



“We talk about everything”

Best friends Nina and Milla were diagnosed with MS 24 years apart

Plus

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Make your donation go further

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The world is facing some tough challenges at the moment. The rising cost of living in the UK is impacting our community in so many ways.

Our #BreakingPoint campaign ([page 9](#)) lobbies the government for more help with the cost of living crisis. We'll continue this fight into 2023 and make sure the community's voices are being heard.

Despite these difficult times, there are still many reasons to be hopeful. In this edition, we're looking at the future of MS. We reflect on what's been achieved in MS research and look forward to what's coming next ([page 16](#)). We also discuss how close we might be to preventing MS ([page 22](#)).

We know people with progressive MS often feel overlooked in terms of treatment. So we talked to Professor Alan Thomas, expert in progressive MS, about the current status of research and future treatment options ([page 19](#)).

Looking at the history of MS timeline ([page 34](#)) and reading about friends Milla and Nina who were diagnosed around 20 years apart ([page 36](#)), it's encouraging to see how far we've come.

As always, please share any feedback you have. We love to hear your thoughts. Email us at mismatters@mssociety.org.uk or call **020 8438 0700**.

And if you're struggling in any way, call our MS Helpline for free on **0808 800 8000** to find out what support is available.

Wishing you all a happy festive season,

Victoria

Victoria Watts Kennedy
Editor

We would like to take this opportunity to convey our respect and sadness on the passing of HM Queen Elizabeth II. She was a prominent figure who dedicated her life to public duty, promoting support of charitable causes and will be deeply missed.

Your Letters



My painting endeavours began with a 'social prescription'. Perhaps more out of sympathy for my caring wife, the neuro occupational therapist suggested I might want to get out more. Sitting at home watching the news and daytime TV was unhealthy.

I took this social prescription and signed up for an art course at the local adult education centre. Art would surely be good for me and allow me to escape being such a rational man – get me in touch with my emotions.

Arriving on a cold October evening, the power chair journey had already tapped my energies. Putting out my brushes and filling my water pots like everyone else, my continual requests for help were sapping my energy and my pride.

They say that watercolour painting produces 'happy accidents'. Looking at my evening's offering, I'd only succeeded in making 'crappy accidents'. Watercolour is



unforgiving. Once you release the melee of water and pigment on paper there's no going back. I went home that evening feeling despondent and exhausted. Not at one with the able-bodied community.

Five years on and I'm addicted to watercolour. It's not a 'hobby'. I don't do it to pass the time. It's how I communicate. I've now engaged with online watercolour courses from around the world. I take reference photos in the field. Only when I get home can I start to see all the wonderful details that my visual symptoms (optic neuritis) have robbed me of during my daytime reconnaissance.

Save the date: You can see an exhibition of Edward Finch's work – Maidstone Figures! – in the Westspace Gallery at Maidstone Museum in Kent from 3 May to 3 June 2023. Visit finchart.gallery to see the watercolours online.



Share your thoughts and feedback at 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**

£2.5 million project to develop NHS treatment for fatigue

Researchers at Kings College London will shortly begin a five-year project to develop a programme to help reduce MS fatigue. The team hope to trial the programme in 12 NHS trusts.

The programme will be delivered online.

People with MS will discuss their thoughts, feelings and actions that may make fatigue worse. And researchers will use this knowledge to develop new personalised ways of managing fatigue.

The team have already reviewed

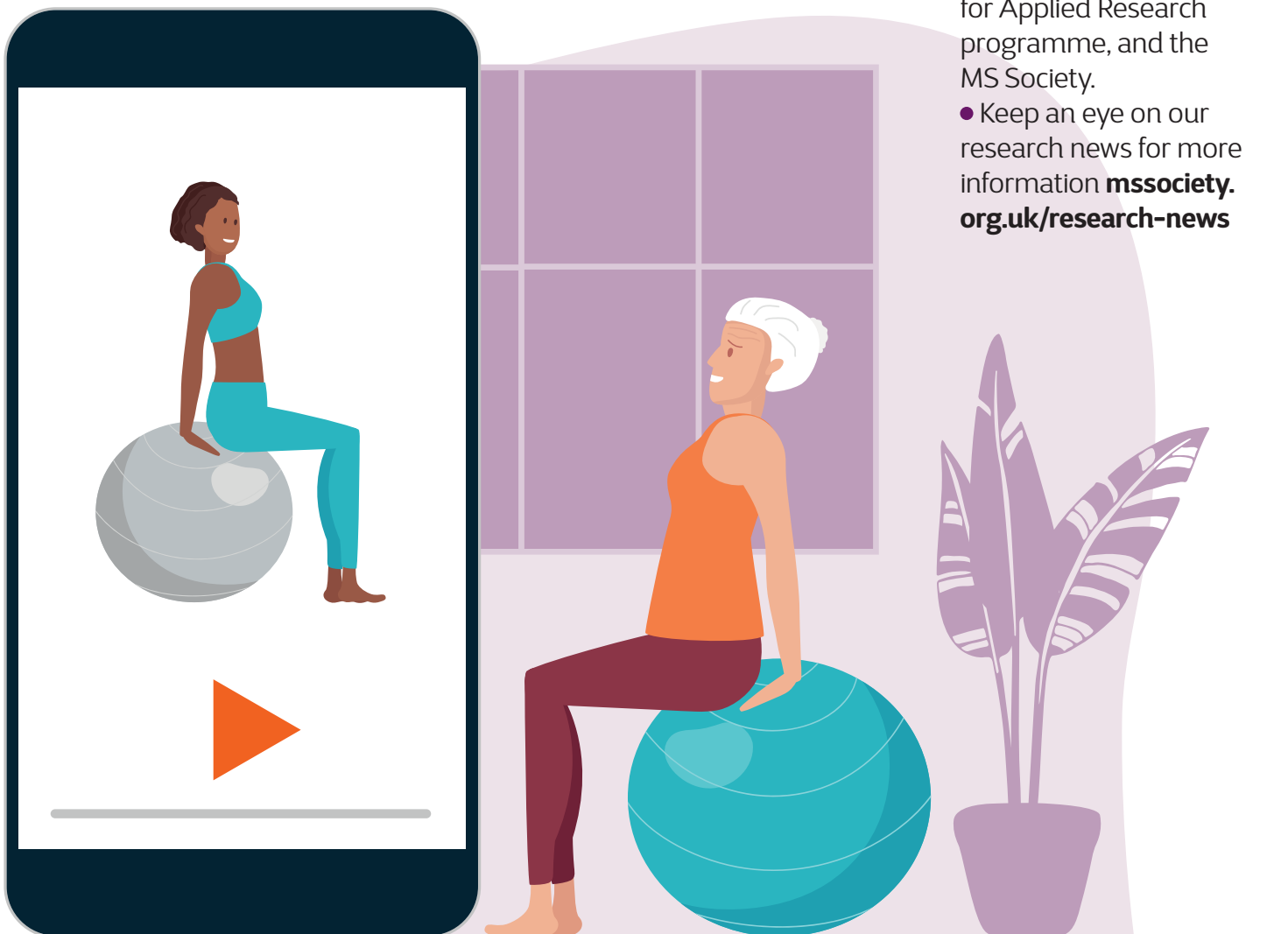
existing research on fatigue. It suggests behavioural or exercise interventions are more effective for treating fatigue than medications.

So the new online programme will include physical activity as well as cognitive

behavioural therapy. Physiotherapists and occupational therapists will also provide guidance alongside the programme.

This research programme is funded by the National Institute for Health Research (NIHR), under the Programme Grants for Applied Research programme, and the MS Society.

- Keep an eye on our research news for more information mssociety.org.uk/research-news





#BreakingPoint campaign calls for urgent support for people with MS

This is a tough time for everyone. But people with MS are being hit especially hard by the cost of living crisis. This has been caused by years of benefits cuts. Government neglect has forced many people to make devastating choices between essentials like food, heating and medication.

We asked people living with MS about this earlier in the year. Of the people with MS who answered the survey:

- Over a quarter don't have enough money for food. One in every 20 people told us they've had to use a foodbank in the past year.

- Almost 2 in every 5 people who claim means-tested benefits can't afford to keep their homes warm. And around a third can't afford the medication or treatments they need.

- Around 3 in every 10 people have had to reduce their spending by reducing or stopping therapies or treatments.

We launched our #BreakingPoint campaign in September to make sure this issue is at the top of the Prime Minister's agenda. Thousands of you signed our petition calling on the UK

Government to roll out a new cost of living package. People with MS urgently need this support to survive the winter and beyond.

JJ, who lives with MS, joined our campaign. She says: "I have to think about how I'm cooking things, and how I can minimise the amount of gas I use. I'm eating less and feeling hungry a lot, which really affects my mood."

We'll keep up the pressure and continue to fight for people with MS.

- To join us, visit mssociety.org.uk/campaign-with-us

Octopus

close to getting the green light

Last year, we introduced Octopus, our new 'mega-trial' for progressive MS. There have been some delays, but the trial is now another step closer to opening.

Octopus' goal is to find treatments that slow or stop disability worsening.

It's the first multi-arm, multi-stage trial in MS. This means it'll test potential treatments more efficiently than traditional trials. It'll test more than one drug at once. And it'll combine what's normally two consecutive trials into one.

Before any clinical trial can open to recruitment, it needs approval from the Medicines and Healthcare Products

Regulatory Agency (MHRA). And it needs ethical approval.

The Octopus team have now submitted the trial 'protocol' for approval. The protocol is like a recipe that describes all aspects of how the trial will be run, from how the drugs will be manufactured to what safety measures will be put in place.

At the time of writing, the team were waiting for the green light from the MHRA. Once it's approved, the team will be able to confirm the first drugs that'll be tested. And people will join gradually over the coming months and years.

- Read more at mssociety.org.uk/octopus

More MS trials for progressive MS

We won't know if the drugs in the Octopus trial can slow disability progression until 2028 at the earliest. In the meantime, we're looking forward to the results of other exciting trials for progressive MS.

This includes ChariotMS, the MS-STAT2 trial, and the drug company Sanofi's trials of a drug called tolebrutinib. These results are all expected by 2025.

MS Frontiers 2022: answering the big questions

MS Frontiers is the UK's biggest MS research conference. It brings together scientists, clinicians and healthcare professionals to resolve unanswered research questions.

This year's conference took place in Swansea in July, with nearly 200 researchers sharing ideas and results.

This included the latest on using magnetic resonance

imaging (MRI) to predict disability, getting cells to make more myelin in the brain, and making MS research more diverse.

- Read more at mssociety.org.uk/frontiers

Campaign updates

Sativex campaign

We've campaigned for a year to end the unfair postcode lottery for Sativex access. And we've seen a significant rise in availability. The number of local NHS bodies in England who routinely fund Sativex has increased by 45%. This means it might be worth contacting your local health body again if they previously said Sativex was unavailable.

We can help you contact them, whether or not you've seen a change in Sativex prescription in your area. There's still a lot of work to do and we're planning our next steps.

- Get in touch at **campaigns@mssociety.org.uk**

Back the 1 in 6

Support continues for Back the 1 in 6, our joint campaign with the Neurological Alliance. We're calling on all four UK governments to create a Neuro Taskforce to address the problems facing neurology services. These include workforce shortages, waiting lists and barriers to accessing support. The petition is still open to sign until early 2023.

- Find out more and sign at **mssociety.org.uk/neurology-now**

STOP MS

Too many people don't have anything to stop their MS getting worse, and some don't have any treatments at all.

That's why we won't stop until we have life-changing treatments for people with every type of MS. We aim to be in the final stages of testing a range of life-changing treatments for everyone with MS by 2025. But we can't get there without your support. Together, we can stop MS. Visit **mssociety.org.uk/stop-ms-donate** to find out how you can help.

Scan and donate today



Fampyra still unavailable in England and Northern Ireland after NICE guidelines update

In June this year, the National Institute for Health and Care Excellence (NICE) published updated guidelines for the diagnosis and management of MS.

The new guidelines have some positive aspects. Healthcare professionals should now offer an annual review of care for people with MS, and reviews for suspected but undiagnosed MS cases. They should also ask people about fatigue and explore ways to help people manage it themselves.

Fampyra decision

One disappointing outcome is NICE's decision not to recommend fampridine (Fampyra) for use on the NHS in England. Fampridine is a treatment which can improve walking in some adults with MS. It's approved for use on the NHS in Scotland and Wales for eligible people, but not in England and Northern Ireland.

NICE rejected fampridine because they don't think it's a cost-effective treatment at the price offered by the manufacturers. This decision doesn't apply to people who've already started fampridine. We're deeply disappointed and are calling on NHS England and the manufacturer, Biogen, to urgently look for a solution.

● For more information visit mssociety.org.uk/nice-fampridine



Dates for your diary

Don't miss these MS community events.

January

My MS Walk

Walk, roll or stroll a distance of your choice by taking part in My MS Walk mssociety.org.uk/mymswalk

26 January and 2 February, 6:30–7:30pm

Life admin webinars

Get on top of your life admin! Join us as we discuss tips for managing tasks like insurance, subscriptions and pensions. mssociety.org.uk/life-admin

14 February, 6:30–8pm

Managing Work While Living with MS

MS symptoms can change over time, which can be a challenge at work. Join our online session to find out what support is available. mssociety.org.uk/managing-work

April and May

Run a marathon

Lace up your trainers for the London Landmarks Half Marathon (2 April) or the Edinburgh Marathon Festival (28 and 29 May). mssociety.org.uk/running

30 May

Skydive

Take the big leap and skydive from 10,000 feet on World MS Day. mssociety.org.uk/skydiving

Find more fundraising events at mssociety.org.uk/fundraise And see our programme of webinars and information events at mssociety.org.uk/virtual-support-events

Our hopes and concerns for the future of MS

We asked our MS Society Ambassadors what they hope the next few years will bring for people living with MS – and what they're most worried about.



“For me, the ultimate aim when it comes to MS treatments is ‘halt, repair and prevent’. We’ve made huge progress in the ‘halt’ area, but I’d like to see similar progress being made in the ‘repair’ and ‘prevent’ areas. I’d like to see more inclusivity when it comes

to participation in and design of MS research, so that future treatments are optimised for everyone. Wouldn’t it be great if you were able to go to your doctor and get a medicine that you know will be the best for you personally?”

Trishna Bharadia

“It’s an exciting time for MS research. I’ve recently taken part in an MS Society clinical trial for a potential new treatment for secondary progressive MS. I’m concerned the cost of living crisis and potential recession could hit funding for research when so much fantastic progress is being made. I’ll continue to do all I can to help raise awareness of how important this work is for the MS community. If it doesn’t help me, I know it’ll help other people in the future.”

Janis Winehouse



“

We need to make sure that everyone across the UK has good access to all the disease modifying therapies (DMTs) available to stop MS. Research is where the answer lies. We must campaign and continue to develop innovative programmes to make this a reality. People living with MS need effective treatments for their symptoms now. I also hope to see more people with MS featured in the media, films and drama. This’ll go a long way to increase awareness of MS in the public domain.”

Stuart Nixon, MBE



“ My hopes for MS in the coming year would be a deeper understanding of what triggers MS. And finding a test for it to be diagnosed early.

A wider public understanding of what MS is and of the different types of MS would help people with it to be more at ease.

New medications are being trialled and tested continuously to help people living with MS have a better quality of life. Finding a medication that could improve the lives of people with progressive MS would be a big breakthrough.

I take each day as it comes and I'm sure I'm not alone. I make the most of what life's handed out. And I keep looking forward to a major breakthrough with MS.”

Mary Phillip



“ Having lived with MS for 25 years, I know that uncertainty often creates stress for me, and this is one of the triggers for my MS “attacks”. Hence, like many, I am struggling with the increasing cost of living that we are all experiencing.

Thankfully the MS Society, and others, are alerting the government and energy companies about our specific difficulties. We all hope they will take appropriate action to support disabled people and people in need in our society. Knowing their plan and what support is available will undoubtedly help reduce my worry.

Sadly, I fear it's going to be a tough few years ahead. So, on a local level, we all need to help our neighbours, especially older people and disabled people.”

Stephanie Millward, MBE, DL

“ Increasing public and media awareness is vital. All research is driven by public funding and donors. This generosity will grow if the public are more aware of the plight of people with MS. This research will lead to new treatments and, hopefully, answers about the causes of MS. It'll also lead to effective ways to stop or even reverse the debilitating symptoms affecting so many lives.”

Tony Johnstone



Reflecting on the past, looking to the future

Dr Emma Gray, our Assistant Director of Research, reflects on what research has achieved in recent years.

Huge progress has been made since I started working at the MS Society 10 years ago. Attention has turned to tackling progression, clinical trials into progressive MS, and there's renewed focus on one day preventing MS. I'm looking forward to seeing what the next 10 years will bring.

Understanding more

We've seen more treatment options for people with relapsing MS. But for years we've been asked "what about my progressive MS?" The



Dr Emma Gray

stock answer was "we don't understand progression yet, and it's hard to study". But our answer is different now.

Ocrelizumab and siponimod are available for some people with progressive MS. We're beginning to understand what causes progression. And our Tissue Bank and Centres of Excellence are identifying promising myelin repair and neuroprotective treatments that could slow disability worsening.



Setting up for success

To make new treatments available, we need good clinical trials that are efficient, high-quality, and accessible to everyone with MS. So in 2015 we set up a network of researchers, people with MS and neurologists to plan collaborative trials.

The new trials we've seen so far are fantastic:

- Octopus – a world-first trial

that'll allow us to test promising drugs as they're found

- ChariotMS – one of the first trials both for people with advanced MS and with no upper age limit
- REFUEL-MS
- MS-STAT2
- DELIVER-MS

We're proud to have shaped these trials. And I hope they find new, urgently needed treatment options.

Preventing MS

We haven't made as much progress as we'd like in this area, and we won't have prevented MS in the next few years. But thanks to recent research on Epstein-Barr virus, more researchers are focused on prevention. And we have renewed plans to address it.

We've learned more about risk factors we can change – like smoking and lifestyle. The thought that less people could go on to develop MS is really motivating.



Sasha Leigh, who lives with MS, reflects on what's exciting for the future.

After I was diagnosed with MS, I joined the Research Network. And for six years I've been fortunate enough to help develop the MS Society's Research Strategy. It's a genuine collaboration between people affected by MS, clinicians, researchers, and MS Society staff.

We all have MS in our lives in some way, but we all bring different perspectives. We all offer support as well as challenge to our debates. I feel my voice is heard, and together we make sure research focuses on what's needed most for people with MS.

Feeling the benefits

Research has given so much to the MS community. But sometimes the day-to-day benefit of research can feel



Sasha Leigh

quite unclear.

We could feel more immediate benefit from symptom management research sooner. If we work with other conditions, and find inventive ways to deliver new services, it could make a real difference to living with MS now. I think we're going to break some ground with the big fatigue management trial, REFUEL-MS.

Including everyone

Taking part in research has helped me cope with the uncertainty of my MS. The UK MS Register helps me get a handle on changes in my symptoms by looking at my personalised reports. And I can easily take part in other studies on its website. I'm looking forward to seeing what researchers will do with its data next.

I think of all the people who've been involved in research in the past. If it wasn't for them, we wouldn't be where we are now.

But we know research hasn't represented the whole MS community. The MS Society have made this a priority – I'm looking forward to seeing change so research applies to us all. I hope research will become more inclusive for both researchers and people taking part.

We've come so far, but MS research is a lifetime project. I'm excited to watch the early career researchers of today become the MS leaders of tomorrow. Generations of researchers will continue to share new knowledge and stay at the cutting edge of research with the MS Society's support.

Read about symptom management research on p29-30



read

Find out more about our Research Strategy at mssociety.org.uk/our-research-priorities and our EDI Research Strategy at mssociety.org.uk/EDI-research. Learn more about the UK MS Register at mssociety.org.uk/MS-register

Progress

in progressive MS

Professor Alan Thompson is consultant neurologist at University College London, and past scientific chair of the International Progressive MS Alliance. He's been researching progressive MS for 40 years. We asked him what's changed and what's coming next.

We know relapses are caused by the immune system attacking the protective myelin coating around nerves. But do we know what causes disability to get steadily worse in progressive MS?

Disability worsening is linked with the loss of brain tissue, especially nerves. This is called neurodegeneration.

For decades we haven't understood the mechanisms causing neurodegeneration in progressive MS. And if we don't understand what's happening in the brain, we don't know what we're trying to treat.

Now we're getting a better grip on the various players:

- You get some inflammation like in relapsing MS.
- The body's natural ability to repair myelin breaks down.
- Nerves without protective myelin become more vulnerable.



Professor Alan Thompson

- Processes that normally help nerves stay healthy stop working properly.

Certain cells are involved that we haven't paid enough attention to before. Particularly microglia. And a part of our cells called mitochondria.

Now we need the master plan of how they all interact. The answer won't be the same for everyone with progressive MS. It's a very variable condition – that's the universal truth of MS.

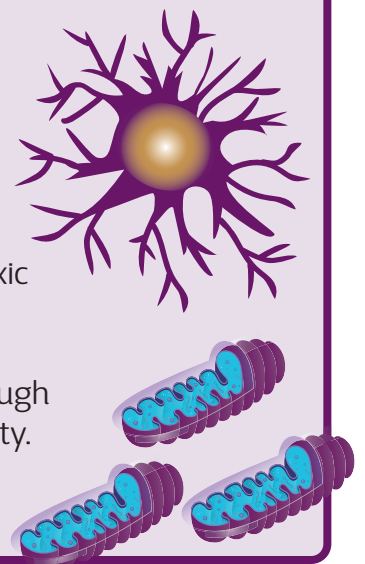
So are we getting closer to a treatment that can slow down disability worsening in progressive MS?

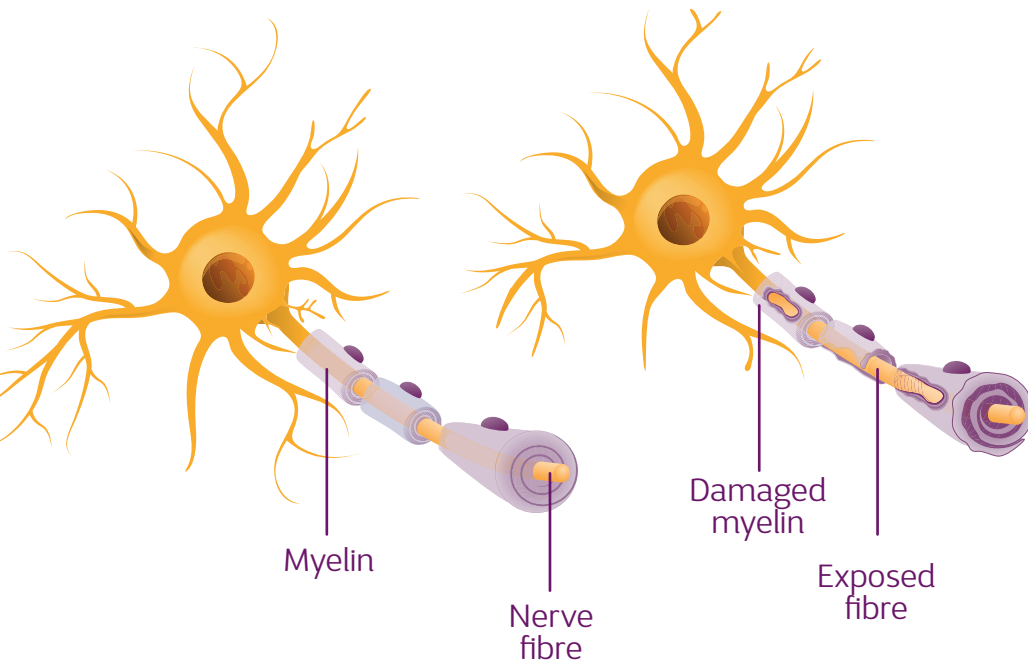
I think we'll have a treatment that protects nerves first. We'll get results of the phase 3 simvastatin trial by 2025. And we've had drugs in phase 2 trials showing positive

The forgotten ones

Microglia are immune cells that usually patrol the brain, keeping it safe. There's debate about whether they're helpful or harmful in MS. But research suggests they become overactive and produce toxic substances that can damage nerves.

Mitochondria make sure nerves get enough energy. In MS, mitochondria may be faulty. This is particularly problematic because damaged nerves need a lot of energy.





effects – like ibudilast. I'd like to see those taken forward to the next stage.

I hope something that repairs myelin will come after that. Although the cancer drug bexarotene wasn't well tolerated, it had interesting results. The anti-histamine clemastine has shown a modest effect in optic neuritis (visual symptoms). And there's interesting work with the diabetes drug metformin happening.

But encouraging myelin repair is challenging. In the past we underestimated how complex this process is. Now we appreciate it more, we know what we're dealing with.

Reducing inflammation has a role too, we shouldn't downplay the progress we've seen there. Ocrelizumab and siponimod – approved for early primary and secondary progressive MS

– slow disability progression by 20–25%. So a modest but positive effect, reminiscent of the first treatments for relapsing MS.

It sounds like things are moving in the right direction. What's coming up that you're particularly excited about?

The approach Professor Jeremy Chataway's taking with Octopus is really encouraging, as is the work of the Progressive MS Alliance.

In MS research, there have been times of high energy and times when it's flagged. Progressive MS is now centre stage. We've got a truly high-energy time and we need to make the most of it.

Do you get neurodegeneration in relapsing MS?

We know people with relapsing MS can experience gradually worsening disability. Historically, we thought they weren't fully recovering from relapses. But studies show this isn't always the reason. And you can still get worse when you aren't having relapses at all. We call this 'progression independent of relapses' (PIRA).

The effects may not be obvious in your symptoms at first. And normal clinical measures like the Expanded Disability Status Scale (EDSS) aren't good at picking up subtle changes over time. But we're realising the mechanisms causing neurodegeneration can begin very early. Researchers in Barcelona found a third of people had experienced PIRA an average of seven years after their first MS symptoms.

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Find out more about research into progressive MS at mssociety.org.uk/turning-point

What the future holds for kids today: are we close to preventing MS?

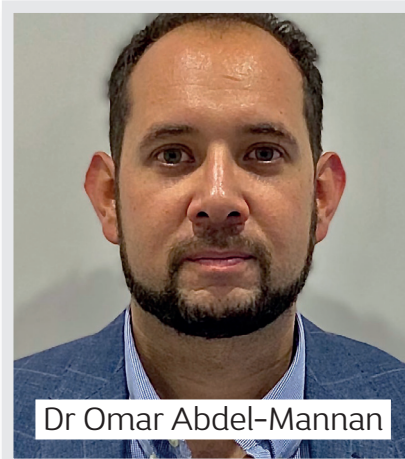
Dr Omar Abdel-Mannan is a paediatric neurologist and Clinical Research Fellow at UCL, focussing on MS in children. **Rabiah Coon**, one of our Research Network volunteers, asked Omar what he thinks the future holds for the UK's youngest population when it comes to MS.

For many people living with MS, their diagnosis came during early or late adulthood. But, for a small percentage, the diagnosis came during childhood or teenage years. Each year, between 50 and 60 people under 18 are diagnosed with MS in the UK. These are some of the young people Omar is focused on helping. He also hopes to see changes for future generations.

Children diagnosed with MS

The ultimate goal in treating children with MS is to make sure they can live as normal a life as possible and do what they want in adulthood. Newer disease modifying therapies are now effective in getting on top of the condition and enabling a sense of normality for these young people.

While continuing to focus on



Dr Omar Abdel-Mannan

disability reduction for both children and adults with MS, the next step is to look at disease prevention. For children born in 2022, is there a way to make sure they never develop MS in the first place? To do this, we need to understand more about how MS starts.

Genetics and MS

There's no one gene passed on from our parents that causes MS. Few of the children Omar sees have family members with

MS. But we know there's some genetic element that makes people more likely to have the condition. Certain genetic variations in people increase the chance they will develop MS during their life.

So it's unlikely prevention would come in the form of gene therapy, even if there was a family history. Omar describes developing MS as a perfect storm, with a combination of genetic and environmental factors.



Rabiah Coon

People with the genetic variants that make them more likely to get MS may then be exposed to the environmental factors. This includes low vitamin D or a viral trigger such as Epstein-Barr virus (EBV). This starts the domino effect of priming the immune system and eventually presenting as MS.

As genetics is not a realistic prevention strategy, researchers have turned to preventing risks from the environment. The possibility of an EBV vaccine being

developed to prevent MS is possible, but we don't know enough about EBV yet.

EBV and MS

EBV is a virus that usually infects people in adolescence and has been linked with MS. It often gives no symptoms, but we can tell whether someone previously had EBV by testing their blood for antibodies against the virus.

About 60% of healthy

14-year-olds will have the antibodies. In children in the same age group with MS, almost 100% of them will have the antibodies. In fact, Omar has yet to see a single child with MS who doesn't have antibodies for EBV.

He thinks developing a safe and effective EBV vaccine may be a step in the right direction towards the ultimate goal of preventing MS. There's currently one vaccine in clinical trials with Moderna, but in very early phases.

But Omar's not convinced EBV is the whole story. There are all the other environmental factors we need to understand better before we can prevent MS.

Can we prevent MS?

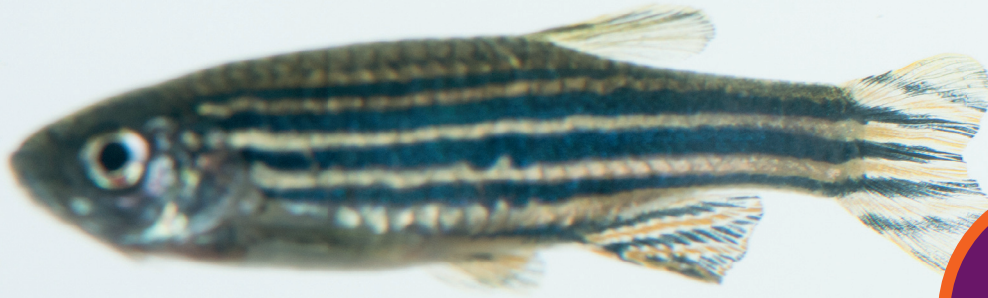
We do need more research into developing prevention strategies. But there needs to be a two-pronged approach with research.

We need to be working on treatments and stopping MS progression, and also eventually preventing people getting it in the first place. It might leave Omar's clinic empty, but it would mean a world free from MS.



read

Find out more about Omar's work at mssociety.org.uk/childhood-ms



Read more
about
Octopus
on p10

Making a splash in research: from zebrafish to Octopus

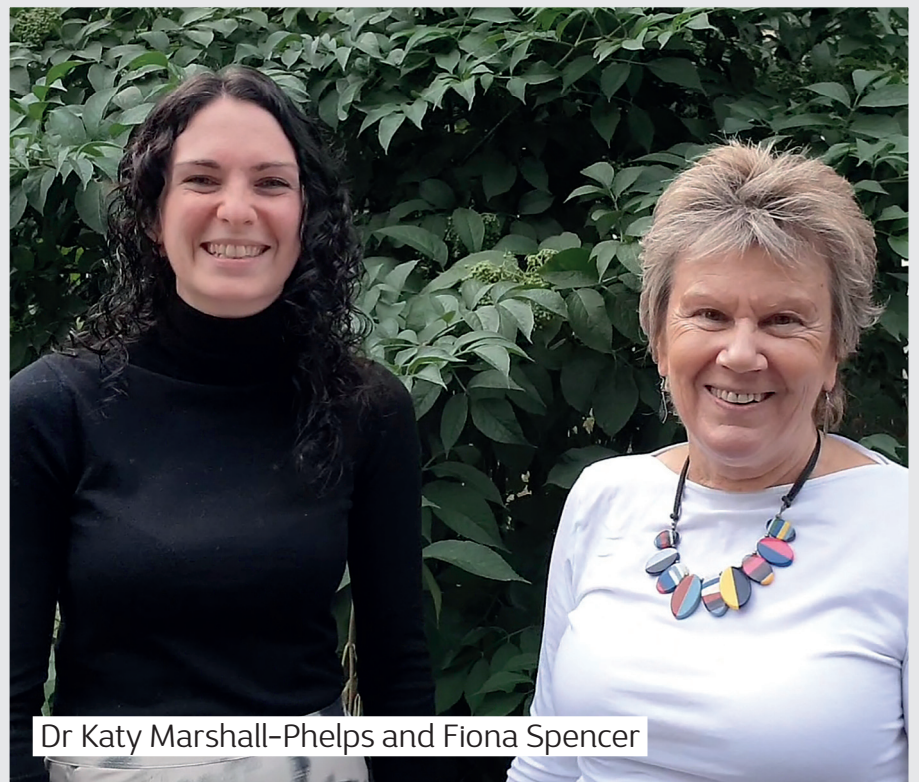


Fiona Spencer from our Research Network recently met **Dr Katy Marshall-Phelps** from the Centre for Discovery Brain Sciences at the University of Edinburgh. Fiona wanted to know how Katy's work feeds into clinical trials for new MS treatments.

As a Research Network member with family living with MS, I'm very aware of how keenly new treatments are anticipated. Progress can feel slow, especially if current treatments don't benefit you. I asked Katy what's being done to speed up the investigation of potential treatments. She uses a computerised drug discovery platform to look into drugs that could slow or stop progression in MS.

Faster with fish

Katy showed me the tiny zebrafish embryos she uses,



Dr Katy Marshall-Phelps and Fiona Spencer

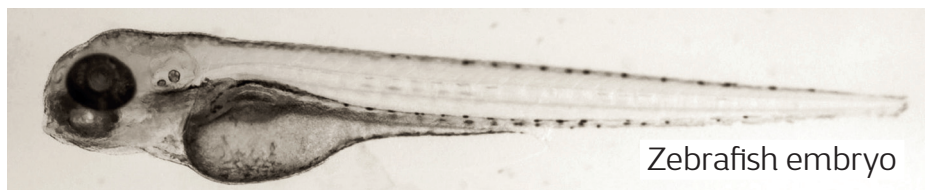
which are just a few millimetres long. She explained that zebrafish have similar genes to humans, so can mimic aspects of MS. They're transparent and I could see the brain and spinal cord in the images she showed me. Zebrafish have short life cycles so researchers like Katy can safely test drugs in a whole organism, and find out the results quickly.

The zebrafish are well cared for. Their water is monitored and they're fed a special balanced diet. In Edinburgh, there's an entire department dedicated to the care of research animals.

Quicker computers

Katy uses the zebrafish in a world-first computerised drug discovery platform. This allows her to carry out a range of tests to get speedier results. She showed me how she moves the fish from their tank into a plastic tray with 96 little wells. Each well holds two to three zebrafish and contains a drug diluted in water for the fish to absorb. So one tray could test 96 drugs.

Once treated, each fish is transferred to a microscope by a robot. It has a camera that images the fish cells. The computer then analyses the results to see what effect the drugs have had. The whole process takes only 30 seconds for each fish. A scientist always checks the images in case something unexpected shows up.



Zebrafish embryo

“Zebrafish have similar genes to humans so can mimic aspects of MS”

Using her panel of tests, Katy looks for a specific effect, such as restoring myelin. If this is positive, she'll do further tests to investigate best doses and possible side effects.

Octopus and repurposing

Katy explained that scientists working on MS regularly discuss their work together. Pooling expertise helps them select what to test next on the drug discovery platform. This collaboration encourages scientists to have a broader view of the research landscape.

Promising drugs that emerge could be tested as treatments in future stages of the new mega-trial Octopus (see page 10). Because Octopus has a flexible design, trial drugs can slot in when they're identified. Researchers are starting with drugs already used for other conditions. This repurposing has advantages because we already know the drugs are safe. They won't need so many

time-consuming regulatory steps for approval later on.

Moving ahead

In the early stages, the development of new drugs often focuses on one aspect of MS, like the loss of myelin. But we know MS is complex. So researchers think testing drugs in combination could be the next step change to accelerate the development of new treatments. With improvements like the drug discovery platform, Katy sees greater potential to investigate this. One trial funded by the MS Society is already investigating if taking metformin and clemastine together can speed up myelin repair.

Listening, I began to see that innovations and the commitment of scientists like Katy are already making a difference. Prospects for the fight against MS are getting brighter.

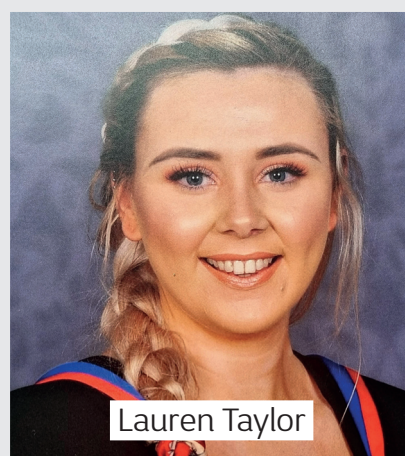


Find out more about research at our MS Society Edinburgh Centre for MS Research at mssociety.org.uk/edinburgh-research



A bright future for cognitive rehabilitation?

We spoke to **Lauren Taylor**, a Clinical Psychology PhD student at the University of Nottingham. She's part of the NEuRoMS project, which hopes to change how cognitive MS symptoms are managed.



Lauren Taylor

Can you explain what cognitive rehabilitation is?

It's a specialised form of neuro-psychological intervention. It focuses on giving people knowledge and information about their cognitive problems – like memory, thinking or concentration.

We talk to people about how MS has affected their cognition, and what's causing it. We offer

reassurance and we focus on teaching different ways to help manage these symptoms. For example with mnemonic devices – these can be rhymes or acronyms that can help people remember things.

We advise using physical aids too, like using a diary, iPad or Alexa. And we talk about how people can use these to help with the

symptoms they're struggling with the most.

Does research show cognitive rehabilitation works?

There's good evidence to support cognitive rehabilitation. We reviewed 44 studies across the world and found it improved memory and quality of life long-term.

We're also carrying out our own trials at Nottingham. The CRAMMS trial compared 10 sessions of group cognitive rehabilitation to usual clinical care. It showed a reduction in everyday memory problems and an improvement in mood for up to 12 months.

But it's not so cut and dry. I've looked into the data further and it shows certain people might respond better to rehabilitation than others.

Is this where your new trial fits in?

Yes! I'll be running a 10-week group intervention based on the CRAMMS trial, but it'll be online. I've had people contact me all the way from Glasgow to London who want to take part. So it has the potential to allow people to access services who couldn't before.

The trial has two objectives. Firstly we want to see if it's possible to deliver this programme online. And secondly, we want to see whether we can use an algorithm to predict who is

Interested in taking part in research?

Lauren's trial is recruiting people with MS between the ages of 18 and 70 who've been diagnosed more than three months ago. To find out more contact helpline@mssociety.org.uk.



most likely to benefit from the sessions. This means we can make more personalised recommendations.

Are there some cognitive rehabilitation services people can already access?

Unfortunately there's not a lot outside of research trials. You might get a referral to a psychologist if your symptoms are severe. But people with mild to moderate issues slip through the net.

Studies have shown that

invisible symptoms, like cognitive issues, can cause more distress than physical symptoms in some people. They can be really frightening. So we need to see more help being delivered.

What do you think the future of cognitive rehabilitation looks like?

I think things will change soon. It's come to a point where we can't deny the evidence or the importance of cognitive symptoms.

Now we really need to focus on ways to get rehabilitation into clinical practice. To do that, we need a programme that combats issues with lack of staff, resources, and funding in the NHS.

We hope the result of the NEuRoMS project will be the answer. We're already carrying out cognitive screening in three NHS trusts. And we've developed a rehabilitation manual we're testing in trials. We could use this to train existing healthcare providers like nurses to deliver it face-to-face and online.

If successful, we hope it's something that could be rolled out nationally so everyone with MS could access it.



Find out more about the NEuRoMS project at neuroms.org And discover more about memory and thinking problems on our website mssociety.org.uk/memory-thinking

Ask the experts

MS fatigue



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

Q How can I help manage fatigue?

A good starting point is learning how to conserve energy. You can do this by pacing yourself and prioritising tasks and activities. Try taking frequent breaks or asking others to help.

Improving sleep may also help reduce the effects of fatigue. We know other MS symptoms, such as pain and using the toilet in the night, can cause poor sleep. This can make fatigue worse. So speaking to your MS team about how to manage these symptoms may help with fatigue.

Looking at lifestyle factors such as diet and exercise might also help. There isn't a specialist diet

that benefits everyone with MS. But eating a varied and balanced diet is good for overall health and wellbeing. And there's been a small but well-designed study showing that two particular diets might help with fatigue: the Wahls and Swank diets.

To find out more visit mssociety.org.uk/wahls

Q Can I exercise if I have fatigue?

There's evidence to show regular exercise can help if you do it at times when you are less fatigued. It's important to find a form of exercise you enjoy and that's right for you. It's best to start any new exercise slowly so your body can get used to it and gauge your limits. And it's



important to include rest and recovery time.

Q Are there treatments for fatigue?

Some people find drug treatments help them manage their fatigue. There aren't any drugs licensed in the UK specifically for MS fatigue. But certain drugs licensed for other conditions are sometimes prescribed.

Your MS team can advise you on treatments and discuss the benefits and potential side effects. NICE guidelines for MS recommend that amantadine, modafinil and selective serotonin reuptake inhibitors (SSRIs) can be used to help manage MS fatigue. Visit mssociety.org.uk/treatment-guidelines

Q Can other medications make fatigue feel worse?

Some medications can increase drowsiness and make fatigue worse. These can include prescription and over-the-counter medications for MS and for other conditions. Medication used in MS to treat stiffness, spasms and neuropathic pain can be associated with increased fatigue. And some disease modifying therapies (DMTs) can also have an impact on fatigue.

If you start a new medication, or change the dose or the time you take an existing medication, your fatigue levels might also change.

Q Why does heat make fatigue feel worse?

Lots of people with MS find their fatigue gets worse when their body gets hotter. This is called heat sensitivity fatigue.

Researchers think it happens because nerves in the brain and spinal cord work best at the body's usual temperature. When the core body temperature rises, signals don't pass so quickly

and easily through the nerve fibre. MS damages the nerve fibre or the myelin sheath around the outside. And that damage might make the nerve more vulnerable when it gets warmer. The body's temperature only needs to increase by about half a degree for the nerve to not work as efficiently.

The effects are usually reversed when you take steps to cool down and your temperature returns to normal.

Q How can I help people understand fatigue?

It can be difficult for others to understand fatigue as it's an invisible symptom. Explaining that it's more than normal tiredness can be a good starting point. Asking people to imagine how they felt if they've ever been jet lagged, hungover or had flu could help. Try to find time to talk about your fatigue when you have energy and feel confident. You might want to point people towards our information.

learn

Our online fatigue management course looks at ways to help manage fatigue. Your MS nurse may also be able to tell you about local fatigue management courses. Visit mssociety.org.uk/fatigue-course

Learn more about diet at mssociety.org.uk/diet-booklet. And explore ways of staying active by contacting our physical activities specialists on our MS Helpline **0808 800 8000** or visiting mssociety.org.uk/move

A brief history of MS

We take a look at some key moments in the history of MS and the development of the MS Society.

1433

The earliest possible case of MS is recorded

in the biography of Lidwina of Schiedam. She later becomes the patron saint of ice skaters.



Late

1990s

The first disease modifying therapies (DMTs) become available for some people on the NHS.

They're licensed for relapsing remitting MS and some people with secondary progressive MS with relapses. There have since been over a dozen more DMTs, including the first for some people with primary progressive MS.

1995

The Disability Discrimination Act comes in.

It gives legal protection to everyone with MS in areas including employment and access to services. In 2010, the Equality Act replaces previous anti-discrimination laws with a single Act for Great Britain. This makes the law easier to understand and strengthens protection in some situations.



2022

We launch our Co-production Champion volunteer role.

Co-production is when people living with MS are fully involved in shaping every stage of a project. This way of working has already led to services like Mind My MS, Pontio, Wellbeing hub (Scotland) and our UK-wide Living Well programme. The champions will inspire even more people affected by MS to get involved in projects.



2005

The Cambridge Centre for Myelin Repair is set up, followed in 2007 by the MS Society Edinburgh Centre for MS Research. We still support both with grants. An important part of their work is advancing research to slow and stop MS progression.



1868

French doctor Jean-Martin Charcot describes “la sclérose en plaques”.

In English, we called it disseminated sclerosis, insular sclerosis and polysclerosis until about the 1950s when we finally settled on multiple sclerosis. Charcot described inflammation and scarring of nerves in the brain and spinal cord. He linked this to just three symptoms: nystagmus (unsteadiness of the eyes), slurred speech and loss of coordination.



1967

Sylvia Lawry sets up the MS International Federation (MSIF). She also founded the world's first MS society in the USA. At first, the MSIF had only a handful of members, including our MS Society. We began in West London in 1953, thanks to our founders Richard and Mary Cave. The MSIF now has 48 member societies and is in touch with MS organisations in every inhabited continent of the world.



1991

We launch our MS Society Helpline.

Alongside local groups – then called branches – the MS Helpline gave people more ways to find support and information. It now includes specialist MS nurses, personalised support for staying active, and benefits and legal advisers.



What's next?

In coming years, we hope to see leaps forward in preventing MS. This could include a vaccine for Epstein Barr Virus and a better understanding of vitamin D and of people's genes. We hope to find more treatments for everyone, including people with more advanced MS and progressive types of MS. And we want to involve more of our community to shape the work we do.



You can find out more about the history of MS research at mssociety.org.uk/history-ms-research and the MS Society at mssociety.org.uk/our-history

“Your life’s not over when you’re diagnosed”

Nina and Milla, both aged 54, are best friends who lived together while studying at Bristol University. Now, they both live with MS. They told us about their friendship and their experiences with MS.



Nina, you were diagnosed with relapsing remitting MS when you were 29. Did either of you know much about MS before then?

Nina: I had a friend at university who told me her mother had MS. I remember thinking “Oh gosh, I should probably know what that means, but I don’t.” But I knew it was something affecting her quality of life.

I was very confused when I first experienced symptoms. I looked them up in a medical dictionary. Nowadays, people would probably Google it.

What did you think when Milla was diagnosed with secondary progressive MS at 53?

Milla: We have a friend who’d suspected I’d got MS for years. But I was in denial, so never looked into it.

Nina: I thought your symptoms looked like MS too!

Milla: I also had bad anxiety when I was being diagnosed. And I wasn’t sure if my symptoms were caused by MS or the menopause.

Do you think attitudes towards MS and disabilities have changed since Nina’s diagnosis?

Nina: I think society is more aware of illnesses now. And friends and family have become more sympathetic

Milla (left) and Nina



How has MS impacted your friendship?

Milla: I feel guilty for not fully understanding what Nina was going through when she was diagnosed. And now I feel a bit like a novice! But it's quite nice to have someone in the same boat as you. We talk about everything and she's shared lots of useful things with me.

Nina (left) and Milla (centre) with a friend at university

as my MS has worsened. It's easier to sympathise when you can physically see something is wrong.

Milla: Disability seems to be spoken about so much more openly and respectfully than when Nina was diagnosed. But we still have a long way to go.

Do you think MS care and treatments have changed much since Nina's diagnosis?

Nina: When I was diagnosed, funding for and access to treatment was a postcode lottery. I know some people still find this. I paid for

Copaxone to start with. A trial for Lemtrada came about, but I wasn't eligible because I'd used Copaxone.

Milla: I'm currently on the MS-STAT2 trial. And I'm hoping I can join the Octopus trial, which is exciting. I'd like to do it because I get regular input from co-ordinators and neurologists.

Nina: It's exciting to see new trials. And I know people being diagnosed with MS at a young age have far more options than I did.

What's one thing you'd like to tell people about MS?

Nina: Your life's not over when you're diagnosed. Your path might change, but it won't all be bad. The good stuff is still there.

read

Octopus is the first ever multi-arm, multi-stage trial for progressive MS. Find out more about Octopus on page 10 and at mssociety.org.uk/octopus-trial Explore other treatments in trials at mssociety.org.uk/explore-treatments

We need a more holistic approach to MS care

Victoria Bradley, 29, is a nurse living with relapsing remitting MS. Her experiences as a patient and a healthcare professional give her a unique insight into MS care.



management mention discussing diet, exercise and stress management. But it's crucial this is put into practice. And more evidence from further research may help support this.



stress management and restorative exercise. In my experience, these topics aren't widely discussed by MS specialist teams and their patients. So the person with MS has to ask their own questions.

This isn't always an effective method of educating us as patients. And if we don't know about something before this conversation, we may never think to ask.

Looking at holistic disease management in consultations could be a really useful intervention to empower us. It could also give us the knowledge to make our own decisions and do our own research, if we want to.

The National Institute of Health and Care Excellence (NICE) guidelines for MS

MS care usually focuses on management with disease modifying drugs and medication for various MS ailments. These are very important. However, I can't help but feel the care we receive isn't always holistic. It doesn't look at every area of someone's life.

The importance of education

There's little education given to people on the importance of diet, lifestyle interventions,

MS care isn't a one-size-fits-all situation

Evidence-based information is vital and there isn't one intervention that'll be suitable for everyone. So healthcare professionals could discuss a range of ideas and resources. This lets someone learn about their condition in a safe and supported way.

An MS diagnosis can make someone feel helpless. But it's empowering to learn and have control over your own choices.

learn

Find out more about treatments and therapies at [mssociety.org.uk/treatments](https://www.mssociety.org.uk/treatments)

What would you like to see next for MS research, treatments, policy and care?

Our goal is to cure and stop MS. But we'd like to know what else would make the biggest difference to your life. You told us what changes you'd like to see.



The role of food on symptoms. If I eat broccoli, I get pain. Why?
Neil

More treatments for primary progressive MS.
Bradley

Don't write off older people with secondary progressive MS. We need to feel there's help for us too.
Jean

Free care and support for people who need it. This is so carers and partners can keep working to survive and not quit their job to stay home on benefits.
Julie

Social care and housing accessibility.
Helen

All money and effort should be put into finding a cure. Don't waste money on flowery things that make no real difference. Research, research, research.
John

There may not be a cure in my lifetime, even with research. I'd like the life I've got to be bearable (at worst) and pretty good (at best). The flowery things, being anything that's not research, may help me to achieve this.
Response to John from Steve

The world understanding that accessibility is a basic human right. I avoid certain situations because I know there won't be a seat and/or toilet.

@Catdoran

A mobility scooter designed using the best technology. Lithium batteries, backup cameras, extending footrests, power ports, a complete redesign for comfort and usability.

@LambaZOne

Fampyra (fampridine) is available in Scotland and Wales. But NICE have deemed it isn't a cost-effective treatment for patients in England. What's the price of walking these days?

Jake

Access to cannabis in the UK. It's unbelievable that it's freely available and legal in lots of other countries as a treatment.

Pierre

More funding for physio equipment like the FES (functional electrical stimulation) device. Five years and waiting for the assessment whilst my mobility deteriorates is depressing.

Karen

Stop stressing "MS sufferers" with assessments to show they still have it.

Andrew

A regular view of how my central nervous system is responding to medication. A looking glass to my future...

@MSScotCouncil

More effort to find treatments for secondary progressive MS.

Ann

Making sure hospitals give regular MRI scans. Also help with fatigue, how to cope in the heat and getting patients on medication quicker.

Pam

share

For our next issue, we're asking: **what helps your mental health while living with MS?** Send in your answers to the MS Matters inbox at **msmatters@mssociety.org.uk** Or keep an eye on our social media (**facebook.com/mssocietyuk** and **instagram.com/mssociety**) where we'll be posting the question later this year.

Supporting everyone affected by MS

Sam Walker, Executive Director of Services and Support, and **Morna Simpkins**, Director of Scotland, tell us about the MS Society's progress and plans to keep improving.

How has the organisation changed over the last 12 months?

Sam: We're bolder and working together in a better way to support our community. We're also doing some great work across the organisation that has been shaped by our community.

Morna: We've returned to face-to-face events and re-opened our local groups. The four nations are working together more too.

How are we making equality, diversity and inclusion (EDI) a priority and what does this mean?

Sam: We have our EDI strategy and plan. And we're working hard to deliver this to make sure EDI is a big part of all our work.

Morna: We want people to feel comfortable calling us out when we've made a mistake.

Do you have any proud moments from the last couple of years?

Sam: Our Leaders by Experience programme (see page 45) has been a big achievement. I'm really grateful to everyone who's put themselves forward to be involved in this piece of work.

How has co-production shaped our work in 2022?

Morna: Our research strategy was co-produced. And 18 of our services were shaped or fully co-produced with people with MS.



Sam Walker



Morna Simpkins

What are your hopes for the next few years?

Sam: I'd like us to expand our service offer for family, friends and carers, and people with more advanced MS. And I'd like everything we do to be co-produced.

Morna: I want everyone to be supported and represented in our services and campaigns, no matter who they are or where they live.

read

Find out more about our equality, diversity and inclusion plans at mssociety.org.uk/edi-plans



“Representation is extremely important”

Natalie is the founder of the Black MS Foundation and #MyMSIsBlack. She’s taking part in our Leaders by Experience programme. Here’s an extract from her blog post.

Leaders by Experience is a progressive initiative. It focuses on marginalised groups in the MS community who feel not enough actionable work is being done to help them with their experiences with MS.

Being invited to take part, as a Black person with MS who is working to make a difference and bring our lives and stories to life, is exciting and humbling.

Representation is extremely important. People should be able to see themselves in a charity’s work.

If a charity is supposed to help people, but they’re not visible in its mission, then it won’t be able to help them. This creates

a disconnect with marginalised communities. I’m part of the Black community and I see this has unfortunately been the case.

Learning how to fix these things, and directly involving marginalised communities to help shape that work, is a commendable start.

Responding to Natalie’s blog on Instagram, Francine said:

I’m a nearly 52-year-old Black woman and was diagnosed with MS in November 1997. For the first six years after being diagnosed I was fine, until I had a relapse. I’m doing okay as I’m on treatment to help slow the progress. It’s nice to have more advice for Black people and more effective treatment, as they did not have this 25 years ago.

Read Natalie’s blog in full at mssociety.org.uk/natalie And find out about the Leaders by Experience programme at mssociety.org.uk/leaders



If you’d like to write for our blog, get in touch at msmatters@mssociety.org.uk

Do you have a comment on something you’ve read in MS Matters or on our website? Let us know!

✉ Email msmatters@mssociety.org.uk

📘 Facebook fb.com/MSSociety

🐦 Twitter @mssocietyuk



5 tips for preparing for the holiday season

The holidays can be full of fun and socialising. But for people living with MS, this time can also be demanding. Getting everything ready before the holidays can help with stress and burnout. Whether you're celebrating Hannukah, Christmas or New Year, read our community's tips on preparing for the holiday season.

1 Go digital

Writing and sending cards can be a fun, family-friendly activity. But if you struggle to write, sending a personalised email or e-card works just as well. You could also make a donation to a charity to go with your message.



2 Stock up

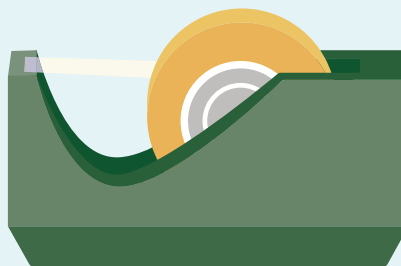
The sales are a great time to buy cards, decorations and gift wrapping supplies. If you're wrapping presents yourself, try tape with a dispenser as this'll be easier on your hands.

3 Set boundaries

Spending time with friends, family and loved ones can be great. But lots of socialising can also be draining, especially if you experience fatigue or cognitive issues. Telling people when you need to rest or take a break is important. And asking for help from other people can make things easier.

4 Keep it easy

Cooking meals for lots of people can be hard work! But frozen or pre-made food can save you time and energy. Part-cooked roast potatoes, frozen doughnuts and other snacks will go down a treat.



5 Enjoy yourself

It's easy to hold yourself to high standards over the holidays. But things don't have to be extravagant. Just enjoying the present moment with loved ones is enough.

help

You can buy Christmas cards in support of us at mssociety.org.uk/christmas-cards



2022 Impact Awards Celebrating success

We held our first Impact Awards on 5 October. MS colleagues, ambassadors and supporters celebrated the incredible contribution of our volunteers. We hear from the people who nominated our six winners.

Sharing Skills and Expertise



Winner:
Robert Oldham

“Robert shares his experience and also ways to disclose MS and discuss reasonable adjustments. We’re lucky to have his expertise on the team.” – **Leann**
Finalists: The Self-Management Co-production Team in Wales (Amanda Jane, Hayley Driscoll, Lynne Madden, Eirlys Ryder, Nikki Flynn, Paul Saurin, Sharon Hier, Valerie Simmons) and Lorraine Russell

Connecting



Winner:
Thomas Sykes

“Thomas’ kindness and personality shaped the Mansfield Group into what it is today – a thriving and vibrant group of members with lots to do.” – **Gina**
Finalists: Vicky Brice and Fiona Salamone

Supporting and Empowering



Winners:
Anne and Chris Todd

“Anne and Chris have made a huge difference at a time when many of us are self-isolating or shielding. I don’t know what would’ve happened without their support. Many of us would’ve gone ‘around the bend’ without it.” – **Terry**
Finalists: Claire Wakefield and Louise Nicholas

Influencing



Winner:
Simon Hoare MP

“Simon has worked with parliamentarians of different political stripes in leading the All Party Parliamentary Group. He’s been a champion for the MS Society and community throughout.” – **Rebecca**
Finalists: Amy Sutherland and Lynne Roberts

Fundraising

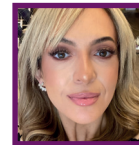


Winner:
Gareth Reynolds

“As well as raising a vast sum of money through his row across the Atlantic, Gareth is a committed stalwart of the MS Society. He supports our local MS communities in Wales, attending events and inspiring others.” – **Ceri**

Finalists: Liam Waddington, Chris and Catherine Heaton, and Winnie Barrett

Informing



Winner:
Charlotte Hecht

“Charlotte’s openness about her experience of MS and her determination to raise funds and awareness for our research is so inspiring.” – **Jennifer**
Finalists: Carla Callaghan and Kirsty Bennett

“I’m bowled over by the volunteering impact we’ve seen this evening. I want to acknowledge all our volunteers whose selfless dedication makes sure people live better with MS.”

Nick Moberly,
Chief Executive

Find out more at mssociety.org.uk/impact-awards-finalists

Getting to know you...

Roxy is a podcaster, MS advocate, fashionista and regular contributor to our blog.



ROXY

Why did you get involved with the MS Society?

I was angry at the lack of representation, specifically for Black MSers and queer MSers. I wanted action for the things the community believes in.

Where's your favourite place you've travelled?

Barbados. I'm Barbadian and Irish and I found it powerful to visit one of my homelands. I first visited when I was 12 and I met family members I'd never seen before. The beautiful beaches were just a bonus.

What did you want to be when you were growing up?

It was a toss-up between a vet and a fashion designer. My heart was with fashion. In the end I became a fashion stylist.

What's your greatest achievement?

I think I'm still to achieve it. I believe my next step is going to be greater than my last, so I wouldn't want to label my greatest achievement.

If you could have dinner with three people, dead or alive, who would they be?

Salvador Dali because surrealism is my favourite art genre. Fashion designer Alexander McQueen because I don't believe anyone has reached his level of mastery of the craft of tailoring, and his shows were iconic. And author Toni Morrison – her books are amazing, and she's taught me so much about activism.

Describe your perfect day

A beach, good food, great company, an art museum and great music.

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

That I basically know nothing! We can find ourselves in a trap if we think we know everything. I may have an opinion but then someone may give me more information that changes things. It's best to have an open mind.



Find Roxy's blogs at mssociety.org.uk/roxy