



**Plus**  
What links MS  
with other  
autoimmune  
conditions?

## A force of nature

Laurence and Jackie Llewelyn-Bowen share their experiences of both having a mother with MS

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Cover photo: Rebecca Faith Photography



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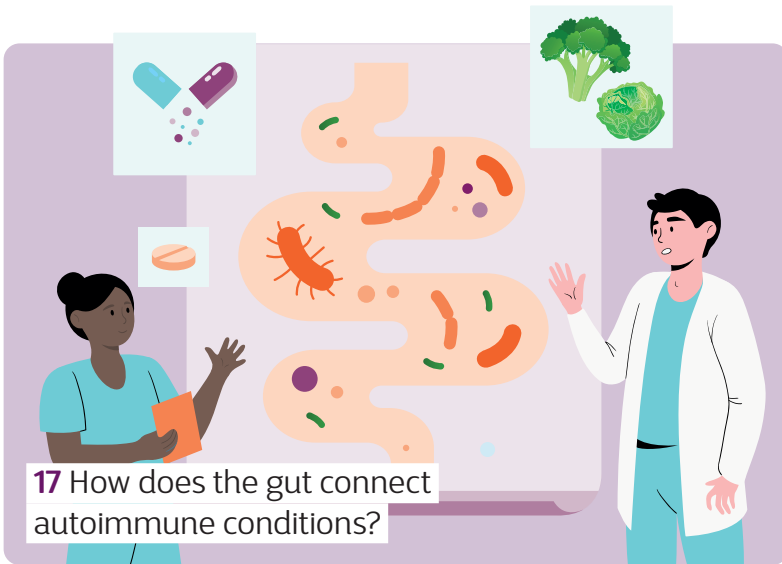
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Issue 141  
Summer 2022

**Normally our CEO Nick writes the introduction to MS Matters.** But this time he's handed the mantle to me so I can introduce myself. I've edited the magazine for three years. And I've been working with a team behind the scenes to try and create the best magazine possible for everyone affected by MS.

This issue is all about family and friends, and the effects MS has on our relationships. I don't have MS myself. But my mum had it from when I was five until she died when I was 25. So I grew up with MS as part of my life.

Despite the challenges MS threw at us, it didn't define our relationship. We laughed and bickered in the way mothers and daughters do. It threw her exceptional strength into perfect focus. But it also caused endless suffering and took her far too young. There are positives to be found, but no doubt all of us who know MS would prefer to be without it.

Thankfully, a future where we can stop MS seems increasingly possible. In this issue, read about exciting new research. And don't miss our story on page 20 about the effects MS has had on people's relationships.

Please let us know what you think. Your feedback makes this magazine better.

*Victoria*

**Victoria Watts Kennedy**  
Editor

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# Your Letters



**We're extremely sad to report that Emily Holt, our cover star on the spring issue of MS Matters, died on 1 May. Emily was an artist who featured in our article "Creative ways of describing MS". Among her works was Virus Diaries, a video project highlighting the issues clinically extremely vulnerable people faced during the pandemic.**

We were honoured to work with Emily, who was passionate about sharing her story to help others. Emily's mum, Anne Holt, wrote to us about how people responded to the article.

Anne said: "Emily really enjoyed seeing the spring issue of MS Matters before she became too unwell. We've had so many responses to the article, both funny and sad, from readers as well as medical staff who wanted to understand more about MS. I read their responses to Emily while she was very ill in hospital, and she was delighted. Here's a small sample of those responses."

"After a miserable day completing my PIP review form, still in my pyjamas, I checked the post and there you were, a beautiful smile and the most inspiring article. I felt motivated not only to change my knickers but to have a shower too."

"I watched Emily's excellent videos with my 13-year-old daughter who's considering some form of career in healthcare. We were very moved by them."

"It made me smile and cry."

"The article truly reflects how she has used art to express how her illness has affected her life. She clearly has a very good sense of humour."

"I shared the video with my research colleagues. [It shows] how the experience of a person receiving treatment can inform how care is given. It is an important thing Emily has done, which I hope will help many others."



Share your thoughts and feedback at [msmatters@mssociety.org.uk](mailto:msmatters@mssociety.org.uk).  
Or use the hashtag **#msmatters** on your social media channels.  
You can call the MS Helpline for support on **0808 800 8000**

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# EBV immunotherapy trial reports early data

New data from an early trial for progressive MS recently hit the headlines. The small trial was investigating whether an experimental treatment targeting the Epstein-Barr virus (EBV) was safe for people with progressive MS.

## EBV in the spotlight

This follows a recent study that provided the strongest evidence yet that EBV could be a cause of MS. This sparked further interest in whether an EBV vaccine could prevent MS. Or if treatments targeting the virus could help stop the progression of MS.

## ATA188

The new treatment in trial is an immunotherapy called ATA188. It involves taking immune cells from a donor who doesn't have MS, and transplanting them into a person with MS. These special immune cells find EBV-infected cells in the

body and destroy them.

Twenty four people with progressive MS took part in the trial. After three years on the treatment, 13 people's disability stayed at the same level. And seven saw an improvement in their disability.

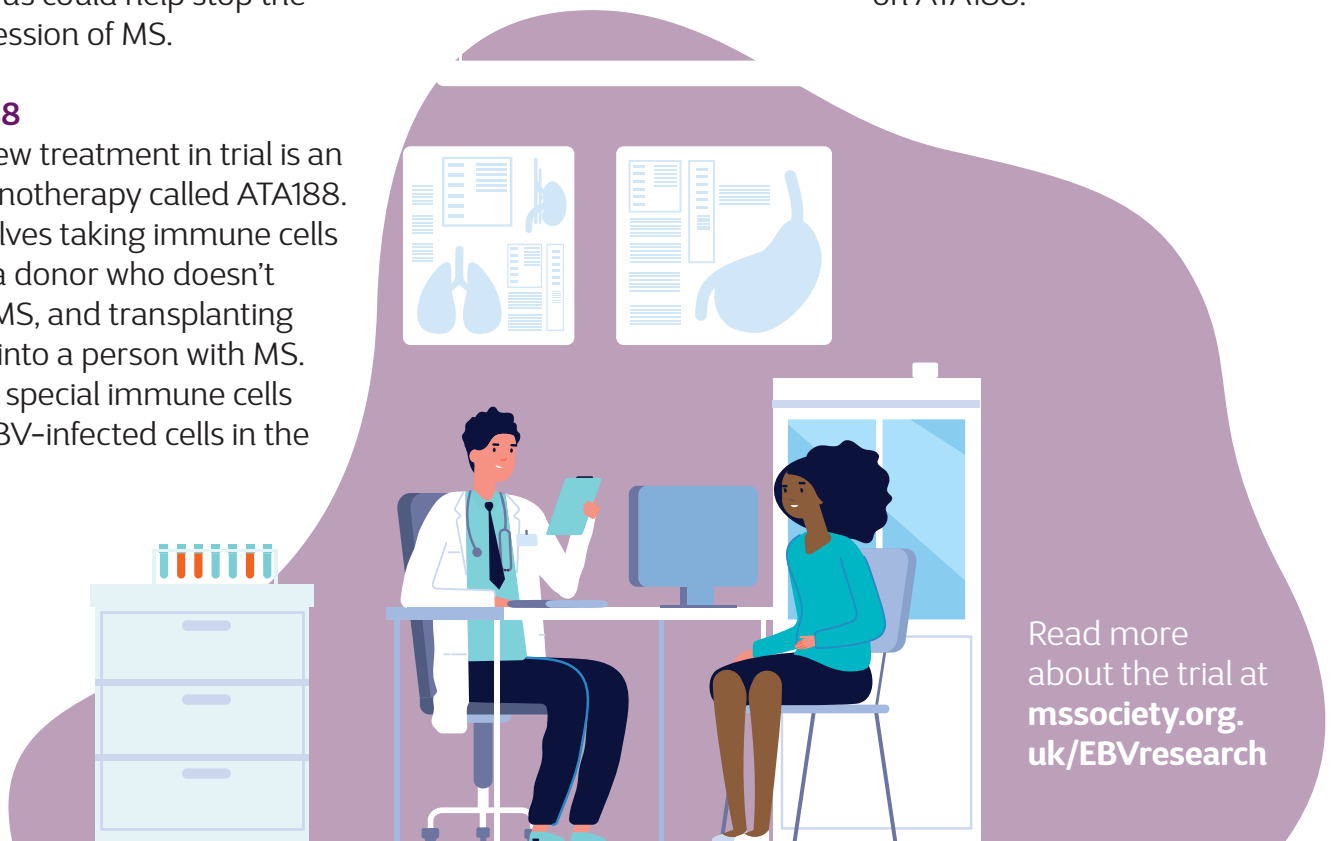
## Promising, but too soon to say for sure

Although these initial results sound promising, there's not enough data to conclude whether the treatment has any benefit yet. The main aim of

this study was to find out if the treatment was safe. And a much larger study comparing the treatment to a placebo (dummy drug) is needed to understand its potential.

## A new trial is underway

We're pleased to see the team are now doing a larger phase 2 trial. This aims to recruit 80 people with progressive MS in the US and Australia. It'll be carried out over five years, and half of the people on the trial will have a placebo. So it could provide more evidence on ATA188.



Read more about the trial at [mssociety.org.uk/EBVresearch](https://mssociety.org.uk/EBVresearch)

# First person joins new myelin repair trial

Annabelle, who lives with relapsing remitting MS, is the first person to join a new clinical trial. It'll test whether two drugs in combination can kick-start myelin repair.

Metformin and clemastine have both shown promising effects on myelin repair in the lab. And because they're already used for other conditions (diabetes and hay fever), we already understand lots of their side effects. Annabelle will take these drugs or a placebo (dummy drug) for six months.

Annabelle said "I was so inspired when I saw the clinical trial and signed up straight away. Just a few months ago I was told there was nothing more I could do. Now I'm the first participant on a new trial! It's given me so much hope."

Professor Alasdair Coles, from the University of Cambridge, is leading the trial. He said



"The recruitment of our first participant is a huge milestone. We're another step closer to a time when a person with MS will be given a handful of treatments to tackle all the different elements of MS. So their life will be minimally affected by the condition."

Fifty people with relapsing remitting MS from Addenbrookes Hospital in Cambridge will be recruited to take part in the trial.

Read more at [mssociety.org.uk/myelin-trial](https://mssociety.org.uk/myelin-trial)

## £2 million for UK MS Register renewal

The UK MS Register is the world's first registry to collect information directly from people about their MS and link it with many years of clinical records. This unique data has already been used in many discoveries about MS.

We've committed to raise £2 million for the register over the next five years. This will allow the UK MS Register to continue collecting data and support ground-breaking research studies. The new grant will also see the UK MS Register play a key role in making our "mega-trial", Octopus, possible. Octopus is due to open later this year and funding will help host a new participant portal.

Read more at [mssociety.org.uk/MSregister](https://mssociety.org.uk/MSregister)

## Spotlight on treatments

### Diroximel fumarate

In April, the National Institute for Health and Care Excellence (NICE) approved diroximel fumarate (brand name Vumerity) in England. It's a

disease modifying therapy for adults with "active" relapsing MS. Following checks, NICE decisions are usually adopted in Wales and Northern Ireland. In February, the Scottish

Medicine Consortium (SMC) recommended diroximel fumarate for use in Scotland.

Read more at [mssociety.org.uk/vumerity-approval](https://mssociety.org.uk/vumerity-approval)

## Back the 1 in 6 – sign our petition

One in 6 people in the UK live with a neurological condition. But there aren't the workforces or services in place to support them. So we recently launched the Back the 1 in 6 campaign with the Neurological Alliance.

The Neurological Alliance also published a new report with findings from its My Neuro Survey. Thank you to everyone with MS who took part.

Delays in life-changing treatment and care, and a lack of mental health support can't continue. Our petition calls on all four UK governments to set up a Neuro Taskforce to deliver real change.

Last year, 8,000 of you signed an open letter for our Neurology Now campaign calling for better access to MS and neurology services. By joining up with other organisations, we hope to see even more progress so people with MS get the vital support they need.



**#BackThe1in6**

MS Society

THE NEUROLOGICAL ALLIANCE

sign Find out more and sign our petition at [mssociety.org.uk/neurology-now](https://mssociety.org.uk/neurology-now)

## Campaigns news

### COVID-19 testing

We've been campaigning with other charities to keep COVID-19 testing free for people with MS and other conditions. The UK government isn't doing everything we wanted, but we've achieved access to free testing for certain groups and professionals.

- Read more at [mssociety.org.uk/free-covid-testing](https://mssociety.org.uk/free-covid-testing)

### Your chance to improve MS support

Our My MS My Needs and Friends and Family surveys guide our priorities.

- Share your views before 1 August so we can understand your needs at [mssociety.org.uk/my-ms-my-needs-uk](https://mssociety.org.uk/my-ms-my-needs-uk)

### Campaigning for carers

"Making Caring Visible" was the theme of this year's Carers Week (6-12 June). We've been campaigning for increased allowance and paid leave for carers.

- Find out how to get extra support for yourself and the person you care for at [mssociety.org.uk/carer-support](https://mssociety.org.uk/carer-support)



Rose Leslie and Kit Harington

## Stars turn out for MS Research

Our SMS Battles event took place in London on 12 May. And a host of celebrities came together to raise funds for MS research.

Guests included Game of Thrones actors Kit Harington and Rose Leslie, Downton Abbey's Sophie McShera and former England rugby player Toby Flood. They were joined by Fantastic Four actor Ioan Gruffudd and his partner, Australian actress Bianca Wallace.

The dinner and quiz evening raised an incredible £242,440 for our Stop MS Appeal. Read more about SMS Battles at [mssociety.org.uk/sms-battles](https://mssociety.org.uk/sms-battles)



Brendan Foster Photography



Nicola Walker



## Fancy Dress for MS

MS Awareness Week ran from 25 April – 1 May this year. And supporters and staff donned their wildest and wackiest costumes for the very first Fancy Dress for MS. Costumes ranged from Worzel Gummidge to Superwoman to the Spice Girls. Actress Nicola Walker, our wonderful celebrity supporter, even got involved.

Well done to everyone who took part and helped raise awareness and funds to stop MS. Read more at [mssociety.org.uk/msaw](https://mssociety.org.uk/msaw)

## Behind the scenes at the BBC Lifeline Appeal

BBC One broadcast a Lifeline Appeal about the MS Society on Sunday 26 June. The short film was presented by Michelin-starred chef Tom Kerridge, whose father had MS. It featured people with MS talking about the research we've funded and the support provided by our MS Helpline and local groups.

Stuart Wood from County Durham has secondary progressive MS and featured in the appeal. He said: "It's been a really proud day. I've really enjoyed it. I'm really proud to support the appeal any which way I can."

Watch and share the film online at [mssociety.org.uk/bbc-lifeline](https://mssociety.org.uk/bbc-lifeline)



Stuart and his daughter Lucy are both living with MS and featured in the Lifeline Appeal

## Support for Ukraine

The war in Ukraine is affecting everyone there, including the MS community. Some of you have asked what can be done to help people with MS caught in the crisis.

The European Multiple Sclerosis Platform (EMSP) is leading the MS community's response in Europe. We're working with other MS societies to help EMSP plan the best ways to support people. Their website has the latest information available at [mssociety.org.uk/ukraine](https://mssociety.org.uk/ukraine)

We're not fundraising for Ukraine, but if you'd like to donate to Ukrainian support, we recommend the Disasters Emergency Committee (DEC) Ukraine Humanitarian Appeal at [dec.org.uk](https://dec.org.uk)



## Dates for your diary

Don't miss these MS community events.

### Multiple dates MS Walks

Join us at one of our incredible MS Walk events this September. Explore a mixture of riverside, parks, and historic buildings in Belfast, London or Glasgow. Whether you take part or volunteer, you'll be helping to change the lives of people affected by MS – now and in the future.

Sign up at [mssociety.org.uk/ms-walk-2022](https://mssociety.org.uk/ms-walk-2022)

### Monday 5 Sept, 6:30 – 7:30pm Living Well with MS webinar: Self-compassion and MS

Hannah McIntosh from Chala Counselling will speak about self-compassion and share tips on being kinder to ourselves. Hannah's a qualified person-centred therapist with extensive experience working in adult mental health. The webinar offers a safe, fact-based space, and you can attend anonymously.

Sign up at [mssociety.org.uk/self-compassion-webinar](https://mssociety.org.uk/self-compassion-webinar)

Find more fundraising events at [mssociety.org.uk/get-fundraising](https://mssociety.org.uk/get-fundraising). And see our programme of webinars and information events at [mssociety.org.uk/virtual-support-events](https://mssociety.org.uk/virtual-support-events)

# Our mothers were a force of nature

Laurence and Jackie Llewelyn-Bowen's mothers both had MS. They share their experiences with us and why they're supporting our legacy campaign.



### Were you already together when your mothers were diagnosed?

**Laurence:** I think my mother was diagnosed in 1969, and we weren't together then. I was far too young to remember it happening.

**Jackie:** No, my mother was in her early sixties when she was diagnosed with primary progressive MS. She was a teacher and she was suddenly aware that her left leg kept sort of shooting out and kicking people.

### How did your mothers react?

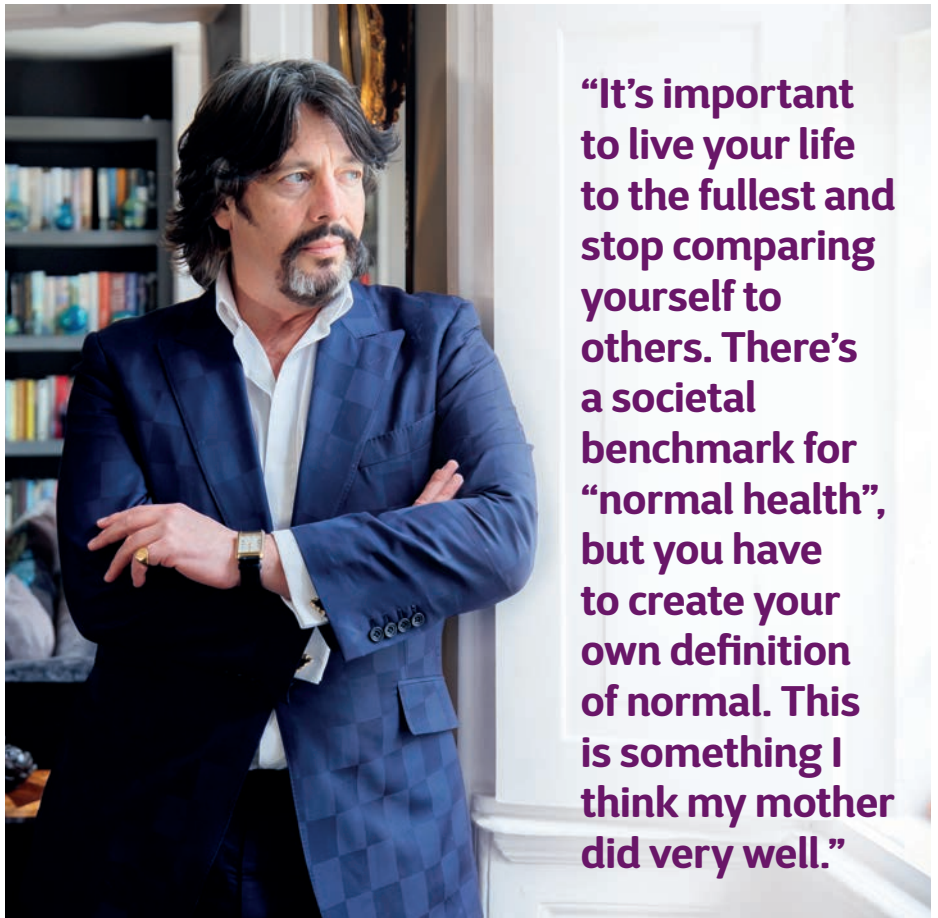
**Laurence:** My father died when I was nine. So our home life was already quite complicated. But my mother refused to let it stop her from living life.

**Jackie:** My mother never said she was "battling" MS. She was very realistic about it and said she was "negotiating with MS" instead.

### How did MS impact family life?

**Laurence:** It was a huge part of my childhood. And there came a point where my mother said, "I'm going to need full-time care. And I want to do that now, before it becomes a big issue."

**Jackie:** We've been together for



**"It's important to live your life to the fullest and stop comparing yourself to others. There's a societal benchmark for "normal health", but you have to create your own definition of normal. This is something I think my mother did very well."**

37 years. So it's always been a big part of our lives. And at times, my mother was quite forceful and difficult. Both of our mothers were forces of nature.

### Thank you for supporting our new legacy campaign! What motivated you to support it?

**Laurence:** I think one of the biggest challenges is getting

people to understand what MS is. With the profile and experience of MS we've got, the least we can do is help people to understand. We can tell our mothers' stories.

**Jackie:** The MS Society is great because they've always kept us updated with new developments. And whenever we're able to help them – whether it's fundraising or just talking about some experiences – we're happy to do that.

### What are your hopes for the future?

**Jackie:** I'm excited about the idea of stopping MS. And I think we'll do that thanks to the incredible research happening.

join

Laurence and Jackie are supporting our new campaign around gifts in wills. A massive 40% of our income is from gifts in wills. So leaving a gift makes a huge difference to the future of MS and supports vital research. Find out more about our free will-writing services on page 51. Or contact Sarah **020 8827 0374** or **legacies@mssociety.org.uk**

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# Research that really has guts

Professor Claudia Mauri and Dr Diana Matei are exploring whether focusing on the gut could lead to new MS treatments. Research Network volunteer Nick Widdowson spoke to them to find out more.



Nick Widdowson

**W**e all know what we put into our bodies can have an impact on our overall health and wellbeing. And the gut is the primary contact with what we eat and drink.

I recently had the pleasure of talking with Professor Claudia Mauri and her colleague Dr Diana Matei. They're carrying out exciting new research at University College London into the gut and its connection to autoimmune conditions such as MS.

## Why is the gut interesting in autoimmune conditions?

In MS, your immune system mistakenly attacks your own cells. The same thing happens in other autoimmune conditions, like lupus and rheumatoid arthritis. This process is understood, but unfortunately it's still incredibly difficult to pin down the cause as there's probably not just one.

Claudia paints an interesting picture of the human body. She tells me around 90% of all the cells in our body are bacteria cells. We're simply a massive

reservoir tank for bacteria, especially our gut!

She mentioned people with some autoimmune conditions, including MS, have different bacteria compared to other people. And this might change intestinal permeability, or gut leakiness as it's more commonly known. Gut leakiness means things from the gut can leak into the blood. Claudia believes this may contribute to MS damage.

## Linking autoimmune conditions together

Claudia previously carried out studies in mice and people with rheumatoid arthritis. She found they both had higher levels of intestinal permeability. And stopping the gut from being leaky reduced arthritis symptoms in mice.

Now they want to find out whether two other autoimmune diseases – MS and lupus – also show this.

## Serotonin from the gut

Claudia and Diana are also



Dr Diana Matei and Professor Claudia Mauri

interested in serotonin, a chemical that helps to send signals between nerve cells. It's sometimes better known for its role as a feel-good hormone.

Production of serotonin is a complex process, but the roots of it can be found in the cells of the gut.

They've previously found mice with rheumatoid arthritis didn't have as many of these serotonin-producing gut cells. And giving them serotonin reduced their symptoms. They want to see if the same is true for MS and lupus.

Some studies have also shown that people with autoimmune conditions such as MS may have lower levels of serotonin. They hope to confirm this and see if mice with MS can be helped in the same way.

Claudia explained serotonin is made from a molecule called

tryptophan, found in leafy vegetables such as cabbage and broccoli. But nobody's suggesting we should all be eating 5kg of broccoli a day. We'd be very unpopular to be around!

### Working together to find treatments for MS

These scientists believe our search for a cure for MS needs to look at all possibilities. The COVID-19 vaccine has shown working together allows us to reach goals much faster and

increase the chances of success. Research collaborations into different autoimmune conditions could do the same.

What excites Claudia and Diana most is that, somehow, the gut could link all these autoimmune conditions together. It's still some way off. But perhaps if we could restore gut health, this could potentially help develop treatments for all autoimmune conditions. They think this would be one of the most interesting and important things they could do.



**read**

We're part of the Connect Immune Research partnership. It joins together leading organisations in autoimmune research to help develop new treatments. This research is one of 10 new

projects funded by Connect Immune Research and the Lorna & Yuti Chernajovsky Biomedical Research Foundation.

Read more at [mssociety.org.uk/connectimmune](https://mssociety.org.uk/connectimmune)



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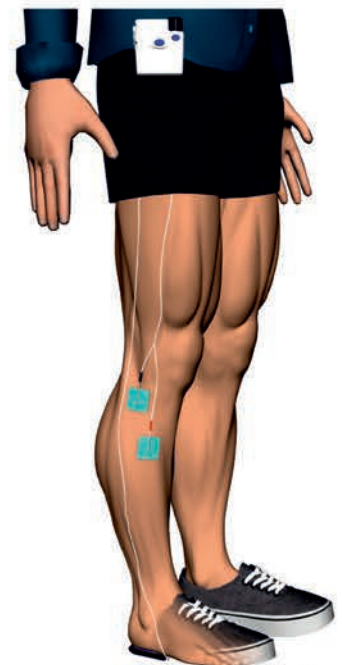
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# Conversations about MS with friends and family

MS affects people living with it and the people around them. A father and daughter, a couple of 50 years and two friends share their stories.

**“I wanted to be there as much as I could”**

**Claudia** was 11 years old when her dad **Steve** was diagnosed with relapsing remitting MS.

**Claudia:** When you were diagnosed with MS, I didn't fully understand what that meant. But now I'm older and I understand MS more. So I wanted to talk to you about your diagnosis journey and how MS changed family life.

**Steve:** My diagnosis took a long time. It started with optic neuritis in 2001 which lasted about three months. They couldn't confirm it was MS, even though they had suspicions. In 2006, I lost sensation in my feet and their heat sensitivity changed. I took another three months off work and was diagnosed in this time.

**Claudia:** How did you feel when you were officially diagnosed?



**Steve:** I remember it vividly. It was a shock and I felt saddened. It became this thing that was always in the back of my mind. Would I relapse? Am I going to be able to work? What's going to happen to my family?

I was used to working, coming back home, and fitting back in. But everyone's focus was on me. I was very much in the spotlight and people worried about me doing things I was fine doing before.

**Claudia:** How did you find that? I remember being mindful of you needing to rest more.

**Steve:** Yeah, I wasn't used to that. I wasn't used to being at home. I'm a qualified carpenter and I felt like I should be out doing things. But it was difficult. I could only take on small jobs.

**Claudia:** How did you feel about telling me and my sister?

**Steve:** Your mom and I didn't want to "burden" you with the news. So we just told you I'd got an illness and I'd have to rest and do a bit less.

**Claudia:** I really struggle to remember that conversation. But I remember you and Mom

handling it well. What were your biggest fears about being a parent with MS?

**Steve:** We didn't want you and your sister's lifestyles to change. And I wanted to be there as much as I could. But there's always the risk you'll push yourself too far. For parents, it's important to remember MS can change the way people look at you. But it's not going to change the way your loved ones feel about you.

**Claudia:** Exactly. We still love you the same!

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# “There have been funny times, good times, bad times”

**Lynne and Alastair Armstrong** met when they were teenagers. Lynne has had MS throughout their 52 years of marriage.

**Alastair:** Having to live life in a wheelchair, what do you miss most?

**Lynne:** Being able to walk and stand independently. It'd allow me to feel less dependent on others, and significantly improve our lifestyle. We can no longer go on holiday or visit our family in Canada and Australia. Airlines do little to make travel straightforward. Away from home, it's very difficult to access essential equipment.

Alastair, what do you think is the most difficult part of living with MS? Because you have to live with it too.

**Alastair:** The volume of activity I have to cope with. I'm a housekeeper, shopper, cook, laundry organiser, chauffeur and gardener. All of which I do willingly, but this doesn't leave much spare time. Simple tasks like picking up things dropped on the floor are regularly required.

**Lynne:** If I'm not very well, and I have to go to bed, Alastair

finds that very difficult. I can see him becoming depressed. He doesn't want to talk about it. I say “Are you OK? What's wrong?” And he says it doesn't matter. But what really keeps us going is making each other laugh.

**Alastair:** Lynne makes friends everywhere she goes. Whether it's the carers, the nurses, the postman, whoever. People warm to her. She can get people to tell her their life story within 10 minutes.

**Lynne:** Like most people, I've encountered many ups and downs in life. But one can't dwell on the bad times. One has to try to stay positive and make the best use of all the help that's offered. I have a lot to be thankful for, including five lovely grandchildren, a comfortable home and a garden which I love. And even though I don't want to tell him this, I do have the best husband ever.



# “I never had any doubts about Alex being there”

When **Mairead** was diagnosed with MS aged 22, she turned to her friend **Alex** for support.

**Mairead (top right):** Alex and I met through work. We were 21 and it was a “going out” kind of relationship. But we quickly became each other’s support system. No matter what happened, I knew I could ring Alex and she could ring me.

When I was diagnosed, I think it solidified how much Alex was going to be my “no matter what” friend. I never had any doubts about her being there. I didn’t have any other friends who visited me in hospital and who weren’t embarrassed to be out with me on a walking stick.

**Alex:** I think your first symptom was losing feeling in your legs. I remember that time before you

were diagnosed when they thought there were cysts on your spine. And then you got tested and it came back that it was MS.

**Mairead:** Yes, it was such a shock. I’d moved back to my hometown and Alex was a two-hour drive away. There were times when she’d message me to say, “How are you feeling?” And I’d say, “Just so s\*\*\*. I’m trying to get my head around it.” And she’d say, “I’m on my way.”

**Alex:** If my friend’s upset, I’ll go and see them and be a shoulder to cry on. A life-changing diagnosis isn’t an easy thing to go through, especially being so young. From a friends and family perspective, it’s about being that good, strong support system.

**Mairead:** Our relationship has changed since I was diagnosed, I’d say for the better, because the pace of life has slowed a bit. It’s forced me to not try to keep up with everyone else. Now, I hold my standards for a friendship up to what Alex and I have.

**Alex:** Mairead’s a strong, funny, beautiful human. It can be hard to find a forever friend, but when you do, you’ve got to keep them.

read

Find out more about family, relationships and MS at [mssociety.org.uk/family-and-relationships](https://mssociety.org.uk/family-and-relationships)

Our MS Helpline provides information and emotional support for anyone living with or affected by MS.

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## How do you talk to your friends and family about MS?

It can be challenging to talk to loved ones about MS. You told us how you approach these conversations and shared some tips.

I used to feel like I had to hide my diagnosis. Like it was something to be ashamed about. But once I openly started telling people, it helped me process things myself.  
**invisible\_load\_of\_life**

I'm open and honest about my cognitive changes. My family are the most important to me. We're slowly adapting to the new Amy/mum/wife/daughter by being kind and patient with each other. And we're trying to laugh at some of the unexpected things I say.

**Amy**

I keep it as simple as possible. Overloading our loved ones can be overwhelming for them despite us just wanting them to understand. Don't take offence if they don't get it. We live with MS and sometimes we don't get it!

**Terri**

Invite a close family member or friend to go with you to appointments. Ask for help, if you can, from a professional like a clinical psychologist. They can meet up with your family to talk about your MS, and the emotional and physical support you need.

**Rebecca**

I use social media, Facebook mostly, to keep my family and friends informed about how MS affects me. I often don't even realise I'm doing it, as MS is a part of daily life!

**Shana**



For our next issue, we're asking: **What does a future without MS look like for you?** Send your answers to the MS Matters inbox at [msmatters@mssociety.org.uk](mailto:msmatters@mssociety.org.uk). Or keep an eye on our social media ([facebook.com/mssocietyuk](https://www.facebook.com/mssocietyuk) and [instagram.com/mssociety](https://www.instagram.com/mssociety)) where we'll be posting the question later this year.

# Doing more for people experiencing domestic abuse

Some people with MS experience domestic abuse. But little research has explored how best to support them. PhD student **Kharis Hutchison** from the University of Leeds tells us about a new project doing just that.

**D**uring the pandemic, some healthcare professionals became concerned their patients with MS were experiencing domestic abuse. My supervisor is neurologist Professor Helen Ford. Helen and her colleagues knew it couldn't just be a lockdown phenomenon. And they quickly realised how little was known about domestic abuse in MS. They thought "we should be doing this research."

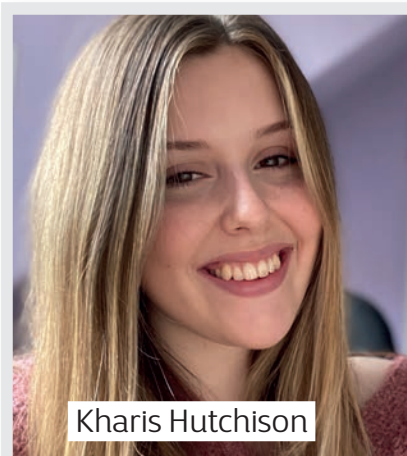
## Our goal is to improve support

I want to understand how people with MS who experience domestic abuse want to be supported. I'm trying to answer questions like:

- What's the nature of the domestic abuse and how is it impacting people?



Our MS Helpline provides emotional support for anyone affected by MS. We're committed to safeguarding and the welfare of people using our services. If you share any concerns with us, we'll do our best to support you. You can email us at [helpline@mssociety.org.uk](mailto:helpline@mssociety.org.uk) or phone us on **0808 800 8000**. The number won't show on your phone bill. If you're in an emergency situation, please call **999**.



Kharis Hutchison

- What are the barriers to accessing support and what should services look like?

Meanwhile, a student at the University of Nottingham is exploring the other side of this – healthcare practitioners’ experiences. And another researcher will use our findings to create a practical toolkit to improve support options.

### **A connection between disability and abuse**

So far, I’ve been reviewing existing research. Previous studies have generally focussed on people with physical or learning disabilities. There are no statistics for MS. But in the general population, disabled women are most at risk of abuse, followed by disabled men. So there’s clearly a connection between disability and domestic abuse.

We think there are factors that might increase the

**“We think there are factors that might increase the risk of someone with MS experiencing domestic abuse. None of them are their fault.”**

risk of someone with MS experiencing domestic abuse. None of them are their fault. I’m looking at social factors. For example, unemployment and financial struggles, reduced independence and changing roles in a relationship.

### **Abuse can take many forms**

The UK Government passed the Domestic Abuse Act in 2021, including the first formal definition of domestic abuse. The act says abusers might be intimate partners or other family members. I’ll also look at abuse by paid carers in a domestic setting.

The act describes different types of abuse, such as physical violence, financial abuse, emotional neglect and coercive control. And the effects are wide-reaching. Like the physical impact of an abuser taking away a wheelchair or purposely misusing medication.

### **Letting people speak**

I plan to collect data by interviewing people with MS who’ve experienced or are experiencing domestic abuse. Then we’ll run focus groups to

dive deeper into our findings about what people want from support services. And we’ll learn about the barriers.

I’ve worked on related research about support for disabled survivors of sexual violence. It’s helped me learn how to do this type of research. Like conducting sensitive interviews where participants feel comfortable and know it’s up to them what to share.

Importantly, we have to make sure our research keeps our participants, and ourselves, safe. I’ll provide everyone with information about existing support.

### **Scientific and personal inspiration**

As a student, I’ve been interested in gender-based violence and disability studies. On a personal level, my mum has two chronic conditions, which makes me interested in MS as another lifelong condition. This PhD brings my interests together.

It’s going to be quite emotional talking to people about their experiences. But I’m hopeful this project will drive real positive change.

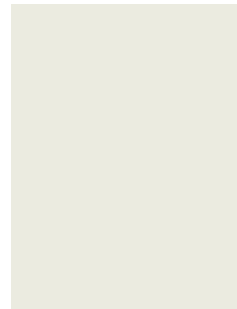


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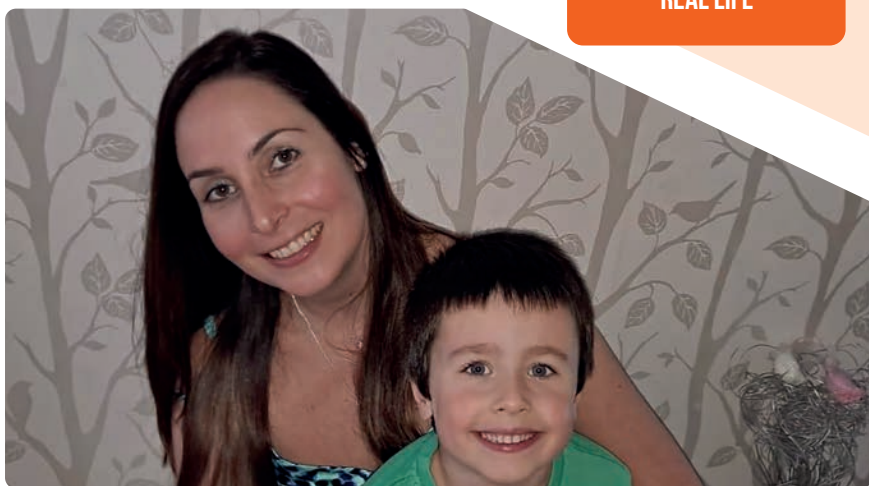


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## Becoming a mum after my MS diagnosis

**Michelle** became a mum a couple of years after being diagnosed with relapsing remitting MS.

It's true what they say – no one can really prepare you for what being a parent is really like. It was a bit of a shock to the system to start with!

I managed the sleepless nights and breastfeeding relatively okay because of having family to help. But because of fatigue and some leg weakness, I found it really hard getting out of the house.

Lifting car seats, manoeuvring the pram, lugging about nappy bags and standing to change him countless times a day was tough. I worried I wasn't


getting him out and about enough, but I didn't feel up to it.

Now my son is older and at school, some things are easier. But it also brings up different challenges. On the huge plus side, having him in my life brings a lot of laughter and there's never a dull moment! Plus all the hugs he gives me help a lot.


Read Michelle's full post at [mssociety.org.uk/michelle](https://mssociety.org.uk/michelle) For more information on pregnancy, parenthood and MS visit [mssociety.org.uk/pregnancy-info](https://mssociety.org.uk/pregnancy-info)

Michelle's blog post resonated with some of you on social media.

 **invisible\_load\_of\_life**

 It's definitely a transition as I've gone from being an energetic, bubbly, fast-paced mum, to a very slow-paced, fatigued and dependent mum. It's important to remember that a diagnosis affects not only the person, but everyone around them.

 **Lorraine**

 I've explained I can't do everything I used to. My 10-year-old made me cry last night. She told me her and her brother will help more to make things easier. I want them to be children.

Find out about support for families where children are doing extra to help at [mssociety.org.uk/young-carers-info](https://mssociety.org.uk/young-carers-info). On page 47, read about a new children's book that explores some of these issues. In some situations, you may be entitled to a social care assessment. Find out more at [mssociety.org.uk/support-for-carers](https://mssociety.org.uk/support-for-carers)



If you'd like to write for our blog, get in touch at [msmatters@mssociety.org.uk](mailto:msmatters@mssociety.org.uk)

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# Improving care in pregnancy and MS

Until recently there's been limited guidance for people with MS before, during and after pregnancy. But researcher and neurologist **Dr Ruth Dobson** is leading work to change that.

**R**uth identified the lack of guidance around pregnancy and MS, particularly which treatments are or aren't safe to take. So in 2019 she helped create new guidelines for managing MS during pregnancy. This gave key advice for clinicians and for people with MS. And helped develop our information.

Now Ruth wants to build a better picture of what it's like to be pregnant or a new mum with MS. So she's established the UK MS Pregnancy Register to find out and build more detailed guidance.

## The UK MS Pregnancy Register

Women with MS who are pregnant or who have had a baby in the last year are invited to answer online surveys through the UK MS Register. They'll be asked questions about their planning process, treatments and pregnancy experience. And there are already 83 participants whose experiences will inform future advice.

Early data from the first 50 participants was recently presented at a conference for neurologists. Seventy eight percent had discussed planning their pregnancy with their MS team. Around half are currently taking DMTs and some are planning to stop these further into their pregnancy.

Ruth hopes the data could help inform guidance about the safety of DMTs and other medications during pregnancy and after birth.

Find out more and how to sign up at [mssociety.org.uk/pregnancy-register](https://mssociety.org.uk/pregnancy-register)

## Can pregnancy teach us more about relapses?

Professor Lars Fugger is investigating why pregnancy sometimes reduces MS symptoms. It might be because a baby is a genetically different person. And the immune response needs to be dampened to allow it to develop.

The team are analysing blood samples from 100 pregnant people with MS. They hope this insight could help identify what's causing the phenomenon and design new treatments for MS.

Read more at [mssociety.org.uk/pregnancy-research](https://mssociety.org.uk/pregnancy-research)



# What's the risk of getting MS when it's in the family?

Sometimes more than one person in a family gets MS. And although genes do affect the risk of getting MS, they're not the only thing involved.

**Y**ou can see from the table below that the chances of getting MS do go up when someone in the family has it. But family members are still far more likely not to get MS. So MS is not passed directly through genes.

## What does cause MS?

We don't yet know for certain what causes MS. But it's likely to be a mix of genes, lifestyle and the environment we live in. Some combination seems to trigger MS. And that combination might be different in each person.

In all this uncertainty, there are potential risks we can't control – like our genes. Or catching extremely common infections like Epstein-Barr virus (EBV) until a vaccine is available. But others we might be able to change, like:

- getting enough vitamin D
- not smoking
- trying to keep a healthy weight.

These things could also help manage symptoms or progression if you already have MS.

## Get “enough” vitamin D

Low levels of vitamin D when we're children could increase the risk of developing MS. Vitamin D has all sorts of benefits including healthy teeth and bones.

The government recommends everyone older than one takes a supplement of 400 international units (IU) between October and late March. That's when we can't get enough of it from sunlight.

Doses of 4,000 IU a day are considered safe for most people over 11.

If you've got dark skin, or your skin doesn't see a lot

For every <b>1,000</b> people	➔ about <b>3</b> will get MS (997 won't)
For every <b>1,000</b> people who have a parent with MS	➔ about <b>15</b> will get MS (985 won't)
For every <b>1,000</b> who have a brother or sister with MS	➔ about <b>27</b> will get MS (973 won't)
For every <b>1,000</b> people who have an identical twin with MS	➔ about <b>180</b> will get MS (820 won't)



of sunlight, they advise taking a supplement all year round.

And vitamin D levels in newborn babies might make a difference to their chances of getting MS later in life. The Association of British Neurologists says women with MS of child-bearing age should

take a vitamin D supplement.

There's no evidence that very high vitamin D levels reduce the risk of MS. But your neurologist might suggest you take a higher dose than other people. They can also advise on the dose your family might want to take.

Read  
the latest on  
Epstein-Barr  
virus and MS  
on page 9

### Give up smoking – or don't start

Smoking increases the risk of MS and how fast MS gets worse. Breathing in other people's smoke can also increase the risk.

The good news is that if you stop smoking it slows down how fast your disability gets worse. And not smoking stops the risk of MS increasing for people around you too.

### Keep a healthy weight

Avoiding unwanted weight gain can be hard and living with MS can have an impact on that.

But there's research that suggests being severely overweight (obese) in early adulthood and childhood can increase the risk of MS. Keeping a healthy weight can also help with some MS symptoms, including pain and fatigue.

So a healthy weight could have many benefits.

learn

Read more about the causes of MS at

**[mssociety.org.uk/ms-causes](https://mssociety.org.uk/ms-causes)**. Read our diet booklet and online information at **[mssociety.org.uk/diet](https://mssociety.org.uk/diet)**. And watch our videos to help you stay active at **[mssociety.org.uk/exercising](https://mssociety.org.uk/exercising)**. Or call our MS Helpline on **0808 800 8000**



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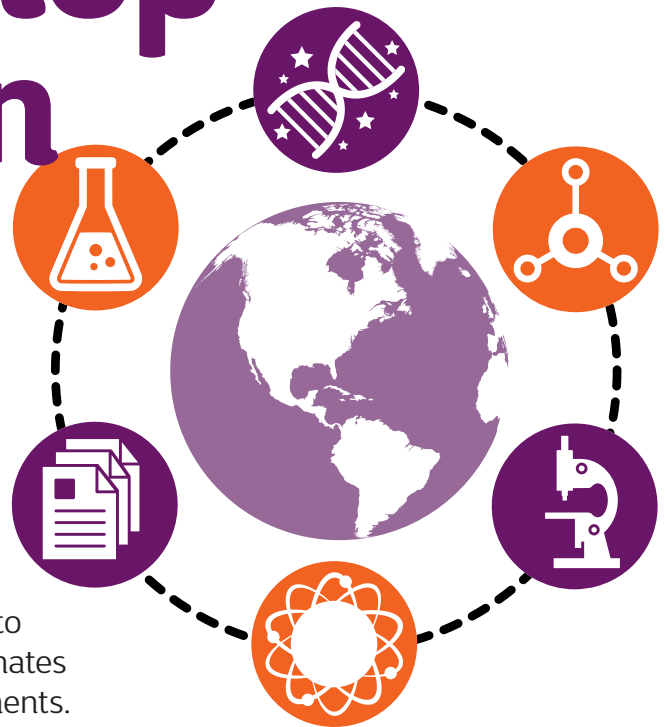
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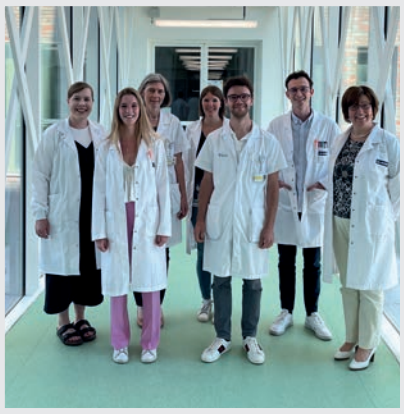
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# Meet the researchers uniting to stop progression

Researchers **An**, **Valeria** and **Simon** are thousands of miles apart. But they all share the same goal - to solve the mystery of what causes the progression of MS.



**A**ll three researchers work on projects supported by the International Progressive MS Alliance, which we're a founding member of. It supports researchers around the world to accelerate research into progressive MS. And it co-ordinates the global effort needed to find more and better treatments.



## Professor An Goris and team

"Our team is based at KU Leuven, the oldest and largest university in Belgium.

It's well known that people with MS all experience the condition differently. Everyone will have different symptoms and progress at different rates.

We think these differences could be caused by a type of brain immune cell called microglia. Their level of activity early on in MS could influence - and even predict - how someone's MS might progress.

So we're looking at disability scores from people over the whole course of their MS. And

using state-of-the-art lab technology to see if the type of immune cells they have could've influenced how their MS has progressed.

We might be able to use this knowledge to predict the course of someone's MS at the time of their diagnosis. And knowing which immune cells contribute to progression, and when, will help us fine-tune current MS therapies. It could even open up new potential treatment targets in the immune system."





## Dr Valeria Ramaglia

“People living with MS can experience major cognitive issues including memory problems. Within the lab of Prof. Jennifer Gommerman, our team looks at different

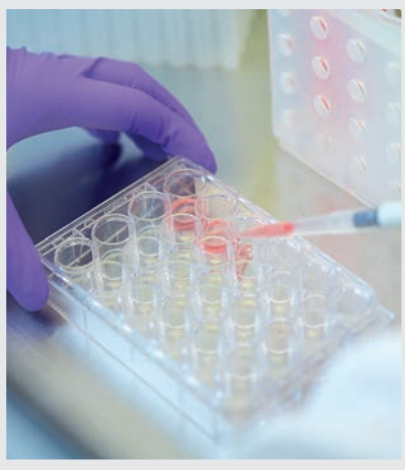
brain regions. This includes the hippocampus – an important part of the brain that allows us to remember things.

The hippocampus has millions of connections between its cells called synapses. These allow brain cells to talk to each other. But in MS we think the immune system mistakenly destroys these synapses, causing memory problems.

We’re using brain tissue donated by people with MS to uncover what triggers this destruction. New technology, called imaging

mass cytometry, is allowing us to look at brain immune cells in intricate detail. We also have extensive data from each brain donor. This allows us to link the amount and characteristics of their brain immune cells with other attributes of MS. For example how long they’ve had MS or the number of lesions in their brain.

If we identify which part of the immune system causes the destruction of synapses, we could develop strategies to prevent or reverse it. We have synapses throughout our brain, so it could help more than just cognitive symptoms of MS.”



## Dr Simon Licht-Mayer

“In our lab, we’re looking at a new way to protect nerves from damage.

When myelin (the protective coating around our nerves) is

damaged by MS, nerve cells need a lot more energy to survive. They need energy to try and repair and it takes more effort to send messages around the body.

During my PhD I found when myelin damage happens, energy-making structures called mitochondria move into the area. It’s a bit like giving the cell an extra battery pack. They give more energy to the nerve and can prevent further damage from happening.

We found a diabetes drug called pioglitazone could boost this

natural process and protect nerves in mice. Now we’re seeing whether it’s safe to use this treatment in the long-term. And, whether inflammation could change how well the response works.

I hope pioglitazone or other drugs that target this natural response of mitochondria prove to be effective in clinical trials. It could be used as an add-on therapy to save vulnerable nerve cells and stop the progression of MS.”

We’re making real progress for people with progressive MS.

Read more at [mssociety.org.uk/alliance](https://mssociety.org.uk/alliance)



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# Ask the experts

# MS and pain



Our MS nurses **Razia Khan** and **Jennifer McNeil** answer your questions.

## Q Can MS-related nerve pain affect any part of the body?

Yes. But if you have pain in one place it doesn't mean you'll have that sensation somewhere else. Some people experience nerve pain like pins and needles or burning sensations in different parts of the body. Optic neuritis can cause pain or discomfort in and around the eyes. And trigeminal neuralgia can cause pain down the side of the face.

The MS hug causes pain and discomfort around the chest and back. This can feel like a tight band around the chest area and sometimes causes pain when taking a breath. Some people experience Lhermitte's sign – a sudden sensation like electric shocks down the spine, arms and legs. This usually lasts for a few seconds and is triggered by bending the head forward. Muscle spasms can cause pain in the limbs due to involuntary tightening of the muscles.

## Q Are there prescription drugs that could help?

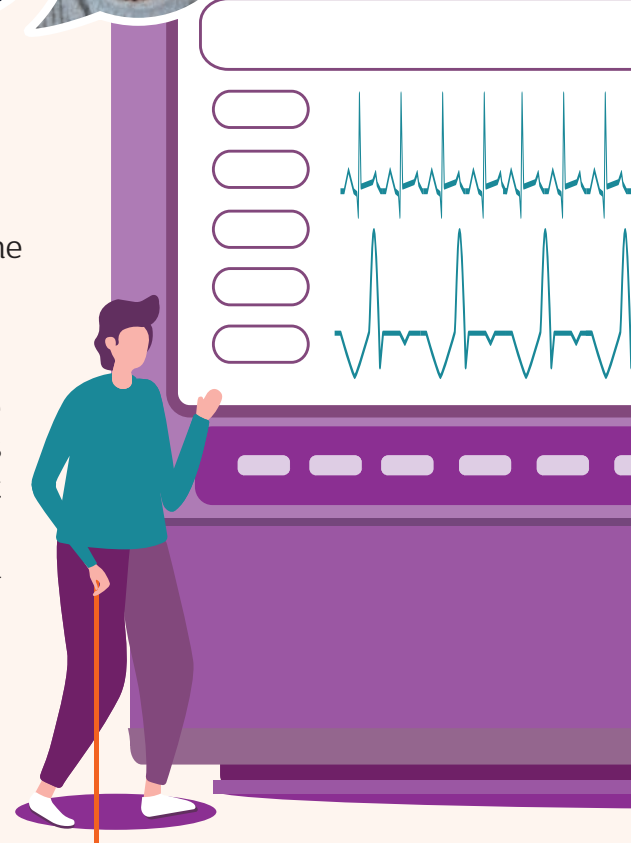
Anticonvulsant medications including gabapentin,

pregabalin or carbamazepine can be effective for nerve pain. And some antidepressants like amitriptyline and duloxetine can help too. Nortriptyline is another antidepressant that might be prescribed. If pain is part of an MS relapse, you might be offered steroids to speed up your recovery.

It can take time to get the best medication to manage symptoms as well as the correct dose. Your MS team or GP can advise you on the most effective treatments for nerve pain, the benefits and potential side effects.

## Q What does MS pain feel like?

MS pain can feel very odd and seem difficult to explain. You might not always think of it as "pain". Some people describe it as squeezing or crushing, cold or hot. Others describe it as a build-up of pressure, stabbing, creeping, like an electric shock, aching or like pins and needles. You may have a totally different description for your pain.



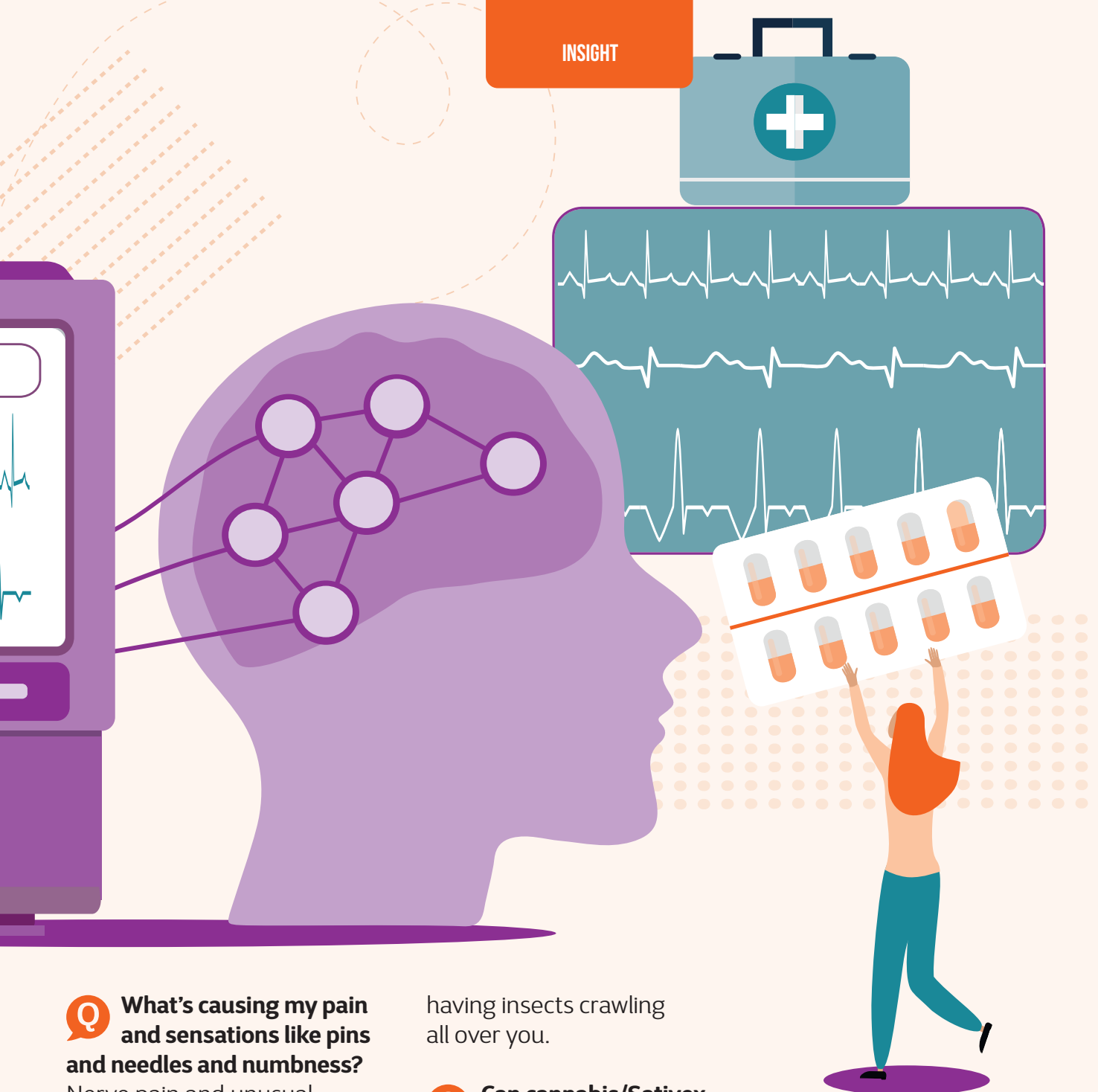
## Q Does MS cause joint pain?

MS can indirectly cause pain in the joints, bones, muscles, tendons and ligaments. It can happen because of the stresses and strains MS symptoms can place on the body. Speak to your MS nurse or GP as they might refer you for physiotherapy if necessary.

## Q Are there any triggers for pain?

Stress, heat sensitivity, cold sensitivity, fatigue, lack of sleep and feeling depressed can make the pain worse. So it's important to get support managing the pain and how you feel about it.





**Q What's causing my pain and sensations like pins and needles and numbness?**

Nerve pain and unusual sensations are caused by damage to the myelin sheath surrounding nerves in the brain or spinal cord. When the myelin is damaged, messages are disrupted. The brain can't interpret the messages it receives as they're outside its experience. To deal with this, it may interpret them as something your body has experienced before, such as itching, burning or pins and needles. Or it may relate it to a sensation you can imagine, like

having insects crawling all over you.

**Q Can cannabis/Sativex help with pain?**

Sativex is a licensed treatment and can be prescribed for muscle spasms and stiffness (spasticity). But NHS prescribing

is very limited and varies across the UK. It's not licensed for neuropathic pain or other MS symptoms.

**learn**

You can find out more about MS-related pain and treatments at [mssociety.org.uk/ms-pain](https://mssociety.org.uk/ms-pain) or from our MS Helpline **0808 800 8000**. The National Institute for Health and Care Excellence (NICE) has guidelines on managing neuropathic pain with drug treatments. Visit [mssociety.org.uk/neuro-pain](https://mssociety.org.uk/neuro-pain) to find out more and learn about our Sativex campaigning work at [mssociety.org.uk/sativex](https://mssociety.org.uk/sativex)

# A cognitive fingerprint of MS

**Annalaura Lerede** is a PhD student at Imperial College London. She told us all about the largest ever cognitive study in people with MS.

In clinical practice the standard way to assess cognitive (memory and thinking) symptoms is with a pen and paper. Testing is time-consuming and has to be done in person. So cognitive symptoms are often overlooked, despite up to 80% of people with MS experiencing them.

## The ultimate tool

Our team hopes to change the way cognitive symptoms

are monitored. We want to do things better and more efficiently. So we designed cognitive tasks that can be done on our online platform, Cognitron.

They're uniquely designed to test reaction time, processing speed, working memory, logic, and attention span.

Over 3,000 people with MS have tried the tasks through the UK MS Register, making it the largest study ever on MS cognition.

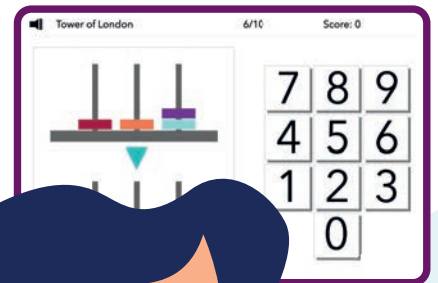
It's showing us which cognitive

symptoms people experience and it could help us predict how they change over time.

We'll pick the six most sensitive tasks and, ultimately, develop an online monitoring tool specific to MS. We hope it could be used around the world by people with MS and clinicians.

## A bigger picture

Some of these tasks were used to measure cognition in the general UK population. So we have so much data at our fingertips. We can compare the Cognitron results of someone with MS to somebody from exactly the same background, age, and gender who doesn't have MS.

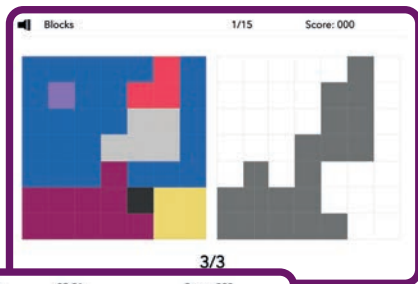


Annalaura Lerede

## A unique cognitive fingerprint

I'm still analysing the data, so I can't reveal too much yet! But what I can say is that we've identified a unique cognitive fingerprint of MS. It's recognised a pattern of cognitive symptoms unique to the condition. And it varies between different types of MS.

So I'm optimistic Cognitron could be used to help people with MS monitor their symptoms. And even help personalise cognitive therapies in the future.



## Sandy, who was diagnosed with MS 13 years ago, tested Cognitron.



About six or seven years ago I started noticing changes at work. I wasn't typing what my brain was thinking, even though I was sure I'd typed it perfectly. And I had some problems with my memory.

I started worrying I had dementia. Eventually, I mentioned it to my MS nurse and had some cognitive tests at the hospital. It was my MS.

### Trying Cognitron

Recently I tried Cognitron on the UK MS Register and gave feedback to the researchers. In comparison to the hospital tests, it's really quite short - around 40 minutes.

It asks questions about your MS first. Then it assesses your motor

skills so they're not confused with cognitive impairment. The other tasks are chosen at random. For example, trying to recall a number of words on the screen.

### Frustration likely

The tasks come with a warning. They can be frustrating, especially if you're competitive. And they can be tiring if you find it difficult to concentrate. After about 20 minutes, I wanted to stop.

But I think it's really important to get across it's not a failure, even if you want to stop after 10 minutes. The tasks are designed to take you to your limit. Anyone doing the tasks would eventually fail.

I'd like to try

it again, maybe in a year to see how things have changed. I think it'd be particularly helpful for newly diagnosed people. So it'd be good to see it integrated with the UK MS Register.

### Coping with cognition

Recognising and helping people cope with cognitive symptoms is so important. I've taught myself to slow down, take deep breaths and try and relax before I do things.

If cognitive impairments can be monitored more routinely with something like Cognitron, we could get more help adjusting to these changes. Rather than feel afraid, like I did at first.

Cognitron has now closed for recruitment. But we hope it'll be integrated into the UK MS Register soon. To find out more visit [mssociety.org.uk/MSregister](https://mssociety.org.uk/MSregister)

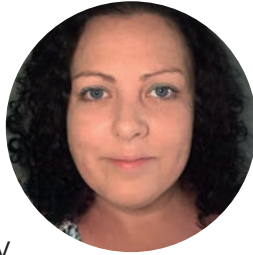
# The people you meet through living with MS

## Parents look out for each other

Tina McGonagle organises a parents group in Northern Ireland. It brings together parents and grandparents to talk about managing daily life, relationships and the ups and downs of MS.

Tina says: "When the group first began, my daughter was in primary school. Now she's ready for university. It's been lovely to meet people planning a family, through pregnancy to meeting their newborns. It's great to have a safe setting to share experiences, stresses and worries."

Find out more by emailing [nireception@mssociety.org.uk](mailto:nireception@mssociety.org.uk)



## Hundreds of new friends

Amy Thompson set up MS Together in 2019 after her diagnosis with MS at the age of 21. Now there are over 900 members and hundreds of friendships have been formed. Amy says: "MS Together is an incredibly positive, friendly and supportive place. We encourage all our members to live the best life they can."

MS Together supports people aged 18-35 living with MS in the UK through a website, private Facebook and WhatsApp groups, and meet-ups.

Find out more at [mstogether.org](http://mstogether.org) or on Instagram [@mstogetherofficial](https://www.instagram.com/mstogetherofficial)

## Men's Shed boosts wellbeing

Eirian Lewis from Narbeth in West Wales attends the MS Society Men's Shed. Men's Shed is an online meeting space for men in Wales living with and affected by MS.

"I've thoroughly enjoyed being a member of the Men's Shed. To be able to (virtually) get to know

other men who are affected by this cruel illness, and to share their stories, is immensely humbling. Not only that, but we have enormous fun. I've found it so beneficial, especially to my mental wellbeing."

Find out more at [mssociety.org.uk/wales-services](http://mssociety.org.uk/wales-services)

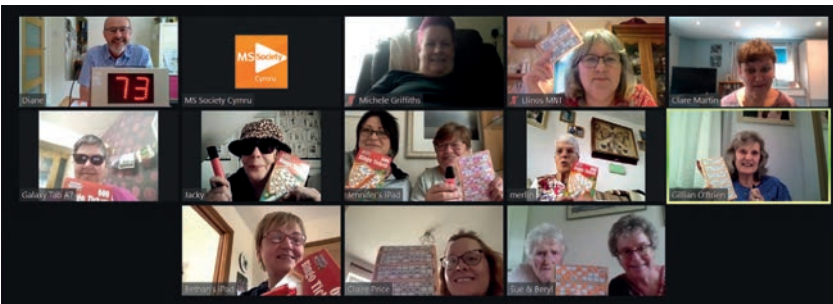


## Bingo evenings spark joy

At the start of the pandemic, not everyone knew what 'Kelly's Eye' and 'All the Threes' meant. Volunteers Brian and Diane Gist from Sully near Cardiff have changed that. They've hosted over 160 online bingo sessions for people across Wales, bringing much joy and laughter each week.

Janet says: "Everyone's really enjoyed the bingo and we look forward to a Monday. It's not only about the bingo though. We're meeting new friends on Zoom and that's helped us through isolation and COVID-19 worries."

Find out more at [mssociety.org.uk/wales-services](https://mssociety.org.uk/wales-services)



## Local group brings friends together

Best friends Wendy and Karen met through the MS Society group in Brentwood and Chelmsford. They supported each other through the pandemic and have been on several trips together, with more planned.

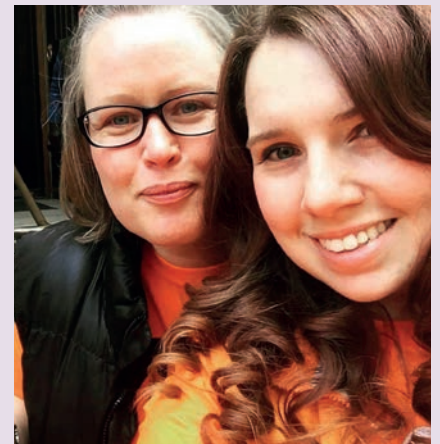
Karen says: "I met Wendy at our monthly pub social. We hit it off straight away and have bonded ever since. We got chatting that night and enjoyed each other's company so much that three months later, we'd booked a road trip together!"



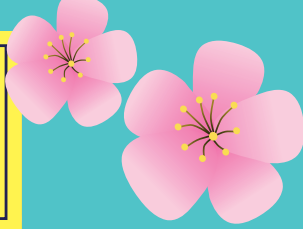
## Treatment buddies

Natasha and Lee-Ann met at Charing Cross Hospital in April 2014 when Natasha had her first dose of Tysabri.

Natasha says: "Lee-Ann could see how young and scared I was, and she totally put my mind at ease. Fast forward eight years and I'm almost at dose 100. Lee-Ann had her 100th dose recently, too. Later this year will be Lee-Ann's 10-year diagnosis anniversary and mine will be in November 2023. So next year we're planning a mammoth year of fundraising around the number 10!"

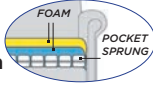


**join** Our local groups are on hand to provide friendship, support and information about MS. To find your nearest group, visit [mssociety.org.uk/local-support](https://mssociety.org.uk/local-support)



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# Children's book tells young carer's story

Femi's Story, by **Adam and Charlotte Guillain**, shows a young boy whose mum has MS facing some of his challenges. We asked them how they went about writing it.

## What was your main motivation for writing the book?

We wrote the book as one title in a series about four children who are in their last year of primary school. Each character has to face their own challenges and we wanted one of them (Femi) to be a young carer. We wanted his character to highlight what that means for a child and positively represent readers who are in that position.

## What approach did you take when writing it? How did you involve the MS community?

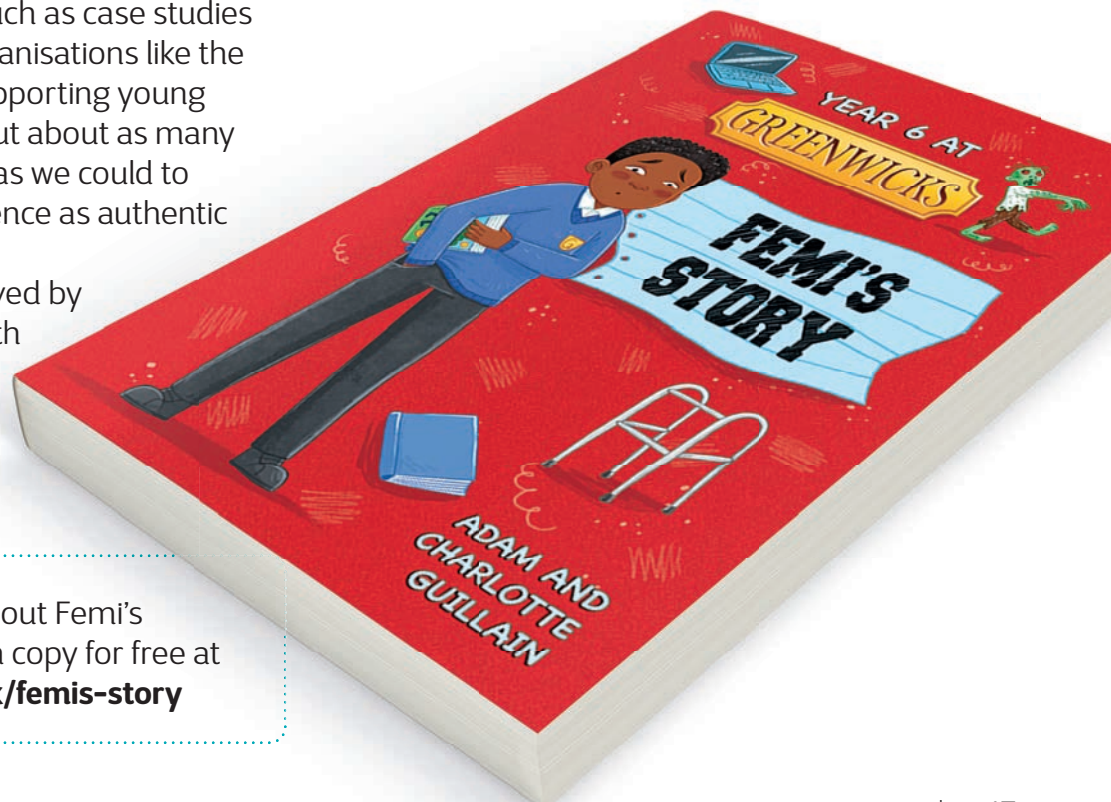
We relied on information, such as case studies and videos, provided by organisations like the MS Society and charities supporting young carers. We wanted to find out about as many different real-life situations as we could to try and make Femi's experience as authentic as possible.

We hope it'll be well-received by children who are familiar with Femi's situation. And by people who are finding out about MS for the first time.



## Some children reading Femi's story might be in a similar situation, and some may not. What would you like them to take away from this story?

We hope any child who reads about Femi will feel more empathy towards any friends or classmates in a similar situation. We want the story to make them stop and think about how they can support their friend. For any reader who relates to Femi, we hope they feel seen, appreciated and supported. And maybe even able to open up about something that's worrying them.



read

Find out more about Femi's Story and order a copy for free at [mssociety.org.uk/femis-story](https://mssociety.org.uk/femis-story)

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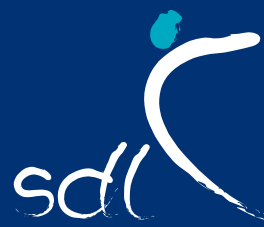


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## Meet our new Chair of the Board

Following an extensive recruitment campaign, we're pleased to announce **Professor Sir Paul Curran** will be our new Chair of our Board of Trustees.

Sir Paul started his career as a research scientist. He's a highly experienced chair and his most recent role was President of City, University of London.

Since his daughter's MS diagnosis, Sir Paul has developed a deep understanding of the condition. He has an empathy with and admiration for people living with MS, their family and friends.

A strong, effective and inclusive Board is important to our success and our ability to drive our strategy and plans forward. Sir Paul joined us in early July. He'll build on the exceptional contribution our outgoing chair, Nick Winser, has made to us over the past seven years.



Find out more about Sir Paul and all our trustees at **[mssociety.org.uk/trustees](https://mssociety.org.uk/trustees)**. Want to know more about how we recruit trustees and how you can take part by joining our Electorate? Find out more at **[mssociety.org.uk/board-and-council-recruitment](https://mssociety.org.uk/board-and-council-recruitment)**

## Volunteer spotlight

# Gary Rushworth



Gary, from Barrow in Cumbria, is walking 1,800 miles to raise money for the MS Society-funded Octopus trial.

My wife Moira was diagnosed with MS in 2002 and we sadly lost her in early 2020. I decided to do something in Moira's memory to make her proud. So I'm walking from Land's End to John O'Groats, and across the length and breadth of the UK, all in 100 days. Moira and I both had a love for walking, and it was one of the first loves that MS stole from her. This year will also mark Moira's 60th birthday and our 35th wedding anniversary.

It was heart-breaking to see her life painfully ebb away and finally be lost far too soon. I hope the walks will give me the opportunity to raise awareness of the needs of people with MS and raise funds for the MS Society and the Octopus trial. I want to help make it possible that what Moira and our family and friends went through doesn't happen to others.

Support Gary's 1,800-mile challenge by visiting **[justgiving.com/fundraising/walking-for-multiple-sclerosis](https://justgiving.com/fundraising/walking-for-multiple-sclerosis)**



# Getting to know you...

**Aoife** is a member of our Research Network and our research editorial board, which helps choose the research topics we cover and reviews articles in *MS Matters*.

## What's your day job?

I work as a parliamentary reporter in the Welsh Parliament. So I produce the official bilingual record of everything said in the parliamentary debates and other proceedings.

## Why did you join the Research Network and *MS Matters* editorial group?

The *MS Society's* publications were so useful to me when I was first diagnosed, and I wanted to use my skills to pay that support forward. I joined the Research Network because I think it's great to participate in the research that's so important to everyone affected by *MS*.

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

Being able to control the weather would be good. It'd be an ideal solution for climate change and my drying laundry would always be safe from rain!



## If you could travel in time where would you go?

I've watched far too many science fiction films to believe time travelling is a good idea. That said, I'd quite like to travel far enough back to see the dinosaurs stomping around. Either that or one week into the future for the lottery numbers!

## What's your greatest achievement?

I ran the Manchester

Marathon last year. I wasn't sure I'd be able to do it. But it's my proudest achievement simply because of the pure determination it took to get me there. Now I'm training for the London Marathon in October to raise money for the *MS Society*.

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

Sometimes things just happen and there's literally nothing you can do about it. Focus on what you can control.

join

### MS Matters editorial group

We're setting up a new editorial group for *MS Matters* to help shape the magazine and the stories we feature. To find out more, please contact [msmatters@mssociety.org.uk](mailto:msmatters@mssociety.org.uk) or visit [mssociety.org.uk/ms-matters-group](https://mssociety.org.uk/ms-matters-group)

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