, health professionals, writers, a designer and an illustrator. The main character, Tingo, is a friendly nerve cell who helps primary-age children understand the condition and how it can affect someone they love. Tingo was also made into a limited edition soft toy for the youngest children.

Back in 2023, Rebbecca Robinson (who lives with



relapsing remitting MS) and James Bailey (Information Editor whose mum has MS) discussed how they could begin the process. As joint leads for the group, they planned the questions that could get things started. One question was driving it all. 'What are we going to make to help kids and adults have better conversations about MS?'

The power of co-pro

The group decided on an illustrated book, with space for the child to draw or write their own thoughts. Something to be read together, or alone, that explained but also opened up discussion.

Group member Niti Patel lives with relapsing remitting MS. For her, the process was "inspiring and collaborative, with everyone sharing ideas and experiences to bring the book to life." Niti says "The evening calls with other MS warriors were a highlight. We bonded and built something meaningful together."

Robert Oldham also lives with relapsing remitting MS and took part. He says "I really enjoyed it! Seeing the designer and artist's interpretation of our idea really brought it to life. And it showed how a group of people with a shared interest can create something fun and educational to address an important need."

More than just a book

Tingo explains MS to younger minds in a calm, reassuring way. It explains the condition clearly, but with warmth and positivity.

Sian McSorley lives with relapsing remitting MS. Reflecting on Tingo, she says "To me, it looks a bit mischievous and cheeky! I can imagine the nerve cell whizzing around my body, peeking out now and again, causing havoc. It actually makes me smile. Maybe Tingo and co-producing the book have helped me accept my limitations in living with MS."

'What is MS to Me?' brings to life a wide range of emotions and experiences of people living with MS. It doesn't frighten younger readers, but it shows the reality of living with the condition. Involving the children helped us make sure we spoke in a way they'd understand. And involving the adults made sure the resource helps them talk with their kids about the issues they need to.

Sian says "We want to be there for our kids and be the best we can be. Sometimes, with MS, this is hard. And it can be hard to explain this to our younger loved ones. I particularly appreciated that our kids could get involved, as this is what it's all about."

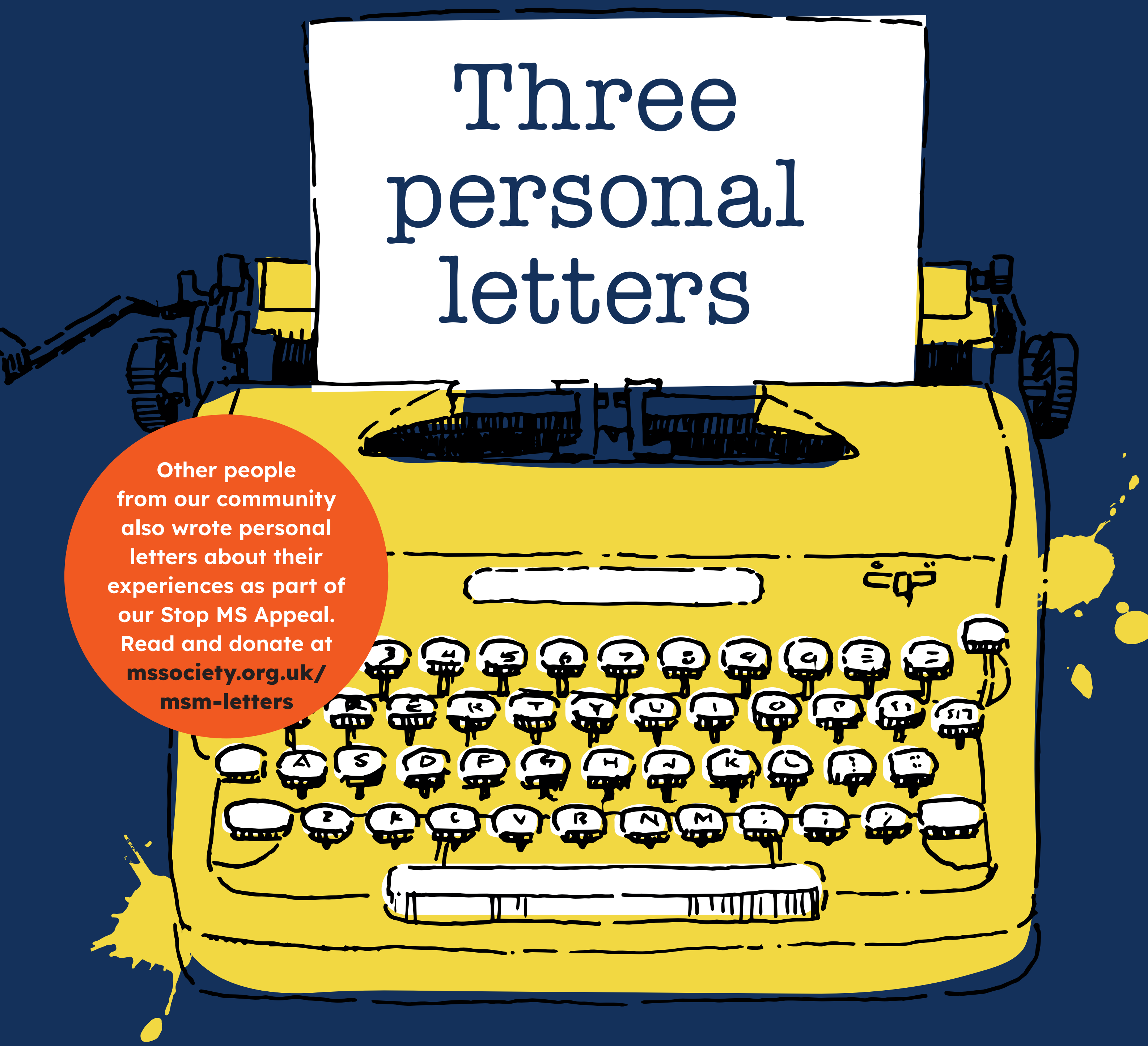
Find out more about... our children's book

All our Tingo toys have gone to good homes now. But you can order a copy of 'What is MS to Me?' for free through our online shop at mssociety.org.uk/shop-tingo

We'd love to hear your feedback, so please let us know what you think! Email msmatters@mssociety.org.uk

Illustrations by Margaret Sturton

Life with MS



Three personal letters

Other people from our community also wrote personal letters about their experiences as part of our Stop MS Appeal. Read and donate at **mssociety.org.uk/msm-letters**

We asked three people to write a letter about navigating MS at different stages in their lives. From a teenage diagnosis to raising a family and managing a career.

Dear Illianna, Jason, Iris and Theo,

I want to tell you that you're all such a blessing.

My first pregnancy with you, Illianna, saved me in a way. I was relapsing every month when I was first diagnosed. When I fell pregnant, it gave me time to breathe. My symptoms improved 100%. It was the same with all my pregnancies.

You know our rule that you have to say what's on your heart? I try to be open with you about having MS, so you can also be open about how you feel.

That's why I want to tell you I'm sorry I sometimes snap when I'm fatigued. It's not your fault. I've tried to explain that fatigue is not just being tired. It means I can't function.

One thing I don't say out loud is that the unpredictability of MS scares me at times. But when I look at you – or give you a hug – the fear goes away.

If you're reading this when you're older, I hope you'll remember things like our 'fish and chips Fridays'. They're a special treat for you that saves me energy. And how Kouka, your grandma, takes you to school on her scooter. It's so important to her to be part of your lives.

Do you remember, Jason, when you built a sandcastle with a wheelchair ramp to make it accessible? And how you all stood up for me when people questioned why I'd parked in a disabled space? Being inclusive and helping people comes naturally to you.

I hope you'll remember coming to the MS Society coffee mornings at our local group where I volunteer. Iris, you love seeing everyone there! It's good to know there's a community supporting us, with people you can talk to about MS if you're worried.

I want you to know that I'm super-proud of you all. You're kind and thoughtful human beings. Having you was the best decision I've ever made.

With love,

Mum

Penny was diagnosed with relapsing remitting MS when she was 29. She's written a letter to her children.

> I want you to know that I'm super-proud of you all

Penny is the coordinator of our West and Central London group. Her mum, Maria ('Kouka' to her grandkids), is also living with MS.

Rebecca Cresta/iStock

Bayan, one of our Trustees, was diagnosed with highly active relapsing remitting MS in 2020. He's written to someone who's navigating the challenges of working with MS.

Dear friend,

I'm writing to share a little of my own journey, in the hope it gives you some encouragement. I want you to know that an MS diagnosis doesn't mean your career – or your ambitions – are automatically over.

This is how it happened for me. I'd just left my job in research science and was three months into a new career in news and media. Then I had my first MS relapse. Suddenly, I hit a massive speed bump.

My symptoms included losing my vision, numbness, balance issues and fatigue. I lost my mobility and had to learn how to walk again – twice. I remember thinking, 'How on earth can I have a career when I can't function?' Perhaps you've had similar worries?

I know everyone's experience with MS is different. Because I have highly active relapsing MS, I was put forward for HSCT. This involved rounds of chemotherapy followed by a stem cell transplant. It took a long time to recover. I spent two and a half years in isolation due to a mixture of the pandemic and having a weak immune system.

I was fortunate that when I recovered, I was able to take a career break. I resigned from my job and backpacked around the world. It was something I'd always wanted to do, that had seemed impossible during my relapses and recovery.

I'm now back at work in a new job, and my outlook has shifted. I used to over-deliver and put in long hours. These days, I try to keep a healthier balance. Although my career is still important to me, I see work as a way to enable other things I enjoy.

I've found it helpful to be open and honest about my MS at work. If I'm fatigued, I speak to my managers and tell them I need more rest. My employer is supportive, although I know this isn't always the case.

It's so important to know your rights. You have the right to ask for reasonable adjustments. And it's your employer's responsibility to make sure you're supported, so your skills and talents can truly shine through.

With encouragement and solidarity,

Bayan

> “I've found it helpful to be open and honest about my MS at work

What is HSCT?

Bayan mentions having HSCT, an intense chemotherapy treatment designed to reset the immune system. Learn more at mssociety.org.uk/hsct-info

Dear 16-year-old Evie,

I wish I could remember how you're feeling, but the truth is I can't, not really. It would be trite of me to say "I know you're scared". Actually, I'm not sure you are. I think you're too shocked to be scared. Your young brain is incapable of processing what "lifelong," "incurable" and "progressive" really mean.

I do know you're crying – huge gasping tears – but a small voice inside you asks "What am I so upset about?" Because nothing has changed. You're the same teenager you were – going back to school and doing all the things everyone else is doing.

"Don't let this diagnosis change anything."

And yet it feels like something seismic has happened. As if you've been dropped into a parallel reality and no one else seems to notice. How can everything be the same, and so completely different?

I thought this letter would offer comfort. I thought I'd tell you how lovely life is, 16 years from now. About the home you have, and your husband, and the work you do. I thought I'd tell you how you've learned to navigate the changes MS will bring with such resilience, humour and patience. I thought I'd let you know happiness and health aren't always bound together.

All those things are true, but maybe they won't bring you comfort. I know how much you simply don't want to acknowledge that the rest of your life will be lived with MS.

What I'll say instead is "thank you".

Thank you for doing what you want to do (even if it isn't always the best decision).

For never using MS as a reason not to.

And for all those miles pounding the streets. You don't know it yet, but walking is great for neuroplasticity. (This means the brain's ability to change and rewire itself – one of many new words you'll come to learn).

You're doing great. I'm so proud of you.

Evie

> Don't let this diagnosis change anything

Evie (aged 32) was diagnosed with MS when she was 16. She's written to herself in the aftermath of her diagnosis.

Evie (aged 16)

Every day is special

Former Made in Chelsea star Jane Felstead (74) lives with progressive MS. She was diagnosed aged 65 after experiencing unexplained symptoms for many years.

Rebecca Cresta Photography

How did you feel when you were diagnosed?

I'd suspected there was something wrong with me since I was 17. I had an episode where my vision went blurry, and I couldn't really see. When I had my children, I started feeling unwell again. I told my mother, who took me to every available neurologist. Everyone said there was nothing wrong with me.

When I had my third child, Binky, I had optic neuritis. I lost my eyesight in both eyes. But the top people in the country still never thought of having me looked at for MS.

I got a lot of conflicting advice. People would say 'You're working too hard, you need to rest more.' Or 'You're not working hard enough.'

That's why I was so relieved to get my diagnosis. Finally, I had a concrete reason for being ill.

What's the most challenging life change you've had to navigate?

In the early stages after my diagnosis, it was getting people to understand what was wrong with me. It's difficult to accept that the people you love don't always get it. They expect a great deal from you. Or they're watching you intently. So if there's something you can't do, they want to jump up and make it better. That's very irritating.

Giving up driving has been one of the worst things. I've always loved cars, so it was a colossal loss. Not just because it was my car and I liked it, but because it was a huge loss of independence.

What's helped you cope?

I concentrated on my bucket list. I love animals, so I bought myself a British blue short-haired cat. A year later, I bought my dog, Flossie. She's a miniature wire-haired dachshund. She is the most hilarious, bad, but wonderful dog. She makes me laugh and lifts my spirits. And having a dog makes me go out.

I like smiling at people as I go down the road in my chair, and they're looking at me thinking, 'Oh, God, what to do?' So I smile. And of course, they always smile back.

And I try to stay relevant. I listen to Spotify, and I like documentaries on BBC 4 and Radio 4. I write my Instagram blog. It's so important to keep your brain active.

The truth is, I've been very lucky. When people say, 'Why me?' It really should be 'Why not me?' I haven't had such a bad time. My kids are grown up now, and I've got eight grandchildren.

Has having MS changed things in your family and friendship groups?

My grandkids are wonderful. But I resent the fact that I >

can't have the sort of fun with them that I used to. I can't bend down to their level, and they struggle to get up on my lap in this chair. I'm just not the same as I was. And it makes me sad.

With my friends, I'm seeing a lot of old mates who I knew when I lived in Sussex. They've all come back into my life, not because of my MS, but because we're all getting older. They come up to London and have a glass of wine and lunch, which is gorgeous.

But I do feel a bit inconvenient, sometimes. With all the love in the world, I don't really fit into the party scene. I'm the same person in my head. But I know people's perception of me is very different.

> I like smiling at people as I go down the road in my chair

Is there anything you'd tell your younger self, before you were diagnosed?

I'd say 'Every day is special' and 'Don't be sensible' – although I never was! I was lucky. My parents were very flamboyant. Everything we did was over the top. When I was younger, and suspected something was wrong, I made a point of doing everything I could. Like going skiing and riding horses. You just never know what's going to happen.

Although Jane sadly had to give up driving, lots of people with MS can continue to drive. Find out more at mssociety.org.uk/driving-info

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Barbara wanted to help stop MS for people after her

Barbara Twigg, who died in January 2023, left a generous gift to the MS Society in her will for MS research.

Her legacy of more than £1 million will help fund MS research at the Cambridge Centre for Myelin Repair.

Gaynor, Barbara's good friend and the executor of her will, says "Barbara had secondary progressive MS. It affected her life quite significantly for the last 10 years, but she wouldn't allow it to take her over. She was fiercely independent and wanted to be known for herself, not for her condition."

Barbara worked as an assistant to Randolph Churchill, Winston Churchill's son and biographer. She then followed a career as a producer for Yorkshire Television and travelled the world making documentaries about religion. After she retired in 1995, she was keen to continue her travels, even as her MS got worse.

Visiting the Arctic

"I took her to Ukraine and the Arctic Circle in a wheelchair," says Gaynor. "She was very outgoing and made the most of her life right up until the end.

"I know she'd have loved to have been part of the MS Society's future research. She was always thinking and asking, if she could send more money, would more discoveries be made for MS treatments? She wanted people with MS to benefit and to help stop MS for other people after her.

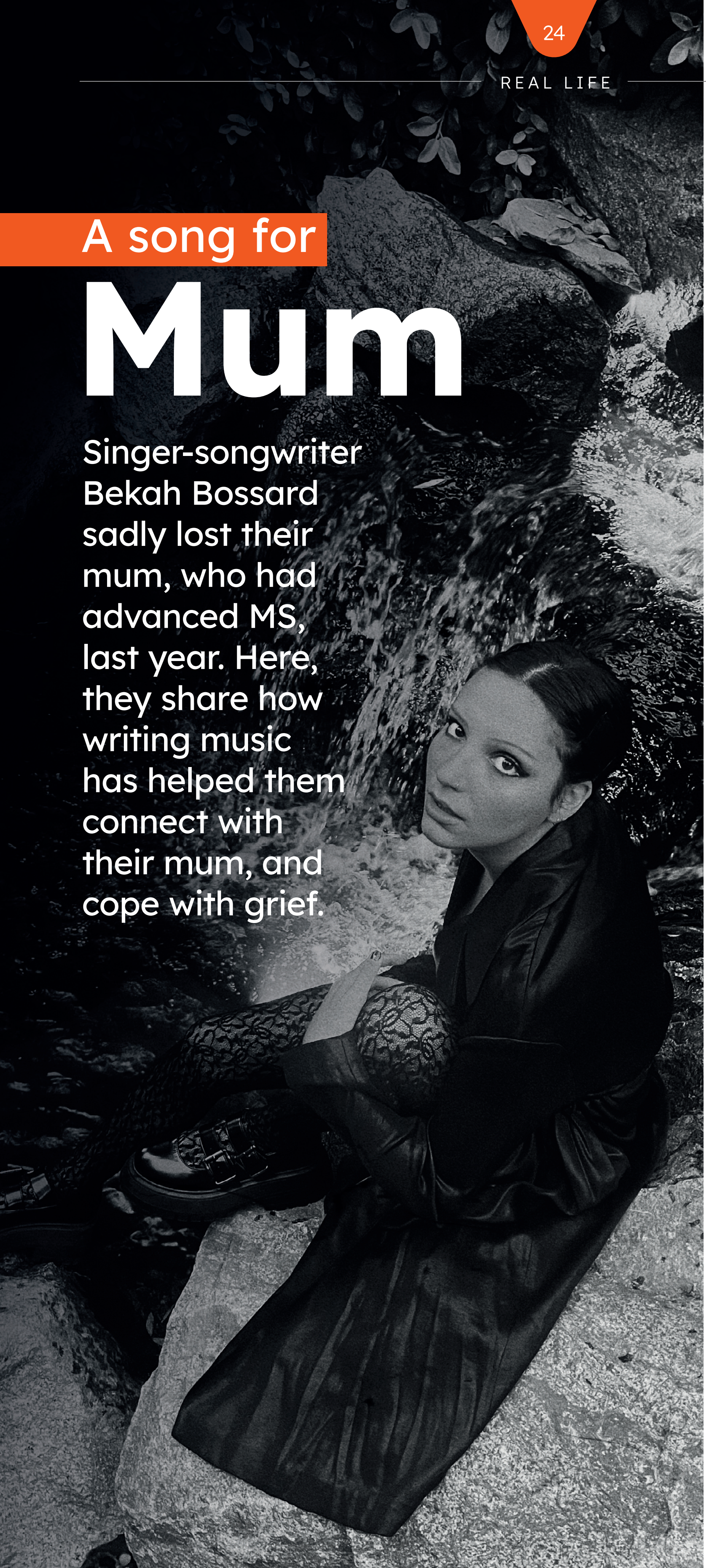
"Barbara was a free spirit who enriched the lives of many during her fascinating journey through life." MS

Learn more about the MS Society Cambridge Centre for Myelin Repair by visiting mssociety.org.uk/mss-cambridge

Find out more about... gifts in wills

Barbara's incredible gift will ensure that her legacy lives on, driving groundbreaking research forward. And you too can leave a lasting impact with a gift in your will, no matter how big or small. If you'd like to join Barbara in creating a brighter future, please order your free will writing guide or use our free will writing services.

Call 020 8438 0828
email legacies@mssociety.org.uk
or visit mssociety.org.uk/msm-legacies



A song for Mum

Singer-songwriter Bekah Bossard sadly lost their mum, who had advanced MS, last year. Here, they share how writing music has helped them connect with their mum, and cope with grief.

Mum was such an awesome person. She was creative, intelligent and had a huge heart. As a pre-school teacher, Mum helped set up Montessori schools in different parts of the world.

And that was how she met my dad – while travelling and working with children. She packed a lot in before she had my brother and me.

Music shaped my life

I'm lucky we grew up listening to James Taylor, Joni Mitchell and Neil Young – 'Harvest Moon' was my parents' favourite song. They all wrote such beautiful words, often coming from painful experiences. I started writing poetry at a young age and then learned to play the guitar, and it naturally transitioned into songwriting. Writing has always helped me process my feelings. I sometimes don't really know how I feel until I've written it down.

Being there with Mum

Mum was diagnosed with MS in her mid-20s. When I was a child, she was already using a wheelchair. As time went by, she lost the ability to use her arms and then to speak.

As hard as this was, it taught me that communication is so much more than spoken words. When someone doesn't have

Bekah and her mum, Sue, who lived with advanced MS

verbal communication, you rely on other things – maybe their 'energy' or just how they look at you.

In her own way, Mum would use all her strength and still be able to say "I love you" right up to the end.

Love and admiration

Mum was always a gentle, loving and compassionate parent. I wrote a song about her called Venus. That song came out of my grief, of not being able to hear her voice and her stories when she couldn't speak anymore. It also came from the huge love and admiration I have for her.

Sharing it with Mum became my way of telling her things I didn't quite know how to say, and how important she was to me.

As long as I can remember, the MS Society has always been a part of my life. They helped Mum a lot. And when I shared my song through the charity, I was touched by the many messages from other people affected by MS.

Grief can sometimes be lonely. So it was good to be reminded that there are people who understand how you feel.

Writing about my feelings

When Mum passed away, being able to write about how I'm feeling helped. It allowed me to process my emotions and not store them inside. Because grief is one of the hardest things to experience. You need to find a way to feel it. Otherwise, you just shut down.

I've been learning to enjoy parts of life by focusing on songwriting, with the grief still going on. I didn't expect it, but somehow there's room for both.

With passing time, something that's also helped is the deep love and connection we shared. The grief can feel so heavy and yet so far away sometimes, but that love is just steady. It's never gone away, and that's helped me keep going. MS

Find out more about... bereavement support

You don't have to face grief alone – support is available when you need it.

Losing a loved one can be incredibly difficult and can affect our emotional and physical health. If you need confidential emotional support and information, the MS Helpline offers a listening ear and someone to talk to. You can contact them on 0808 800 8000 or helpline@mssociety.org.uk

You may also find help through Cruse, the leading bereavement charity. visit mssociety.org.uk/bereavement

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Updated guidelines

to improve MS diagnosis

The diagnostic criteria for MS, known as the McDonald criteria, have been updated based on new research. This could make getting an MS diagnosis quicker and easier.

The criteria are revised every few years to reflect our growing understanding of MS. The latest update was first presented in 2024, then finalised and published in September 2025. The new criteria incorporate new insights into how MS shows up on MRI scans and through lumbar puncture tests. And they include new evidence of how symptoms develop over time.

What's new?

The new criteria won't affect people who've already been diagnosed with MS. But they should make diagnosis faster and more accurate, and reduce the risk of misdiagnosis. And they could help make sure people with MS can access earlier treatment. Some of the changes include:

- **earlier diagnosis:** MS could now be diagnosed in some people who have no symptoms but have signs of MS on MRI scans.
- **including the optic nerve:** Neurologists can now consider lesions in the optic nerve when diagnosing MS.
- **looking closer at MRI:** Neurologists can now use extra details that show up on MRI scans. Two particular types of lesions, known as the 'central vein sign' and 'paramagnetic rim lesions,' can help them distinguish MS from other conditions.
- **reducing misdiagnosis:** New recommendations help diagnose MS in children, people over 50, and people with existing health conditions like high blood pressure and diabetes.

Professor Olga Ciccarelli was involved in updating the criteria. She says "The 2024 McDonald criteria are the result of an international effort to bring precision and speed to MS diagnosis. They'll help deliver faster, more accurate answers. And fewer misdiagnoses, so people can move forward with the right care."

Doctors can now use the updated McDonald criteria when diagnosing people with MS. And we're continuing to fund more research to make diagnosing and monitoring MS even more accurate and comfortable.

Read more at mssociety.org.uk/mcdonald-criteria

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Drug combination

shows promise in myelin repair for relapsing MS

Early results from the CCMR2 trial were announced at the ECTRIMS research conference in Barcelona in September. They suggest a combination of two existing drugs could boost myelin repair in relapsing MS.

CCMR2 was a phase 2 trial run by Dr Nick Cunniffe and his team of researchers at our Cambridge Centre for Myelin Repair. Seventy people with relapsing MS took part over six months. One group took a combination of two existing drugs: metformin and clemastine. The other took placebo (dummy drug) tablets. Everyone continued to take their normal disease modifying therapy.

The team used a test called a 'visual evoked potential' to look at the effects of the drugs. This measures how quickly messages travel between the eyes and the brain. In the group taking the drugs, the signals stayed at the same speed over the six months. In the placebo group, the signals slowed down. The difference between the groups was small, but meaningful.

Boosting myelin repair

People on the trial also did tests to measure their disability and vision. These didn't show a difference between the groups. But we wouldn't expect to see changes in symptoms in only six months. The team also looked for evidence of myelin repair on MRI scans, but we don't have these results yet.

The results Nick presented suggest the drugs could be boosting myelin repair in the brain in relapsing MS. It's the third trial of potential myelin repair treatments to show this.

Nick says "I'm increasingly sure that remyelination is part of the solution to stopping progressive disability in MS. We still need to research the long-term benefits and side effects before people with MS consider taking these drugs. But my instinct is that we're on the brink of a new class of treatments to stop MS progression. Within the next decade, we could see the first licensed treatment that repairs myelin and improves the lives of people living with MS."

Read more at mssociety.org.uk/ccmr2-results

Research at any age

Why representation is important

MS research should reflect the needs and experiences of everyone affected by MS. So it's important that people of all ages take part. We spoke to Rowan, Georgie and Jane about what taking part in research means to them.

Rowan is 15 years old. He took part in the ARMOUR One study. It aims to help us better understand myelin repair in people with MS, from childhood through to old age.

I was diagnosed with MS when I was 11 years old. After my diagnosis, I just went to my clinic appointments to get my infusions. I wanted to think about my MS as little as possible.

But then I learned about the ARMOUR One study from my MS nurse. The research team explained to me how the study may help other people with MS later on. I've largely benefited from the research people before me have done. And I think it's important to give back, so I decided to take part.

Rewarding experience

I went to Cambridge every six months for my study visits. They include a bunch of different tests, like eye tests, blood tests, questionnaires and a reaction time test.

My mum and I usually made a day of it and got lunch or did something fun afterwards. The day itself could be quite tiring, but I also found it very rewarding.

Importance of including younger people

I think it's really important to include younger people in MS research. Most research is done in middle-aged people and there's so little done with younger people. But only by including us can we change the narrative of what MS looks like. And I'm very happy to be involved in that and give back wherever I can.

> **"When Rowan had his first symptoms, we'd never even heard of anyone that young with MS. It's important for younger people like Rowan to take part in research so we can increase our knowledge and awareness for people like him."**
> **Rowan's mum, Kelly**

Jane is 69 years old. She's taking part in the CharoitMS trial. The trial is testing whether a drug called cladribine can slow the worsening of arm and hand function in people with advanced MS. Jane's daughter Anna supports her with this.

I'd already completed another clinical trial for a different drug a few years ago. So when my clinician told me about ChariotMS, I was immediately interested. I think it's very important that people who are further on in their MS journey still contribute. This means we'll know more about what's useful and what isn't.

Positive experience

My research visits are always very positive. I'm on first-name terms with the nurses. And everyone is respectful, helpful and charming. My daughter Anna comes with me to support me. And the trial team covers the travel costs for both of us.

Making advanced MS visible

A long time ago, I worked in nursing. And I remember that back then, a lot of older people with MS just got wheeled to the side. But I don't just want to sit here and not do anything. I want to say "I'm Jane and I've got MS. But I'm not defined by it."

And I want to take part in research that will help push our knowledge further. That's why I think it's so important to have a trial like ChariotMS for people with more advanced MS.

My hopes

If we could stop the progression of MS, that would be absolutely wonderful. I hope we'll find treatments to help me maintain the abilities I've got at the moment.

>

Our Stop MS Appeal helps fund clinical trials. To support clinical trials like these, visit mssociety.org.uk/msm-stop

> **"It's been an absolute pleasure supporting my mum with this. A lot of great research has been done for relapsing MS. It's good we now finally have research that includes the older generation and people with more advanced MS."**
>
> **Jane's daughter, Anna**

Georgie lives with relapsing remitting MS. She took part in the DELIVER-MS trial. It investigates whether a more intensive or less intensive treatment is better when someone is first diagnosed.

I had my first ever MS symptom when I was 20 years old. I lost the vision in my left eye. At first, it was dismissed as nothing to worry about. But after it didn't resolve, I got a private referral for an MRI and lumbar puncture. I was diagnosed with relapsing remitting MS at 21.

When I first heard about the DELIVER-MS trial, it was like music to my ears. Some people start with a less intensive treatment when they get diagnosed and only get on a more intensive one if their MS gets worse. This is called an escalation approach. Others start with a more intensive treatment as soon as they get diagnosed. That's the early-intensive approach.

I was keen to start the more intensive treatment from the get-go, rather than waiting for things to get worse before escalating my treatment. I didn't want my MS to affect my studies or lifestyle. So taking part in DELIVER-MS was a no-brainer for me.

Taking part

Once I signed up for the study, I was randomly selected to be on the early-intensive treatment arm of the trial. That was exactly what I had hoped for. During the trial, I had regular phone calls with the research team. They asked me questions about my health, and I had the opportunity to raise concerns if I had any.

I also had in-person appointments. That meant I was lucky to have far more MRIs and neurological tests than I would've had under regular NHS care.

> **"I hope this research will help determine the best treatment approach for newly diagnosed people. In the long run, this could hopefully improve people's quality of life."**
> **Georgie**

Give it a go

Taking part in DELIVER-MS is the best thing I've ever done. If you're interested in getting involved in MS research, I really recommend you go for it! Have a curious mind and ask questions.

Find out more about... Taking part in research

If you're interested in taking part in research, like Rowan, Jane and Georgie, you can learn more at **mssociety.org.uk/join-research**


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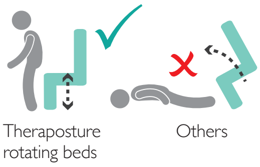
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Work-life realities

and the power of being understood

Most people with MS are diagnosed right in the middle of their working lives. Dr Blanca de Dios Pérez is researching how to help people stay in work after diagnosis. Beth Slade caught up with her to find out more.

Dr Blanca de Dios Pérez
Senior Research Fellow at the University of Nottingham

Beth Slade
Health and Safety Consultant and Research Network member

Less than half of people with MS are still working 10 years after diagnosis. That's a statistic I've read many times recently, but it still shocks me. And as someone living with MS, it hits hard.

When you receive an MS diagnosis, one of the most terrifying unknowns is how it will affect your ability to work. Many of us consider our job to be part of our identity and a source of purpose, independence, and pride. As someone driven by their career, the thought of losing it was terrifying. But it was a topic my healthcare professionals never mentioned. I'd received a life-changing diagnosis without any support on how it was going to affect one of the biggest areas of my life: work.

That was 10 years ago. And awareness of supporting disabled people at work has improved now. But even employers with good intentions can still get it wrong.

Support matters

Blanca has spent 12 years working with people with MS. Initially, she focused on understanding the cognitive difficulties people with MS face. But through these conversations, she consistently heard how important people's professional lives were to them. She's now exploring how people with MS can be supported to stay in work, and what that support should look like.

Blanca is working to embed timely, expert guidance into existing services to stop us navigating these challenges alone. She's currently testing a new way to offer individualised online employment support, delivered by trained staff at MS charities like the MS Society.

Tailored support is key

In our conversation, Blanca challenged assumptions around adjustments: "Flexible working is the most underestimated support." It's not a costly or complex change, just the flexibility to work around symptoms.

She also stressed the importance of timely, not just early, support. She says "Some people want help straight after diagnosis. But others need space to adjust before they're ready for that help. It can't be a one-size-fits-all approach."

Another thing that surprised me

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was people's positive response to remote support. It's flexible, less tiring, and often more comfortable than in-person meetings. I think this support should be embedded into every care conversation.

Realising your value

During our chat, Blanca shared with me an anonymous quote from one of her research participants. It really stood out for me: "You don't realise you have value until someone tells you." This stopped me in my tracks. It's about more than access to work. As Blanca puts it "It's about identity, confidence, and being seen as someone who still has a lot to offer".

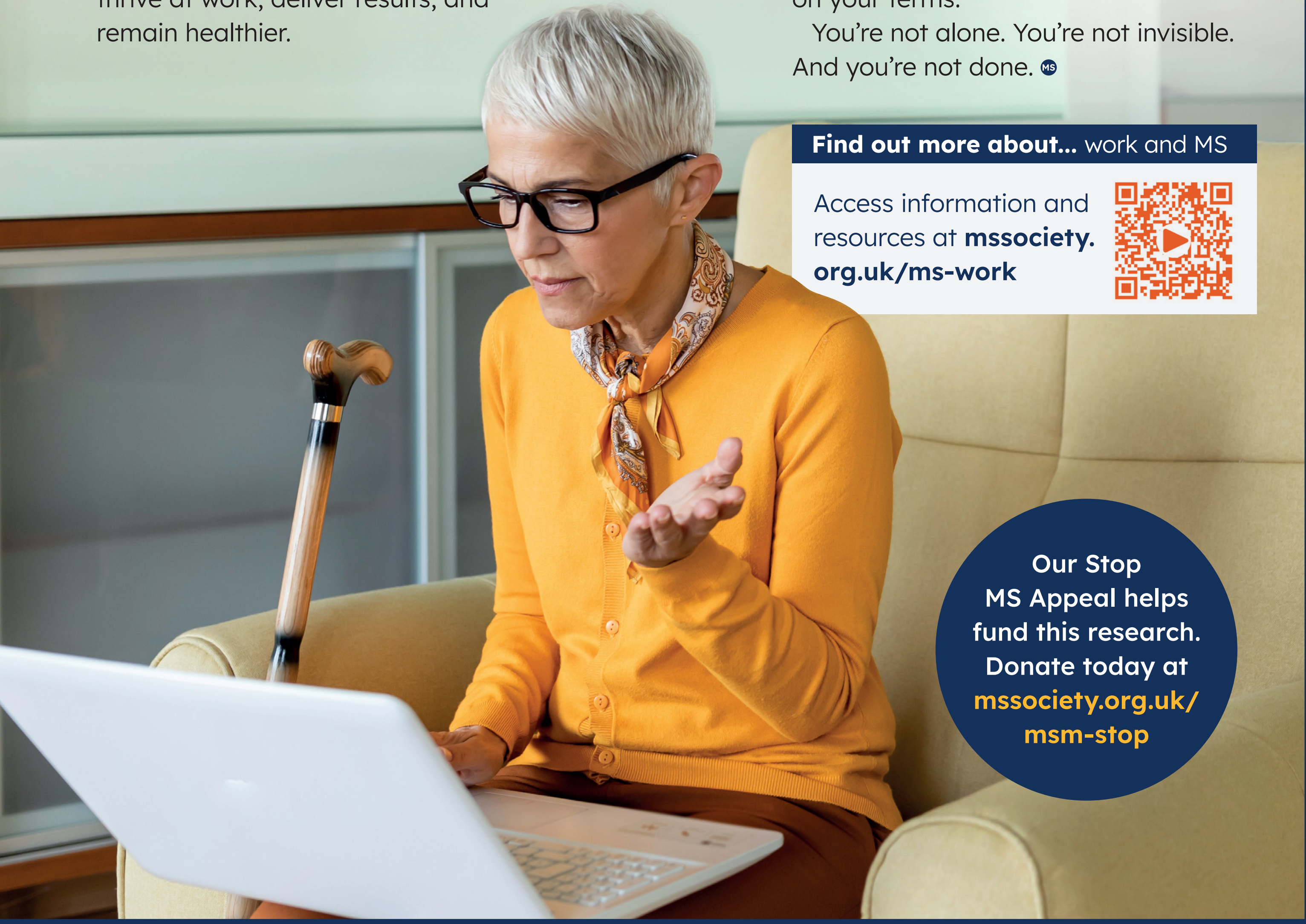
Her research is showing that with the right support, people with MS can thrive at work, deliver results, and remain healthier.

Don't rush to decide

As we ended, I asked for Blanca's advice for anyone newly diagnosed who may be worried about their work: "Don't make big decisions in a moment of crisis." Those early days can feel like a free fall, but don't rush into decisions before you've had time to breathe. Ask for help and understand your options.

I wish this message had reached me 10 years ago. I left the conversation feeling full of hope. Support doesn't have to be big or expensive. But it does need to be timely, practical, and human. And that's exactly what this research is working towards. The right support can mean staying in work with MS isn't just possible, it's powerful. You can shape your future on your terms.

You're not alone. You're not invisible. And you're not done.



Find out more about... work and MS

Access information and resources at **mssociety.org.uk/ms-work**

Our Stop MS Appeal helps fund this research. Donate today at **mssociety.org.uk/msm-stop**

When MS develops later in life

Researching late-onset MS

MS is typically diagnosed when someone is in their 20s to 40s. But it can be diagnosed at any age. We caught up with Dr Sara Collorone to learn more about her MS Society-funded research.

Dr Sara Collorone
Consultant Neurologist at UCL Queen Square Institute of Neurology

Firstly, please could you tell us what late-onset MS is?

In the clinic, we tend to see people diagnosed with MS between the ages of 20 and 40. But this does vary. Some people are diagnosed at a younger age, while others might be diagnosed later in life. We classify anyone who experiences their first symptoms after the age of 50 as having late-onset MS.

Do you see differences in people who are diagnosed with late-onset MS, compared to those diagnosed earlier?

In general, it seems that people who are diagnosed with late-onset MS experience earlier progression of disability. These people tend to reach a higher EDSS (the scale used to measure disability) after fewer years.

But we don't know for sure if this is

Our Stop MS Appeal helps fund this research. Donate today at mssociety.org.uk/msm-stop down to MS or because ageing itself has an impact. The brain may be less able to compensate for the changes associated with MS as we age. And people who are diagnosed later in life often have other health conditions, like high blood pressure. This might also be impacting the brain.

What is your research focusing on?

I want to understand more about the features of late-onset MS and the different factors contributing to disability progression. For example:

- how people's symptoms affect them
- what level of disability they experience
- the treatments they have access to
- the impact other health conditions might have

I'm using data from the UK MS Register and also looking at MRI scans.

How does data from the UK MS Register help your research?

The MS Register is an invaluable source of data. There's an online portal where people with MS can fill out surveys about their health, treatments and lifestyle. And this can be combined with clinical data added by clinicians. This gives us a really rich source of data about the population of people with MS in the UK. It can tell us about other health conditions people with MS have. And the treatments they take, and why people might change or stop treatments.

Late-onset MS is quite rare. So data from the Register can give us more information than if we were collecting data from just a single research centre. It can help us build up a better picture of this type of MS.

> “By doing more research with people with late-onset MS, we can raise awareness about it and even go on to design more inclusive clinical trials

How could this research help people with late-onset MS?

Late-onset MS feels like a neglected area of research. So this is a step towards gathering more data about the condition. By doing more research with people with late-onset MS, we can raise awareness about it and even go on to design more inclusive clinical trials. This could let us gather data about the safety of disease modifying therapies (DMTs) in older people. Because we know that many trials currently have an upper age limit and can exclude people who are over 60.

Ultimately, I hope this research makes an impact on the treatment choices available to people with late-onset MS. The more effective DMTs can come with additional risks, like an increased rate of infections. And there are limits to the treatments that can be used in people with MS who have cancer – something we know is more common as people age. This can make it difficult for healthcare professionals and people with MS to weigh up the risks and benefits of taking a treatment. Knowing more about late-onset MS could help to tailor decisions about treatments to each person.

Find out more about the impact of ageing on the brain on page 40

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Ask the expert

Most women with MS will experience menopause after their diagnosis. We spoke to Professor Ruth Dobson about what we know, and still need to learn, about how this life transition can impact MS.

Q What drew you to investigate menopause in MS?

In the clinic, I've seen many people face the challenges of their symptoms worsening during menopause. As we can keep people healthier for longer with DMTs, we notice the things that cause 'wobbles' in their health. And from a research perspective, I'm interested in women's health throughout the whole course of their lives.

Q What do we know about how menopause affects the symptoms and progression of MS?

We know something, but there's still lots to learn. Some studies suggest that MS can worsen during or after menopause, but others haven't found a link. These studies are based on healthcare records, so they focus on things like walking ability. They don't capture the full experience of people living with MS.

Because menopause is closely tied to age for most people, it's difficult to separate menopause effects from the natural process of ageing. Menopause symptoms like bladder problems, sexual dysfunction, hot flashes, fatigue and cognitive fog are also common in MS. We also know some menopause symptoms could worsen MS symptoms. For example, hot flashes can make MS symptoms worse while they raise the body's temperature, just like hot weather can.

This uncertainty over whether symptoms are due to MS or menopause can be frustrating for people with MS and their clinicians. For some, it can bring back the feelings they had when they were first diagnosed, when symptoms felt unpredictable and confusing.

Q What do we know about the science behind this link?

We don't know enough yet. Most of our understanding of MS comes from animal

> Menopause has also historically been ignored in research due to cultural and social factors. But this is changing

studies. But there are very few species that go through natural menopause and then live a long time afterwards. Menopause has also historically been ignored in research due to cultural and social factors. But this is changing.

We've learnt a little from studying pregnancy. During pregnancy, oestrogen levels are particularly high, and there can be a relative remission in MS. We know that oestrogen can affect the immune system, but we need more well-designed human studies looking specifically at menopause. We also need to know if the changes during menopause are temporary or if they cause lasting changes in disability.

Q Should all women with MS be offered hormone-replacement therapy (HRT)?

It's often impossible to untangle whether a symptom is caused by MS, menopause or a bit of both. But it's important to be able to offer treatments where we can. HRT isn't necessarily right for everybody. But I think all women with MS should have the chance to discuss it and decide based on their personal situation. It's about taking a holistic, personalised approach to care, rather than just thinking about all the symptoms from an MS perspective. For example, topical oestrogen can be life-changing for some people with bladder symptoms or sexual dysfunction.

Q What advice would you give to someone with MS approaching or going through menopause?

My first piece of advice is to talk to people about it. Talk to your MS nurse, your GP and your neurologist. Second, try not to over-worry. Not everyone has a terrible experience with menopause. Some people breeze through with no problems at all. Third, if your symptoms worsen, focus on treating the symptom rather than going around in circles trying to figure out the exact cause.

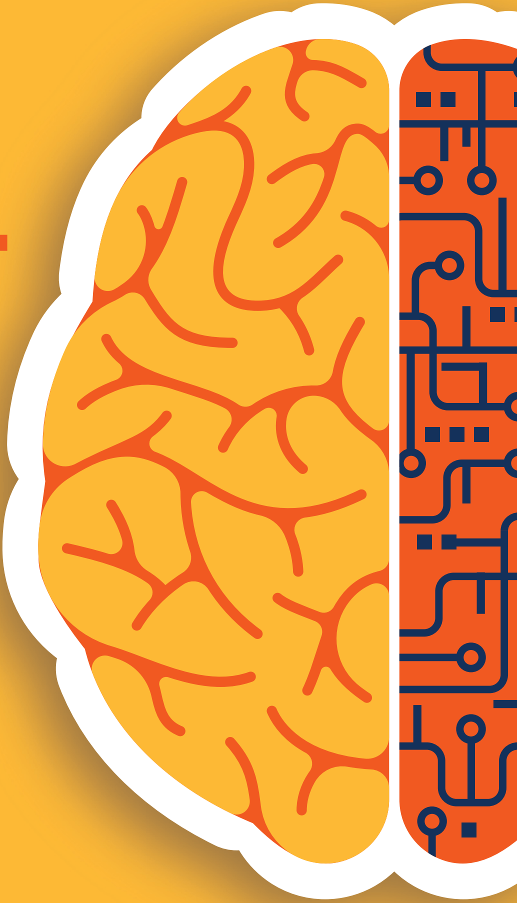
Finally, remember there are many treatment options beyond HRT. Non-hormonal approaches like supplements, exercise, mindfulness, and cognitive behavioural therapy can have a huge impact on quality of life. It's also important to view it as a period of change and flux. Symptom changes aren't necessarily permanent. Everyone's experience with MS and menopause is different. Focus on the support and treatment that's right for you.

Find out more about menopause and MS at mssociety.org.uk/menopause

MEET THE EXPERT

Professor Ruth Dobson
Consultant Neurologist and Professor of Clinical Neurology at Queen Mary University London

What is brain reserve and why does it matter?



Our brains have an amazing natural ability to compensate for damage. We ask Dr Antonio Scalfari to tell us more about how this works.

Dr Antonio Scalfari,
Consultant Neurologist at Imperial College NHS Trust

What does 'brain reserve' mean?

When I see people in clinic, they often think a lesion in a specific region will cause a certain type of symptom. But that's true only to some extent.

The brain actually works as a massive network. Most focal damage surprisingly doesn't cause direct symptoms, as alternative routes through the network allow signals to bypass damaged areas and keep things functioning.

This compensation ability is what we call the brain's 'reserve capacity'. It's the reason we often detect new lesions on MRIs, while people remain free of new symptoms.

Why is brain reserve important in MS?

Imagine the damage from MS is like a series of tiny punches inside the brain, similar to someone hitting a solid wall again and again. Even the strongest wall eventually starts to crumble.

In the brain, your reserve protects you from the punches for a while - the wall holds. But eventually, once a certain threshold of ongoing damage is reached, your reserve capacity can't make up for it any longer. That's when symptoms arise.

How does reserve relate to ageing?

The clinical features of MS tend to change with age. As you grow older, symptoms generally become more progressive and the classic relapses are rarer.

One explanation for this is brain reserve, which naturally declines with ageing. As you grow older, even if

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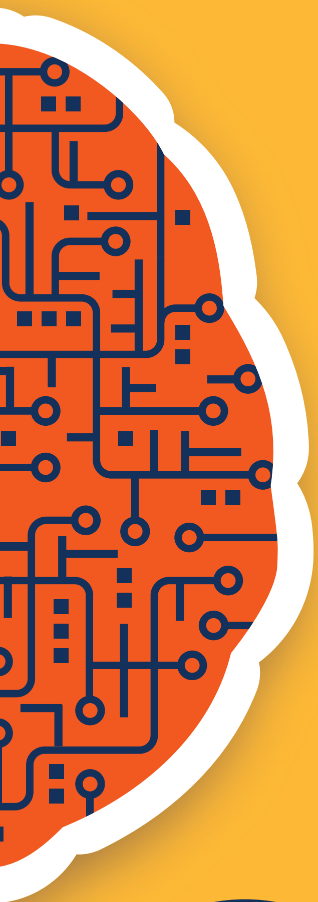

you're not affected by MS, you may become more forgetful or your walking more impaired, for example.

So in people with MS, brain reserve is being affected by both normal ageing and ongoing MS damage. Indeed, to some extent we refer to MS as "accelerated brain ageing".

That's why it's so important to adopt strategies to protect our reserve from the early stage to later life.

How can people protect their brain reserve?

Disease modifying therapies indirectly help protect reserve by limiting the damage that eventually can overcome the brain's reserve capacity.

In addition, there are lots of lifestyle factors that affect reserve, like smoking, diet and exercise.

These are emerging concepts in MS research, but they've been studied a lot in the general population. So they apply to people with MS too, even though we don't always have specific data on MS.

- We know from large bodies of evidence that smoking can have a bad effect on MS progression. If you stop smoking, even if you've smoked for many years, it can make a significant, positive difference.
- We don't have evidence that a specific diet benefits MS, but generally speaking, a healthy, balanced diet helps protect our hearts and brains. This involves limiting ultra-processed foods and alcohol, and focusing more on fruit and veg, healthy fats and fibre.
- Exercise has been proven to enhance the brain's reserve capacity. That is why I encourage my patients to keep moving and being physically active as much as possible, while adapting to their level of disability.
- The same applies to cognitive reserve. Activities like reading or playing cards might help build it. Social isolation can have a negative effect too. So taking part in social activities could help.

The goal of such changes is to help avoid extra damage, and prevent extra disability worsening in the future. So people with MS might struggle to see a direct impact of making changes, and it's important to promote realistic expectations. All these measures work together within the large umbrella of keeping our brains as healthy as we can.

> "That's why it's so important to adopt strategies to protect our reserve from the early stage to later life

Learn more about lifestyle factors and MS at **mssociety.org.uk/lifestyle-factors**

Brain reserve versus cognitive reserve

We sometimes talk about two types of reserve, although they're interconnected:

- **Brain reserve** is like a computer's hardware and is related to its physical structure: its volume, the number of neurons, synapses and so on.
- **Cognitive reserve** is more like the software. It varies among individuals, according to what cognitive input someone's been exposed to throughout their life, such as education or other complex mental tasks.

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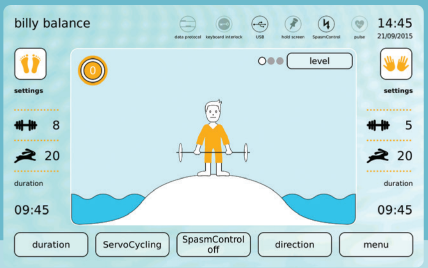

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Planning ahead can offer peace of mind

People have the right to be involved in decisions about their current healthcare. But how often do we think of what we may want in the future?

Thinking about what care we may want at the end of life can be difficult and emotional. We often put off thinking about this until we have to. But planning ahead can offer peace of mind that wishes will be heard. And it helps some people feel more in control at what can often be a very uncertain time.

Possibly, the most familiar way we might think about the future is to make a will. For many of us, this is an important part of planning ahead. It's a way to make sure your wishes are followed and that loved ones are provided for in the way you want.

Some people may also think about making a lasting power of attorney (LPA). This is a legal document that lets people appoint a trusted person to speak for them and make financial or health and care decisions on their behalf, if they can't.

Advance care planning

It may be a good idea to discuss specific wishes about future care with loved ones and healthcare professionals. This process is called 'advance care planning' (ACP). In Scotland, it's referred to as 'anticipatory care planning'. People can share what treatment they may or may not wish to have.

As part of this process, some people choose to record their wishes in a written statement. This is known as an 'advance statement' or sometimes an 'advance care plan'. Again, it can be a good idea to share this document with loved ones and healthcare professionals.

Advance care planning is an entirely voluntary process. People can change their minds about anything in their advance statement at any time.

An advance statement is not legally binding. But it can help offer guidance in decisions being made about important aspects of the person's life and how they may wish to be looked after.

Jennifer McNeil,
MS Nurse

You can find out more about planning ahead at mssociety.org.uk/planning-ahead Or you can call our MS Helpline on 0808 800 8000.

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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.

Have your say

We asked you for your top tips on managing your MS symptoms in the winter.

Sunset prayer times are a lot earlier in winter than in the summer so it means I can get an early night. Waking up and starting work at home when it's still dark outside is the perfect setting for me. Getting into a routine makes things more manageable.
Ayad Marhoon

Exercise. Positive attitude. Healthy eating. Meeting up with friends who make me laugh.
Debora Branch

I wear trainers all year round with my favourite woolly socks…I put them on as soon as I get up. Wear layers as overheating can be a problem, which I feel is worse. Staying active helps me with regulating my core temperature and ventilation in a steamy bathroom is a must. I often leave the back door open to let fresh air into the house.
Kate Thompson

Thermal clothes. My spasms tend to be aggravated by different temperatures, whether it's too hot or cold. My body tends to protest.
frannydz83

Keep warm with a heated blanket, thermal socks and thermal leggings. Avoid going out if it's too cold and wet. Try a warm meal or soup. Staying in touch with friends helps if you're struggling. Just take each day as it comes.
Kerry Henderson

A cap or a hat to deflect the cold wind from your face.
juicyjohn12345

Lots of thin layers as opposed to big chunky ones! Elasticated waistbands if you're like me and get numb hands in the cold. Hand warmers and a hat (my mum's nagging wins this one). It's also important to prepare mentally for a bit of cabin fever as the weather affects whether I can go out. So indoor activities and leaning on the 'cosy season' helps me.
Chronically_re_

For our Spring issue we're asking…

Which invisible symptoms do you find most difficult to explain to other people?
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

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Your thoughts

An exceptional young carer and a £100,000 fundraising milestone.

Our amazing young carers

When I was diagnosed with MS, one of my biggest concerns was the impact my illness would have on my son, who was six at the time. I had to ask myself how I could be a good mum, despite living with MS. It's a hard question, one that a lot of us have probably asked ourselves.

However, I hugely underestimated how amazing my son Oliver is – and how amazing children can be! He takes my disability in his stride, and he shows me how to embrace MS. We're a team and, together, we achieve things I can no longer do on my own. But, at the age of 12, he carries a huge responsibility as a young carer.

In recognition of Oliver's strength, he was nominated by his grandparents – and won – the Exceptional Young Carer 2025 award in Kent in September 2025. It was wonderful to celebrate Oliver, and it was truly deserved.

Oliver doesn't think that anything he does for me is worthy of recognition. That's what makes him so amazing, because he sees me for me, his mum. I'll never be able to truly show him how special that is.

Jen Baines

Young carers can find support on our website **mssociety.org.uk/young-carers**

Fundraising from dawn until dusk

In August, the MS Society Sutton Group reached its target of raising £100,000 for MS research from collections at major rail stations in London.

A dedicated team of collectors, who mostly live in the London Borough of Sutton, made the collections over the last few years. Each collection day lasted 12 hours, from dawn until dusk. I'm honoured to be the Group Coordinator of such an enthusiastic and relentless band of collectors who got us to this tremendous milestone. And I'm told they're already making plans for raising the next £100,000!

Vicki Brice,
MS Society Sutton Group Coordinator

Do you have something to share?

Please get in touch and let us know your views.

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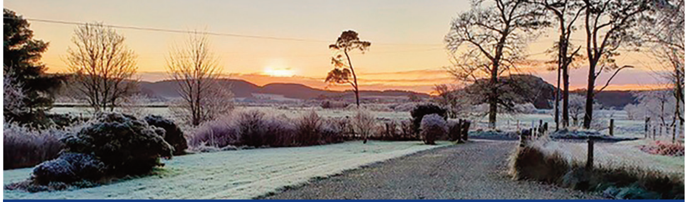

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Volunteer spotlight

"I felt I risked losing my identity by giving up my career"

Kate was diagnosed with secondary progressive MS at 52. She started volunteering with the MS Society South Devon Group over 20 years ago, shortly after having to retire from her job as a social worker.

Volunteering boosted my morale after giving up work. The most appropriate role for me was a Support Volunteer, and I later became our group's Chair (now Group Coordinator). I've also been the National Chair of a forum that helped volunteers reach more of the MS community.

I'm deeply concerned by the issues around welfare reform. I've been in contact with my MP and interviewed on Radio Devon on the issue. But my proudest achievement is linking Citizens Advice with our local group. We have a designated Citizens Advice worker to assist people with MS with all the practical problems arising from their diagnosis.

This has required considerable fundraising efforts to keep the post going, and I started applying to grant bodies. The largest amount we received was £95,000 from The National Lottery, which covered the cost of the post for five years.

Volunteering provides structure

I felt I risked losing my identity by giving up my career. To others in the same situation, I'd say look beyond the immediate upset. Find a way of putting structure in your life through other activities. For me, this is volunteering. It gives me a strong sense of still being useful.

I'm now 80, but I still get satisfaction from campaigning on current issues. This is in a less active role than previously, but there's a lot I can do through online meetings and writing letters. It definitely helps dispel some of the frustration of living with this condition!

Are you interested in volunteering with your local group? Visit mssociety.org.uk/volunteer-locally

Getting to know you

Bita Gordon

Bita is a manager at our Altrincham shop in Manchester.

Why did you join the MS Society?

I joined the charity in March this year as a volunteer at the Sale shop, part-time to start with. This would become my first step back into the workplace since 2016. Later, I found a vacancy for a paid role, managing the Altrincham branch.

What's the best thing about working in the MS Society Shop?

The people and the shop layout. The flexible hours that suit me as a mum. And how easy it is to talk to the management team if you have any issues or queries.

What's the best advice you've ever received?

You are who you are. You do your best, and if you happen to fail, you can try and try again! Mistakes can sometimes shape who you become in a positive way.

What gets you out of bed in the morning?

Smiles on our customers' faces when they find bargains in my shop. Or whenever they notice something I've displayed in the shop, and compliment me!

If you could have a superpower, what would it be?

To be in two places at once!

What makes you hopeful?

Seeing takings at our Altrincham shop rise each day since July. And seeing the positive impact I've made on the shop has been really rewarding. I'm hopeful that, in the future, we can move to a larger shop as a result.

Find out more about... our shops

Our shops offer a wide range of donated household goods and clothing at great prices. They're also friendly places where local people can find information about MS and how they can support the MS community.

We're currently looking for volunteers in our shops in Manchester. If you'd like to join the team, please visit mssociety.org.uk/volunteer-shops

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