Autumn/Winter 2023 · Issue 145

MS Society msmatters

What caring means to you

Perspectives from our community

Plus

Latest news about our clinical trials

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COMMUNITY

Issue 145
Autumn/ Winter 2023

I joined the MS Society in June this year. And I've been inspired by the passion and dedication of my colleagues and the community of people living with MS.

It's a privilege to work on the production of MS Matters – to listen to you and hear your stories.

In this issue we focus on caring for people with MS. We know friends, family members and professionals give a huge range of care, and everyone's experience is different. In this issue we hear from just a few of you who care for someone with MS.

Turn to page 18 to read about R&B artist Junior Giscombe who cared for his daughter Jenique. Or skip to page 27 to hear from married couple Lynne and Alastair Armstrong about their day-to-day realities of living with advanced MS. And on page 40 we speak with stand-up comedian Ivo Graham who's hosting this year's Volunteer Impact Awards.

We hope the real-life stories from the community provide you with some comfort and practical information. If you'd like to share your story, please email **msmatters@mssociety.org.uk** - we're always looking for new people to feature.

And if you'd like to talk about any of the topics in this issue, please call our MS Helpline for free on **0808 800 8000**. We're here to support you.

Amy

Amy Allum, Marketing Strategic Lead

Your Letters

Don’t give up on PIP

As I read through MS Matters I came across Rhianna’s article (Summer 2023 issue, page 23). Rhianna says she doesn’t claim PIP as she’s put off by the process. I, too, found it horrendous, unhelpful and unfriendly.

Like Rhianna, I also have relapsing remitting MS. Some days I feel marathon-ready with my walking. Other days I can barely move and just want to rest and sleep.

My initial PIP application was turned down. So I rang to contest the report and ask for a mandatory reconsideration – the first step if you don’t agree with the decision. The man on the phone didn’t write down what I’d said. I know because I recorded the call.

After the mandatory reconsideration, I had a telephone assessment. The lady who conducted the phone call stunned both me and my husband. She put things in her report that I hadn’t said and totally ignored what I had said.

I decided to go to a tribunal at one of our local courts to contest the inaccuracies in the reports. The panel consisted of a judge, a doctor and a disability specialist.

They were lovely people and they involved my husband throughout the 90-minute meeting. I got through a box of tissues - but I wasn’t embarrassed. I think it was the relief that someone was listening to me.

My PIP decision was overturned in my favour and backdated to 2022, when I’d first made the application. What kept me going was the fact I answered all questions truthfully, on the forms and on the phone.

I’d like to say to Rhianna and others in this situation, don’t give in. This condition isn’t our fault. We pay our way through taxes throughout our working lives. Now we need a little bit of help.

Kay

- **Do you have a question about benefits?** Contact our MS benefits advisers by calling our MS Helpline for free on **0808 800 8000** or email them at **msbenefitsadvice@dls.org.uk**

share Let us know your thoughts at **msmatters@mssociety.org.uk**
Or use the hashtag **#MSMatters** on your social media channels.

Clinical trials
continue successful recruitment

Octopus

The first participants for Octopus are now taking part at several trial sites, including London, Edinburgh and Cardiff. More sites are opening across the UK. Eventually there'll be up to 30 sites.

What is Octopus?

Octopus is the first multi-arm, multi-stage trial for MS. It's a smarter way of testing potential treatments for progressive MS – up to three times faster.

- Find out more on our website: **mssociety.org.uk/octopus**

When will we know the results?

We won't know the first results until at least 2028. Because Octopus is combining what would normally be two separate trials into one mega-trial.

In the meantime, we're watching out for the results of our other MS trials, like ChariotMS.

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ChariotMS

ChariotMS has now recruited 100 participants. This puts them halfway towards their recruitment goal. A huge thank you to everyone who made this possible!

What is ChariotMS?

ChariotMS is testing whether the drug cladribine can help people with advanced MS keep the use of their arms and hands. That can be especially important for people who use a wheelchair.

If it's shown to slow the worsening of disability in advanced MS, cladribine could eventually be a treatment for people with advanced MS.

This is really exciting because at the moment people in the UK lose access to disease modifying treatments (DMTs) if they have advanced MS.

How can I take part?

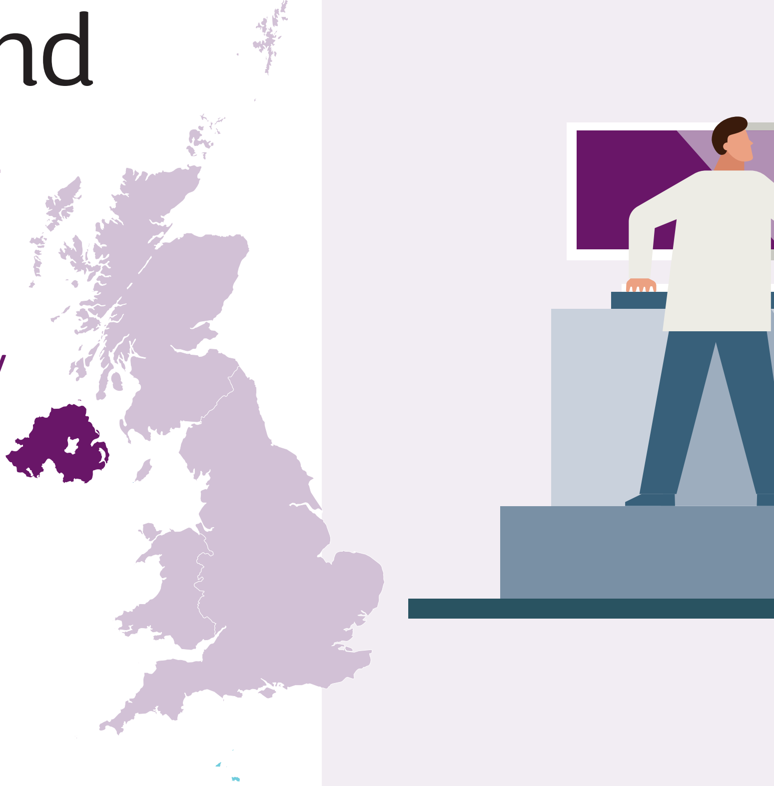
ChariotMS is open for recruitment at 20 sites across the UK. Email the trial team to find out more at **chariot@qmul.ac.uk**

Tina Morris was the hundredth person to join the ChariotMS trial.

"When I was told I was the hundredth person to be eligible for ChariotMS I couldn't believe it! My family are all so pleased too – it's wonderful. The trial is really exciting. When I think there are some 130,000 people in the UK who have MS I feel very privileged to be part of it."

Growing MS research in Northern Ireland

A vital part of MS research is ‘basic science’. This is early-stage research often using tissue, cells or animals in the lab. It helps us discover and understand what happens in MS. It’s the first exciting step on the journey to finding new treatments.



We’re funding three new basic science projects in Northern Ireland. It’s great to see MS research expanding at Queen’s University Belfast.

The role of immune cells in myelin repair

Dr Yvonne Dombrowski is researching whether she could boost myelin repair with just one molecule. Myelin is the fatty coating that wraps around nerve fibres. It helps messages to travel quickly along the nerves. In MS, some immune cells mistakenly attack and destroy myelin around nerve fibres. That’s what can cause the symptoms of MS.

Other immune cells are more helpful. They can reduce inflammation and contribute to repairing myelin. Yvonne is looking at a specific molecule that may control these types of immune cells and their helpful activity.

She wants to understand how important the molecule is for myelin repair. She’ll remove it from the brain in mice with an MS-like condition and test whether this affects myelin repair. If it plays a key role, it could become a focus for future therapies.

Special proteins and their role in myelin repair

Dr Selinda Orr investigates immune cells. She’s looking at immune cells called microglia and macrophages that help clear away old myelin debris. Because for our brain to put new myelin on nerves, it first has to get rid of the old damaged myelin.

Recently researchers found special proteins that sit on these immune cells are more common in people with MS.

Selinda wants to study these special proteins in the context of MS. She wants to know whether they change how immune cells clear away myelin debris. And if they influence myelin repair.

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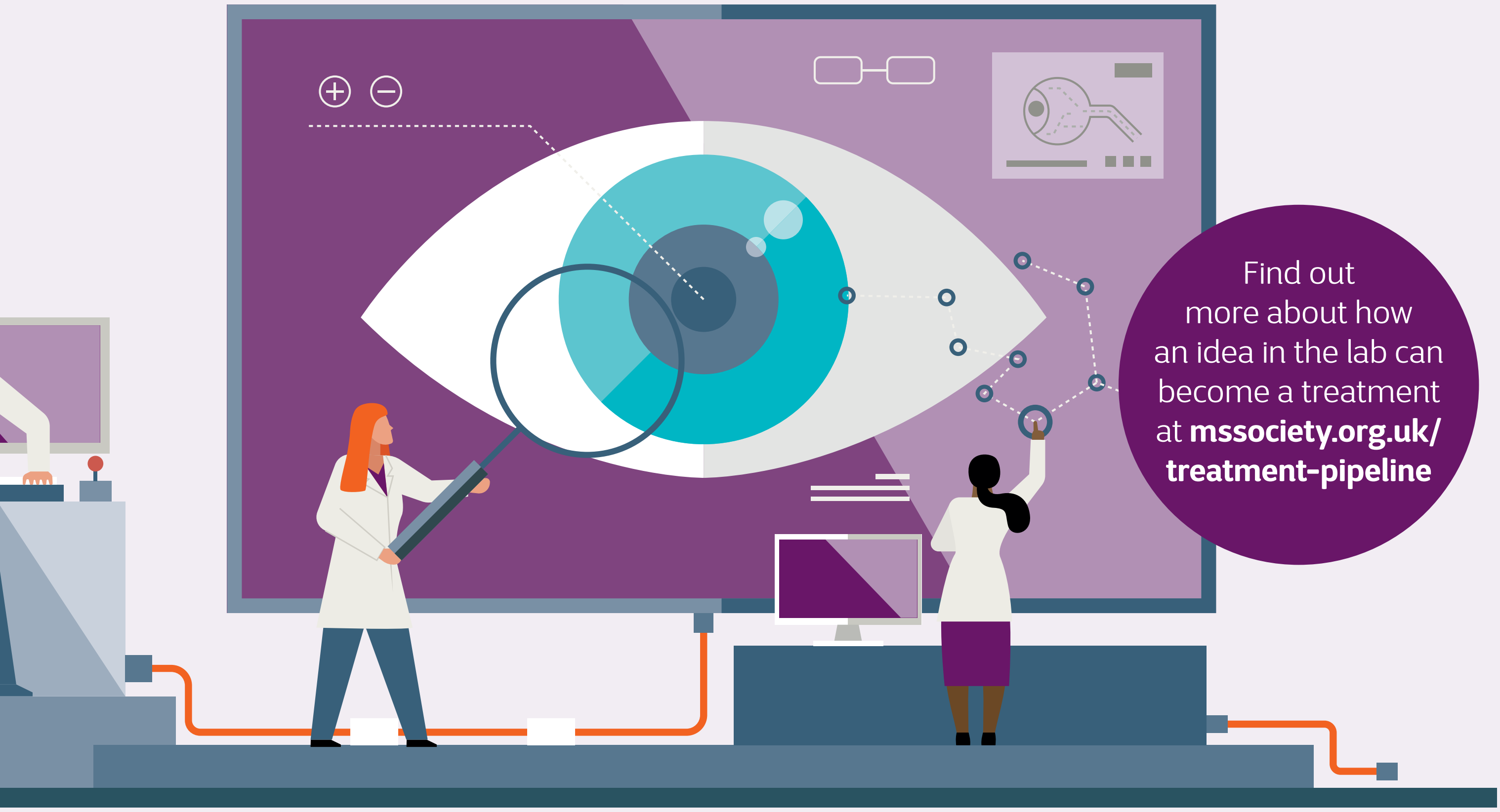

Find out more about how an idea in the lab can become a treatment at **mssociety.org.uk/treatment-pipeline**

The eye as a window to brain inflammation

Professor Denise Fitzgerald wants to find better ways to measure changes in the MS brain.

In progressive MS, inflammatory cells can become trapped in the brain and spinal cord. This is called compartmentalised inflammation. Current disease modifying therapies (DMTs) don't work well on this type of inflammation. And it's difficult to measure using MRI scans of the brain.

That's why Denise is looking for new ways of measuring compartmentalised inflammation. She's looking for this type of inflammation in the back of the eye. If she can find it in the eye, and it matches inflammation in the brain, the eye could be a better location to monitor this type of inflammation.

How will these projects help people with MS?

Sometimes it can be difficult to imagine how basic science projects will help people with MS in the future. But they're an essential building block for all new research discoveries. MS research would stand still without them.

Insights from Selinda's and Yvonne's projects could be used to develop new treatments for myelin repair. That's exciting because currently there's no approved treatments that can promote myelin repair.

And if Denise finds compartmentalised inflammation in the eye it could help people with MS in the future. Doctors could use existing eye imaging technology to measure compartmentalised inflammation. That would be more comfortable, cheaper and more detailed than measuring it with a brain MRI.

New finding in the genes of people with MS could point towards new treatments research

MS is not directly inherited from parent to child. There's no single gene that causes it. But having certain versions of some genes can make it more likely someone develops MS, even though they don't directly cause it. New research shows genetics might also influence how MS progresses.

Genes supply the instructions to tell living creatures how to develop. Researchers recently found a new gene variant in some people with MS that is associated with faster progression.

When people had two copies of this gene, one from each parent, they needed a walking aid on average 3.7 years sooner than people with no copies.

What did they do?

Researchers studied the genes of over 12,500 people with MS. They were looking for a gene variant that was common in people who had particularly severe MS. They measured how much someone is affected by their MS. And whether having particular types of genes affected the rate of progression.

How could this lead to new treatments?

This discovery doesn't mean doctors can predict how someone's MS will progress based on their genes. We don't yet know how to use genetic information like this on an individual basis.

But this discovery could help find new ways to approach the development of treatments. It's unlikely treatments for progression would aim to alter the genes themselves. But researchers could try to develop treatments to change the effects of the genes. Or to encourage improvements in the immune system or in cell repair.

What's next?

This study only used genetic samples from people of European ancestry. So future research should see if the same gene variants change progression in those from other ethnic backgrounds.

And the research team is now collecting a larger set of genetic samples from people with MS. They want to find other variants that could contribute to disability progression.

read Find out more about genes and MS at **mssociety.org.uk/genetics-and-ms**

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Campaign updates

It's been 10 years since the introduction of the disability benefit, Personal Independence Payment (PIP).

For 10 years the broken PIP system has caused stress, indignity and humiliation for people living with MS. We're calling on the UK Government to launch a full review to finally fix PIP.

We've been campaigning to improve disability benefits across the UK for years. Having MS is hard enough on its own. It shouldn't be made harder by a welfare system that makes claiming support difficult and emotionally draining.

PIP is meant to help people manage the extra costs of living with conditions including MS. These can include care and treatment costs, adapted vehicles and mobility aids. But earlier this year we surveyed over 3,500 people with MS and found:

- **two in three** people with MS (65%) said applying for PIP had a negative or very negative impact on their physical and mental health
- **six in 10** (61%) said their assessment report did not give an accurate reflection of their MS
- **over three in five** (62%) said their assessor didn't consider their hidden symptoms

Stress of PIP applications

Bethen, from Somerset, lives with MS. She's been assessed for PIP three times and had to take them to tribunal twice. Bethen told us "I've had quite severe depression and my symptoms have worsened with the stress of PIP applications. It's had a huge effect on me, mentally and psychologically."

During our latest campaign calling for a review of PIP, thousands of you signed our petition to raise the voice of people with MS. We also raised our concerns directly with MPs at our Parliamentary drop-in event. A huge thank you to everyone who signed the petition or invited their MP to attend our event. Your support is invaluable!

- Find out more about the campaign at **mssociety.org.uk/10-years**

A landmark victory for carers

In May we were delighted to see the Carer's Leave Bill pass its final stages in the House of Lords. The bill became an Act of Parliament and will come into effect in 2024.

The new law will give all unpaid carers in the UK the right to take up to five whole days of unpaid leave for their caring responsibilities. Until now, people who care for a loved one with MS were not legally entitled to leave from work for caring responsibilities. Now, by law, employers will have to accommodate their employees with caring responsibilities.

This is a landmark victory for the MS community. But we know there's still a way to go and will continue fighting the corner of carers. We're also campaigning for a full reform of Carer's Allowance as part of the Carer Poverty Coalition. Together with the MS community, we're calling for more people to be eligible, and the benefit to pay more.

- Find out more about the Carer's Leave Act at **mssociety.org.uk/carers-leave**

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Dates for your diary

Wednesday 6 December, 6.30pm

What's next? Newly diagnosed webinar

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

mssociety.org.uk/newly-diagnosed-webinar

Thursday 14 December, 6.30pm

Carols by Candlelight

Join us at Westminster Chapel, London for an evening of joyful readings from our celebrity supporters and incredible musical performances. Tickets from £35.

mscarols23.com

Spring 2024 – various dates

Challenge events

Join us for Challenge 29 in February 2024. You can choose your own activity and challenge yourself to do it for 29 minutes every day in February. If you'd prefer to take part in an organised event, sign up for the iconic London Landmarks Half Marathon (7 April) or the buzzing Edinburgh Marathon Festival (25 and 26 May). Or experience the thrill of skydiving in the Big Leap (26 May).

You can find out about all these fundraising events and more at **mssociety.org.uk/get-fundraising**

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

Unpaid carers forgotten by healthcare system

Unpaid carers are the unseen heroes of our healthcare system, caring for people with MS every day in all sorts of ways. People with MS shouldn't have to rely on their family and friends for care. But lack of funding and staff for social care services, and rehabilitation services like physiotherapy, mean that many have to.

MS can place a huge strain on relationships between people with MS and their loved ones. Our recent Mental Health and MS report highlighted this.

As access to social care and rehabilitation services gets worse, pressure mounts on unpaid carers to provide more support. Our 2022 Family and Friends survey showed that two in five (42%) of unpaid carers spend 35 hours or more a week caring. That's the equivalent of a full-time job.

This can have devastating impacts on carers' mental and physical health. When we asked what impacts MS had had on their lives in the last 12 months, two-thirds (67%) said they'd experienced stress or worry. Over half (52%) experienced anxiety.

What would help?

Unpaid carers are being forgotten by the healthcare system and left without enough support or recognition. People who completed the Family and Friends survey said the following things would make a difference to them:

- emotional support (22%)
- reforming Carers' Allowance so more people are eligible to claim (17%)
- recognition of their role by healthcare professionals (17%)

Unpaid carers need help now. We're calling on the NHS to make sure all health professionals signpost people to the right mental health support.

And, as members of the Carer Poverty Coalition, we're calling on the UK Government to reform Carer's Allowance so more people can access it.

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join

Stay up to date by joining our campaigns community at **mssociety.org.uk/campaigns**. Read our Mental Health and MS report at **mssociety.org.uk/mental-health-policies** and our Friends and Family survey findings at **mssociety.org.uk/care-and-support-evidence**

“It was an honour to have been Jenique’s father”

Our new Ambassador, R&B artist **Junior Giscombe**, talks about caring for his daughter, Jenique, who had MS. Sadly, Jenique died on 1 May 2017.

My connection with MS started in the 1980s. Jenique’s mother, Nardia, was diagnosed with MS when she was 24. The effect was devastating on my family because nobody knew anything about MS at that time. We were left on our own trying to find information about how to help her.

And when our daughter Jenique was 10, she started having problems with her legs. By the time she was a teenager, she was starting to fall a lot. She was diagnosed with primary progressive MS when she was 24. Then just six months after Jenique’s diagnosis, her mother Nardia died.

Holistic approach

With Jenique, I wanted to take a holistic approach to her mental and physical health. I’d realised one dress size doesn’t fit all. You have to find things that work for that person. For example, we’d give her things like porridges, which are used in Jamaican culture for the immune system.

I had a flat I’d converted for my mum. But my mum was unable to live there, so Jenique asked if she could have it. Six months after she moved in, her MS started to get worse. Then

“One of a kind, Jenique Giscombe”

Junior is singing at our Carols by Candlelight concert at Westminster Chapel in London on Thursday 14 December. **For tickets visit mscarols23.com**

it was about making sure she could be independent.

We made sure she could reach things on the shelves. We knocked down a wall so she could move around on her electric bike and use the kitchen. And we converted the bathroom.

Photo: Rebecca Cresta

Keeping positive

Jenique was a laugh. She was a fun person to be around – plucky and independent. When she was little, if you wanted to give her something she didn’t want, she wasn’t having any of it. She could be really hard-nosed, but she was so loving and caring. She was her own person – she stayed true to who she was.

When she started to get into music, every day she would wake up and sing. And when she sang, she really sang. Everybody listened. She continued to live life. She wouldn’t be beaten down.

In the family, we kept positivity as the basis of everything we did. Nobody switched and started to have the mope. Everybody was always up. I think that helped keep her mind up and running.

Caring for Jenique

When Jenique was 30, she became very ill and had to go into hospital for surgery. It was heart-breaking. I just wanted her home. I was thinking “She’s my daughter. I know her.” It wasn’t a chore. I wasn’t thinking “How am I going to do this and still have a career?” It was about trying to help her.

Jenique changed all our lives. At the time you’re going through it, you don’t really see it. But you’re being taught an incredible lesson – as a human being, as a man, as a family. She was my baby. It was a pleasure and an honour to have been her father.

As an Ambassador, I’d like to find out more about how the MS Society works on the ground and how I can help. It’s about being proactive and sharing knowledge to find different ways we can help people with MS.

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MS and genetics

While MS can occur more than once in a family, it’s more likely that this won’t happen. Find out about the role of genetics in MS at **mssociety.org.uk/genetics-and-ms**

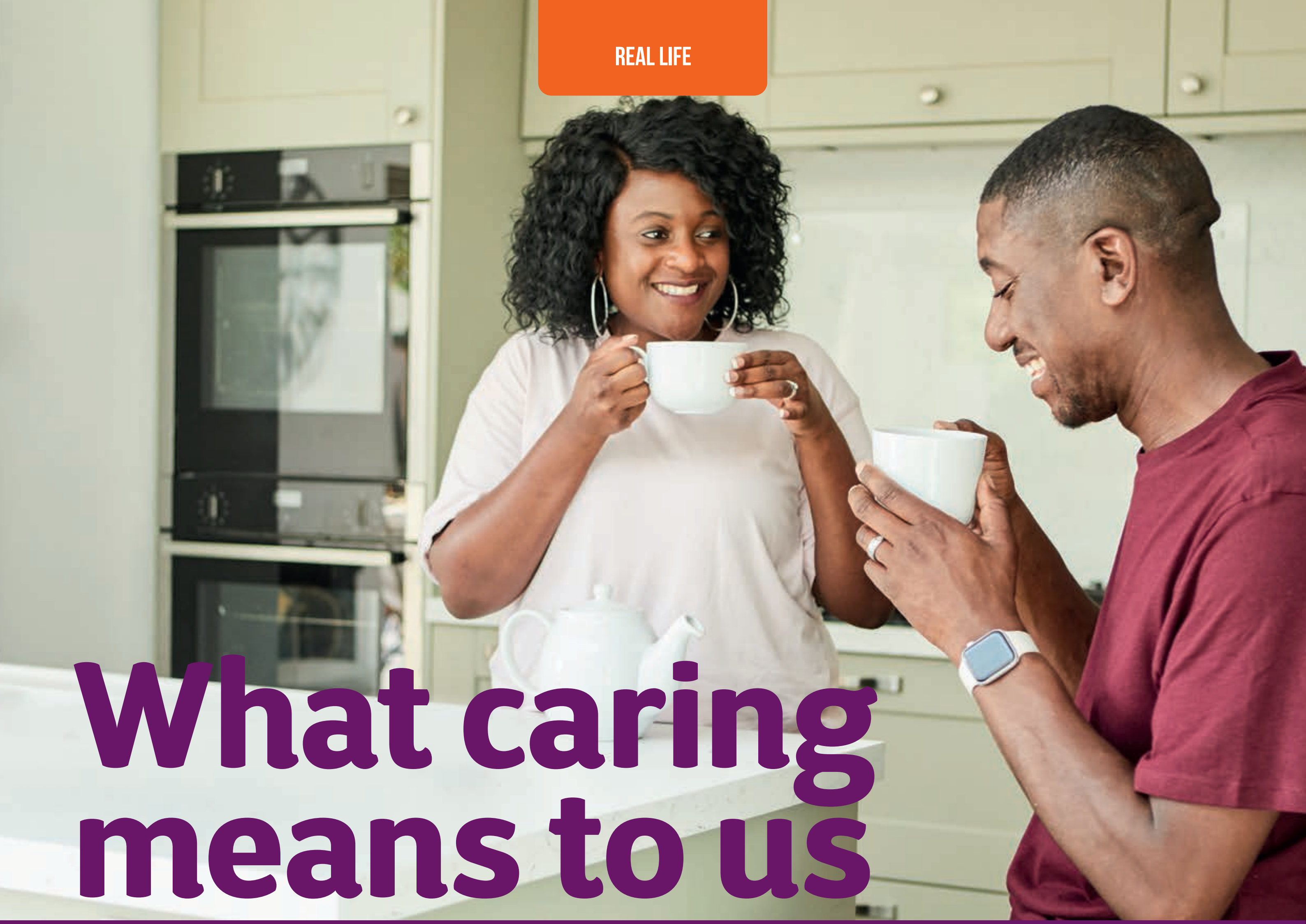

Photo: Alex Grace

What caring means to us

Two couples talk about how relapsing remitting MS has impacted their relationship and what caregiving means to them.

Nikoma, who has MS and his wife, **Simone**.

Simone: In the beginning, the term 'carer' didn't resonate with me. Over time I've reflected on it. Now I do refer to myself as a carer in some arenas. But it's just one of my roles – it's not me in totality.

Nikoma: I'm quite an independent person. It's been a change to hand over a lot of my responsibilities to you, Simone. And the things I need help with change. I can start the day a bit more independently. But as the day goes on – maybe because I've done too much or I've got too hot – I literally can't do anything. You have to take over.

Simone: It's physical things like cooking, cleaning, helping you get around. And now I take the lead on a lot of the finances, house things and phone calls. Sometimes you can push through but then you'll be knocked out for the day. The difficulty is knowing when to step in.

Nikoma: For me, being a man, there are some aspects of the relationship I'd want to lead with. It's hard because that's been taken away.

Simone: I think this change in dynamic did create a strain in our relationship. But we do communicate a lot. We've been very intentional about not allowing it to destroy our marriage and our lives.

Nikoma: Then there's the financial aspect. I was doing very well in my career as a sound engineer. My career definitely stalled and had to take a new direction.

Simone: Financial support is a major

thing. It took so long to even get PIP because of having to prove how ill you are. The earnings limit for Carers Allowance is really low. My income is over it – so I'm not eligible.

More mental health support – such as free counselling – would also really help, for the person with MS and their family. That's why I'm an advocate for carers.

Nin, who has MS, and her husband **Harry.**

Nin: I was diagnosed in March 2022. It didn't really sink in when I was told I had MS until I got home and started Googling. Harry, on the other hand, was totally proactive.

Harry: You were diagnosed in hospital without us around you – that was an extremely tough situation. I was angry about how you'd been given the news. But I also know it wasn't time for anger – it was time to do all I could to bring you home. I started planning what to do next.

We didn't tell our daughters about their mummy's diagnosis straight away. They were quite young at the time, four and six. But they knew she was poorly because she'd spent a week in hospital.

Nin: They also knew something wasn't quite right as I wasn't able to fulfil my usual role.

Harry: It was easier to just say "Mummy's poorly".

Nin: It was only recently we shared the word 'MS' with them, after a neurologist appointment at the hospital. They came with us for the very first time. We found a booklet on MS in terms children could understand and we got it for them.

We've also defined the term 'carer' in our own way. When I hear it, it sounds quite scary. It makes me feel I'm unable to do anything myself.

Harry: I think the term 'carer' is fitting in a professional setting. But what we have is a partnership. Whether we're caring for each other in different ways or having fun – it's all part of our life journey.

Nin: I agree to a certain extent. But I still feel guilty when I have to lean on Harry to take on most roles in the home. Even though he doesn't mind, I do.

Harry: I don't think it's affected our relationship in a bad way, though. There are naturally some changes. We've always been a team, but our team is now stronger. And I've learned that being a carer isn't always about doing something. Quite often it's about being there emotionally and being present.

read Caring for someone with MS can take its toll. We're here to support you. Find out more about help available for carers at **mssociety.org.uk/carer-support**

Why we're doing our research

Every day researchers dedicate their work to investigating MS. But many of them also have a personal connection to MS. Three researchers told us about what motivates them.

Dr Rachael Hunter

Clinical psychologist and MS researcher at Swansea University.

In 2012 I was working as a clinical psychologist in the NHS when I was diagnosed with MS. I had two small children, and it was a devastating blow.

As a clinician I was lucky to be able to make sense of current research. I saw how the main focus of MS research was on drug treatments. But I really wanted to see more research into what people can do to help themselves, in the here and now. The research I found on lifestyle and behaviour change helped me to stay positive, healthy and hopeful. And I felt a responsibility to share and contribute to that research.

Getting involved in research

A year after my diagnosis I had the opportunity to get involved in research at Swansea University. I now contribute both as a researcher and as a person with MS.

I also work with charities including the MS Society and Overcoming MS. This has given me a huge sense of purpose. I enjoy helping people make sense of, and apply, science in the real world.

Hopes for the future

I've been lucky to have had great support from research groups I work with. But it hasn't always been easy. What's important to a person with MS is sometimes different to clinicians and those funding research. Overall, my experience has been really positive.

But we need drastic changes in how we provide healthcare and a greater focus on the holistic needs of people with MS. For example, support for the lifestyle changes we know are so important. And we need more diversity and more voices of people with MS in the research community. To keep pushing for the research and change that's important to the MS community.

Mollie McKeon

PhD student at the Cambridge Centre for Myelin Repair.

My research is looking at the genetics of MS progression. I'm building on a recent international study that found a small change in someone's genes was linked to faster MS progression. Now, I want to find out what inheriting that genetic variation could mean for people with MS.

Hopes for my research

We want to understand more about what the genetic variation does in the body. We hope one day this could help to develop a new class of treatments to specifically target MS progression. I want to bridge the gap between genetic research and how people with MS are treated.

My personal connection to MS

My mum has lived with MS my whole life. It's a very frustrating and unpredictable condition, but it was also normal for me growing up. It was about being resilient and adapting to things.

I think having a personal connection to MS is grounding. It focuses my research time and effort. I'm often conscious of what might be the priorities for my mum – it might have stopped me going down some rabbit holes. I want to do MS research that has the potential to improve people's lives.

My mum's determination, independence and resilience are what instilled in me the same attitude towards my own research – and life!

- Read more about the research that inspired Mollie's PhD on **page 13.**

> I have great admiration for the people involved in this complicated and detailed research. I recognise that making progress is painstaking and time-consuming.
>
> I know I personally am unlikely to experience any direct benefits. But it's thanks to the commitment and tenacity of researchers, like Mollie, that we may make progress in the treatment and prevention of this unpredictable condition. If any others can benefit in any way then Mollie's research, and the contributions of people like myself, will have been of significant value.
>
> **Ceridwen Roberts, Mollie's mum**

Dr Charlotte Spicer

Researcher at University College London.

learn Find out more about the Research Strategy Committee at **mssociety.org.uk/research-strategy-committee**

Research is a big part of my life, in more ways than one. I'm a Postdoctoral Researcher trying to develop a treatment for Kennedy's disease. It's a rare condition that mostly affects men and causes progressive weakening of muscles. I also volunteer as a member of the MS Society Research Strategy Committee.

My connection to MS

MS has had a big impact on my life so far. My dad was diagnosed with primary progressive MS when I was around seven and I cared for him throughout my life. He sadly passed away in November last year. In 2023, I ran the London Marathon for the MS Society in his memory.

Shaping MS Research

I'm in a unique position because I have personal experiences as a carer, but I also understand how research works. That's why I joined the MS Society Research Strategy Committee. I help with things like reviewing research priorities and making recommendations for funding.

My dad took part in research into managing MS symptoms. But there were no treatments available for him. I want there to be more hope for others in the future. I'm really excited that now there are treatment trials like Octopus for people with progressive MS.

Importance of community

We were lucky to have a fantastic support network when we were caring for my dad at home – including family, friends and an amazing MS nurse.

My advice is to make people aware of your caring responsibilities. This can be really difficult. But by telling them, people can check in to see if you need any support. And you might be surprised how many others around you are also carers.

Juggling responsibilities

I'm really grateful to have had such a supportive boss and team at work. It made the challenge of being both a carer and researcher much easier.

But everyone deserves a break, which isn't easy when you're a carer. That's why organisations like the charity Carefree, where carers can apply for a much-needed break, are so important.

The realities of our life with advanced MS

Lynne Armstrong lives with advanced secondary progressive MS. She uses a wheelchair to get around. Her husband **Alastair** is her main carer.

Alastair

As we've grown older, it's become much more difficult. The consultant has said there are no disease modifying therapies (DMTs) available for Lynne. That's hard to accept.

Lynne relies on me for everything. She's lost the use of her hands, so she gets frustrated dropping things so easily. Carers visit twice daily and help with transfers in and out of bed. Generally, they're excellent, but there's a high staff turnover. We're not told in advance who's coming, so I feel I have to be available to manage them.

It's difficult to plan activities because of the uncertainty of Lynne's health. So friends tend to drift away.

We're fortunate that, after 53 years, we continue to have a good relationship. This helps overcome the bad times.

Lynne

I'm well looked after by an excellent GP, district nurse and MS nurse. I don't like having to rely on others though. At times I get very depressed and frustrated at how little I can do. I'd love to visit our grandchildren in Australia and Canada – but airline travel is now impossible for me. The wheelchair and my bladder and bowel issues make travel difficult.

I recently asked Alastair "Why did I have to get this sort of MS?" Everyone with MS is different, but it can feel that people like me are forgotten.

When I don't want to laugh, it's Alastair who makes me. And my grandchildren bring me a lot of joy. This summer they all came here and we had a holiday together at Longford Center Parcs in Ireland. It was possible because, unlike most hotels, they had rooms with electric beds.

In terms of care, it's important to build up good relationships. Find out how to navigate health and social care services and identify who to get in touch with. Don't be afraid to ask for help.

read

We're here to help people living with advanced MS. Learn about the support available at **mssociety.org.uk/advanced-ms-support**. Call our MS Helpline on **0808 800 8000** for emotional support.

“It’s fantastic having people who can communicate with me”

Matthew Gennery has advanced progressive MS and is also Deaf. His wife, Julie, has created a dedicated care team who use British Sign Language (BSL).

Julie

Matthew is severely disabled and needs 24-hour care. We now have a team of six carers, including me, who use BSL. I found them through word-of-mouth within the Deaf community.

For me, the most challenging thing is the immense planning that goes into every single aspect of everyday life. Spontaneity goes out of the window.

As Matthew’s primary carer, I take regular breaks to maintain my health and wellbeing. Having something to look forward to gives me the strength to carry on. Then Matthew’s other carers step up.

I’m very protective of Matthew. His life is literally in his carers’ hands. It’s taken a while, but I do have confidence in everybody in his care team.

Matthew’s been through an awful lot. But he never gives up. He still lives a full and positive life.

Matthew

I used to feel left out when the hearing carers were talking. I didn’t know what was going on. It’s fantastic having people who can communicate with me now.

I played football before I had MS, now I enjoy watching it on TV. I support Manchester United. I like going on holiday and being at home. It’s cosy – home sweet home!

I’m an easy-going person. I’ve always been a fighter and I don’t let things get me down. But I do think there needs to be more awareness of MS.

Stephen

As one of Matthew’s carers, my role involves everything from helping him shower, wash, dress, brush his teeth and eat. If he wants to go out, I’ll drive him in his accessible car. In a few weeks I’m going to Filey on holiday with the family, and I’ll be caring for Matthew there. I like to support people and I can see it’s good for him to be at home, not in a residential setting.

Stephen (left), Matthew and Julie

read If you’d like help building a supportive team of carers like Matthew’s, we’re here to guide you. Find out about social care support at **mssociety.org.uk/about-social-care**

Caring for someone severely affected by MS

The challenges of caring can change through the MS journey. When someone has advanced MS, there might be new things to consider.

Healthcare when there's no DMT

Contact with the neurologist and MS nurse can easily drop off if the person with MS doesn't take a disease modifying therapy (DMT). Perhaps the expectation is the GP can take over. But guidelines recommend an annual visit to an MS specialist – no matter what the stage of someone's MS. Advanced MS needs more medical attention, not less. So stay in touch with services to access specialist symptom care. Most neurologists stay with patients for their entire MS journey.

Hospital stays

Our Advanced MS carers handbook has tips for smoother hospital stays and a good discharge. For example: tired of endlessly telling staff details about the person you care for and their needs? Then fill in the form in the handbook and give copies to staff. You'll no longer need to keep repeating yourself.

If the person you care for goes into hospital for longer than 28 days (in one stay or over several), then you'll lose the Carers Allowance you receive. You must tell the benefits authorities as soon as the person you care for enters or leaves a hospital (or a care home).

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Legal matters

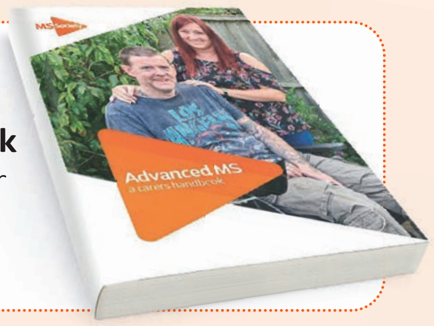
Planning ahead can bring peace of mind. Get down in writing what the person with MS wants to happen about their finances and future medical care. This needs to be done while they can communicate what they want and are legally capable of making decisions. Some people with advanced MS eventually lose this ability. Look into:

- an Advance Decision
- Advance Statement
- Advance Care Plan
- a Power of Attorney
- a will

Learn what these are from our handbook or the MS Helpline on **0808 800 8000**.

read

Order our free **Advanced MS carers handbook** from **onlineshop.mssociety.org.uk** or call **0300 500 8084**. Or search our website for 'care and support for advanced MS' and download it there.



Looking after yourself when you're a carer

Sarah Mather cares for her wife, Karine, who has primary progressive MS. **Jo English** is a volunteer counsellor with our Belfast-based counselling service. Her husband, Jude, has secondary progressive MS. They talk about self-care when you're a carer.

Sarah: Why is self-care especially important for carers?

Jo: When you're caring for someone, you need to have balance. You're committed to supporting that person, but you have a right and the responsibility to maintain your own wellbeing. You need to be able to "keep yourself right", as we say in Northern Ireland.

Sarah: So, what exactly do we mean by 'self-care'?

Jo: I'd say it's whatever makes you feel more connected with yourself and gives you some headspace. This is different for everybody. I think self-care has been stereotyped as things like going for a spa day. But it can be the simplest of things. For me, it's taking the dogs for a walk in the fresh air.

Sarah: I agree. Just having the house to myself for a bit – that's the sort of self-care I'm talking about! Or hiding away in my workshop, where I do bookbinding, woodwork and furniture restoration. We both enjoy spending time at our allotment.

Look out for each other

Sarah: So, do you think self-care means taking care of your mental health or physical health? Or both?

Jo: It's both. Although I appreciate it's not always easy.

Sarah: It can be very difficult. I'm an ex personal trainer and I had to stop working because of arthritis. That impacted my mental health. I can't go running and I've gained weight, so I don't feel as good in my head. It's a vicious cycle. I tend to push things to the back of my mind. Whereas Karine will be the one who'll say "Don't you want to talk about what's going on in your head?"

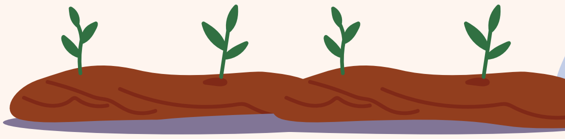
Jo: My husband and I have a code word we use when things are getting too much. Do you and Karine check in with each other regularly?

Sarah: Yes, we look out for each other. It's been a learning curve, but we're a good team. We don't have a code word, although we talk about our energy levels in terms of 'spoons'. As in "How many spoons have you got left today?"

Take a break

Sarah: Are there other signs of needing to take a break that carers should look out for?

Jo: Be aware of physical signs such as changes in weight. It's also important to notice if you're withdrawing socially or not doing things you enjoy. Irritability is another big one. If you can't tolerate the stuff that gets thrown at you, that you normally could, that's a warning sign.



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Jo English


Sarah Mather

Sarah: So where do you think is a good place for carers to start with self-care?

Jo: Try identifying the things you love doing. Then take small steps towards prioritising those things and recognising they'll help both you and the person you care for.

Sarah: I think it's important to understand that it's OK if these things change. I used to love reading, but when I'm depressed, I don't want to pick up a book. Now Karine and I listen to audiobooks together – and I love it!

Jo: Yes, sometimes you need to recalibrate or adjust what helps you. I think a lot of self-care is about listening to yourself and not being ashamed to prioritise your needs alongside other people's. You can't pour from an empty cup.

For more information on looking after yourself when you're a carer visit **mssociety.org.uk/taking-care-of-yourself** or call our free MS Helpline on **0808 800 8000.** Sarah also recommends Samaritans if you're struggling and want to talk. Visit **samaritans.org** or call **116 123** for free.

What one brain can do:

25 years of the UK MS Tissue Bank

We've co-funded the UK MS Society Tissue Bank since it began in 1998. We asked the founding Director **Professor Richard Reynolds** to reflect on its successes. And we spoke to the current Director **Professor Richard Nicholas** about its future.

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Over the past 25 years, the UK MS Society Tissue Bank has collected thousands of brain and spinal cord tissue samples. These samples are processed and stored ready to be shared with researchers. It's now the largest collection of its kind in Europe. And its success is due to donations and support from our community.

When someone pledges to donate their brain, they make a huge impact on MS research after they pass away. One brain can support many vital MS research projects. It can contribute to lots of findings.

Professor Richard Reynolds, founding Director of the UK MS Society Tissue Bank.

The Tissue Bank is not a single research project or programme, it's an essential part of the national and international MS research infrastructure. It's played a vital role in MS research around the globe and

> **“I’d like to say a big thank you to people who have signed up and to the families of previous brain donors. The research cannot happen without you.”**
> **Professor Richard Reynolds**

will continue to do so.

We’ve provided tissue to around 500 projects over 25 years. Each donated brain can be divided into over 200 samples. But it’s difficult to put your finger on how many projects one donation can support.

Important findings

I remember our first really important finding using tissue from the Tissue Bank. We found that myelin repair in the MS brain could be very extensive, which was surprising. It obviously fails in some places at some points. But we realised it was a process that could be successful in the MS brain. So we knew we should be able to make it successful again.

Inspiring new treatments

We also found immune cells called B cells were surviving and multiplying in the brains of people with MS. They’re usually found in the body away from the brain. When we found B cells, there seemed to be more damage across the outer layers of the brain.

This was one of the reasons some pharmaceutical companies decided to develop and test anti-B cell therapies for progressive MS. Such as ocrelizumab. This became one of the first drugs to really show an effect of any sort in progressive MS. And it all started at the MS Tissue Bank.

Supporting the latest research

Since the Tissue Bank was set up we’ve adapted to meet the needs of researchers. The tissue can be used in all the latest research techniques. Many of these techniques seemed like science fiction 20 years ago.

The current big push in MS research is to find drugs that will slow progression in MS. Some of the treatments being tested now are based on research that started at the Tissue Bank. This really is a success story – and people donating their brains to the Tissue Bank are part of that story.

learn Find out about the Tissue Bank at **mssociety.org.uk/tissue-bank-questions**

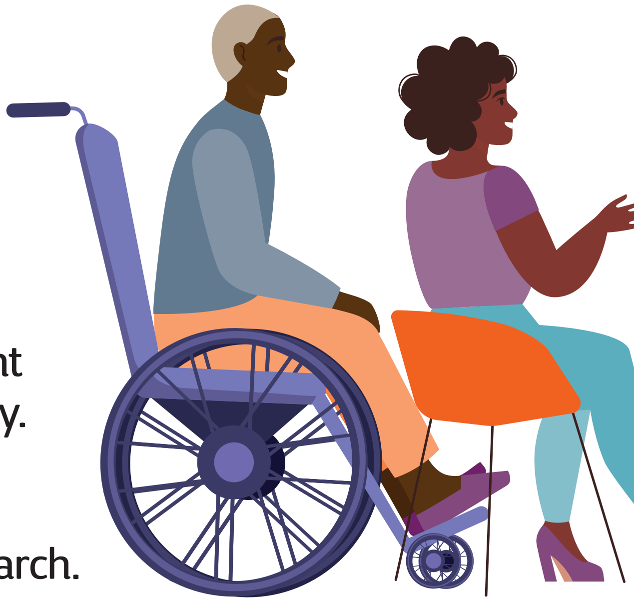
Professor Richard Nicholas, Director of the UK MS Society Tissue Bank since 2019.

We’re always trying to make the MS Tissue Bank an even better resource for researchers around the world. The Tissue Bank is special because it’s the only way to look at the reality of what happens in the brain in MS.

And we can now combine the tissue with other information from the UK MS Register. The Register records how a person experiences MS. That can be linked to clinical data. And we can see if that might have an impact on the brain tissue. Having this extra information makes every single donation even more powerful.

We’re now working towards making a collection of our own images of the tissue, which could be available to lots of researchers. Then, one image of one brain could contribute to even more projects. Making the most of every donation is important to us because we know they are so valuable.

Improving MS care for people from minoritised ethnic backgrounds



Dr Alison Thompson is a senior lecturer in patient and public involvement at Queen Mary University. She wants to design better, more inclusive MS services by making sure people with lived experiences are involved in all stages of MS research.

We know people from minoritised ethnic groups face inequalities accessing healthcare. And we know they have been systematically excluded from research. But research is only good when it's done fairly and inclusively. And there are still gaps in what we know about the experiences of people from minoritised backgrounds. We'll run focus groups and interviews to learn more about the experiences of people living with MS from Black and South Asian backgrounds.

Dr Alison Thompson

Can you tell us about your research project?

We want to know what barriers and challenges they experience when accessing treatment and support for their MS. And come up with tangible plans of how we can improve services to make them more accessible and useful.

Why is this research so important?

Many things can influence how easy it is for someone to access MS care and services. For example, someone's culture, language barriers and religious beliefs. But also historical experiences of healthcare systems and racial discrimination.

It can impact the quality of care for people from minoritised backgrounds. And it ultimately can affect their health and how their MS is treated. And that's why it's so important everyone has access to care that they need and that works for them!

What are your hopes for the future?

I hope research will be more inclusive and representative in the future. And that the participatory approach will help us include diverse people with lived experiences in every aspect of MS research.

We're trying to come up with practical ways to improve MS care for people from minoritised ethnic

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What research methods are you using?

We use participatory research methods. This means putting people with lived experience of MS at the centre of research. They lead and shape the research at all stages of the process. Like writing grant applications, being in steering groups and collecting and analysing data with us.

Our peer researchers are people affected by MS from non-white backgrounds. We provide research training for them, for example in interviewing and analysing data. So people can become peer researchers even if they don't have experience working in research. It's open to everyone.

backgrounds. For example, promoting awareness of access barriers. And developing guidelines on how we can improve services to consider their needs.

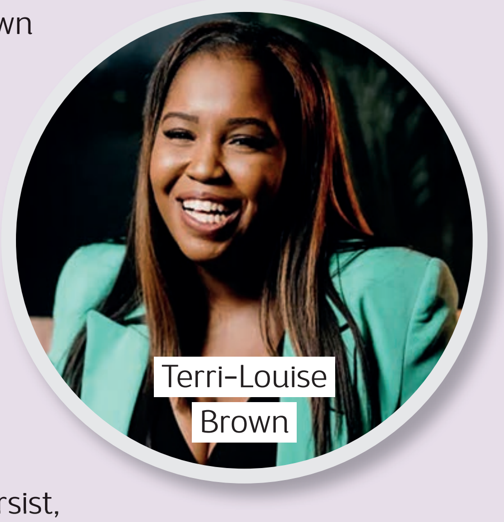
How can people get involved?

People can get involved in our interviews and focus groups. We're currently looking for people from Black and South Asian ethnic backgrounds who live in East or South London or Yorkshire.

- Contact Alison at **a.thomson@qmul.ac.uk** to find out how to get involved.

read Read more about Alison's project at **mssociety.org.uk/improving-ms-care**

Terri lives with relapsing remitting MS. She's the CEO and founder of Talks With MS. This is a charity creating safe spaces where people in the MS community can engage and relate to each other.



Terri-Louise Brown

"Including Black and brown people in MS research in the UK is crucial for several reasons. Firstly, MS affects individuals from diverse racial backgrounds, and studying this diversity can lead to more tailored treatments and interventions. Secondly, disparities in healthcare outcomes persist, with under-representation making these issues worse. Inclusive research helps bridge these gaps, ensuring equitable access to care and improved health outcomes. Articles like this highlighting inclusion are essential. They raise awareness, promote diversity in research, and foster collaboration to better understand and combat MS across all communities."

Peer support for male carers

Andy is part of a support group in Portsmouth for male carers whose partners have MS. He's been attending for the past five years.

Andy says "The first time I went, there was an immediate sense of relief that it's not just me. It's still incredibly helpful to meet other chaps in the same position. Things get shared that are really helpful – little strategies and coping mechanisms. You find out things that are available."

There are three male carer support groups across Hampshire. And each group meets monthly at a pub for a meal and a chance to talk. They were started by MS Society volunteer Caroline Birch.

She says "There are nine or 10 men in each group, all caring for their partners, while working and usually looking after children too. The meetings offer them an opportunity to confidentially talk about anything they want. I've seen the huge difference it makes for men to speak to another man who totally gets what they're going through. The groups are very positive."

- For information on the male carer support groups in Hampshire, visit **mssociety.org.uk/lymington-new-forest-group**

This service is local to Hampshire, but all our groups welcome people with MS and their carers. Find what support your local group provides at **mssociety.org.uk/local-support**

Our information, articles and podcasts

We've got free information, blogs and articles on a huge range of topics.

And in September we launched our first podcast: 'Sleep and MS'. Experts answer questions from people with MS. Find all six episodes on our website, on Spotify, Soundcloud and Apple. Also new to our website is 'Thinking about HSCT?', an in-depth article by a leading neurologist. It features moments from people's own experiences.

Look out for upcoming articles, blogs and animations about benefits, pregnancy, diagnosis and living with progressive MS.

- Find everything, including free booklets and downloads, at **mssociety.org.uk** or call **0300 500 8084** to order booklets.

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VOLUNTEER IMPACT AWARDS 2023

It's time to celebrate our volunteers

Join us for our Impact Awards to celebrate the commitment, achievements and successes of our volunteers – and our 70th anniversary.

The awards shine a spotlight on volunteers' amazing contributions and the impact they have on people affected by MS. And they culminate in a star-studded annual event, live streamed across the UK!

Comedian Ivo Graham will host this year's event on 30 November. We'll also be celebrating 70 years of the MS Society, which was started by volunteers in December 1953.

Nominations come in throughout the year from service users, volunteers and staff across six categories. These are assessed by our panel, made up of experienced MS Society volunteers from a variety of roles. Four times a year, they meet to find volunteers who've gone above and beyond their regular volunteering and recognise them with an award.

For our Impact Awards event, the panel selects an overall winner and two runners-up from each category. And the winners are announced on the night by special guests.

We spoke to some of our panel members about why they're supporting the awards and what makes MS Society volunteers so special.

Yolanda Barker

Panel member

I'm so proud to be part of the Impact Awards panel and to acknowledge amazing volunteers and the wonderful work they're doing. I have an incredible feeling of achievement because I've found an area of volunteering I hadn't thought about before. I get a buzz from the work the panel does.

Pat Crossley

Panel member

I feel it's important to acknowledge volunteers, especially these days as volunteers are scarcer and demands on people's time are increasing. No one who volunteers is looking for a reward. But if an Impact Award comes along, it will give even greater encouragement.

join

You can join our awards event livestream on 30 November at 7pm by going to **youtube.com/mssociety**

Trishna Bharadia

Panel member

I love hearing the stories behind the nominations and learning about the wonderful work volunteers are doing for the MS community. It never fails to put a smile on my face, uplift and inspire me!

Susannah Robinson

Panel member

I look forward to showcasing the astounding work that volunteers do and showing the real difference they make to people with MS. It's about being able to give back just a tiny bit of credit where a huge amount of credit is due.

Stuart Nixon MBE

Panel member

When choosing the winners, impact says it all. Whether on an individual level or having an impact on a wider group. It's a testimony that gives you that 'tingle', which shows the effect someone has delivered.

Helena Fagan

Panel member

I'm excited to join the Volunteer Impact Awards panel and hear about all the fantastic work our volunteers continue to do! I can't wait to be part of a team that gives our volunteers the recognition they very much deserve.

Ivo Graham

Impact Awards host

I'm hugely proud to be an MS Society Ambassador for two reasons. Number one, because the Society does so much to help people like my mum, who has lived with the various challenges of MS for most of her life. And number two, because I love getting to call myself an Ambassador.

I'll be bringing exactly that combination of sincere gratitude and unchecked ego to the Volunteer Impact Awards on 30 November. I expect to be deeply moved by the amazing work done by the nominees and the wider MS community. And also to mention my sub-three-hour marathon time within the first five minutes of the event.

So, whether it's for the genuinely heroic volunteer stories or my new material about getting emergency Vaseline at mile 20, I'd thoroughly recommend joining the livestream. And let's raise a glass (prosecco/Lucozade) to the MS Society on its 70th anniversary!

Read more about Ivo's support at **mssociety.org.uk/ivo-graham**

If you're caring for someone with MS, what support do you need the most that you're not getting?

Our community on Facebook and Instagram share their experiences.

It feels like I can't say anything to anyone because I'm not the person in pain or suffering. They aren't getting all the support, assistance, therapy and medication they deserve. So why should I get extra support when they need it more? My sister and I have never been fully educated on how to look after our mum or what the future will look like. We've done most research ourselves.
Olivia and Jess

Everything. My husband is now quadriplegic and permanently bedbound. I get zero help from social services. I can't get NHS continuing healthcare because I "look after him too well", leaving no clinical evidence of problems. I get just six days of respite per year. My mental health is the lowest it's ever been.

The social care system is in tatters. Carers like me are suffering extremely poor mental and physical health with no support. I've been begging for help for over a decade since my husband became bedbound to no avail. We're completely forgotten.
JD Wharrier

share

For our next issue, **we want to know about your recent experiences with the NHS – positive and negative.** Send your answers to our inbox at **msmatters@mssociety.org.uk**. Or keep an eye on our social media **facebook.com/mssocietyuk** and **instagram.com/mssocietyuk**. We'll also post the question there.

Caring for my adult son with relapsing remitting MS is challenging. He rarely complains but I see him struggling. I'm often accused of mothering. That's what mums do, try to ease the struggles.
Jane Hunt

A life-changing gift

Stanley and Valerie's gift will help people with MS in the future.

Over a third of our income is from gifts in wills. Many of these are kindly left to us by people like you, who understand how difficult it can be to live with MS. Gifts like this create a lasting memory and make a huge contribution to a future free from the effects of MS.

Stanley and Valerie Greenough died within a year of each other, leaving very generous gifts to several charities, including the MS Society. Their gift will support future research and services for people living with MS. It was left in memory of Stanley's younger sister Pauline, who lived with MS for many years.

Stanley's nephew, Richard, says "Stan and Val didn't have any children of their own, but they were much loved by me, my sisters and cousins. They were childhood sweethearts and shared many interests including sailing, a love of good food, cycling and all things French.

"Stan was a lecturer at a technical college. He was also an excellent sportsman who played rugby semi-professionally for Widnes. Valerie taught French at secondary school and rose to the position of Deputy Head."

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Ed Tait, our Executive Director of Engagement and Income Generation, says "We greatly value the kindness of Stanley and Valerie, and people like them. Their generosity will help transform the lives of thousands of people living with MS in the future."

help

If you're interested in writing or updating your will, we offer our supporters free access to a range of will writing services. These can help if you're concerned about the cost or difficulty of visiting a solicitor

Our services include:

- using solicitors local to you
- will writing online or by telephone
- home visits, if getting to a solicitor would be difficult

To find out more contact **Ilkay Atay** on **020 8438 0828** or email **legacies@mssociety.org.uk**

Days when I can't walk, I can cycle

Neil from Invergordon in Scotland was diagnosed in his 20s and now lives with secondary progressive MS. He finds walking difficult but can cycle pain-free, as he explains in this blog post.

I used to cycle competitively when I was young. I gradually lost interest in cycling as I got older and got a car and motorbike.

Just before lockdown, a friend who has cancer suggested I try The Oxygen Works in Inverness. The morning after my first oxygen therapy session I did 50 miles on the bike! Before that I had no 'oomph' at all, I was just flat. For that first ride, I used an electric bike, but I now have several different bikes.

I'm not in pain at all when I'm cycling, which is so strange. If I walk, with my stick or my big cane, just literally round the corner to the shop, I'm sweating and I'm in so much pain. But I can cycle, no bother.

● Read Neil's full post at **mssociety.org.uk/neil-blog** and find out more information about oxygen therapy at **mssociety.org.uk/hyperbaric-oxygen-therapy**

Many people from our Instagram and Facebook communities related to Neil's cycling experience.

msanddee
I'm exactly the same! On days when my legs are painful, I can cycle into work no problem!

Simon Reader
This is quite a wake up. I thought it strange that I can cycle all day, but struggle to walk far. Loving seeing so many others with that same strange outcome.

Jeff Moore
I'm dizzy most of the time. But after my neurologist found out that I was a keen cyclist, he encouraged me to get back on my bike. I now ride my bike dizziness free.

share

Stories like Neil's matter. They help people feel less alone. If you'd like to write for our blog, email **stories@mssociety.org.uk**. Do you have a comment on a story in MS Matters or on our website?

✉ Email **msmatters@mssociety.org.uk**
Facebook **fb.com/MSSociety**
Instagram **@mssocietyuk**
Twitter **@mssocietyuk**

Volunteer spotlight

Pat Crossley

As we mark our 70th anniversary, we talk to one of our longest-serving volunteers. Pat tells us how things have changed for the better during the 40 years she's been a volunteer.

I started volunteering for the Ballymoney Group almost four decades ago. It's one of the Society's longest standing groups. It's been going for over 60 years! It was started by a lady with MS, along with some others who recognised a lack of support in the area.

However, it was a group for fundraising at first – not a group as we know it today. But they got started and, just as importantly, they raised interest.

When I joined around 20 years later, the group was run by some wonderful ladies. We continued the social gatherings. We started exercise classes and physio.

What's become apparent over the years is people's need for social connection. The way people communicate has vastly changed since I joined, when everything was done by phone or mail (at a huge cost!). There's a range of support to suit everyone now. Whether by phone, face-to-face or online.

I've seen a noticeable difference in the diversity of the MS Society's community. Including younger people who are reaching out more often. I think that's down to awareness of MS and its symptoms. People are getting diagnosed sooner. They have better access to information and treatments. And they can see others living well with MS because more people are empowered to speak up about it.

I've made so many friends in my different volunteering roles over the years. My journey has kept going and I've grown with the MS Society. I feel privileged to have been part of it for so long. It's become almost like family to me.

read Pat is a member of the judging panel for our 2023 Volunteer Impact Awards. Turn to **page 40** to read more about our awards event on 30 November.

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Getting to know you...

Nick Keveth was appointed as a Trustee and the Treasurer in July 2023. He's a chartered accountant with over 25 years' experience working as a finance executive in large international companies and accountancy firms.

What motivated you to get involved with the MS Society?

My wife was diagnosed with relapsing remitting MS in March 2020. My job at the time was quite intense. It didn't allow me to strike the work-life balance I was looking for to support my wife and family.

I took early retirement in March 2022, but didn't want to be completely put out to grass! The MS Society Treasurer role is a great opportunity to apply my professional skills to a cause close to my heart.

What are your hopes for the MS community?

I hope research develops better treatments that are more effective for progressive MS. And that we make advances that'll ultimately stop MS. I also want to see improved access and consistency of access to treatments and support.

What do you think are the biggest challenges facing carers?

Fortunately, my wife's care needs aren't high. But I do have an insight into the emotional challenges of helping my wife navigate the NHS. You want the person to have access to the right support and treatment. Trying to unlock that can be frustrating. Standing back, I also imagine the cost of living crisis is adding to the pressures faced by many carers.

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

Don't try to do everything – it's a route to failure. But I believe if you really dedicate yourself to something, you can be successful. For example, my wife has recently started running. She's dedicated herself to it and is now doing 10ks.

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

Be clear about your priorities and spend your time and energy on those things.