

# This can't continue

Our Neurology Now  
campaign is calling  
for an urgent plan for  
neurology services

## Inside Rising stars

How we're  
helping to  
protect the  
future of  
MS research







Issue 139  
Autumn/Winter 2021

**I hope this magazine finds you well.**

It's been another challenging year for everyone, but there have been some wonderful highlights along the way – see a round-up of our favourites on page 14.

One of our current focuses at the MS Society is improving access to neurology services. It was a poor situation before the pandemic, and the last 18 months have made things even harder. We need a new plan for neurology, so that everyone can access the services they need. Read more about our Neurology Now campaign on page 18.

One person affected by the current state of neurology services is Sue who wrote to us in response to our star letter in the summer issue of MS Matters (read Sue's letter on page 6).

I want to personally say thank you to Sue and everyone else who writes in with feedback about the magazine and living with MS. It's invaluable for us to hear your views. Everyone's experience of MS is different, so it's a challenge to represent everyone in the magazine. But with your help, we can make MS Matters as inclusive and representative as possible. Thank you for your support.

Wishing you all a happy Christmas and New Year. I hope that 2022 is a simpler year for everyone.

**Nick Moberly**  
Chief Executive

Cover photo: Alex Grace



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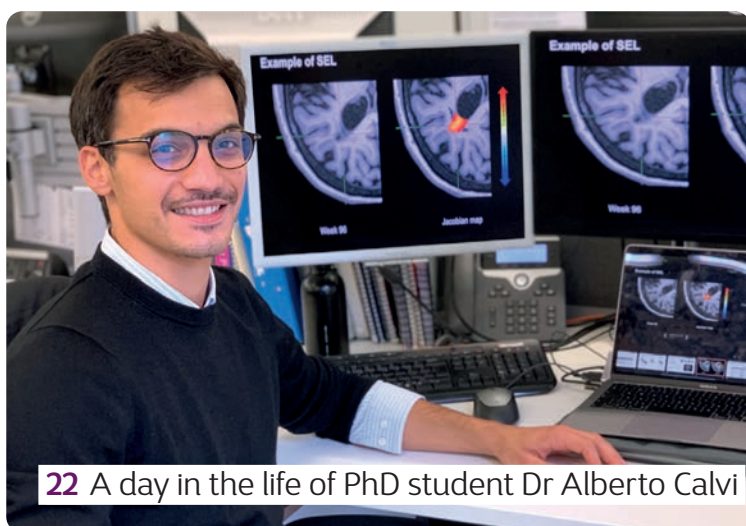
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### Send some festive cheer

With Christmas just around the corner, why not get ready for the festive season and buy your Christmas cards today? Check out our new designs for 2021 and buy your favourites at [mssociety.org.uk/xmascards](https://mssociety.org.uk/xmascards)



### Make your donation go further

Did you know that giving direct from your salary is one of the easiest and most tax-efficient ways of donating to our work? Because your donation is taken out of your wages before tax, if you donate £5 to us, it actually only costs you £4, or even less if you’re a higher rate taxpayer.

Find out more at

[mssociety.org.uk/payroll](https://mssociety.org.uk/payroll)



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# Your Letters



We had several replies to Wayne's letter in the summer edition of MS Matters, agreeing and saying that the magazine doesn't always feature relatable stories for people living with progressive MS.

Thank you to everyone who wrote in. Feedback like this is really important to us and we are working hard to improve the magazine and make it as inclusive as possible. Please continue to write in with your thoughts and suggestions.

## Where are the MS teams?

I find the incessant upbeat tone [of MS Matters] depressing.

Many articles end with: "Speak to your healthcare team/consultant." I've lived in three separate counties in England, and wherever I've lived, there's never been a 'team'. I haven't seen a neurologist for over five years and twice that for an MS nurse.

My last relapse caused my GP to ring the county hospital for advice every day for four days because nobody got back to him. On day five, he called the ambulance himself.

My contention is that MSers are not well supported. These 'teams' are not always available, and it's our GPs we rely on for help. Even they are unsupported, or have their hands tied by NICE or local NHS Trust prescribing rules. What GPs may freely prescribe in Yorkshire



is forbidden in Lincolnshire, for example.

The fight, as Wayne says, is exhausting, depressing and relentless, and all the while the MS is progressing.

- Sue

**MS Society** - We agree that it's unacceptable that people living with MS aren't always well supported. So we've launched a campaign, Neurology Now, about improving access to neurology services.

We've been in touch with Sue about her dreadful experiences, and we've spoken to others with similar experiences for our campaign.

Read more about Neurology Now on **page 18**. And see answers to frequently asked questions about neurology care, including how often you should see a specialist, on **page 20**.

## Help make fampridine available for us in England

I was entered into a drug trial for fampridine versus a placebo in 2016. Luckily, I was given fampridine with really good effect – so much so that I've continued to purchase it privately since then.

I find it very expensive at £575 every three calendar months, but consider it worth it as it really helps. I pay out of my occupational pension as I worked as an SRN/midwife for almost 40 years.

Can I ask you to help me campaign to make NICE approve the drug for prescription for us living in England? It's available on the

NHS in Scotland and Wales, but not in England or Northern Ireland. This is a grossly unfair situation, discriminatory to all of us in England.

- Jenny

**MS Society** -We agree that the differences in access to fampridine around the UK are grossly unfair.

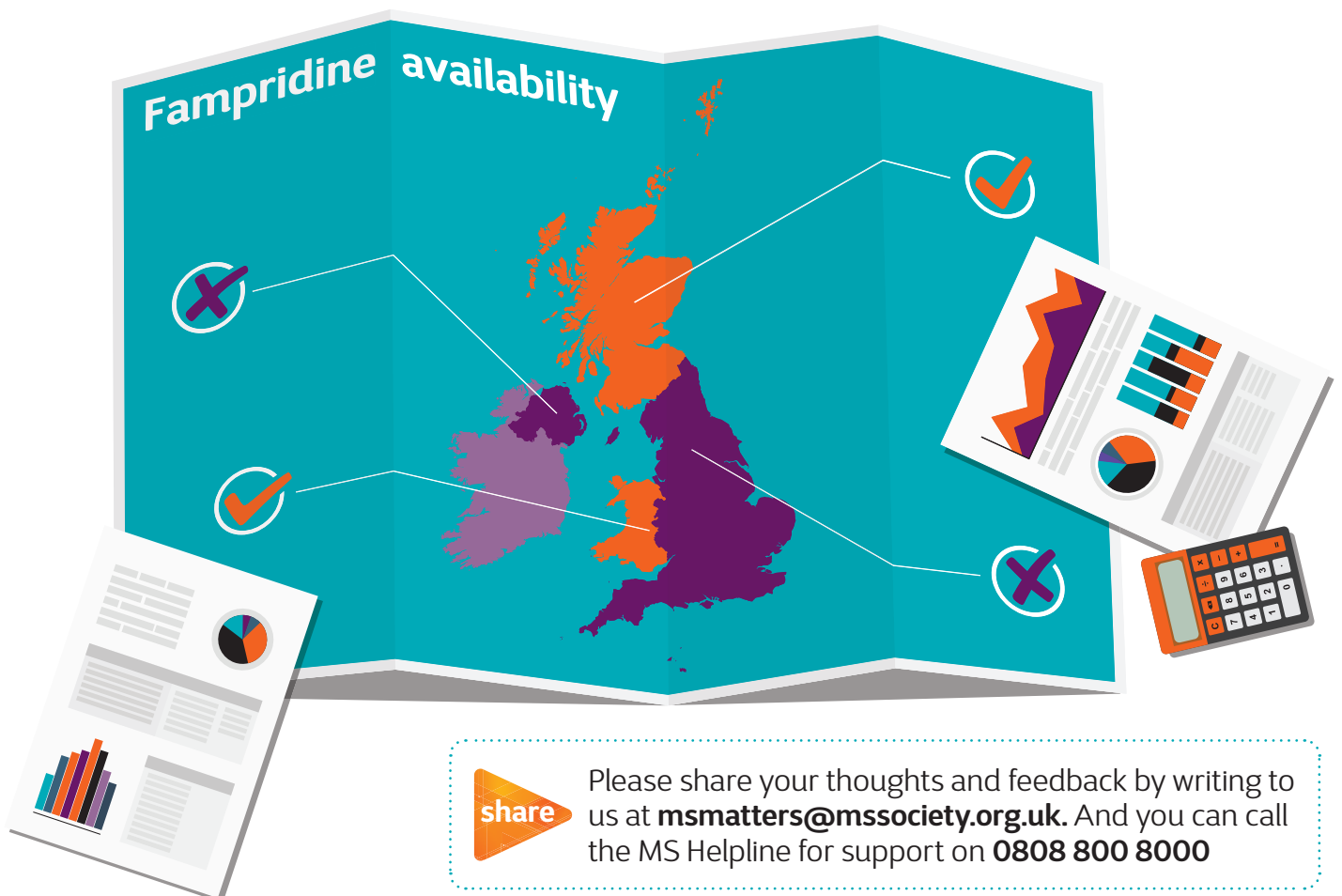
In 2014, the National Institute for Health and Care Excellence (NICE) recommended against the use of fampridine to treat lack of mobility for people living with MS. As a result of this, fampridine isn't routinely available on the NHS in England.

NICE is currently updating its advice, due to be published in July 2022. Biogen, the company who manufacture fampridine, have provided NICE with new data and real-world evidence on the effectiveness of the drug.

We'll continue to speak to NICE and Biogen regarding the update, which we hope will finally recommend fampridine for use on the NHS in England.

NICE recommendations about treatments are also reviewed by governments in Northern Ireland and are usually adopted.

We'll continue to work across the UK to ensure fampridine is made available to everyone that could benefit, no matter where they live.



share

Please share your thoughts and feedback by writing to us at [msmatters@mssociety.org.uk](mailto:msmatters@mssociety.org.uk). And you can call the MS Helpline for support on **0808 800 8000**

# We won't stop until we stop MS

In November, we're launching the next phase of our ambitious and bold Stop MS Appeal.

The message is simple: we won't stop until we stop MS. By 2025, we want to be in the final stages of testing treatments for everyone with MS. And over the build-up to Christmas and New Year, you'll see lots more Stop MS adverts.

Stop MS is our biggest ever fundraising appeal, and we're over halfway to our £100 million target. But we won't stop until we have treatments for everyone with MS. With your support, we can bring stability and hope for a brighter tomorrow.

We won't stop until we stop MS. Are you with us?



**Sasha, who has been living with relapsing MS since 2019, is one of the stars of our upcoming Christmas campaign.**

“My diagnosis came just after the birth of my youngest. It was really difficult. For a while, it took away the feeling that I'm a mum.

“Since starting treatment, I've got my life back. It's done amazing things for me.

“If we can get a drug that could stop MS, that would be amazing. I don't want anyone else to have to go through what I have.”



To find out more about the Stop MS Appeal, visit [mssociety.org.uk/stop-ms](https://mssociety.org.uk/stop-ms). You can make a donation at [mssociety.org.uk/wewontstop](https://mssociety.org.uk/wewontstop)

## Register your interest in Octopus

One of the projects Stop MS is funding is Octopus, our revolutionary mega-trial that will transform the way we test treatments for progressive MS. It'll provide a smarter way of testing multiple potential MS drugs up to three times faster than usual.

Later this year, we hope to announce which treatments Octopus will test first. And people will start taking part soon after.

In the meantime, the Octopus team are inviting people with progressive MS to register their interest in the trial. By registering your interest, you'll provide basic information, like your age, location and some details on your MS. The researchers will send you more information about the trial when they're ready to recruit participants. Register your interest to take part at [mssociety.org.uk/sign-up-octopus](https://mssociety.org.uk/sign-up-octopus)



# How we celebrated Black History Month 2021

Last year, in recognition of the Black Lives Matter movement, we renewed our commitment to equality, diversity and inclusion.

We're committed to sharing stories from everyone in our community, all year round, but Black History Month is a chance to celebrate and recognise the history, struggle and achievements of our Black MS community.

This year, the theme of October's Black History Month was 'Proud to be'. We shared stories from our community, including Ady Dike, who is one of our trustees, and Mary Phillip, ex-captain of the women's UK football team (read more from Mary on [page 43](#)).

And we also spoke to a researcher who's looking at which genes in people from African and South Asian ancestries might be linked to MS.

Read more on the blog at [mssociety.org.uk/your-blogs](https://mssociety.org.uk/your-blogs)



Mary Phillip



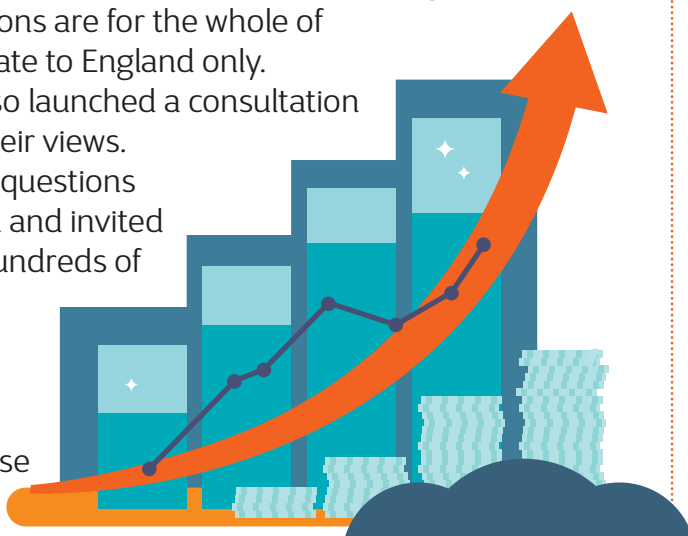
Ady Dike

## Plans to improve disability benefits

In July, the UK government released their long-awaited proposals to improve disability benefits, known as a green paper. Some of the suggestions are for the whole of the UK and others relate to England only.

The government also launched a consultation for people to share their views. We identified the key questions from the consultation and invited people to respond. Hundreds of you took part.

We've fed back your responses and are expecting the government's response in early 2022.



## £1.2 million into progressive MS

The International Progressive MS Alliance, which we're a member of, is funding 19 new research projects around the world. Three are being led by researchers in London and Scotland.

If your MS is progressing, it means some of your nerves are damaged. The researchers are exploring different ways to stop it happening in the lab. They're asking things like:

- Does the diabetes drug pioglitazone protect nerves from damage in brain tissue donated by people with MS after they pass away?
- Can protecting nerve cells from becoming dangerously over-excited help prevent their death?

### Dr Clare Walton, our Head of Research, said:

"There are some treatments emerging for early active progressive MS (where there are still relapses or signs of inflammation on MRI). But too many people still don't have any treatments to stop their MS getting worse.

"We believe we can stop MS. And by finding out what drives MS progression, these projects will bring us one step closer to finding treatments for everyone."

# Cricket helped me process my mum's MS

We chatted to our Ambassador **Felix White** about his new book, *It's Always Summer Somewhere*, and why raising awareness about MS means so much to him.



**F**elix is a musician, writer, and presenter of BBC Radio 5 live's Tailenders cricket podcast. In his new memoir, *It's Always Summer Somewhere*, Felix writes about the effect of his mother Lana's MS on the family as he grew up.

**The book documents your life and career through the central theme of your passion for cricket. Why did you decide to do that?**

It's about cricket and music, but mostly it's a story about loss. And about watching my mum get ill and then processing grief. That's really

the spine of the story.

I thought it was really interesting that I'd developed an affinity with the England cricket team in the 90s who lost all the time. This was while I was trying to process the more unthinkable loss of my mum getting more and more ill with MS.

**You and your brother Hugo have been supporting the MS Society since your band The Maccabees became successful more than a decade ago.**

It means so much to be able to do something tangible. Without thinking about it back then, it was about making something positive out of it.

**What would it mean to you to stop MS?**

It's too big a thing to answer, but it would be an unreal achievement. It would be testament to all the many people who struggled for it.



Watch the full interview at [mssociety.org.uk/felixwhite2021](https://mssociety.org.uk/felixwhite2021). Felix's book, *It's Always Summer Somewhere*, is out now.



# 2021 Highlights

It's been another challenging year, but 2021 has also been full of some incredible successes and highlights. From Paralympic medals to milestones in MS research, here are just some of the amazing things our community has achieved in 2021.

## First

### participant in ChariotMS

In August, 70-year-old Carol from Bromley became the first participant to join ChariotMS, a groundbreaking clinical trial we're co-funding. The trial will test if a drug called cladribine can slow down the worsening of arm and hand movement for people with advanced MS. ChariotMS is the first MS trial to focus on people who can't walk, and it's also the first with no upper age limit.

Carol lives with primary progressive MS and is an avid painter. She says: "It would mean so much to me, and reduce my anxiety, if there was a treatment that could help me retain limb function and slow down the progression of my MS.



"If there was a treatment that could preserve my use of my hands for painting, that would be incredible."

Find out more about ChariotMS at [mssociety.org.uk/chariotms](https://mssociety.org.uk/chariotms)

## 2,000

### people take action for Approved but Denied

This summer, we launched 'Approved but Denied', a new campaign to make sure people with MS in England aren't facing an unacceptable postcode lottery.

Sativex, a cannabis-based spray, was approved to treat moderate to severe spasms when other treatments haven't worked in 2019 in England. But our report found that it's only being funded in 49 out of 106 of England's local health bodies.

Over 2,000 people took action by contacting their local health body to call for change. We worked in partnership with the Daily Express, and also received support from members of the All Party Parliamentary Group for MS and our ambassador Janis Winehouse.

So far, as a result of our campaign, NHS England has listened to our concerns and wrote a letter to clinical commissioning groups (CCGs) in England, reminding them that the National Institute for Health and Care Excellence (NICE) recommended the treatment in 2019.

Join the campaign and read about access in other parts of the UK at [mssociety.org.uk/approved-denied](https://mssociety.org.uk/approved-denied)



# 3 Paralympians living with MS

British athletes living with MS inspired us with their fantastic performances at the Tokyo Paralympics in August and September.

Kadeena Cox proved unbeatable in the velodrome, winning two gold medals in the women's C4-5 500m time trial and mixed C1-5 team sprint, setting two new world records in the process. And on the running track, Kadeena gave a season's best performance, placing fourth in the women's T38 400m final.

Swimmer Stephanie Millward competed in her fourth Paralympics and made it through to three finals. And Dave Phillips reached the quarter finals of the mixed team recurve and men's individual recurve. He beat the world number one along the way.

Kadeena Cox



Stephanie Millward



Dave Phillips





## 2021 Fundraising highlights



## 7 stars join Team Stop MS

Lights, camera, action – Kit Harington, Rose Leslie, Andy Serkis, Scott Mills, Ainsley Harriott, Alun Armstrong and Ivo Graham have all joined #TeamStopMS!

We launched our star-studded campaign film in July to encourage people to get behind our Stop MS Appeal, which needs to raise £100 million to find treatments for everyone living with MS (read more on page 9).

# 300

## MS Superstars complete the London Marathon

Our amazing 300-strong MS Superstars team took on the biggest ever London Marathon in October. Over 100,000 runners took part in the face-to-face and virtual events. The donations are still coming in, but it looks like our team raised £600,000!



## 5 MS Walks

Congratulations to all our MS Superstars who walked, rolled or strolled to stop MS in 2021. As well as returning to London and Belfast, MS Walk also came to Bristol, Cardiff, and Manchester for the very first time.

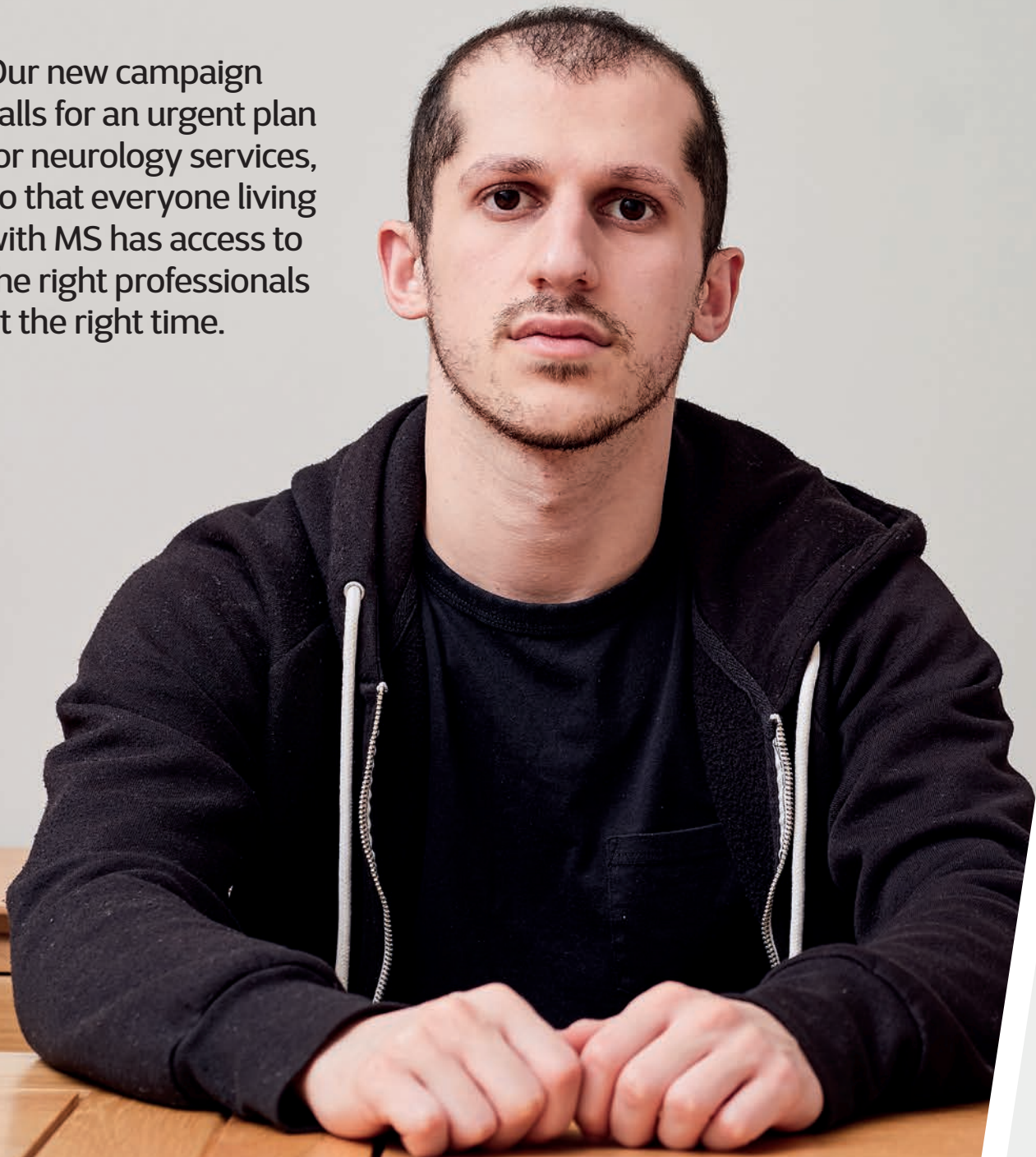
join

Find a fundraising challenge to suit you at  
[mssociety.org.uk/get-fundraising](https://mssociety.org.uk/get-fundraising)



# Neurology Now – this can't continue

Our new campaign calls for an urgent plan for neurology services, so that everyone living with MS has access to the right professionals at the right time.





One in every six people in the UK lives with a neurological condition. But neurology and MS services have been stretched, underfunded and overlooked for years.

Our Neurology Now campaign calls for an urgent plan for neurology services so that everyone with MS has access to the right professionals and treatment at the right time, across the UK.

The campaign highlights how services were neglected long before the pandemic. Many people with MS weren't getting the vital support they needed. And a new report we launched in October shows that things are even worse now.

Our research found that nearly a third (29%) of people living with MS had appointments cancelled or delayed due to the pandemic. People also reported worsening symptoms, with half putting this down to a lack of specialist support.

### Services under pressure

We know that healthcare professionals, like MS nurses, want to support people with MS – but there simply aren't enough of them and the backlog from the pandemic is huge.

It's recommended that MS nurses have a caseload of 315 patients, but almost all of them (over 90%) have more patients than this. We found that only 1 in every 10 neurology professionals felt their service could meet the

needs of patients, and many described their ability to provide MS care as very challenged.

### Campaigning for change

Since October, our campaigners have been signing our open letter to governments across the UK, sharing their stories, and inviting their MPs to a parliamentary event. Our open letter asked for specific actions in each nation of the UK because every nation is at a different stage of developing a long-term plan for neurology services.

We're also working alongside other organisations, including the Neurological Alliance, to call for change, and will continue to work together over the coming months.

## 29%

of people living with MS had appointments cancelled or delayed during the pandemic.

## 63%

of neurology professionals told us they find it very challenging to provide a good level of service to all their patients.

Source: MS Society survey 2021



Read more about the campaign and how to get involved at [mssociety.org.uk/neurology-now](https://mssociety.org.uk/neurology-now)



**Ayad, 24**, has had a difficult experience with getting support from his MS team throughout the pandemic.

He said: “Understandably, during the pandemic, it wasn't possible to have face-to-face appointments. But my condition was rapidly declining. To get through to the consultant was almost impossible because even telephone appointments were far and few.

“Unfortunately, over the course of the pandemic, I have gone from skipping daily to using a wheelchair daily. As much as I understand the pressures that the NHS has been through, I do somewhat feel like my MS team has failed me.”

# Ask the experts

## How to access neurology services

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



**Q You often talk about MS teams in MS Matters, but I don't know who my MS team is. The only person I speak to about my MS is my GP.**

Your MS team should be made up of various healthcare professionals who work together as part of a 'multidisciplinary' team. In other words, a team with different roles. Often, your team will include an MS nurse, neurologist, physiotherapist, occupational therapist, continence services, clinical psychologist, and speech and language therapist, although this will vary from person to person.

The other important member of the MS team is you, the person with MS, plus those who might support you. The professionals should help you play an active part in decisions about your MS treatments and management.

Your MS team will often liaise with your GP, but your MS nurse should be your main point of contact for any concerns or questions about your MS. If you don't have your MS nurse's

contact details, they are available on the MS Trust website where you can enter your postcode and find your local nurse ([mstrust.org.uk](http://mstrust.org.uk)).

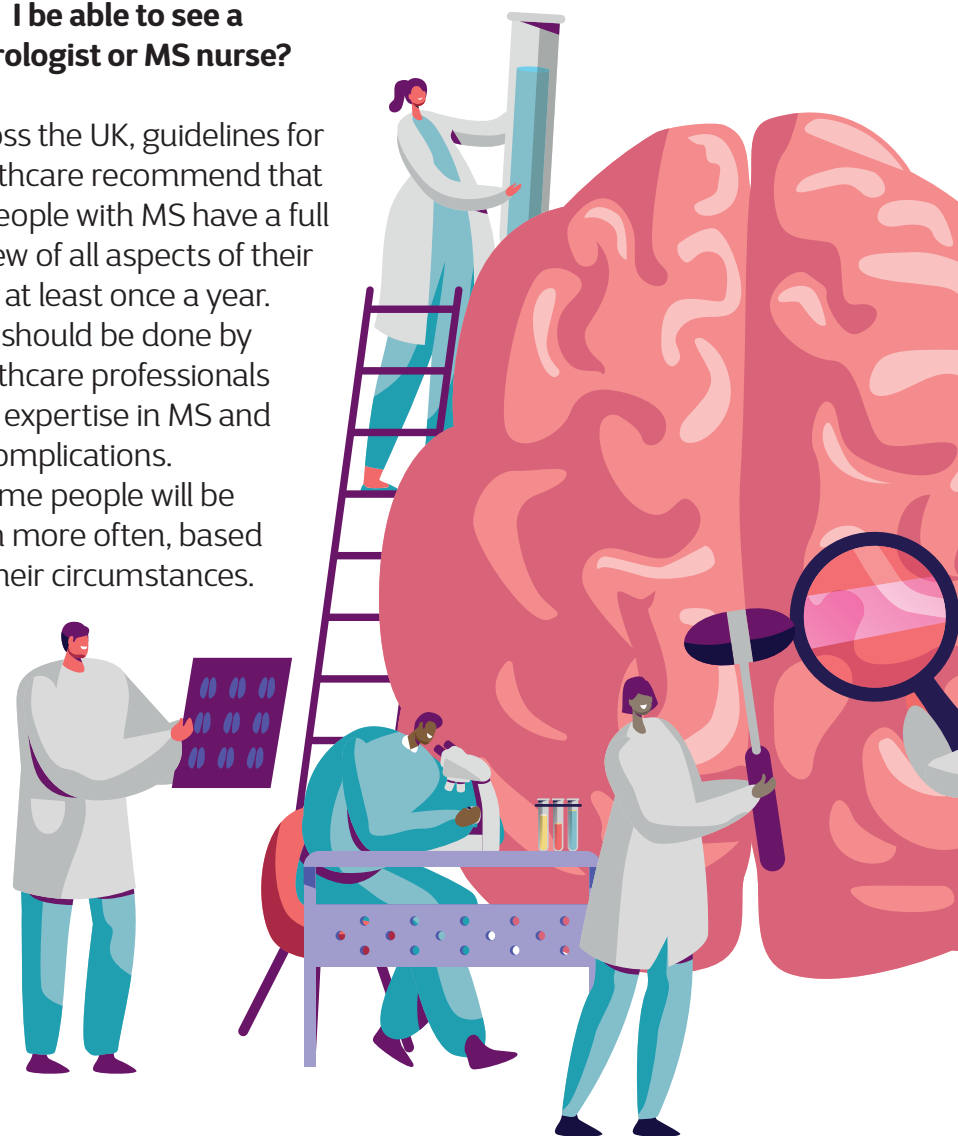
**Q How often should I be able to see a neurologist or MS nurse?**

Across the UK, guidelines for healthcare recommend that all people with MS have a full review of all aspects of their care at least once a year. This should be done by healthcare professionals with expertise in MS and its complications.

Some people will be seen more often, based on their circumstances.

**Q What should I do if I think I'm having a relapse?**

You can contact your MS nurse if you think you're having a relapse. During a relapse, you might get new symptoms, or your existing symptoms might get worse. Contact your nurse if the symptoms last for more than 24 hours and you've





previously had a stable period of at least one month.

If your relapse affects how you can do your usual tasks, your MS nurse or consultant should offer treatment as early as possible. This should be within 14 days of symptoms starting.

**Q I was diagnosed months ago but I'm still waiting to see a neurologist face-to-face to have a discussion about DMTs.**

Guidelines for England, Wales and Northern Ireland say neurologists should offer you a face-to-face follow-up appointment with an MS expert within six weeks of diagnosis. And in Scotland, a specialist MS nurse should be in contact within 10 working days of diagnosis.

Some treatments have been delayed to allow

### What we're doing to help

We know that not everyone is able to access the care they need, so we've launched a campaign to demand a better plan for neurology services.

Read more about the Neurology Now campaign on **page 18**.

people with MS to have the COVID-19 vaccine. But you're unlikely to need to delay if you're starting beta interferons, glatiramer acetate (Copaxone and Brabio), teriflunomide (Aubagio), dimethyl fumarate (Tecfidera), or natalizumab (Tysabri).

Your MS team can tell you how long it's likely to take to start your DMT.

**Q Is there anything I can do to self-manage my MS while I wait to start a DMT and see a neurologist?**

Coming to terms with your diagnosis may take time. But having good knowledge about MS and DMT options can help in your conversations about healthcare.

It can also be helpful to adopt a healthy lifestyle, such as managing stress, keeping active and eating healthily. If you eat a healthy, balanced diet, your overall health and quality of life could improve. This is even more important when your body has to cope with living with a long-term condition like MS.

**Q When should a GP make a referral to a neurologist? I have MS symptoms, but I've gone back and forth to the GP for months without a referral so far.**

In each UK nation, GPs have guidelines they should follow depending on the symptoms a person is presenting with.

Whatever the symptoms, your GP should give you clear information, talk with you about your options, and listen carefully to your views and concerns. They should explain what they suspect is causing your symptoms and what will happen next. If you need to see a specialist, they'll tell you how quickly you should expect to be seen.

**learn** You can find out more about accessing services, DMT options, diet and keeping active on our website **mssociety.org.uk** or from our MS Helpline **0808 800 8000**



## Future-proofing MS Research



We fund both current and future leaders of MS research, so we can be sure world-class **MS research** can continue for many years to come. In this issue, we're featuring some of the researchers we've supported, from PhD students kickstarting their research careers to senior lecturers and professors at the top of their fields. **Find out how they've been paving the way to a brighter future for people living with MS.**

# A day in the life of our PhD students

**Lavinia Austerschmidt** is a PhD student studying heat sensitivity in MS at the Blizard Institute at Queen Mary University of London.

**M**y name is Lavinia, and I'm a third-year cellular and molecular neuroscience PhD student.

My PhD research focuses on heat sensitivity. We've known for a while now that raising your core body temperature can make MS symptoms worse and cause new symptoms to appear temporarily. My work focuses on better understanding this mechanism.

For me, every day is slightly different as it depends on whether I'm doing experiments, analysing data on the computer, or writing up my PhD thesis.

### A morning in the lab

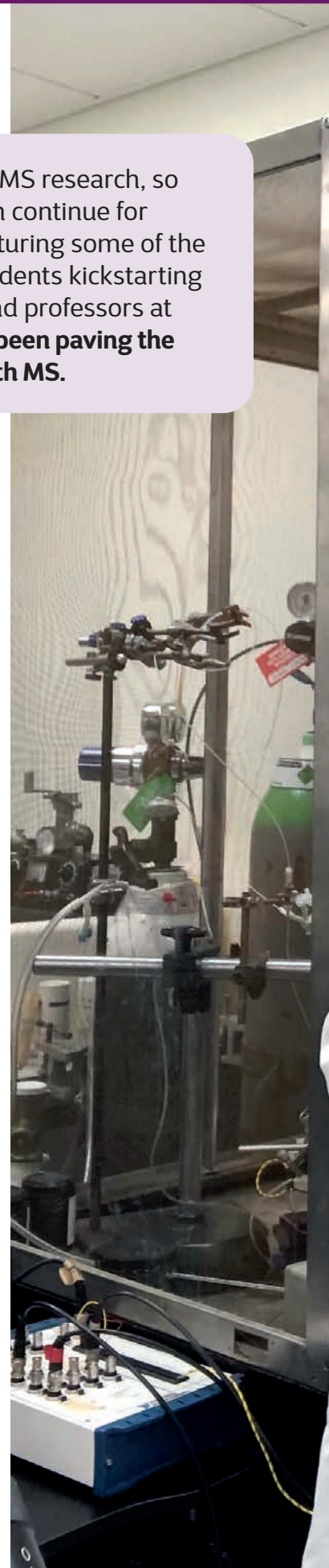
After I arrive at the university in the



Lavinia looking at nerve cells  
under the microscope

morning, I read over my protocol for the day, which tells me what I need to do for each experiment.

For example, today I had to isolate and grow some cells. The cells come from rats and are called retinal ganglion cells. They're interesting to me because they are







**Lavinia** is embarking on a research career with a PhD funded by the **MS Society**



Lavinia in the lab

part of the optic nerve, which allows us to see, and can be affected by MS.

### Testing a new theory

Our lab, which is led by Dr Mark Baker, has proposed a reason for heat sensitivity, based on observations in optic nerves. We believe that when it's warm, it becomes harder for messages to travel along these nerve fibres. So I study how optic nerves react to temperature changes.

Recently, I've been investigating how these cells from rats react to temperature using a microscope and a special fluorescent dye. The dye has the brilliant property of being able to move in or out of the cell. When I change the temperature, I'm looking to see if it changes how the dye moves. This tells me how temperature can affect how the cell is working.

### Time to go home

I usually end the day with a workout or a run. This helps me to wind down and get a good night of sleep before the next exciting day of research!

I'm very passionate about neuroscience research, and I particularly enjoy my PhD project because I want to help people with MS. If we can better understand the mechanism behind heat sensitivity, there might be the potential to find a treatment to target it in the future.



**Dr Alberto Calvi** is a neurologist doing his PhD at University College London.

**M**y name is Alberto Calvi. As a PhD student, I have a very intense day, filled with being curious, reading and researching MS. I think it's one of the most interesting topics in neuroscience.

My work is focussed on developing advanced MRI markers. These are things we can see on MRI scans that show if a treatment is working, and could improve how we test treatments in clinical trials.

In particular, I study what are called 'slowly expanding lesions'. These are areas of inflammation that can damage nerves, even when you aren't having a relapse. We think they may impact how people's MS progresses. I'm investigating how this type of lesion develops, by using the power of computers.

### Morning coffee and clinical trials

After a good espresso (or maybe more than one...) I start work. I dedicate half of my time to doing assessments with people taking part in clinical trials like MS-STAT2. There's a lot of work to keep trials going smoothly, with



Alberto analysing an image of a slowly expanding lesion

so many researchers and people enrolled.

I really enjoy collecting important data and spending time phoning participants to give any sort of support they need. My background is strongly linked with this element of my research, after my medical training in Italy. I enjoy spending time with

people with MS, explaining what my project is about. I learn so much from them.

### An afternoon of learning

The other part of the day is dedicated to analysing MRI scans and improving my knowledge on how this technology can help stop MS. Funnily enough, I have never





been good at dealing with computers so this challenge has pushed me to learn more skills.

I take part in video-training, teaching, and meetings with my supervisors and other researchers. I'm learning how to analyse complex data, to find the MRI markers that could be useful for future research.

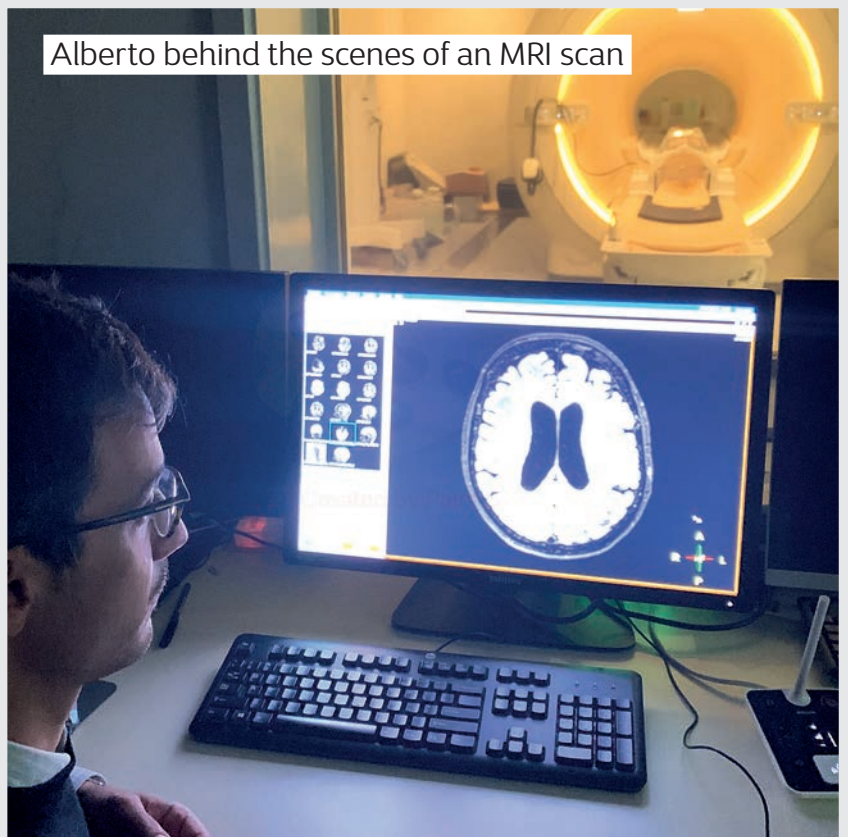
### Reflecting on the day

The day is only made of 24 hours, but after analysis and assessments, there is still some time to enjoy a good chat with the team about how we did and what can still be improved.

Sometimes a nice culinary reward is even achieved - once we had a meal cooked (a lovely masala curry) by a clinical trial participant to enjoy with the team.

I strongly believe in the connection among the worldwide MS research community. We have the passion to discover what's behind MS and to tackle it together.

Alberto behind the scenes of an MRI scan



# Can studying brain volume help understand the progression of MS in children?

**Dr Omar Abdel-Mannan** is a paediatric neurologist trainee at Great Ormond Street Hospital London.

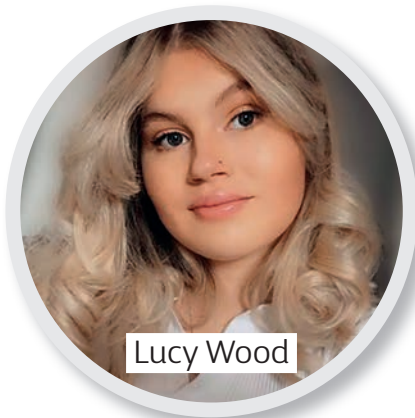
He's researching better ways to measure progression in childhood MS. **Lucy Wood**, who was diagnosed with MS at the age of 5, spoke to Omar about his research.

**A**round 5% of people with MS are diagnosed before they're 18. The condition presents different challenges for children, as changes in their brain are happening as they're growing.

After being diagnosed myself with MS so young, it was really interesting to chat with Omar. He spoke passionately about using his research to help young people with MS.

## How did you get into childhood MS research?

My father's a paediatrician,



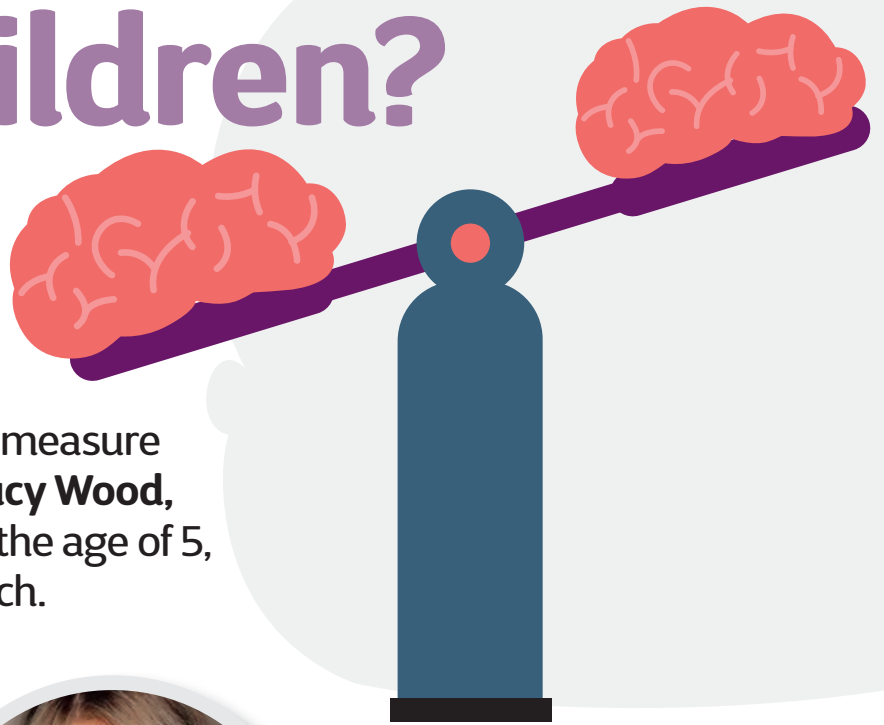
Lucy Wood

so he inspired my career initially, and I've always been fascinated by how the brain works. So combining these passions made complete sense! Newer drugs are appearing for MS, so I felt it

was an area of research with the potential to completely change the condition.

Children and adolescents with MS often have a more aggressive disease course - I've seen the impact it can have on my patients' quality of life. So I was keen to find ways I could help.

It took perseverance, but I now have research funding from the MS Society and the Association of British Neurologists to research what I'm most passionate about.





## What is your project about?

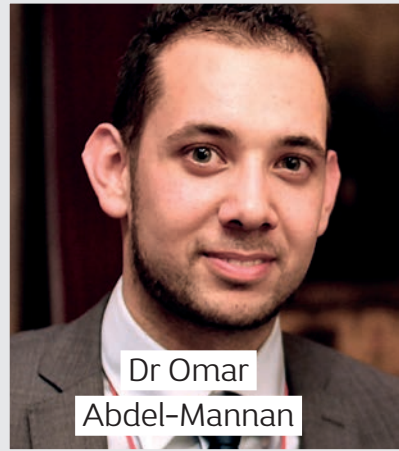
We're measuring brain volume (the size of the brain) in children with MS. By using newer MRI scanning techniques, we can look at the size of different areas of their brain, and compare them to healthy children.

Everyone's brain shrinks over time, but in people with MS it happens at a quicker rate. Research suggests loss of brain volume can be linked to longer term cognitive and physical problems in young people with MS. So there's a shift away from just looking at relapses, to looking at overall brain health and how we can prevent brain tissue loss.

I hope my project will help us understand how brain tissue loss affects young people and to see if it's a better way of assessing children with MS longer term.

## Why might measuring brain volume be better than how disability is measured currently?

Researchers and neurologists measure disability with something called an EDSS score, which involves looking at things like your mobility and co-ordination. This scale was developed for adults, so it's not as useful in adolescents. You wouldn't know the majority of young people I see in clinic have MS until they describe their symptoms.



Dr Omar  
Abdel-Mannan

**“Children and adolescents with MS often have a more aggressive disease course - I've seen the impact it can have on my patients' quality of life. So I was keen to find ways I could help.”**

There's a risk of thinking their MS might not be very active if we solely look at their EDSS score. There may still be new lesions, or more brain tissue loss, which there aren't physical signs of yet. So brain volume could give us a better indication of how well their disease is controlled.

## How could this help young people with MS?

We know the brains of young people without MS should grow until they're around



21, before natural tissue loss begins. So, if a patient is diagnosed young, there's a window of opportunity. If we find the right treatments, we could have a positive impact on their brain growth and their future. We need to ensure we're giving young people with MS the best possible outcomes and quality of life – and improving their brain health is the first step to this.

## Where do you think this research could lead to in the future?

My project is part of a much larger one that's looking at adults too. We're hoping to see a shift in day-to-day practice for all MS patients. Once we know how brain health affects people with MS and we can measure it, we can start to look at tailoring medication and new treatments.

In 5 to 10 years from now, I really hope we'll have treatments available that are targeted at maximising brain health and volume.

# Adjusting to life with MS

## A health psychologist's research



**Dr Angeliki Bogosian** is a researcher and Senior Lecturer in Health Psychology at City University London. Research Network member **Mary Douglas** spoke to her about her dedication to helping people adjust to a new MS diagnosis.

**A**ngeliki has been involved in MS research for over 10 years – ever since she came to the UK from Greece to do a master's degree in health psychology.

It was a revelation to speak to her about her research. Her work is different as it doesn't look at the physical aspects of MS, but the enormous psychological impact MS can have. She told me all about her research looking at the impact of being first diagnosed with MS, transitioning from relapsing to progressive MS, and how to cope with it.

### Impact of MS diagnosis on family

Angeliki's research career was



kickstarted with funding from the MS Society to do a PhD and then a research Fellowship. She interviewed the families of people with MS to see how diagnosis had impacted them. She found there can be a big difference between how the person diagnosed and their family members respond. Family can often feel isolated, wanting to look for support and

information, and to tell other people, straight away. Whereas sometimes the person with MS may want to learn to cope with their diagnosis in private.

Angeliki said there can also be feelings of guilt among family members. I remember when I was diagnosed, my mother immediately wondered if it was because of something she'd done, but of course it wasn't.

### Coping with a progressive MS diagnosis

MS comes with much uncertainty, which makes it even more challenging to adjust to psychologically. Angeliki told me how research has shown that people with progressive MS in particular are at higher risk of developing psychological issues, including anxiety and depression. So Angeliki's recent research has been looking at what people with





primary progressive MS can do to help them adjust to their diagnosis. After returning from a career break to have her two children, Angeliki is picking up where she left off and hopes to publish the results on this soon.

### Personalised psychological support

Angeliki said the more we discover, the more we can personalise interventions. Her plan is to use her research to create a psychological care package that can be adapted to people's personal needs. For example, some people might be dealing with uncertainty, while others might need social support. This aspect is important, as she explained the more tailored an intervention is, the more successful it will be.

There are many ways to approach a long-term health condition like MS, but Angeliki's fascinating work gives some very important insight and hope for the future.

### Angeliki's advice on adjusting to diagnosis

Angeliki said the better you're able to manage the psychological impact of MS, the better you're able to manage the physical impact. Here are just some of the tips she's discovered through her research:

- Take a flexible approach to issues and challenges – look at different ways of overcoming problems because some can't be solved in a practical way.
- Get involved with the MS Society and other organisations.
- Sharing your time and getting in touch with people (not only those with MS) can give a new perspective and bring enjoyment.
- Practice mindfulness and meditation – Angeliki's research showed this could reduce distress for some people.



Angeliki's research career was kickstarted with funding from the **MS Society**



# Can rehabilitation be effective in MS?

## Yes it can!

Research Network member **Pauline Knott** spoke to **Professor Jenny Freeman**, from the University of Plymouth, about her decades-long career researching MS rehabilitation.

**J**enny, a trained physiotherapist, developed an interest in research in 1993. Her spark for learning more on rehab resulted in a PhD conducting a first-of-its-kind trial testing the effectiveness of rehab in progressive MS. Now, nearly 20 years later, she's one of the top experts in the field.

### Right support at the right time

In that first trial, Jenny tested an in-patient rehab programme for progressive MS. She followed people for up to a year after they were discharged to see if the effects worked in the



long-term. She found rehab significantly improved both disability level and emotional well-being. But this declined over time, which shows how important it is to maintain a good rehab regime.

Since then, she's worked on all sorts of different MS

research projects, from testing the effectiveness of Pilates, to supervising a PhD student investigating falls. And thanks partly to her efforts, our understanding of MS rehab has come a long way.

For example, now Jenny's work as a physio focuses on a whole care package with targeted intervention. For example, she'll focus on aerobic fitness and strengthening at the same time, and involve other specialists, like speech and language therapists or occupational therapists. A bigger team can look at the whole range of needs for someone, targeting specifically what is right for them at that time. This means they can more realistically keep doing things successfully for themselves at home.

### Jenny's proudest moment

Jenny told me about the time she led research looking at the use of standing frames with a group of 140 people who were severely disabled. The project called SUMS (standing up in MS) asked people to use a frame to stand three times a week for 20 weeks.

It showed that regularly standing at home with a frame can improve strength and functional ability. It may also help with symptoms that could come from not being

### What is rehabilitation?

Some therapies, like physiotherapy, aim to keep symptoms under control and maintain function. Rehabilitation is an umbrella term for these therapies. The aim for rehabilitation is to reduce the impact of health conditions on a person's life.



mobile, like spasms. She's proud because this research has really improved the quality of people's lives. Six years on, people are still using their frame.

One aspect of rehabilitation Jenny has been interested in over the years is goal-setting, which is helping people figure out what is relevant and meaningful to them. Many rehabilitation activities take effort and persistence, so having that additional understanding helps Jenny to support her patients. She tells me of

Jenny has been involved with the **MS Society** for 20 years

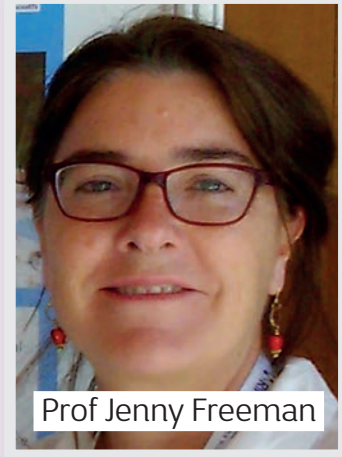


### A physio's top tip

Jenny's advice to me was to work at a level that moderately challenges myself with physical activity. This would be completely different for each individual. If it gets easier, then challenge a bit more. And crucially, adjust that activity according to your own daily or weekly pattern. On a good day, challenge yourself a bit more. On a bad day, a bit

less. And always keep doing it, so that exercise becomes a habit. Do something you enjoy. The main thing is sticking at it.

It left me inspired to revisit my goal to walk for 30 mins every day. How I feel each day will dictate the speed, but I will get out and not feel guilty that I'm walking slowly.



Prof Jenny Freeman

a father who took part in the SUMS study, wanting to use his standing frame to walk his daughter down the aisle - a clear goal and deadline.

She says things like this make it so much more rewarding as a researcher and therapist. You find out what makes people tick, and if you can help them achieve their goal there's nothing more satisfying.

### And the next big thing?

Jenny is working on a multi-centre trial called CogEx, looking at how rehabilitation can help people with progressive MS who have cognitive symptoms, such as problems with

memory. The programme is looking at the effectiveness of exercise and cognitive rehabilitation, and whether they work better independently or together. It's the first international study of its kind, with six countries involved and 360 participants speaking four different languages.

Jenny says her work benefits from shared experiences within healthcare and learning from others. The massive progress neurology has made with disease modifying therapies for MS is very exciting. But listening to Jenny has certainly convinced me that this should be coupled with effective and continuous rehab for symptom management.



# Let's talk MS

Talking about MS can be hard. So we said #LetsTalkMS and invited stories from our community. Here are three of the people who got involved.

## Jo, 40, from York is living with primary progressive MS

I've always been really open about my MS. It's been a bit of a balancing act because, on the one hand, I don't want my MS to define me. On the other hand, I think people need to know I have MS in order to get to know me and understand me properly.

My husband knows everything that I'm going through, I told my friends right from the beginning, and I've always been really open with my kids too. They're 11 and 8, so it's all they've known.

When they were little, we'd say things like: "Mummy's a bit wobbly!" Now they're bigger, they understand a bit more about what MS is. I do worry about them googling MS though, because they might read things that are untrue or scary – or see stories about people who are affected differently to me.

As my condition has progressed, I've actually found it easier to talk about my MS. When I started using a walking stick, it was a relief, because beforehand I would get really wobbly and worry people were looking at me thinking I was drunk.

I'm a teacher and I remember it was a really big deal when I walked into the classroom with a stick for the first time. The kids asked: "Miss, what are you doing?" But after their initial surprise, they were very accepting. I needn't have worried.

I'm much better at speaking up now, I've gained confidence over time. I've never really had an awkward conversation about my MS – I think sometimes you build it up in your head and think people will react badly, but then in reality it's always been OK.

**"I think people need to know I have MS in order to get to know me and understand me properly"**





## Stewart, 74, from Somerset is living with progressive MS

My sister died at 65 from complications of a more severe MS than mine. I was diagnosed a year before her death. It was really scary because I could see what she was going through with seemingly the same condition.

At first I didn't want to tell people as a matter of pride. There are some people who view people with disabilities as inferior or not quite whole. I mainly just told my family, and to others described it as having a 'designer limp'. I've had to start being more open about things as my MS has progressed. I use a walking stick almost all the time, so it's a lot more obvious.

I lost my daughter in a car accident when she was 18, and I find that the issue of bereavement is very similar to MS, in the sense that people don't know how to talk about it. I think it comes from embarrassment and a lack of knowledge. Sometimes they just avoid you because they want to avoid the topic. Very few people are prepared to listen. Then there are some people who try to do too much for you, and although very kindly meant, I don't need it.

As far as some people are concerned, there's only one type of MS, and they think it always becomes fatal. I want people to



**“I want people to understand that MS isn't always severe”**

understand that MS isn't always severe – mine is progressing slowly, so I'm able to live my life and do a lot of things. I can't do everything that I want to do, and there are limitations, but I adjust to what I can do.

### Our survey

We spoke to 800 people living with MS and 35% told us they've kept their diagnosis a secret.



## Bayan, 25, from Sutton is living with relapsing MS

When I was first diagnosed, I met this guy with MS who was a bit doom and gloom – he told me that after a relapse you never recover to where you were before. He suggested I join some Facebook support groups, and the very first post I ended up seeing was from a guy whose brother had passed away from MS.

I went into a downwards spiral at that point, thinking: ‘Will I ever be able to find a wife and have kids?’

Then a uni friend mentioned a support group for young people called MS Together. I joined and it completely flicked a switch in my brain. I remember seeing a post from a girl saying her MS had actually made her healthier, because now she was being much more careful about her diet. It changed my perspective and made me see things in a much more positive light.

I was really nervous about telling friends and family, but I used some MS Society leaflets to explain it and had a bit of a script in my head. It was quite stressful at the beginning and I felt like I was ‘coming out’ as having MS, but ultimately it helped me relieve pressure on myself.

I’m not actively looking for a relationship at the moment



“I felt like I was coming out as having MS”

because of coronavirus, but I do worry about how it might impact future relationships. I worry about when’s the right time to tell someone you’re seeing that you have MS. I hate the idea of being considered a liability or being the one in the relationship asking for help.

I think when the time comes, I’m going to be as open as possible right from the beginning – if someone can’t accept my MS then it’s better to know early.

share

Read more on talking about MS

on our website at [mssociety.org.uk/talking-about-ms](https://mssociety.org.uk/talking-about-ms). And you can also read more **#LetsTalkMS** stories at [mssociety.org.uk/lets-talk-ms](https://mssociety.org.uk/lets-talk-ms)

If you have a story to share, please contact us at [msmatters@mssociety.org.uk](mailto:msmatters@mssociety.org.uk)



# How I keep going

**Elaine Moore** shares her thoughts on coping with the stresses of progressive MS.

**E**verything about MS is unpredictable, so it isn't surprising that depression and anxiety are common. And it isn't just the MS-person, it's those close to them, their friends and family, who are also challenged by the illness.

Perhaps it's because of this that I often say "I'm fine" even when I'm not. Most of my symptoms are invisible, so it isn't too hard to put on a performance when I see people, and then pay a price later in private.

## Group support

I follow an MS support group on Facebook and I regularly see posts from people who are struggling to cope with all aspects of their MS. Many posts mirror how I feel about my loss of independence and the relapses that put 'normal life' on hold for a while.

But one post made me very sad. It was from someone who felt they were 'surviving not living' and seemed to be considering assisted dying. The question was asked (not for the first time), why can we put pets out of their suffering but not ourselves?



So, do I ask myself if life is worth living? Yes. There have been times when I didn't want to end my life, but wanted to go to sleep and not wake up. No, it doesn't make sense, but there you go. Fortunately, these days, it happens very rarely.

## Dealing with uncertainty

I know that life is not going to get any easier. I know I have an uncertain future. I know that, due to the unpredictability of MS, I will sometimes make arrangements and have to cancel them (but please don't stop inviting me). I also know (hope) that my current MS relapse won't last forever.

Without wishing to alienate other MS-people and

come across as completely insufferable, I know that a positive mental attitude is essential to what keeps me going. Well, that and my husband. And humour.

Read more on Elaine's blog: [wheellife.co.uk](http://wheellife.co.uk)



If you're affected by any of the issues raised in Elaine's story, our MS Helpline can provide emotional support. Call **0808 800 8000** or email [helpline@mssociety.org.uk](mailto:helpline@mssociety.org.uk)



# “Every week we have a laugh about something”

Laura, 40, was matched with Kimberley, 36, to give a weekly support call as part of our befriending scheme in Wales. Both women are living with relapsing MS.



I wanted to get involved because the MS Society has given me so much. I heard about befriending, which I could do over the telephone from the comfort of my own home.

I thought I was going to help somebody else, but I've got so much out of it myself.

I really look forward to our calls. Every week we have a laugh about something. I've learned a lot and I take something away each time we speak. It's definitely two-way traffic.

**Laura**



I like to talk to people. I do my dad's head in as he's the only person here. I thought: "How nice would it be to connect with somebody else who knows what you're going through and you can talk to about whatever?" It's really helped me and it brightens up my week.

I'm the youngest in all the MS groups I go to. I get on great with people of all ages, but it's nice to be in contact with someone my age. We couldn't believe that we were living just around the corner from each other, and we have so much in common.

Instagram is such a big part of both our lives. We post about living with MS and our animals who support us.

**Kimberley**



Laura is a volunteer with our National Lottery

funded Pontio project, which provides emotional, befriending and one-to-one support for people living with MS in Wales. If you're interested in being a Pontio befriender or would like a support call, contact **sophie.dyment@mssociety.org.uk** We also have a befriending service that covers the whole UK. You can find out more at **mssociety.org.uk/befriending**

You can follow Kimberley and Laura on Instagram at **@bella\_the\_beautiful\_warrior** and **@saluki\_life\_southwales**





## “I focus on what I can do”

Mary Phillip is a former English international footballer and England captain. She's now a voluntary manager and coach at Peckham Town FC. Mary was diagnosed with relapsing MS in 2017.

I'm still an active person, but every time I relapse it takes a small part of me with it. I've had to accept that I can't run as far as I used to, and I can't lift as much weight as before.

My advice on staying active with MS is to work with the body you've got. It's about adapting and setting realistic goals. Perhaps you can't push yourself as far as you used to, but there will still be a type of exercise out there that works for you.

I focus on what I can do – I can still manage a light jog, and I walk and cycle as much as possible. I also took

up yoga, which is so good for the mind and body.

For me, the worst thing would be to stop exercising altogether. I feel like a part of me is gone when I'm not keeping active. I have to find ways around things – if there's a will, there's a way.

I know my body better than anyone else and I know how far to push myself.

Read the full post at [mssociety.org.uk/mary](https://mssociety.org.uk/mary)

Mary's blog struck a chord with many of you on Instagram.

 [@annie4life](#)

“I have RR [relapsing remitting] MS and I play women's walking football at my local club. It's great and I get such a buzz after training and taking part in tournaments. I am so thankful it's a sport I am able to enjoy and participate in.”

 [@rach\\_mswarrior](#)

“I love being active, but after my diagnosis last year, I get comments about how I shouldn't exercise so much. Some people just don't get how much being active means to others. Stories like this give me hope for my future self.”

 [@artistatno4](#)

“I take inspiration from you and I'm sure others will too. We cannot cure our disease but we can support each other to get through this.”

Explore ways to keep active with MS at [mssociety.org.uk/keeping-active](https://mssociety.org.uk/keeping-active)



### Are you a budding blogger?

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



# Can diet help my fatigue?

New research suggests two diets high in fruit and vegetables and low in processed foods have positive results for some people with MS.

**N**ew research into the Wahls and Swank diets suggests they could help with fatigue. In the six-month study, people with relapsing MS on both diets felt less fatigued.

These two diets are high in fruit and vegetables and low in processed food, and people in the study took certain supplements too. They also had support from dietitians to help them stick to the diets.

There's not enough evidence to recommend these or any diet for everyone with MS. But lots of people say they feel better on a particular diet.

For more about this research, visit [mssociety.org.uk/diet-research](https://mssociety.org.uk/diet-research) or call our MS Helpline on **0808 800 8000**.



## Tips for managing fatigue

**Whether or not you follow a special diet, these tips might help you manage your fatigue.**

- Eat small, frequent meals and snacks rather than large, hot meals.
- Starchy carbohydrates, like potatoes, bread and pasta, can give a slow release of energy to keep you going for longer.
- Drink plenty. It doesn't just have to be water. Tea, fruit teas, and coffee can all help you stay hydrated. There's no evidence that moderate amounts of tea or coffee will make you dehydrated. Though too much caffeine can leave you feeling more tired after the initial 'kick' wears off.
- Some particular nutrients might help with fatigue if you include them in your usual diet, including iron, selenium, folate and B vitamins. If you take supplements, remember high doses of certain vitamins can sometimes be harmful.

A dietitian can help make sure you get the nutrients you need in your meals. And MS nurses, doctors, physiotherapists and occupational therapists might all help you find ways to manage fatigue.

learn

There's more about food and drink in our free booklet 'Diet and nutrition'. Order at [mssociety.org.uk/online-shop](https://mssociety.org.uk/online-shop) or call **0300 500 8084 (option 4)**. And you can try our online MS fatigue management course at [mssociety.org.uk/fatigue-online](https://mssociety.org.uk/fatigue-online)



# Join our online wellbeing sessions



Our self-management wellbeing sessions are a safe and friendly space for people to chat, share and reflect about their experiences.

## “I immediately felt like I’d found my tribe”

**Rhian Lewis from Cardiff explains how she found the support and community she needed at one of our online wellbeing sessions.**

When I was diagnosed with relapsing MS in 2018, I really struggled to find support that suited me. I didn’t know what to expect after diagnosis, but thought the NHS would automatically offer me support. When that didn’t happen, I presumed there was no support for actual life with MS.

A friend recommended the MS Society’s newly diagnosed sessions, and during the first session, I immediately



felt like I had found my tribe.

I was treated for depression and complex PTSD in 2020, but my life didn’t start coming together until I started attending the MS Society sessions. I immersed myself in art therapy, which was a technique suggested in the sessions.

Being able to do these activities over Zoom rather than in person, which wasn’t always possible for me, made life so much bigger and really allowed me to come to terms with my diagnosis.

I keep describing how I feel now compared to my first MS Society meeting as ‘like night and day’, which is true, but honestly something I never thought I’d be able to say.

## Dates for your diary

### ● 20 December: Friends and family time to chat

A monthly virtual session for the friends and family of people living with MS to chat with others across the UK.

### ● 21 April: Research information webinar

A chance to hear about the latest MS research.

join

Find out more and sign up at [mssociety.org.uk/virtual-support-events](https://mssociety.org.uk/virtual-support-events) or call **020 843 8083**

# Fundraisers travel the UK to stop MS

The journey from Land's End to John O'Groats is a fundraising classic and MS superstars have been tackling the 874 miles to help stop MS – all in different styles.

Cyclist **Richard Sanderson** raised over £2,000 for his challenge, which was the furthest he'd ever cycled. Over the years, Richard has raised £11,000 and has previously completed 200-mile challenges around his home county, Fife.



**Mark Parsons** and his 13-year-old son Jack from Flintshire also cycled the route, starting on one of the hottest days of the year. They even cycled the whole way back. Mark and Jack raised over £7,000 to support people living with MS.



And finally, **Louis Ware** added some style to his journey, walking the route while wearing a kilt. He also climbed Snowdon, Scafell Pike and Ben Nevis along the way. Louis raised over £7,000 and completed the challenge in memory of his grandad who lived with MS.



## Dates for your diary

Ready for a challenge? Take part in one of our events and help us get closer to stopping MS.

### 27-28 November

#### Game Over for MS

Are you or your family members into video games? Get involved in the Game Over for MS marathon weekend.

### 5 December

#### Santa Skydive

Add a festive twist to your leap of a lifetime – jump from 10,000 feet in your free Santa suit. Choose from one of five locations: Salisbury, Brackley, Nottingham, Norwich and Brigg.

### 27 March

#### Cardiff Half Marathon

Join 25,000 runners through the heart of Cardiff. The flat and fast route is ideal for beginners.

### 3 April

#### London Landmarks Half Marathon

Take in all the sights of the capital on this friendly closed-road run.

### 29 May

#### Edinburgh Marathon Festival

Be part of Scotland's biggest running festival, with a fantastic atmosphere and distances to suit all abilities.

Visit [mssociety.org.uk/get-fundraising](https://mssociety.org.uk/get-fundraising) or call **01382 279378** for up-to-date information and to sign up. Due to COVID-19, events may be subject to change.



# Expressing myself through poetry

**Richard Millis** was diagnosed with secondary progressive MS while he was at university. His poem 'Me and MS' explores his experience of living with a condition he'd once only heard about in lectures.



**Richard said:** "Writing is beneficial to my wellbeing. I like to write about myself, my feelings, what I'm going through. They are emotive subjects.

Expressing my feelings through the written word relaxes me and enables me to say things that I wouldn't normally. My advice to others writing poetry is to release the mind and write what you think. You can always delete it and write again."

## When I was at school

I certainly was no fool  
To the career adviser I was sent  
So along I went  
Follow my interest they say  
Seems that science is the way.  
With a fondness for biology  
It's off to university  
To study neuroscience, biochemistry and more  
All at a thoroughly decent score  
I really enjoy everythin'  
And then the horrors begin

## Wake one morning with eyesight nout but a blur

Off to the docs to seek an answer  
To the hospital I was referred  
Optic neuritis was quickly diagnosed  
Told it may be an early sign of multiple sclerosis  
Not too long before I'd heard about it in lectures  
Never mind never give up that's what I say  
Saw me all the way through to graduation day  
For the final year in neuro I did specialise  
An apt choice I thought to focalise  
Understand the beast  
Of course it didn't stop the feast  
Knowledge is power it kept me serene  
The need to know and to learn kept me keen

## A 2:1 made me swell with pride

Oh no, my health is taking another slide  
The MS badly affecting me  
Getting a job or career became less and less likely  
Progressive it was termed  
That's it confirmed.  
I once had a future that was bright  
Then it turned up out of sight  
All thanks to  
Caused by MS  
Learn to take the negatives with grace  
Keep any positive at heart with smiles upon  
the face

## Multiple sclerosis certainly makes one sigh

And unavoidably occasionally cry  
Positivity is key to deal with distress  
Particularly when you are forced to fight MS