MS Society msmatters

Summer 2020 · Issue 135

Scott Mills lifts spirits with virtual pub quiz

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Our Never Alone campaign
How we've been reaching out to support you at home

Issue 135
Summer 2020

Life with MS is unpredictable enough without all the uncertainties of the last few months. In this issue of MS Matters, we look at how – together – we've responded to coronavirus.

As some of our staff were furloughed, and to save money on printing, we've combined MS Matters and Research Matters for this issue. We will bring out both magazines again in the autumn. We're still committed to pushing forward vital MS research despite the effects of coronavirus (read more on page 16).

We know MS can be isolating at the best of times and we did everything we could to make sure that although we were at home, no one was alone. We launched new online and telephone services (see page 12) and continued working hard to influence decision-makers across the UK on issues that have affected you during the pandemic (see page 11).

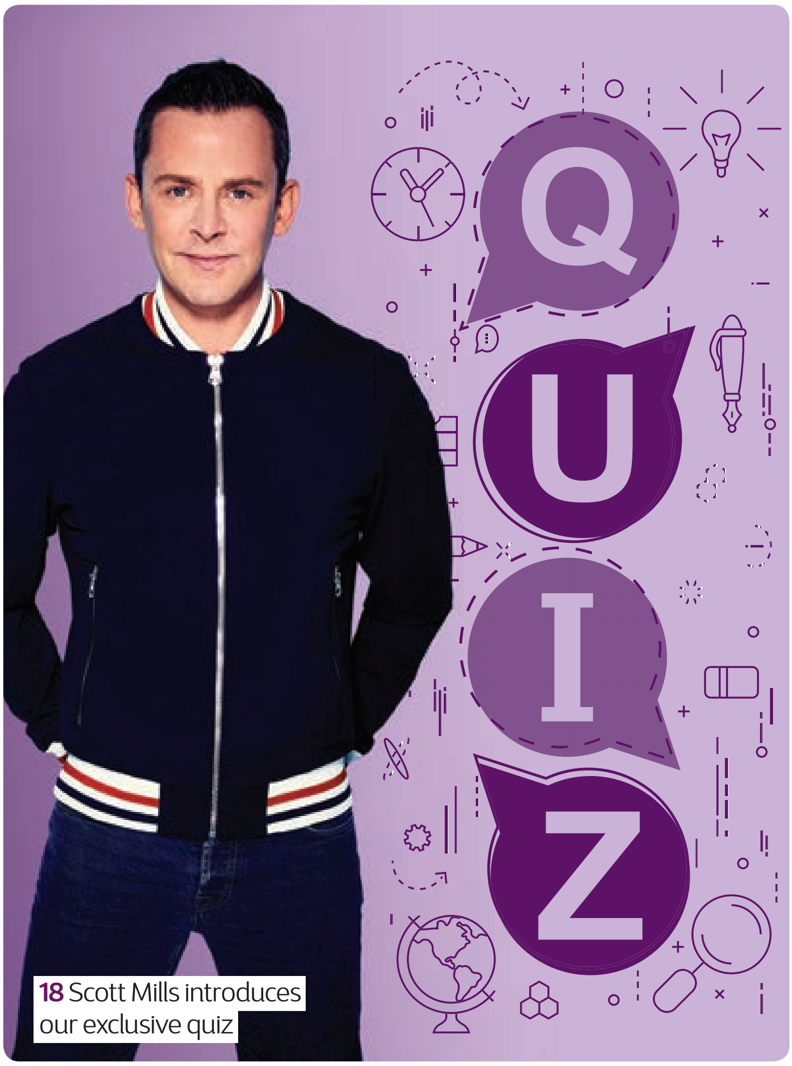
To bring some light-hearted entertainment to the long weeks in lockdown DJ Scott Mills hosted a regular virtual pub quiz for us, which raised £55,000. In case you missed it, there's an exclusive quiz from Scott for MS Matters readers on page 18.

I've been so impressed by the way the MS community has risen to the challenge. Local groups across the UK quickly got to grips with technology like Zoom to reach out to members (see page 22). And on page 52, we look at how you've adapted your fundraising activities to the constraints of the lockdown.

Like many charities, coronavirus has had a negative impact on our finances. We do need people to carry on supporting us through fundraising and donations. However, we also know that many of you will have been affected financially and appreciate that now might be a difficult time.

At the beginning of July, as I write this, I know that some of you are likely to be shielding still and may feel anxious about resuming daily life. Please keep an eye on **mssociety.org.uk/coronavirus-updates** or call our MS Helpline on **0808 800 8000** for the latest information.

Nick Moberly
Chief Executive



18 Scott Mills introduces our exclusive quiz

NEWS

INSIGHT

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**

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Research stories

Find out how the MS Register is building a picture of life with MS (page 8), learn about sex hormones and MS (page 26) and discover the latest research into stress and anxiety in MS (page 28).

talk

Need support or information? Call our MS Helpline on 0808 800 8000 or email **helpline@mssociety.org.uk** Want to talk to other people with MS? Our online forum is a welcoming space for you to share experiences. Get to know your MS community and join the conversation. Visit **community.mssociety.org.uk**

Got a question about membership? Need MS Matters on CD? Call our Supporter Care team on 0300 500 8084.

REAL LIFE

COMMUNITY VIEWS

COMMUNITY NEWS

GET INVOLVED

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Our renewed commitment to being a more equal organisation

Events over the last few weeks following George Floyd's tragic death have affected many of us deeply – and have led us to reflect on our practices here at the MS Society.

In response, we've spent time looking closely at our organisation and whether we're living up to our commitment to having an equal, diverse and open culture. Some might say it isn't our core purpose to speak out on these issues, but we need to acknowledge the impact racism has on people – including the MS community and our colleagues.

Our pledge

We're making a renewed commitment that the MS Society will be a more equal organisation and will better represent people from diverse communities across the UK. We know we have a lot of work to do.

- At leadership level we're not diverse – we need to change that. We've recently introduced name blind recruitment processes for all roles. We're also engaging a specialist recruitment agency who will focus on attracting applicants from Black, Asian and minority ethnic (BAME) backgrounds to apply to become a Trustee of the MS Society.

- We'll increase our efforts to support and encourage BAME applicants to all senior vacancies across the organisation. We'll put in place a dedicated talent programme to encourage the development of staff to secure promotions, with a focus on those from backgrounds that are currently underrepresented.

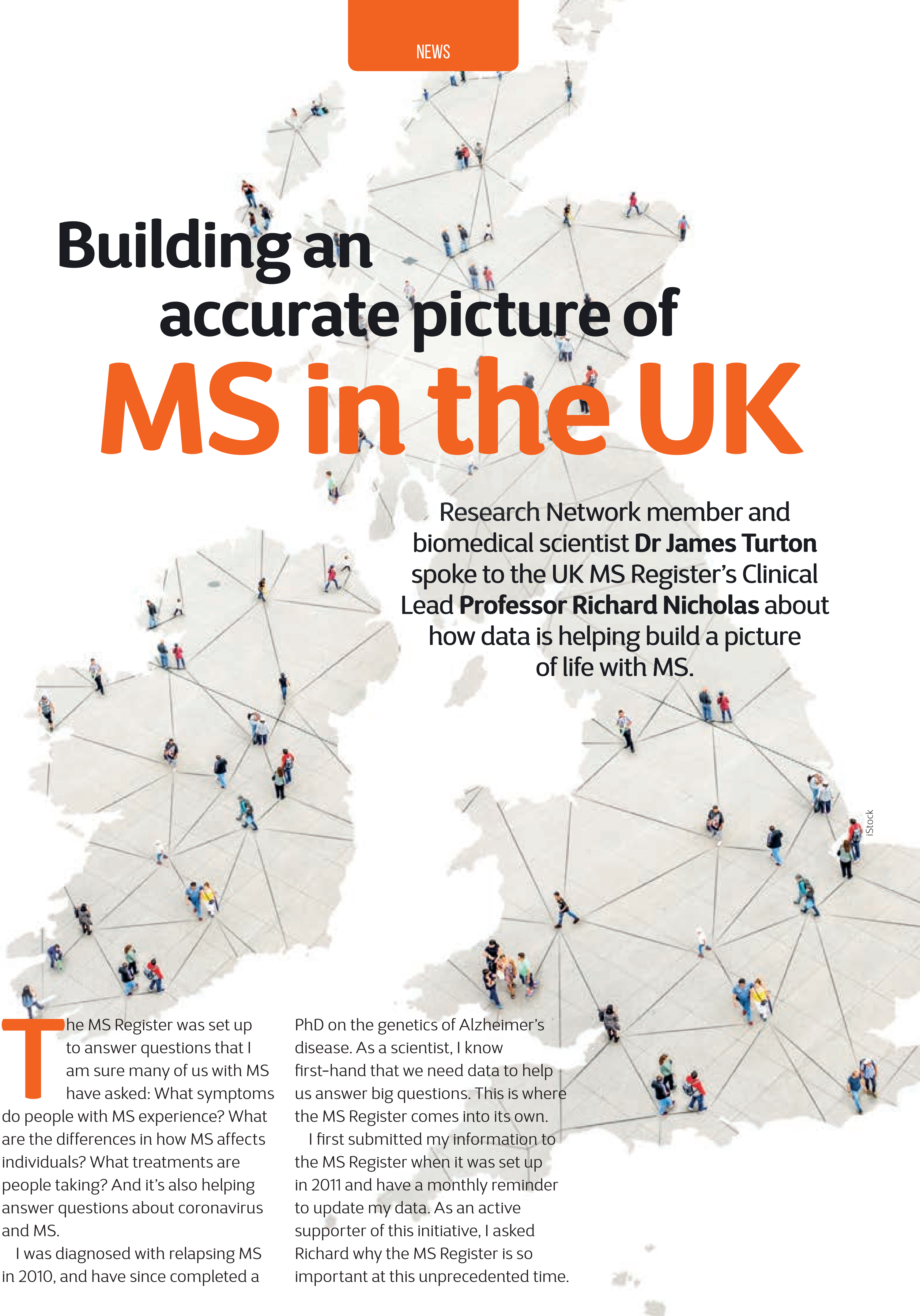
- On the back of a research project we commissioned last year into the experiences of people with MS from diverse backgrounds, we'll continue to work with BAME members of the MS community to understand how we can make our organisation more welcoming and inclusive, and to work out whether new services are required to meet their specific needs.

But we know this is not enough. We'll continue to reflect and discuss, and we are currently revising our Equality, Diversity and Inclusion strategy.

To find out more, please visit **mssociety.org.uk/equality-commitment**

We usually publish a selection of letters from MS Matters readers on this page. However, in response to recent events, we wanted to share our commitment to better represent people from diverse communities.

Your letters will be back in the next issue of the magazine. We love to hear your feedback on the magazine and the articles you've read. Do share your thoughts by writing to us at **msmatters@mssociety.org.uk**



Building an accurate picture of MS in the UK

Research Network member and biomedical scientist **Dr James Turton** spoke to the UK MS Register's Clinical Lead **Professor Richard Nicholas** about how data is helping build a picture of life with MS.

iStock

The MS Register was set up to answer questions that I am sure many of us with MS have asked: What symptoms do people with MS experience? What are the differences in how MS affects individuals? What treatments are people taking? And it's also helping answer questions about coronavirus and MS.

I was diagnosed with relapsing MS in 2010, and have since completed a PhD on the genetics of Alzheimer's disease. As a scientist, I know first-hand that we need data to help us answer big questions. This is where the MS Register comes into its own.

I first submitted my information to the MS Register when it was set up in 2011 and have a monthly reminder to update my data. As an active supporter of this initiative, I asked Richard why the MS Register is so important at this unprecedented time.

So how does the MS Register work?

People affected by MS submit information through online questionnaires and UK hospitals also provide information from participants' medical records – if they give consent. The responses are stored securely and can be linked together to build up an accurate picture of MS in the UK. The MS Register is principally people-driven, as opposed to many other international MS registers which are driven by healthcare professionals. New surveys are constantly being added as we learn more about the condition. It's been funded and supported by the MS Society since the start.

How do people with MS shape the MS Register?

Patient and public involvement has always been part of the MS Register. Questionnaires are generated by people with MS, alongside researchers and clinicians. Ultimately the data is "donated" by the MS community. It's very valuable and must be treated appropriately.

What can the data be used for?

Evidence from the MS Register can help us find out more about living with MS in the UK. For example, data from the MS Register recently revealed some of the hidden costs of living with MS and that many people with MS also experience depression and anxiety. It also helps us lobby the government on issues affecting people with MS and develop better services.

Evidence is especially important during this pandemic. As new information arises recommendations may change. We need to know how people with MS are affected to work out the best course of action.

> **"Because COVID-19 is so new, we are all still learning"**

How much data has the MS Register collected?

During the last nine years, over 90,000 questionnaires have been answered, many of these with 20-30 questions in each. Over 17,000 people have submitted data.

How has the MS Register responded to COVID-19?

The MS Register team reacted swiftly, and set up questionnaires to gather information about how COVID-19 is affecting people with MS. It was important to do this in "real time" and not by looking back after the event. We wanted to know: How many people with MS get infected? What symptoms do they have? How are they affected psychologically? What is the effect of shielding? We've been working with the MS Society and other collaborators to make sure we're gathering relevant information.

What have we learnt about COVID-19 and MS?

The data told us that some people had their pay or hours reduced due to COVID-19 and 35% said the outbreak would negatively impact their finances. Some people have also had their care reduced or cancelled. This information has helped the MS Society to make sure people are getting the support they need.

Initial data from the UK also suggests that people with MS aren't more likely to get coronavirus or get worse symptoms, which is similar to what we're seeing in other countries. We're continuing to monitor this, though, as we don't know what will happen as restrictions ease. Because COVID-19 is so new, we're all still learning.

The MS Register is a vital tool for understanding all aspects of living with MS. We're delighted to have been able to use it to help quickly answer questions about COVID-19, which are so important for our ongoing learning curve about the virus.

Find out more about the UK MS Register and how you can take part: **ukmsregister.org**

MS REGISTER

Speaking up for our community in lockdown

Photo: Shutterstock

It can be difficult enough to deal with MS without coronavirus and lockdown in the picture too. We've been working hard to influence governments and decision-makers across the UK on issues affecting our community during the pandemic.

The issues are evolving all the time

When lockdown began, lots of you told us you couldn't access food and essentials, so we've called on supermarkets and decision-makers to give vulnerable people and carers priority access.

We also heard that many people with MS weren't able to register as "clinically vulnerable" to access vital support. We raised this with governments across the UK and we're pleased that changes have been made.

Now, we're speaking up alongside other charities to make sure that as the lockdown measures change, the right support is still there for everyone. This could be mental health support, for example, or not having to return to work until it's safe to do so.

Getting the right care and treatment

We know that the pandemic has put even more pressure on carers. We've heard from people with MS who've felt they have to cancel paid care to protect themselves from people coming into their home. Some of you may have had your care reduced by your local authority, or found that your carers aren't available due to being unwell or isolating.

We're calling for an increase to Carer's Allowance across the UK, and for carers to have access to personal protective equipment (PPE) and testing, to help keep them and the people they care for safe. We're pleased testing is now available, and there's now guidance for carers on accessing PPE.

As we move beyond the peak of the pandemic, the NHS is slowly starting to return to normal service, so we're speaking to decision-makers about the need to prioritise neurological conditions.

You've been speaking up with us

We've been speaking up loud and clear as a community too. As part of the Disability Benefits Consortium, we came together to call for Employment and Support Allowance and other out-of-work benefits to be increased by £20 a week. The petition has been signed by over 116,000 people. We'll keep you updated on what happens next.

Many of you have shared your lockdown experiences with us – but we're always keen to hear more. You can share your story with us by visiting **mssociety.org.uk/share-your-story**

For information about coronavirus and MS visit **mssociety.org.uk/coronavirus-updates** or call the MS Helpline on **0808 800 8000**.

At home, but not alone

How our Never Alone campaign has been supporting people living with MS during the coronavirus crisis.

When the UK went into lockdown on 23 March, we had to quickly rethink how we supported each other, without being able to connect in person. From physio on FaceTime to chatting online, we worked together to make sure that although we were at home, no one was alone.

Keeping in touch

After lockdown there was a big surge in calls to our MS Helpline. Many people calling were anxious about being isolated.

Helpline Services Volunteer Manager Ahra An said, “We wanted to do something to help, so we adapted and brought forward aspects of our new befriending service, which we’d planned to launch later in 2020.” Within weeks, Ahra and her team had set up the telephone service Keep in Touch, which offers people a weekly catch up with a friendly volunteer.

To get things going quickly, some MS Society staff volunteered for the service, including Evidence Officer Brooke Lumicisi. Brooke said, “It’s been lovely to be a part of the service. We’re in such uncertain times, and a friendly chat can really lift the spirits on both ends of the line. Even something as seemingly small as a phone call can help us to feel connected.”

Our new befriending service

Before lockdown, we knew many people with MS were already experiencing isolation and loneliness. We hope our full befriending service, which is planned to launch at the end of July, will support anyone feeling this way. The service will be available long after lockdown is over, while Keep in Touch will run until the end of September.

Ahra said, “The befriending service matches you to a particular volunteer, who’ll call you once a week for about three months. Whereas with Keep in Touch, you speak to a different volunteer each week. Either way, the calls can make a big difference.”

A lifeline to the outside world

Kate has been using Keep in Touch. “I’ve been pretty anxious,” she said. “My carer is not coming to see me now and I had struggled to get prescriptions and pick up shopping. The isolation has not been easy either – I haven’t seen a soul for four months.

“Keep in Touch has been a lifeline to the outside world. It’s a friendly voice on the other end of the phone when I have literally no contact with anyone else. It’s been lovely to talk to someone who wants to know how I’m doing and takes an interest.”

MS nurses join our helpline

Our very first MS Helpline nurse, Jennifer McNeil, began work on Monday 23 March – the day the lockdown started. Unsurprisingly, Jennifer has been answering lots of questions relating to coronavirus. “I’ve certainly learnt a lot about it!” she said.

Jennifer has also been supporting people who got their MS diagnosis during lockdown. “It’s a shock and people have lots of questions but many of the nurses and neurologists were redeployed,” she said.

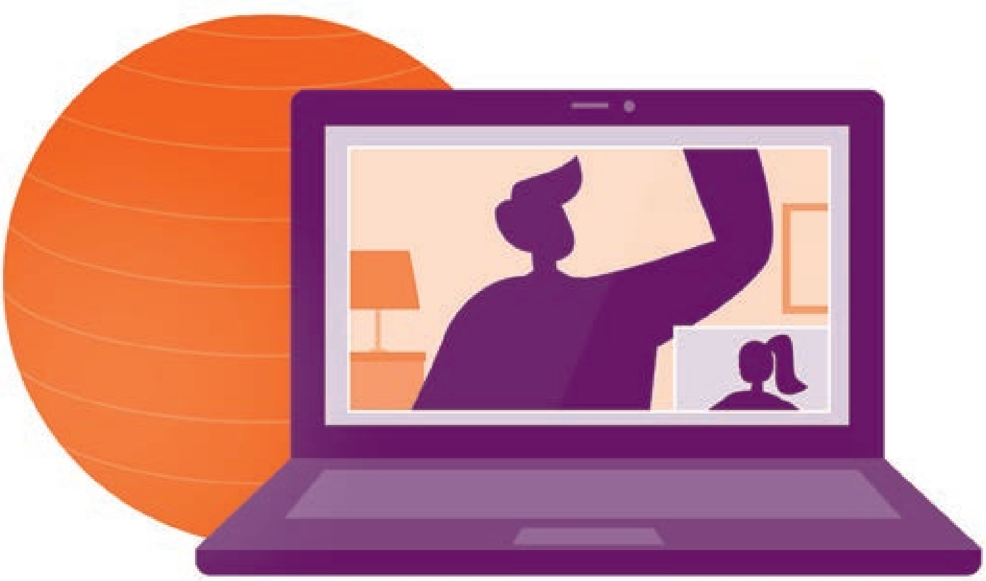
Life has still been going on despite the pandemic, and MS doesn’t take a back seat. “People are getting diagnosed, people are having symptoms, people have questions about medications,” Jennifer said. “It’s important you still get the support you need. We’re always here on the MS Helpline as an extra resource if you’re struggling to get hold of your MS team, or if you’d just like some more time to go over things.

“We can’t give direct medical advice so always remember you can contact your GP – they are still here for you. It’s the same with the MS nurses – leave a message even if they can’t get back to you quickly.”

Jennifer’s been joined by our second MS Helpline nurse, Razia Khan (who tells us about herself on page 47). Our nurses will be here for everyone affected by MS after this crisis is over.

Ways to connect online

Our team of staff and volunteers in Scotland have been developing online support for a few years now, and were starting to roll it out across



the UK. So, when the pandemic struck, they were well-placed to quickly increase this support. This includes wellbeing sessions, interactive information webinars and Time to Chat groups (informal virtual meet ups).

Clair Bryan, who leads the team, said, “We knew a lot of people were feeling scared and overwhelmed with information about coronavirus. In response, we held a number of webinars about COVID-19 and MS with top neurologists – 250 people attended our first one. Now we’re doing one or two webinars a month on issues such as health anxiety, employment and exercise. And we’ve run 64 Time to Chat sessions, so people can share their experiences and support each other. Volunteers with lived experience of MS have led or co-delivered all our online sessions, and they’ve been absolutely brilliant.”

Craig Herbert, who co-delivered a webinar on anxiety, said, “The chance to ask questions and even provide some answers myself was valuable. It’s great to see people connecting and keeping in touch when they might not have been able to otherwise.”

Friendship and comfort

Barbara is among those who have taken part in Time to Chat. “I wanted to feel a little bit less alone during this time,” she said. “I was looking for friendship and the comfort of speaking to other people who just ‘get’ MS but also who understand the particular impact this crisis is having on us. Everyone had a chance to speak (or not if they didn’t want to) and it was just like getting together with some mates. I really hope this kind of thing continues when we go back to ‘normal’ as I think it can be really beneficial.”

New ways to offer support

Physiotherapist Rachel Flinn normally works at our Belfast Resource Centre, providing one-to-one physiotherapy and running Pilates classes. After lockdown, she set up her classes and one-to-ones online.

Rachel can give advice on posture, exercising, strengthening and stretching. She misses seeing people in person but has also found benefits. “It’s opened up the service to people in Northern Ireland who live far away from our Belfast Centre.”

In Wales, our team have also found new ways to reach out. They put in a successful bid to the Lottery COVID fund to extend their Welsh-wide project My MS, My Rights, My Choices until the end of 2020. This means the MS community in Wales can still access one-to-one support with emotional, financial, employment, health and housing issues - now over the phone or by Zoom.

What’s next for our services?

Although lockdown is easing for many, we still don’t know what the future holds. Will delivering more services in this way be our “new normal”?

Clair believes it shouldn’t replace what we do, but can add to it: “Face-to-face contact will always be important, and in time we’ll be able to restart those services,” she said. “But even without coronavirus, meeting face to face can be challenging. MS fatigue, geography, work and childcare can all make it difficult for people to travel. Services you can access at home give people more choice in how they get support. Hopefully, that can only build the MS community and make us stronger.”

Read about how local MS groups have been supporting people on page 22. To find out more about our services, contact our MS Helpline on **0808 800 8000**, email **helpline@mssociety.org.uk** or visit **mssociety.org.uk/never-alone**

Keeping MS research moving

Dr Emma Gray, our Assistant Director of Research, explains how we're still committed to stopping MS despite the effects of coronavirus.

Every year we invest millions in new research projects, funding major breakthroughs in the UK and bringing scientists across the world together to speed up progress. This has got us to a critical point, and we can see a future where nobody needs to worry about their MS getting worse. But coronavirus is affecting many of the vital research projects we support – projects that could change what it means to live with MS.

Social distancing means many laboratories had to close. The face-to-face visits in most studies paused. And researchers stepped in to support the NHS. We're also facing a significant loss to our fundraising income and, unfortunately, that means our research programme will be affected. Many planned new research projects could be postponed and we're unable to immediately fund the promising new work that is desperately needed.

Adapting to coronavirus

We've taken the decision to focus on supporting our researchers to complete projects they've already started and helping them keep studies going. MS researchers across the world are keeping in touch and sharing ideas virtually. Lab workers are analysing results and writing up findings from home. Researchers have adapted clinical trials so that they can carry out follow up visits by phone and participants can complete questionnaires by email. This means researchers can still gather the vital data they need but participants are kept safe. And we're still planning our efficient clinical trials platform, which will speed up the search for new treatments.

Photo: iStock

We're also supporting the UK MS Register to run a survey to help us better understand how coronavirus affects people with MS (read more on page 8).

Our plan to stop MS

We know that finding treatments to slow or stop the accumulation of disability is what people with MS want and need. Our Stop MS Appeal aims to address this by identifying promising treatments and delivering them to everyone with MS as quickly as possible. Since the Appeal launched, we've secured over £53 million to support this vital work. And although coronavirus has put the brakes on our progress, we're still committed to pushing forward the search for new treatments.

Today there are over a dozen treatments available for people with relapsing forms of MS, and some emerging for progressive MS. But there are still lots of people living with progressive MS, like Liz (right), without any options, and the treatments that do exist only work on one aspect of MS: the immune system. We need treatments that repair myelin – the protective layer surrounding our nerves, which is damaged in MS – and protect the nerves from damage.

We believe we're on the cusp of major breakthroughs.

Our ambition hasn't changed. By 2025 we want to be in the final stages of testing a range of treatments for everyone with MS. And – coronavirus or not – we're committed to doing everything in our power to make this happen.

We've secured

£53 million

for MS research

Thanks for supporting our Stop MS Appeal

Research successes, many funded by the MS Society, mean that we now have an unrivalled opportunity to develop a programme of effective treatments that could slow or even stop the damage caused by MS.

But to make this a reality we need a dramatic increase in investment in research. So, in 2015, we started fundraising for our Stop MS Appeal and, late last year, we launched the public phase. The response so far has been fantastic!

Thank you to everyone who's baked, cycled, donated, walked, played our raffle, and fundraised in imaginative ways to help us get closer to new treatments.

Find out more and get involved at **mssociety.org.uk/stop-ms-appeal**

"It's like sunshine through the clouds"

Liz Hyland is taking part in our MS-STAT2 clinical trial. She explains why research is vital despite the pandemic.

I've had MS for 26 years but after I developed secondary progressive MS there were no treatments available. That's why I was keen to take part in the MS-STAT2 trial, which is testing if a cholesterol-lowering drug called simvastatin could help people like me.

I was due to have a trial check-up in April, but the lockdown meant I couldn't travel to London. To continue on the trial, I needed to have a blood test to check for any side effects so my research nurse Sarah arranged for me to have this at my local GP. Fortunately, this came back clear and my next batch of tablets were delivered by courier. And rather than coming in for tests, the team asked me about my walking ability, speed and balance over the phone.

For me being on the trial is like sunshine through the clouds. It gives me that hope. And even during the pandemic, it's important that researchers can still gather this information to help find treatments for everyone living with MS.

To express interest in the MS-STAT2 trial visit **mssociety.org.uk/msstat2**

Welcome to our pub quiz with Scott Mills

We know that many of you have been isolating at home during the lockdown and some of you may still be shielding. We appreciate it's been a tough time. That's why we wanted to provide a fun way of being together while staying at home. What better way than a virtual pub quiz, hosted by our Ambassador Scott Mills!

Scott says: "I hosted a series of quiz nights on Facebook and YouTube to raise funds for the MS Society, which is a cause close to my heart. My mum, Sandra, has primary progressive MS and has been isolating at home during the lockdown.

"I'm so pleased that more than 23,000 people played over the six weeks we ran the quiz, raising £55,000 to help people living with MS feel less isolated during this time.

"I loved hosting the quiz and I wanted to open it up to those of you who couldn't join me online. So here it is. An exclusive set of questions, including three from MS Society celebrity supporters Laurence Llewelyn-Bowen, Nicola Walker and Richard Hawley.

"You can find the answers at the bottom of the page but no cheating!"

Photo: Nicky Johnston

Round 1 - General knowledge

1. On a standard UK Monopoly board, what colour is Trafalgar Square?

A: Red
B: Blue
C: Yellow
D: Green

2. At what kind of show do cowboys traditionally exhibit their skills?

A: Fiesta
B: Honky Tonk
C: Rodeo
D: Industry Trade Show

3. The Florian gold coin was originally minted in what Italian city?

A: Turin
B: Florence
C: Venice
D: Naples

4. What year did the MS Society UK form?

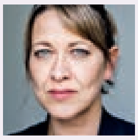
A: 1951
B: 1952
C: 1953
D: 1954

5. Eric Carle wrote a series of children's books about 'A Very Hungry...' what?

A: Monkey
B: Caterpillar
C: Frog
D: Mouse

6. Who is fifth in line to the British throne?

A: Prince Louis
B: Princess Charlotte
C: Princess Anne
D: The Fresh Prince of Bel Air



7. Nicola Walker asks: I was part of the Footlights drama club when I was at uni in Cambridge. Which of these comic actors wasn't a member of Footlights?

A: Richard Ayoade
B: Michael Palin
C: Hugh Laurie
D: Olivia Coleman

Round 2 - European geography

1. On which island of the British Isles are the towns of Shanklin and Sandown located?
A: Isle of Wight
B: Isle of Man
C: Isle of Skye
D: Isle of Dogs

2. What is the capital of Norway?
A: Tromsø
B: Bergen
C: Oslo
D: Leeds

3. What are the colours of the Belgian flag?
A: Black, white and red
B: Black, yellow and red
C: Yellow, white and orange
D: Purple with yellow spots

4. In what city would you find Saint Peter's Basilica?
A: Madrid
B: Paris
C: St Petersburg
D: Vatican City

5. What is the only country in the world to use the Zloty as its official currency?
A: Switzerland
B: Poland
C: Latvia
D: North Macedonia

6. Which of these countries is not a former member of the Soviet Union?
A: Lithuania
B: Belarus
C: Finland
D: Ukraine

7. Laurence Llewelyn-Bowen asks: In which German town or city would you find the famous Vitra Design Museum?
A: Berlin
B: Weil am Rhein
C: Nuremberg
D: Rothenburg ob der Tauber

Round 3 - TV and film

1. Who played James Bond in the 1967 film version of Casino Royale?
A: Daniel Craig
B: Roger Moore
C: David Niven
D: Timothy Dalton

2. Where was classic British sitcom Fawlty Towers set?
A: Plymouth
B: Torquay
C: Falmouth
D: Beijing

3. In 2009 which British actress won the Best Actress Oscar for the film The Reader?
A: Emma Thompson
B: Kate Winslet
C: Olivia Coleman
D: Kirk Douglas

4. Who played Phoebe Buffay in the US sitcom Friends?
A: Lisa Kudrow
B: Christina Applegate
C: Courtney Cox
D: Brian Cox

5. Worldwide, what was the top box office grossing film of the 1980s?
A: Back to the Future
B: Return of the Jedi
C: ET: the Extra-Terrestrial
D: Top Gun

6. Which actor, famous for starring in TV's Last of the Summer Wine, was also the voice of Wallace in the Wallace and Gromit films?
A: Peter Sallis
B: Peter Sellers
C: Ralph Fiennes
D: Dustin Hoffman

8. Richard Hawley asks: I play Johnny Connor in Coronation Street. How many cobbles are used on the famous set?
A: Over 9,000
B: Over 10,000
C: Over 11,000
D: A million

Answers: **Round 1:** 1a, 2c, 3b, 4c, 5b, 6a, 7b, **Round 2:** 1a, 2c, 3b, 4d, 5b, 6c, 7b , **Round 3:** 1c, 2b, 3b, 4a, 5c, 6a, 7c

Top tips for hosting your own online quiz

1 **Decide on the platform you are going to use.** We'd recommend livestreaming via YouTube.

2 **Set a time and date.** Promote your quiz to friends and family via your social media accounts or email.

3 **Decide how you are going to ask for donations.** We recommend you set up a JustGiving page, sharing the link before your quiz and asking for a suggested donation of £3 per player.

4 **Write your questions** – perhaps with a new theme each week – and double check your answers.

5 **Keep it short -** 45 minutes to an hour is about right.

For more tips and to download Scott's free DIY quiz pack, visit **mssociety.org.uk/diy-quiz**

Treatment which can improve walking approved in Scotland

Fampridine (Fampyra) has been given the green light by the Scottish Medicines Consortium (SMC) for people with MS who have a walking disability.

Fampridine helps about one in three people who take it and can speed up walking by about 25%. It is a symptom management treatment (SMT), meaning that it helps people with the symptoms of their MS, as opposed to disease modifying therapies (DMTs) which control the condition itself.

Who can take fampridine?

It will be available to people who are scored 4-7 on the Expanded Disability Status Scale (EDSS). (You can read about the scale on our website at mssociety.org.uk/about-edss)

It's taken as a tablet and most people are prescribed one tablet in the morning and one at night. If your healthcare professional thinks that it's the right medicine for you, you should now be able to have the treatment on the NHS in Scotland.

Scotland is the second UK nation to offer this treatment on the NHS following its approval in Wales.

We're working to get this drug made available on the NHS to all people who could benefit from it – no matter where in the UK they live.

Dancing at her daughter's wedding

Nina Campbell has lived with MS for over 25 years and has been taking fampridine.

"When I was first told that I'd progressed from relapsing to secondary progressive MS my consultant at the time simply said, 'there's nothing to do, just look after yourself'. But when I moved further north I had a new consultant who suggested I try Fampyra (fampridine) and it's been brilliant.

"Since starting it I've had more movement in the toes of my right foot, which I hadn't been able to do for years. I have more energy and just feel able to do so much more.

"It still takes a bit more time and I need to think and plan ahead for most activities, but I'm now able to walk further for longer.

"One of the most fantastic things was on my daughter's wedding day, I didn't have to use my wheelchair at all.

"Even when the dancing started I was still standing!"

Nina and her husband Laurence at her daughter's wedding

JUMA photography

Find out more about fampridine and treatments for balance and walking problems at **mssociety.org.uk/balance-treatments**

Our groups embrace technology to stay connected

Our groups across the UK found new ways to support people at home during the lockdown. We asked four group coordinators how they've helped people feel less isolated.

Image: Dumbarton and Vale of Leven Reporter, Newsquest Media Group

"We're reaching out in any way we can"

Sheena Rollo, Group Coordinator for Dumbarton and District Group

My sister, who is 65, was diagnosed with secondary progressive MS when she was 28. I got involved with the Dumbarton Group about 12 years ago.

We're such a close-knit group, even though our 72 members are not only from Dumbarton but also the surrounding areas, including the vast and remote region of Argyll and Bute. We usually have lots of events and outings all year round, so the lockdown hit us hard.

But we got things moving again with Angela, an exercise instructor who used to come to our drop-in facility. Concerned that people wouldn't be moving as much as they should, Angela is now hosting her weekly exercise class as well as a new meditation session on Zoom.

Although many of us are new to meditation, we're really seeing the benefits of deep breathing and mindfulness.

One session was so relaxing that someone fell asleep and we couldn't wake her up – we were worried at first, but her son was at home and she was ok!

Those who join our classes on Zoom are absolutely loving it. What's more, we've decided to continue with our meditation sessions online, even when lockdown is over.

Isolation is a big worry for people living with MS at the best of times. This crisis has only magnified it, especially for members who don't have access to technology. But our closeness and the friendships we've built up over the years mean that we have continued reaching out to one another in any way we can – whether that's through our Messenger chat room, or by just picking up the phone.

We've even produced a feel-good video using photographs from our past events and clips of our members marching and moving to the song, I'm Gonna Be (500 Miles) by The Proclaimers. It's nothing slick, just for laughs, and by sharing it on our group's Facebook page, I hope it reminds us of all the wonderful times we've had together.

"Perhaps there's room for Zoom in the future"

Peter Branson, Group Coordinator for West Oxfordshire Group

My daughter Josie was diagnosed with relapsing MS about 13 years ago, and I've been the Group Coordinator for eight years now.

Our group has 130 members, of whom 90 are living with MS. We're an active group offering a variety of weekly sessions for our members, including aquatherapy, Pilates, physiotherapy, yoga, massage and podiatry. We also meet up for social events such as quizzes and meals out.

When the COVID-19 pandemic stopped all our normal activities, we resumed our physiotherapy sessions via Zoom but quickly learned that we couldn't just provide one class for everyone. Not wanting anyone to feel left out, we decided to offer two different sessions each week to cater for people with varying levels of mobility.

We now have an activity on Zoom every day, from Monday to Friday, including two Pilates sessions and one yoga session.

In our social group sessions, we usually start with a general Q&A to provide practical information and support. But people mainly use these sessions to say hello and find out how everyone's doing – with pet cats and dogs often making an appearance.

At first, it was a big challenge to get people set up on Zoom. As a group, I think we've adapted, learned to use new technology, stayed connected and kept our spirits up.

Some of our members have even said that it's been easier to go online rather than get transport to a session as they would have done before. It's too early to say, but perhaps there's room for Zoom in the future, after the lockdown.

At the end of the day, having a cup of tea at home is not quite the same as going out to meet people and chatting to them face to face. But for now, we'll continue with our Zoom sessions for as long as they're needed to keep our members active – both physically and socially.

Want to get involved?
Find your local group online at **mssociety.org.uk/local-support**

“People are keen to share their hopes and fears”

Janet Williamson, Group Coordinator for Newry, Mourne and Armagh Group

I was diagnosed with relapsing MS about 24 years ago, and I’ve been Group Coordinator for the last 15 years.

With many of our members living in rural areas, staying in touch has become much more important now, especially for people’s mental health.

We use our Messenger group to share information and for peer support, as someone is always there to listen and respond. People are keen to share their hopes and fears about the future, so we’re getting an insight into how everyone’s getting on during the lockdown.

Janet receives an award from CEO Nick Moberly (left) and broadcaster Joe Mahon

Using WhatsApp video, we’ve replaced our weekly art class with a chit-chat every Tuesday and moved our yoga class to an online session every Thursday.

Until things go back to normal, we’re asking our members to try different ways of staying connected – by posting a message, talking to others, or joining an online activity.

Our group is like a family and just being there for someone can be such a positive thing. When one of our members who lives in a nursing home was feeling down, we all wanted to help cheer her up. We gave her gifts so she could open one every day – for two weeks! Knowing that other people were thinking of her really lifted her spirits.

“Our connections have become even stronger”

Ann Hodgson, Group Coordinator for Chepstow Group

I’ve had relapsing MS since 1987. I started getting involved with the Chepstow Group almost 15 years ago. We used to meet weekly as a group for coffee and a chat, and for yoga classes.

Within two weeks of the lockdown, our coffee and chat sessions were up and running again on Zoom. We tend to keep our conversations upbeat and, as you’re seeing many different faces, it can help people feel less isolated.

We’re also using our WhatsApp group chat to send messages to each other and since Easter, we’ve moved our yoga sessions to Zoom.

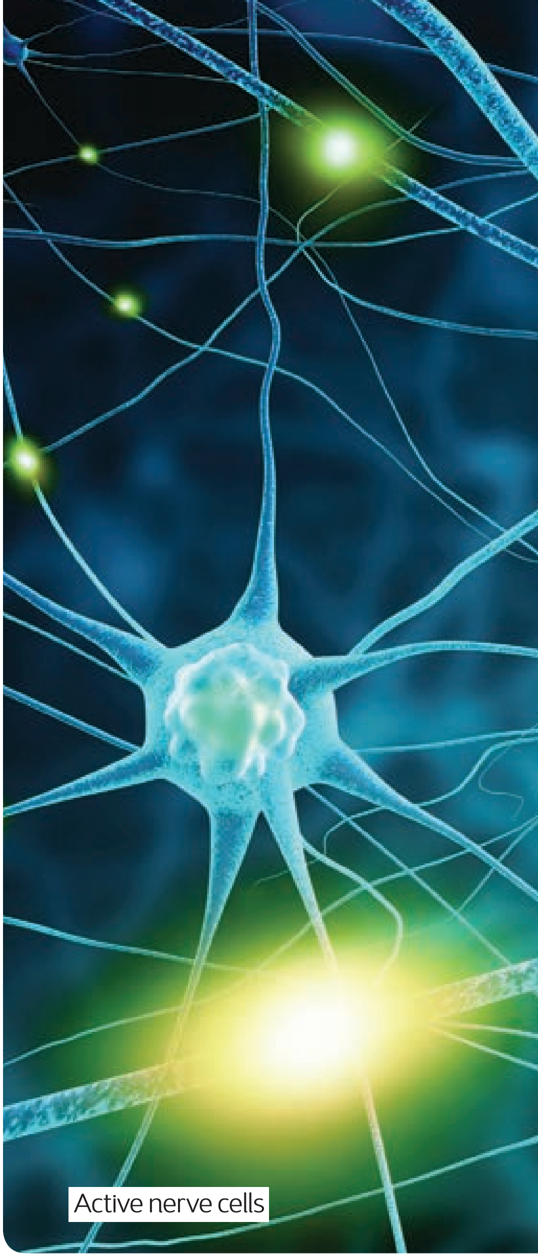
Our Local Network Officer lets us know what’s going on across different MS groups in Wales. That means we can choose to be part of various other online activities such as the popular Friday afternoon quizzes, mindfulness and Pilates classes, and the choir. We have tried singing along to the piano when we meet up virtually for the choir but, as you can imagine, it’s not the easiest thing to do on Zoom!

Being online has helped us to connect with new group members from other parts of Wales. I can happily say that the connections we had before the lockdown have become even stronger now.

Email **sian.tucker@mssociety.org.uk** for more information.

Let's talk about sex hormones

Beth Shorthouse-Ullah, who lives with MS, spoke to **Dr Riley Bove**, from the University of California San Francisco, about the role of hormones in MS.


Active nerve cells

First things first – what are hormones?

"Hormones are chemical messengers found in the body. They help one part of the body communicate with another, by travelling through the bloodstream to pass on messages. There are lots of types of hormones, and each type plays a different role in the body. For example, sex hormones like oestrogen and testosterone play a role in sexual development and reproduction, whilst gut hormones like ghrelin can stimulate your appetite."


Beth Shorthouse-Ullah


Dr Riley Bove

Is there a link between hormones and MS?

"When people talk about hormones and MS, the focus tends to be on the sex hormones. Research suggests that there is a strong link between sex hormones, like oestrogen and testosterone, and the immune system. We know that the risk of developing MS is higher for women than men. It has been noted that when puberty begins, the risk of developing MS increases in women in comparison to men. But although men are less likely to be diagnosed with MS, the course of their condition is often more severe.

We also know that during pregnancy, when women experience many hormonal changes, they often have fewer relapses. But in the first three months after birth the risk of relapses rises.

We don't fully understand what causes these differences between men and women but it's very likely that hormones are involved."

Could hormones play a role in the treatment of MS?

"Research has shown that exposure to oestrogen is able to promote myelin repair in mice. And oestrogen exposure in both male and female mice has been shown to reduce the effects of an MS-like condition.

> "We know that MS affects three times more women than men. So it makes sense to look at the hormonal differences between men and women."

For testosterone, one study has shown that high levels of testosterone in male mice triggered an immune response that protected them from an MS-like condition. And low levels of testosterone in female mice increased their risk of developing an

MS-like condition. These are promising findings for the future of treatments for MS, but what we really need to know is whether these results apply to humans.

What has your research shown?

"I've always been interested in the hormonal changes that occur at different stages of women's lives, like puberty and pregnancy, but the area I felt really needed exploring was how the hormonal changes associated with the menopause impact MS.

In my research group, we've been exploring whether rates of disability progression are different before and after the menopause. The results seem to suggest that disability progression speeds up a little around the time of menopause. But we also know that MS progression is linked to ageing. So it's difficult to disentangle the effects of ageing from the effects of the menopause.

We know women often report that their MS symptoms get worse during the menopause. With support from the National MS Society in the USA, we have done a small pilot trial to see whether hormone replacement therapy improves MS symptoms in menopausal women with MS. We're currently analysing the results of this trial, and hope to share them later in the year."

What are the next steps for hormones research?

"To date, most studies with people with MS have just observed the correlation between hormonal changes and MS symptoms, which doesn't tell us enough about what's actually happening in the body.

So we need to complete interventional studies (where you actually change people's hormone levels and measure the effect on MS symptoms) to understand how a treatment targeting hormone levels could benefit people with MS.

Clearly, we are scratching the surface of hormones as an area of research as a whole. But these studies will pave the way for future clinical trials and potential treatments."

Read more about MS and hormones at **mssociety.org.uk/hormones**

Image: iStock

Ask the expert: Stress and anxiety

MS is unpredictable so it's not unusual to experience stress and anxiety if you have the condition. And right now, there's even more uncertainty in the world. **Professor Rona Moss-Morris, psychologist and Stop MS Appeal Scientific Ambassador,** answers your questions on why it happens and how to manage it.

Q What are stress and anxiety?

Katie

Lots of things can cause stress. It could be a major event like coronavirus, or daily hassles like traffic jams or dealing with medication. These are called stressors and can mount up over time.

We respond to stressors in different ways. Our heart beats faster and our blood pressure goes up. We also respond emotionally. We can feel angry, frustrated, upset or helpless. Or we can feel anxious.

We can't always change the stressful things that are happening around us. But we can sometimes change how we respond to stress.

Q On days when I feel MS symptoms are worse, my anxiety is higher. Why is this?

Karine

We don't fully understand the link between stress and MS symptoms. But it's normal to feel anxious when you're experiencing symptoms, especially new ones.

Stress can make you tired, upset your stomach, or cause pain if you're really tense. So it can be hard to know which symptoms are due to MS and which are down to stress and anxiety.

Stress can also exaggerate symptoms. If we are not getting enough sleep, we might find it harder to deal with symptoms. It can be a vicious cycle. If we can find ways to manage stress, we're likely to feel better.

Q Do stress and anxiety cause flare-ups in symptoms?

Claire

We know that stress makes us more vulnerable to certain diseases like colds. And we know that there is a link between stress and how the immune system responds to invaders. But there's not much research on the link with the immune attacks that happen in MS. There is some evidence that stress might make relapses worse, but more research is needed so we can understand what's happening in the body.

Q Can stressful events in childhood increase your chance of getting MS?

Claire

Researchers have found a link between childhood adversity and increased risk of disease. There are some theories that if you have lots of stress during childhood it can change our nervous system which makes you more disease prone. But there's no evidence that MS is caused by stress.

Q Are there ways to deal with stress and anxiety without medication?

Barbara

We know that disease modifying therapies are really important for long-term health and slowing down the build-up of damage. But it's important that we consider the emotional impacts of MS as well if we want to stop MS.

MS is an unpredictable condition and we're living in uncertain times. Showing signs of stress is normal in these situations. But if the stress is getting in the way or makes you feel anxious or depressed then there are some things that might help.

Compass is an online digital therapy

> "It's normal to feel anxious when you're experiencing symptoms"

We know that exercise can help with mood and mobility, as well as some MS symptoms. This could be intense aerobic exercise or something like yoga – whatever works for you. Things like mindfulness, that help you think about the present moment, can also be helpful.

It may also be possible to get support from psychologists. Some people find cognitive behavioural therapies (CBT) helpful. These are talking therapies that help you become more aware of your thoughts and find different ways of thinking and doing things. There's also Acceptance and Commitment Therapy (ACT) which is similar to CBT but includes some different techniques like learning that thoughts are not necessarily facts. Although these therapies are very effective at treating anxiety and depression, our research suggests that they need to be adapted to take into account the specific challenges of having MS.

To address this, we've developed an online digital therapy called "COMPASS: Navigating your long-term condition". This helps people navigate the unique challenges of living with long-term conditions.

For example, many people with MS find they focus on the things they need to do to manage their condition. But it's important for mood to allow time for activities you enjoy as well. The programme can help you find ways to do that. And it can help you deal with uncertainty, maintain exercise and establish a routine that works for you. The programme was developed alongside people with MS and other long-term conditions. We want to research this further so that in the future the therapy could be more freely available in the NHS.

Q Do you have any tips for managing work stress?

Noor

Working with MS can be challenging. It can help to pinpoint the problem. Is it the stress of working when you have MS symptoms like fatigue, or is it issues with your manager's expectations or other relationships at work? Breaking down problems into chunks can help things seem more manageable.

Look out for our call for questions for the next MS Matters on our Facebook page at **facebook.com/mssociety**

Read more about stress at **mssociety.org.uk/stress-and-anxiety**

Photo: iStock

Support with finances and wellbeing in Manchester

Our Improving Quality of Life Project helps people with MS in Greater Manchester to improve their emotional wellbeing and financial security.

Sam tries out a scooter

Sam Liddy is one of more than 50 people who have benefited so far from the project, which is run in partnership with Citizen's Advice Manchester (CAM) and funded by the National Lottery Community Fund. She talks about the impact it has had on her life.

Why did you get in touch with the project?

My MS nurse thought it would be good for me to receive more support with my finances and benefits and to find a way to help me to get outdoors.

What kind of support have you received?

I got funds to be able to get a scooter. I've received the funding, but it is currently on hold because of coronavirus and not being well. Mark, the Project Officer, supported me so I was able to go and test scooters out and find the right one – I wouldn't have been able to do that otherwise.

Did the project help you get the funding?

Yes. I wouldn't have known what was available – it would have taken me years. Mark also helped me to dispose of an old scooter which was given to a local charity. It was too large and had been passed to me from my grandmother, who passed away recently.

How did Citizens Advice Manchester (CAM) help you?

They helped me by phone, with benefits and making sure I was receiving the right income. They sorted out issues I had with Universal Credit which I was scared of doing. It eased my mind and helped me get up to speed with my money and entitlements. CAM was good in explaining it all to me, being patient and offering further support, for example around housing.

Is there anything else you'd like to share?

They didn't forget about me but stayed in contact. Having that connection really helped. Mark made it possible for me go out, which I couldn't have done otherwise, because I'm housebound. I got support from someone with an understanding and knowledge about MS, which helped immensely. It is like a safety-net in that respect. They'll catch you because they know what you're going through.

To find out more, email **mark.pritchard@mssociety.org.uk** or visit **mssociety.org.uk/improving-quality-life**

Our UK-wide MS Helpline offers a Benefits Advice Service and can let you know about other financial support services, including grants. Call **0808 800 8000**.

How volunteers helped me

Three people talk about the impact our volunteers have had in their lives.

Sam from Larne in Northern Ireland on how volunteers are helping her get back on her motorbike.

I'm very lucky with my MS. There's lots of things I can still do. I'm not going to let it destroy my life. When I was diagnosed in 2003, I said to my doctor: "But I still have too much to do."

My MS hasn't stopped me from moving to China. It hasn't stopped me from moving to England. But it has stopped me riding my motorbikes. I've got two Honda Blackbirds in the garage and I always walk past them thinking, "I wish". But I'm determined to get back on, so I've started going to my local MS Society exercise classes again. Caroline, a volunteer, set them up and I'm so thankful she did.

Every Tuesday I go down to the gym and there's a professional trainer there to personalise a workout for me. Because of my MS, I have no feeling in my left leg, and I've lost most strength in my right leg. This means my balance is completely off, and you need balance and strength to hold onto a motorbike. But from these classes, I can see the difference already. Even if I can't get on the motorbike myself, I'm going to get strong enough to hold onto my husband and go for a lovely leisurely drive down the Antrim coast road. I'll have Caroline in big part to thank for that!


Sam on one of her Honda Blackbirds

You're only on this planet once. I plan to grow old disgracefully, and hopefully on the back of my motorbike.

"From these classes I can see the difference already"

Our volunteers are superheroes

Our 3,500 volunteers support people through our local groups, respond to enquiries on our MS Helpline, raise funds and campaign for change. Volunteers also play a vital role in coproducing our services, and in making sure we provide reliable information and invest in the right research projects (see Volunteer Spotlight, page 45). We simply couldn't do what we do without them!

If you'd like to find out more about volunteering, contact us at volunteering@mssociety.org.uk or visit **mssociety.org.uk/volunteer-with-us**

Soulla, whose son Chris has MS, talks about the comfort and practical support volunteers have given her family.

As a family, we are immensely proud of Chris and the things he has achieved in the most difficult circumstances. Chris was diagnosed with MS in 2007. Despite treatment, three nasty relapses later he needs a walking frame and mobility scooter to get around. This is where the impact of the MS Society comes in. We were so lost, scared, upset, lonely, and on our own. There were so many emotional feelings.

Then our MS nurse put us in touch with Tony, a volunteer at the MS Society Sutton Group in London. The group helped me to think there is hope. I truly believe that without the help of my local group, my son could not have achieved the confidence he has today. These angels have been there for all of us with advice, comfort, and loads of activities. Whenever you need them, they are there. I can just pick up a phone if I'm stuck for anything, but they also reach out.

If that isn't enough, over the last 10 years Chris has been able to get financial help from the group to buy equipment for his health and mobility. We will always be indebted to our local MS Society and what they have given us.

> “Whenever you need them, they are there”

Soulla (top right) with her husband Kyriacos, son Chris and daughter Joanna

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Mark explains how the support he received from Susannah and the Gwynedd and Mon group has changed his life.

When I was diagnosed with MS, I could no longer relate to myself at all. I could no longer work, and I had no idea what was going on with my body. I was a mess. But Susannah picked me up out of the gutter. I don't think I would be here today if it wasn't for Susannah and my local MS Society group.

I first found the Gwynedd and Mon Group in Wales through their Pilates class at my local leisure centre. When I got there, Susannah popped her head around the door. She introduced herself straightaway and said, “I'm from the MS Society. If there's any way I can help you I will.”

That's why I volunteer now. I raise money, and help other people, to say thank you for how much MS Society volunteers did for me. I get such a buzz from volunteering. It stimulates my mind, gets my body moving and I get to help people.

Susannah also introduced me to boccia, the soft ball sport. Before I knew it, she said do you fancy coming on an instructor course? Now I teach boccia classes for people with MS and other disabilities. My classes keep people active and get them out of the house, and I'm happy with that.

> “I get such a buzz from volunteering”

Mark now volunteers with Susannah

iStock

You could WIN £3,000!

Summer Raffle

Play along to support people with MS

Come together for the MS community by entering our summer raffle. When you buy a ticket, you'll also be in with the chance to win a fantastic prize.

Don't miss out on your opportunity to be one of our lucky winners. Give us a call or head online to play along today.

Why I support the summer raffle

Vicki Horton was one of our winners last year. She said: "I was very pleased to win the prize of a hamper in last year's Summer Raffle. I love being part of the journey to raise funds for research into a disease which I was diagnosed with in 2017. I don't think I can undertake the South Coast challenge again (see photo) so instead, I get involved with the raffle, and encourage family and friends to play along as well! Thank you MS Society for all you do."

Prizes

1st prize	2nd prize
£3,000	£1,000
3rd prize	**4th prize**
£250	£100

£25 M&S vouchers x 20

To play the raffle visit raffleentry.org.uk/mssociety or call 0330 002 0267

"Everything I do has to fit into my routine"

After Colin Goodman, from Belfast, was diagnosed with MS in March 2017, he experimented with dietary and exercise changes until he found a lifestyle that worked for him.

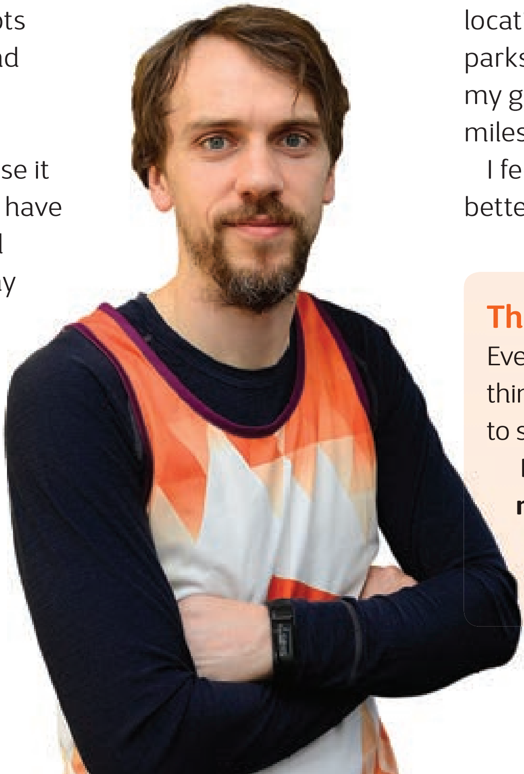
The first thing I did was to read up everything I could about MS. I found out a lot about what I can control, which was food. Obviously taking your medication is super important as well. For me, that's Tecfedira.

I tried something called the Paleo diet [foods available to early people before farming emerged]. This involves eating lots of nuts and berries and cutting out dairy and anything processed. I didn't continue because it wasn't sustainable – I have three young boys and it didn't fit well with my family life.

Plant-based diet

After that, I decided to take it slow. I stopped eating meat although I still eat fish. Then I moved on to cutting out dairy. I've also cut out fast food and alcohol. What has helped me eat a highly plant-based diet is the fact that I've really got into cooking. I'm loving my food!

I've started growing my own fruit and veg in the back garden, like raspberries, tomatoes, kale, spinach and strawberries. I think it's an important skill. There's something nice about being able to go outside and get your own food and knowing where it's come from.



Sunday World

MS is a passenger

Since being diagnosed, I've also taken up running and have done a half marathon and two marathons. I've continued running during the lockdown – in off-road locations rather than in the parks and streets – and my goal is to run 1,000 miles this year.

I feel a million times better than I did three or four years ago. I'm in a totally different place. MS is a passenger, it's there in the background, but it doesn't have any say in my life. As a Christian, my faith is also very important to me.

Everything I do has to fit into my routine so, to anyone looking to make changes, I would say do it gradually and make sure it fits your lifestyle. You don't want to do something that's going to cause stress. Everyone is different – and you need to find out what works for you.

Thinking of making changes?

Everyone's lifestyle is their personal choice, but if you're thinking of making any big changes, we encourage you to speak to your MS specialist first.

Download our Diet and Nutrition booklet at **mssociety.org.uk/eating-and-drinking**.

Call **0300 500 8084** or visit **mssociety.org.uk/publications** to order a paper copy.

During these challenging times, it's easy to get caught up in your thoughts and worries. With this in mind, **we asked you how you've coped during the lockdown**. Quizzes, music and video chats were among your top responses.

What's helped you cope with life in lockdown?

Shutterstock

"I've been working from home. By not travelling it's gained me an hour a day. I've been baking, crafting and gardening; all things I enjoy but for which I usually struggle to find time and energy."

Tracey

"I'm finding this time very difficult and stressful but with the help of my gorgeous doggy Ella I'm surviving."

Katerina

I've been cycling virtual routes around the world to keep in touch with my disability golf family. I stay home but I'm keeping my world as big as possible. It's been wonderful for my mental health and my fitness.

Aimi

“Music, being in my garden and video call quiz nights with my friends.”

Scarlet

Using social media and doing some sketching. I have had phone support from my local community nurses as well. However, it has been extremely difficult not getting any fresh air! I’ve been unable to leave the house due to neighbours not following the rules around lockdown.

Clive

“Scott Mills’ quiz night and finding other quizzes online like Marvel and Star Wars helps you stretch your brain and, most importantly, have fun!”

Kerry

Being with my family every day, whether they’re working from home (husband), doing schoolwork (teenage son) or furloughed (eldest son). It’s nice just knowing they’re there and safe.

Dawn

I’ve discovered the Paracise Community Exercise classes, specially designed for those of us who are less mobile, or just a little older, with the option of doing the exercises seated. They have broadcast live sessions on Facebook every morning during lockdown. It gets me out of bed and improves my mood.

Debbie

“Video chatting with family and friends I haven’t been able to see for months. Doing different things around the house (decorating, clearing out) to make my surroundings better. Knowing I have a safe environment around me, and it won’t be forever.”

Lauren

Using my MS exercise DVD helps to fill the gap of my three classes which are not on. Keeping in touch with some other MSers from my classes. Video calls every day with my daughter. Relaxing in our inflatable Lay-z-spa. Having my husband here. Listening to the birdsong. Reading on my Kindle.

Heather

“Tidying up the house. I can now see my dining table. And video calls with friends.”

Kay-Anne

We’ve deferred the question we asked last time to our Autumn issue. Thanks to those of you who’ve already replied! There’s another chance to tell us: What’s your best achievement while living with MS? Email us at **msmatters@mssociety.org.uk** or keep an eye on our Facebook group, **facebook.com/mssociety**. We’ll post the question in the autumn.

Making the invisible visible

"'But you look so well!' If I could have had a pound every time I used to hear that said, the MS Society collecting bucket would be overflowing," writes Jacqueline on our blog.

Outward appearances can be deceptive. Even more so now, when all you see of friends and loved ones is the scaled down version on the Zoom or Houseparty screen.

I know only too well about the invisible, but visible to me, symptoms of MS from which I suffer. Here are two of them.

Trigeminal neuralgia, or TriGemN, as I call it for short, is a sudden, severe and sharp nerve pain that shoots down the side of my face. It feels like having an electric shock in the jaw, teeth and gums. There is no other pain like it and when it hits, it leaves me floored, literally.

It usually happens in short, unpredictable attacks and hits my upper right jaw, lasting for about two minutes, every three to four hours. It occurs for up to 10 days and nights at a time and then the attacks stop as soon as they start.

You get lulled into a false sense of safety and think it's over. Then, out of nowhere when you least expect it, WHAM! It hits you again. There is no escape.

Perhaps a more common invisible symptom known to many with MS is having trouble with memory and thinking. "Cog fog" as it's often called. Again, there's nothing to be seen.

It's easy to disguise, I did for several years before finally I had to give up work. I just thought I was getting more stupid as I struggled with even the easiest of tasks like shopping online or booking travel.

Many of you have experienced similar symptoms. Here are a few of your responses on Facebook:

Sonia
Really well-written, thank you. The cog fog is why I had to give up my job, too. It's so hard to explain!

Karen
Thank you for sharing Jacqueline. I understand the cog fog difficulties as I experience these too. I'm lucky the issues lie with me because it's a lot harder for my fiance and those closest to me to understand when it's invisible. Stay strong beautiful #mssister. If you have a down moment/day remember it's ok to not be ok sometimes.

Charlotte
Cog fog was a frustration until I realised it was MS and there is a reason why I struggle. Hard to explain to others though!

Read more about invisible symptoms at **mssociety.org.uk/signs-and-symptoms**

Are you a budding blogger?

If you'd like to write for our online community, get in touch with us 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**

How lockdown has opened up a virtual world

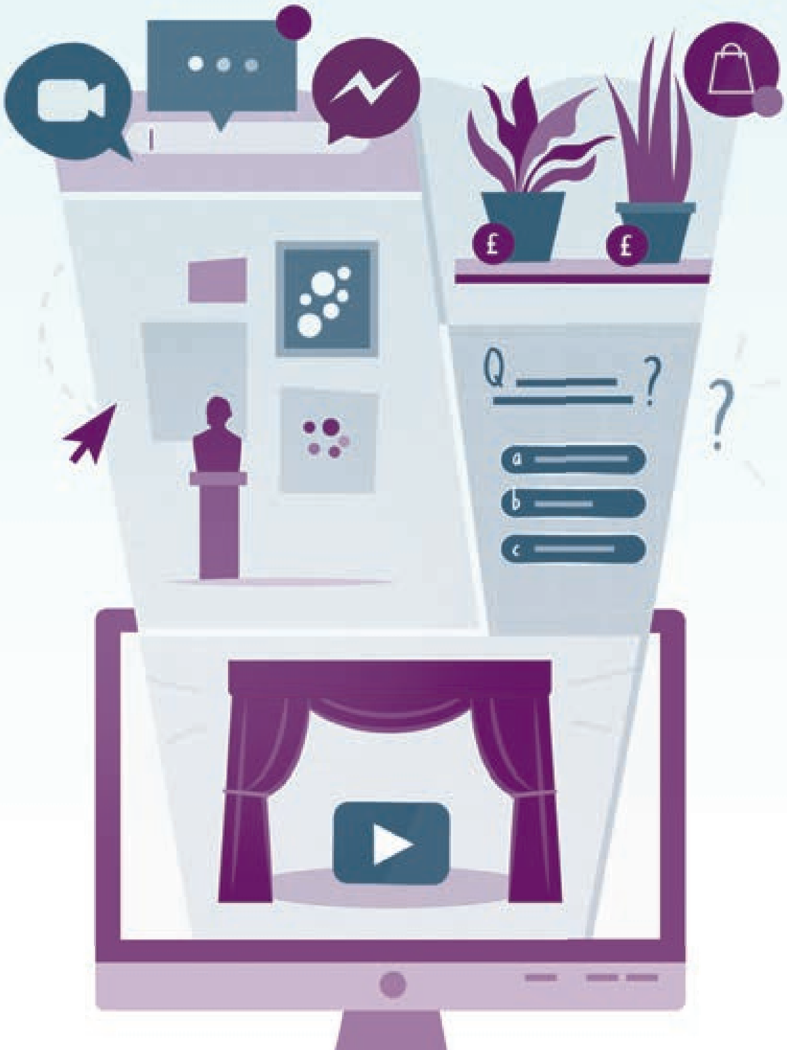
From musicals to museum tours, **Theresa Sullivan** has been exploring what's on offer online.

Since the outbreak started, I've been using my computer to do things I've never thought about or knew how to do before.

One of my favourite finds is virtual tours of museums, like the Science Museum, where I could view the first magnetic resonance imaging (MRI) machine. I was interested to see inside an MRI without being put inside it. Usually, when I have a scan I close my eyes before the face mask cover is put on and the table moved inside. I dislike having MRIs and always try to make a list of jobs to do in my mind to distract myself. However, viewing the MRI on the virtual tour still interested me a lot.

The shows are still going on

I used to go to theatres a lot with my family and especially liked going to pantomimes. On YouTube, I've been enjoying Andrew Lloyd Webber's "The Show Must Go On" channel. I've watched Joseph and the Technicolour Dreamcoat and from his TV show, the Dorothy auditions for The Wizard of Oz, which is a special film in mine and my daughters' lives. I can use YouTube on the television too so I can watch in comfort.



Shopping and socialising

I've ordered birthday cards and presents so that no one misses out during lockdown, and have accessed websites for things like clothes and plants. I've been taught how to use Facebook and just recently learnt how to insert photos. My daughter has set up Zoom for me so I can chat to family and friends, and take part in the quizzes which seem to be popular right now!

I'm sure that even after lockdown, I'll continue to use some of these new resources. I'm learning new skills, reaching out to even more people than before and enjoying some of my older hobbies from the comfort of my own home.

Want to learn how to make the most of the internet?

If your confidence needs a boost, Age UK has a handy guide at **bit.ly/AgeUKgetting-online** (useful however old you are).

Building a stronger community

In the last issue of MS Matters, we talked about our proposed new approach to membership. In this issue, we ask Nick Winser, Chair of the Board of Trustees, and Emma Whitcombe, Executive Director of Engagement and Income Generation, what this means for you.

Why are you making changes to membership?

NW: We want to reach many more people affected by MS. We currently have a membership of about 30,000 but we estimate that MS in the UK affects more than a million people when you take account of the 130,000 people who have the condition and all their friends and family. These membership changes will help us to support more people, build a stronger community, and drive forward our goal of providing vital support services and world-leading MS research.

EW: Membership numbers are also declining and by developing a new approach we hope it will help us reach many more people who have a link to MS, and enable everyone to get the information they want and need from us in a way that works for them. The proposed changes will mean legal responsibilities are transferred from members to trustees and National Council chairs.

Does this mean the Board will be less accountable to members?

NW: Not at all. Trustees and National Council chairs will remain accountable to everyone in the MS community. We will still be run on democratic principles and we're determined that the voice of the community will continue to be the main way in which we decide what we do. We'd like to move away from a system where that democratic right isn't exercised by many people and create an electorate which, hopefully, will be much larger.

This electorate will continue to elect the majority of the board and help us set our strategy.

What differences will I notice?

EW: We're building an exciting online space that you can personalise to get information that's tailored to you. This will give you control of how you get involved with the organisation, as well as a chance to connect with other people affected by MS, and your local MS Group. You'll still get MS Matters magazine, either by post or online, three times a year.

Interestingly, during the COVID crisis, we've seen that lots of people are starting to take part in online activities for the first time. So, when you receive the magazine, we'll let you know about some of the online sessions we're running. Whichever way you choose to be involved, we'll invite you to take part in the latest research and be part of our new electorate so you can have your say.

NICK WINSER

Do I need to sign up again to be a member?

EW: If you're an existing member we're planning to transfer you into the new membership. We'll be writing to you to explain how being involved in the new model works, but you'll continue receiving the magazine and you'll still be able to vote in trustee elections. You'll be able to opt out if you wish.

EMMA WHITCOMBE

What about my membership fee?

EW: We don't want cost to be a barrier to anyone wanting to join us. The online space, and the links it will provide to our MS community, will be available to all.

However, members make an incredibly valuable financial contribution to our support services and research, so we will also be asking for donations. That means people can donate whatever they feel able to, at a time that's right for them. We also hope that, wherever possible, anyone who is currently a member will be happy to continue their annual contribution.

Will my local MS group lose out on my membership fee?

NW: Local groups are a key part of delivering vital services and support locally, and building the MS community. We are committed to providing them with equivalent funding for the first three years and will work closely with them, so they don't lose out in the longer term.

What impact will these changes have for people living with MS?

EW: Reaching the widest community possible will give us a louder voice when we talk to the government and stand up for people with MS. And the more people who know about us, and get involved in what we do, the better our services will be for everyone who needs support.

What should I do if I have questions?

NW: We're going to be sharing more information on the proposals with members in the coming months, including opportunities to join online sessions where you can ask any questions you may have before we ask you to vote at the AGM.

Further information can also be found at **mssociety.org.uk/membership-developments** or by emailing **membership@mssociety.org.uk**

AGM and election arrangements

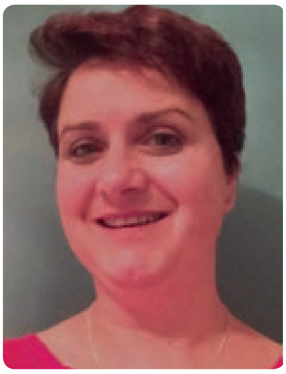
In response to the COVID-19 pandemic, we've decided to move this year's AGM to Saturday 5 December. If you're an MS Society member, we'll contact you in October with formal notice of the meeting, the AGM booklet, and details of how to vote on resolutions and elect new trustees.
See **mssociety.org.uk/agm** for details.

While trustee elections will take place as usual, we've decided to suspend National Council elections this year. Instead, we'll fill vacancies by co-opting people. Being co-opted means that following receipt of your application and a successful interview, your role would be confirmed by the existing National Council members for one year, rather than being elected by our membership for a three-year term.
Find out more at **mssociety.org.uk/national-councils**

Volunteer spotlight: Lyndsey Shellard Research Network Volunteer

I used to be a scientist but unfortunately, I lost my job because of MS. I thought, this is ridiculous, I've got all this training and I'm just sitting here. I want to do something useful.

Being a volunteer member of the MS Society's Research Network gives me an opportunity to use my science background and think about new research into MS. And I've made good friends with some incredible people living with MS along the way.



My first project was to join the review panel of the MS Society Tissue Bank, which uses brain and spinal cord tissue to help hundreds of MS research projects. It was fascinating. I've also interviewed lots of MS researchers for Research Matters magazine. It's been great to talk science with them.

Recently I joined a group of MS researchers and people living with MS looking at what treatments should be trialled in the MS Society's new clinical trials platform. I used my personal experience of living with MS to comment on the impact of how a drug is taken, its potential side effects, and how interactions with other drugs and MS symptoms might affect the daily life of someone with MS. A treatment might look good on paper, but it's important to consider if people will actually take it in real life.

You don't have to have a scientific background to join the Research Network. The most important thing you can contribute is your experience of living with MS. Not all research takes place in a lab, there's also projects on diet and exercise. If something sparks your interest, go for it!

Find out more about the Research Network at **mssociety.org.uk/research-network**

Image: Shutterstock

Behind the scenes

Tune in for MS

This World MS Day (30 May), 140 people from the MS community in 33 countries came together to perform the song Lean on Me by Bill Withers for thousands of online viewers.

Cliff Davies, MS Society Scotland council member, joined the choir.

It took plenty of organisation for everyone involved and was quite different from a usual performance. We were sent audio files with different parts for us to get familiar with and practise.

First, we rehearsed with acclaimed choral director Mark De-Lisser, where we went through the song arrangement. Then we rehearsed at home and, once we were happy with our parts, recorded them to be compiled for the final recording.

Later we came together again for performance rehearsals to make sure we were all on the same page to perform along with the recording – Top of the Pops style!

It really was a fantastic thing to be part of, joining people from places like New Zealand, Brazil and Egypt. Singing can give a real physical and mental boost and there was a buzz around it. I'd love to be involved in something similar in the future.

Watch the performance at **worldmsday.org/tune-in-for-ms**

Getting to know you...

We interviewed MS Nurse **Razia Khan** who joined us in May as a member of the MS Helpline team.

Why did you take on this role?

I've been working as an MS nurse for the past nine years and I took on the role as I was keen to work for an organisation that has a passion for supporting people with MS. The MS Society has always been on my list of places to work due to the support they provide and awareness they raise of the condition.

What's your greatest achievement?

Becoming a nurse. I went into nursing because of a life-changing experience. In 2000, a family member was diagnosed with a long-term condition and the support of a specialist nurse was invaluable. One day, we went to see the consultant, who told us the long wait to see a specialist nurse was because there was a shortage of nurses. I went home and decided that I wanted to become a nurse and support people. Within a few weeks of making the decision, I had signed up for an access course. I completed my nurse training at the University of Sheffield.

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

The best advice came from my dad who always encouraged me to learn as many skills as I could. As an example, before I got my first car, he taught me how to change a tyre. Many of the skills I've learned due to his advice have been useful throughout my life.

Describe your perfect day

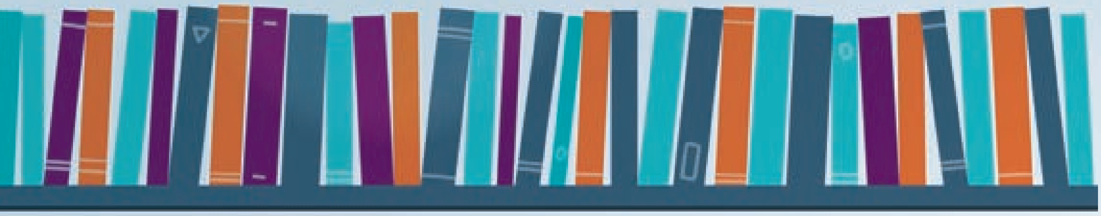
I am an early riser and I'd love to start my day by running. A perfect day would involve being able to give people living with MS the support they need. I would then end the day with some gardening and bake Danish pastries to enjoy after dinner. I love reading a book.

If you could have a superpower what would it be?

Sometimes there's not enough hours in the day to do everything I want to do. Being able to time travel would be my superpower!

How can our MS nurses help?

Our MS nurses are available on the MS Helpline to give you medical information on things like treatment options, side-effects of medication, and managing symptoms. They can give you information, support and talk to you about how to get help (but they can't give advice about your specific condition). You can call the MS Helpline on 0808 800 8000.



We'll be there for everyone with an MS story

After listening to your unique MS stories, we've developed our new strategy and three long-term goals to support everyone in the UK who is living with MS, as well as their carers, family and friends.

Keith's story

No one tells you what to expect when your partner gets diagnosed with MS. It was a shock for me when my wife Shona got her diagnosis. I didn't really know what MS was.

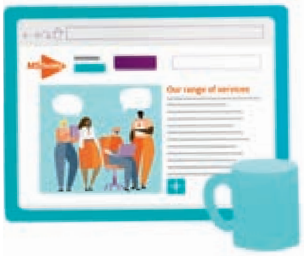
Shona has good days and bad days. She's taken ill health retirement from her job as a bus driver. We have two dogs, and we used to walk for miles and miles but now Shona can only walk so far. There's a local shop two minutes up the road and she finds it difficult to carry back a few pints of milk.

She will forget things, then she'll repeat things and I wonder to myself: is this part of MS? That can cause arguments and disagreements. I try not to think it affects us, but I think it does.

No one explains to the partner what MS is, and what help is out there. How do you balance work and the other side of life with your partner? I feel like carers are put back on the burner and left to get on with it themselves.

People living well with MS

We want to make sure people with MS get the services, treatments and support they need. We'll continue to expand our range of services, to help people understand their rights, manage their condition and do the things in life that are important to them. We'll give carers the best quality information to help them understand MS and their rights and we'll keep developing the support we offer to help everyone's health and wellbeing.



Suki's story

When my fatigue levels are really high it's easier to say I'm tired as people just don't get it. Other symptoms I get include numbness and tingling, weakness in my limbs and pain. Because it's invisible it's very hard to express and explain to people.

I had an opportunity to do a talk about MS in front of about 100 ladies at my local temple. They listened in disbelief, but then I explained the invisibility of it. People asked questions and I felt I'd reached out. In society we need to reduce ignorance and raise awareness. It's important to me that I help to do that.

Gradually over time I've become more isolated. I don't know if that's what other people have done to me, or if I've made the conscious decision to not be included because I need to preserve what energies I've got left.

When I got diagnosed I thought I'm going to fight this like a lioness. And it is your fight on your own because even the closest people to you don't understand.

Connected communities, powerful voices

MS is different for everyone and many symptoms are invisible. People living with MS often face barriers and challenges in everyday life. We'll raise awareness and increase public and political understanding of the realities of MS. We want to support MS communities to become movements for change and we'll help people living with MS to develop the skills and confidence to speak up on issues they care about. We don't want anyone to feel alone, overwhelmed or misunderstood. We'll increase the ways people can share experiences, tackle common issues, foster friendships, build confidence and reduce isolation.

Amelia's story

If there was a treatment that could stop progression, I'd be so happy I would cry. It would be life changing.

I was diagnosed with MS when I was 19. I was really upset about it at the time. I knew something was wrong with me, but I didn't expect it to be a lifelong condition like MS. It made me feel strange and I didn't know how to react at first.

MS has affected my life in lots of ways. I used to work full time. I used to go out all the time with my friends. Everything's changed. I haven't been on a night out for over a year, and I've unfortunately had to stop working.

I'm 25 and my life is completely different to how my friends live. On a good day I can go for a short walk to the shop. But even then I get sensory overload and feel like I need to escape and go into my bedroom.

MS is unpredictable, so you have to get on with your life as much as you can.

Effective treatments and preventing MS

For people with MS, not knowing how their MS will change over time is a huge challenge. We'll be prioritising our work with international partners to improve our understanding of how and why MS gets worse. We believe we can slow, stop or reverse the effects of MS, for everyone. And to get there, we're funding a first-of-its-kind clinical trials platform to develop treatments up to three times faster than we do now.

Find out more at mssociety.org.uk/strategy

Enjoy a virtual Cake Break!

The Hairy Bikers and **Kadeena Cox** are encouraging people across the country to host a virtual Cake Break to raise funds for people affected by MS.

We've teamed up with the celebrity chefs and Paralympian Kadeena to get friends and family together online to enjoy a Cake Break – whether via Zoom, Teams or House Party – throughout the summer months.

Dave Myers, whose mum lived with MS for over 30 years, is a proud supporter of the MS Society's Cake Break. He said: "My mother lived with MS from when I was a boy until she died, and the MS Society was always a great support to us."

Keep up the momentum

He added: "As the MS Society has grown it's helped an awful lot of people with this unpredictable condition and is making incredible strides towards stopping MS. We simply cannot take our eye off the ball because of the pandemic, and hosting a virtual Cake Break will help keep the momentum going."

Kadeena, an MS Society Ambassador, became known for her baking skills as well as her sporting achievements after taking part in The Great British Bake Off. She helped launch Cake Break in June by making a baking tips video with Dave. This includes ideas for making a cake without flour – a popular internet search during the lockdown.

Whether you're lucky enough to get your hands on some flour, or plan to showcase some ready-made treats, raising any kind of dough could make a big difference.

Get competitive with presentation

Dave said: "As most people won't be able to taste each other's bakes this year, now is the perfect time to get competitive and up the ante in your cake presentation! Si [Simon King] and I find covering cakes with icing sugar is a great way to hide imperfections without anybody knowing!"

Kadeena said: "Don't forget to sign up for a virtual Cake Break and get together with your family and friends online, just like Dave and I have. There's a fundraising pack with recipes and everything else you need for hosting a Cake Break during these times. Enjoy your baking!"

Register at **cakebreak.org.uk** and share your virtual Cake Breaks using #CakeBreak2020

Fundraising at home

During the lockdown, many of you came up with imaginative ways to carry on fundraising. Here are just a few.

Sweet success

When Charlie Back found out about the 2.6 Challenge to create her own fundraiser at home, she decided to give it a go – alongside housemate Lily O'Dowd.

Charlie said: "We both love baking but instead of baking 26 cupcakes for the 2.6 Challenge, we thought, why not 206? They're small, cute and easy to give out. And everyone loves a cupcake!"

For the challenge, Charlie and Lily spent 12 hours making their cupcakes. They used social media to tell neighbours, friends and family and organised contact-free deliveries across Bristol.

"Everyone was so sweet – we still can't believe we raised £965! Fundraising during lockdown can be tricky so make sure you have fun with it."

A marathon effort

On Sunday 26 April, our amazing MS Superstar Pete was meant to be running the London Marathon. Instead, he took on the 2.6 Challenge. He ran 26.2 miles in 26 consecutive hours outside on his treadmill, starting at 12pm on the Saturday and running through the night. He finally finished at 1pm the next day. Pete's family, friends and neighbours cheered him on and brought him cake to keep him going.

Pete chose to fundraise for us because his wife, Emma, has lived with MS for over 16 years. Pete says Emma is his inspiration to run. Although he couldn't run the marathon on 26 April, he wanted to do something else to mark the day.

Pete raised a fantastic £3,700, which brings his London Marathon total to almost £10,000 – incredible! Thank you so much, Pete.

Garden challenges raise £2,100

For most people, to have one fundraising challenge cancelled is hugely disappointing. But Angharad Lloyd had four – three 10K runs and a 25K coastal walk that were scheduled to take place between March and May this year.

Angharad, who was diagnosed with MS in 2018, said: “I was gutted when I knew none of these events that I’ve been training for were going ahead. But I didn’t want to give up on the people who’ve supported me.”

With a spin bike, second-hand treadmill and some Zumba moves, Angharad completed all four challenges in her garden for our Stop MS Appeal, plus an extra 10K run to support our work in Wales. Her fantastic achievements raised over £2,100.

> “I knew none of these events that I’ve been training for were going ahead but I didn’t want to give up”

Now that’s what I call fundraising

A fundraising gig in the Highlands wasn’t muted by the coronavirus pandemic as organisers moved their mini-festival online, raising £4,564 in the process.

The third annual charity gig, organised by Jack McPhee, was scheduled to take place at a local hotel. But with the support of 12 other artists people from the area were instead entertained virtually.

Jack said: “I am just blown away by everyone’s generosity. We initially hoped to raise around £500 and could not believe the total as it crept up and up throughout the day. A massive thank you to everyone involved.”

Laura’s lockdown gallery

Laura Thorne from Brighton decided to curate a virtual lockdown gallery while raising funds. She asked friends and family to submit photos of their creative activities for a small entry fee.

Laura, who is a Stop MS Champion, says: “The idea for the gallery came from me and my mum thinking about how we could do something together while we were apart.”

By the end of May, Laura had raised £330. She has kept the gallery open for submissions from the wider MS community.

“The brief is quite open, which means you can capture your creativity through any activity. It doesn’t have to be drawing or painting – it could be gardening or baking. It’s about thinking about what you can do and taking your time”

To view the gallery and submit your creative work visit **justgiving.com/fundraising/lauralemontree**

Tigers, habitats and the environment by John Conneely

For more ideas on how to fundraise at home, visit **mssociety.org.uk/fundraising-at-home**. You can also contact your local Area Fundraising Manager for more support at **myfundraising@mssociety.org.uk**

Lily walks 100 miles to stop MS

Inspired by her dad, Lily raised more than £2,500 for MS research

Lily Atkinson, aged 14, signed up for My MS Walk in memory of her dad, Simon. She walked 10 miles a day for 10 consecutive days in May, raising £2,553 for our Stop MS Appeal. Lily's socially-distanced walks took place around her home in Looe and along Cornwall's coastal path.

Lily said, "On 10 January 2020 my dad very sadly passed away from pneumonia after battling with secondary progressive MS for nearly 22 years."

Something positive

"Living with my dad's illness was a huge challenge for me and our family. My dad never gave up on himself, throughout his illness he accomplished many things, including a skydive. I was incredibly proud of my dad and so I wanted to do something positive in his memory.

"At the start, I thought I was going to struggle to keep it up every day. But a few days in, I started to realise that I could do it.

"When my dad was alive, I used to go along with him and do supermarket collections. I think that because I've had all the support around me, it's made me realise that I'm doing this for my dad and I'm doing it in his memory. It has really helped me come to terms with what has happened."

A sense of purpose

Lily's mum Melanie said, "Lily came up with this completely independently. She took the challenge on and really enjoyed it – getting up every morning with a real sense of purpose. I know her dad would be so proud of her.

"I would very much like to think that for other people who are diagnosed with MS, one day there will a cure. And when Lily looks back on this, she'll be able to think: 'Wow, I did that for my dad.'"

Sign up for My MS Walk

My MS Walk is a great way to get active while raising money for life-changing MS research. It doesn't matter whether you walk up and down the stairs, roll around your garden, or take a socially-distanced stroll in your local area. Ask your friends and family to sponsor you and use a fitness app like Strava to share your progress and view your and others' achievements on our website. Find out more at **mymswalk.mssociety.org.uk**

A gardener for life

Sky Sports Golf commentator and MS Society Ambassador **Tony Johnstone** talks about how gardening helps him relax.

As a kid living in Zimbabwe, I never understood my mother's passion for gardening. My only interest in her flowers was to see if I could shoot the heads off her dahlias with my air-rifle! Sorry mum.

While waiting for furniture to arrive in our own first home, I thought the garden could do with some tidying. So I went to the local hardware store to buy the basics like a spade, rake and some hand tools.

Well, I've never really understood what happened then. But after 15 minutes of getting down and dirty I knew I was hooked and that I'd be a gardener for life!

When I'm in my garden, I'm totally focused on the moment. It's hard to find another relaxing activity which can clear my mind so completely.

My love of gardening has always been a great comfort to me – especially after being diagnosed with MS. I was fortunate enough to be able to continue enjoying my garden, although I'm not able to expend as much energy in it as before.

Yes, the physical effort has sometimes made me ask if I'm a little crazy for being obsessed with the pastime. But when I look out the window or sit outside on a summer's day, I know the effort and satisfaction are worth it.

There's something about the vibrancy and fragrances of a garden and the perfect beauty of each flower that somehow makes the struggles of life much easier to cope with.

My life would have been much poorer if I couldn't say those three words..."I'm a gardener!"

Read more gardening stories (inside and out!) at **mssociety.org.uk/lockdown-gardening**

Activity corner

Keeping cool

Each issue, we feature a tip on staying active with MS. This time, we're talking about keeping cool while exercising.

Many people with MS are sensitive to heat. Some people adjust the exercise they choose, while others find effective ways to stay cool and keep effects to a minimum.

Here are some practical things you can try if you are heat sensitive:

- Break up exercise sessions into smaller sections, with regular breaks
- Drinking ice drinks, wearing a "cooling vest" and taking a cool bath before exercising might help you to exercise for longer
- Keep the exercise space well-ventilated. A fan might help.

Be careful if you apply ice or cold packs directly to the skin, or when using cooling garments or cold water to cool down.

MS can cause changes to the way you experience temperature. It can distort the feeling that would normally tell you when something is too hot or too cold – so take care not to damage the skin. Your GP, physiotherapist, occupational therapist or MS nurse can help make sure cooling techniques you try are not harmful.

For more on the effects of temperature on MS visit: **mssociety.org.uk/hot-and-cold**

"Writing makes me feel free"

After taking ill-health retirement from her job as a nurse, Samantha Henthorn didn't know how to fill the gap in her life. Then she found a creative writing course at her local library. Four years on, she's published seven books and discovered a new identity.

After losing my job, I thought I'd be brave and try to get some of my confidence back. The writing course was just two hours a week, so I went for it. Fortunately, the teacher was really encouraging.

One of the stories I wrote was sparked by a man who had a row with me for parking in a disabled space, saying I wasn't old enough to need it. I thought "what an old curmudgeon" and wrote a story about people who are always moaning about other people.

Now that's turned into a series of four books – Curmudgeon Avenue. They're comedy dramas about a fictional street in Manchester, narrated by a very critical house. Some of the reviewers have said it's made them laugh out loud. I've also published a collection of short stories, a novella and a historical novel.

Given that my MS means I can't really do deadlines, I thought I'd self-publish so I can just write what I want. I promote my books online and have just published my first audiobook with a fabulous narrator I found through Amazon.

And I'm part-way through a part-time Open University course in creative writing. When I started I was worried that people would say if you can do that, then why aren't you still working? But it's totally different. You can do it from home, I don't need to stand up and there's loads of time to do the essays.

I sound dead busy but I'm not really. There's loads of tricks I've learned to do things quickly. Brain fog can be a problem for me, but I've found ways to cope, like writing down notes. I stick to a routine that helps me manage my MS and my fatigue. I get up, do physio, sort out the pets, potter about and then write for half an hour.

With writing, I can take my time, pace myself and it doesn't matter whether I do it or not – I'm free and it's fun! I get a big sense of achievement from it and it's boosted my confidence.