



Coronavirus won't stop us stopping MS

How our clinical trials are
moving forward

Inside

Siponimod gets the green light
Treatment for active secondary
progressive MS approved



Issue 136
Autumn/Winter 2020

MS research is facing new challenges, but we remain on the cusp of a major breakthrough – and must keep going. In this issue, you can read about three clinical trials that will help us Stop MS (page 8) and hear from people who are involved in these trials. On page 21, we also bring you the exciting news that siponimod has been approved for the treatment of active secondary progressive MS on the NHS in Scotland, England and Wales, with a decision expected in Northern Ireland in the coming months.

As I write, the pandemic is still having a big impact on our lives. But whatever the challenge, we'll continue to make sure your voices are heard. Many of you have told us that since the lockdown began, you've struggled to access essential services, such as physiotherapy and occupational therapy. Together, we've been telling local health leaders and governments across the UK that people with MS have too much to lose when they can't get access to these therapies (page 14).

We also know that many of you have found it difficult to get the support you need to work safely. On page 16, find out how we're speaking up for people with MS in the workplace and helping employers understand what adjustments they need to make.

Sadly, the pandemic has impacted our finances and we're having to make some changes to our organisation. On page 13, you can read about this in more detail.

Coronavirus put some of our plans on hold, and we've had to adapt. But we're still fighting for what you tell us is important. Supporting the MS community, campaigning for essential change, and keeping MS research moving to find treatments for everyone.

Visit mssociety.org.uk/covid-19 for information on MS and coronavirus.

Nick Moberly
Chief Executive

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#TooMuchToLose

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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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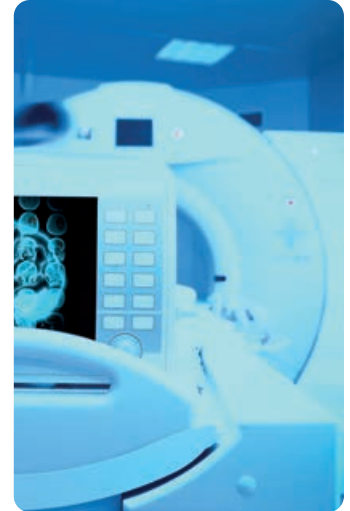
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Research stories

Turn to the centre of MS Matters to read Research Matters. We explore the latest evidence on the question: can a healthy lifestyle, alongside effective medication, help us live our best lives with MS?



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.

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Your Letters

Positive PIP experience

I have just read Ben's account of his PIP assessment (Spring issue, page 38), which must have been soul-destroying. I would like to add my comments about my assessment. Like Ben, I was on DLA indefinite on the higher rate for both mobility and care and I was called for my PIP reassessment in January. I attended the centre in Norwich with great trepidation. I was met by a lady who introduced herself as a nurse. She was polite, friendly and understanding in her questioning, which took well over an hour. Six weeks later, the brown envelope dropped through the door. I was granted the higher rate of mobility and reduced to the standard rate of care, which I thought was very fair. I could not fault the assessor's behaviour or questioning.

Mike



Watch your step

The letter from Penny about being able to walk fast round Sainsbury's (Spring issue, page 7) reminded of my Blue Badge applications. One time I was asked about walking on a football pitch. My first thought was that if there was a thick tuft of grass in my first few steps I would fall over. So, the answer was I couldn't walk very far. Of course, they are probably talking about Wembley whereas I am thinking of my own village team's ground. Another time there was space for me to write my own comments.

I said that in a supermarket or shopping mall, with my trolley, I could walk far and fast. However, I still need a Blue Badge as most footpaths are very uneven and nothing like Sainsbury's!

Janice



iStock

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

Please give me space

Some of you have told us that you're worried about people not social distancing in public spaces. This is making you anxious about going out, especially those of you more vulnerable to the virus if you were to catch it.

The UK government has collaborated with charities to develop a "please give me space" symbol. This is available as a card and badge that anyone may choose to carry to encourage other people to socially distance.

We polled some of you on Twitter to ask whether you'd find wearing a badge or lanyard helpful. Of the 131 people who responded, 62% said yes and 37% said no. We hope some of you will find this option helpful and we'd like to hear your experiences if you do wear one. Please email campaigns@mssociety.org.uk

We know it will take more than wearing a badge to help some people who are more vulnerable

Please give me space.



to COVID-19 feel safe when out and about. We're working with the government to ensure they make public spaces safe and accessible for people with conditions like MS as we continue to live with the virus.

You can print and create your own badge or lanyard for free at <https://mssoc.uk/2Tgwli1> They are also on sale as a badge, face mask and more from pleasegivespace.uk

Together we can stop MS

Clinical trials test whether new treatments are safe and effective. They are a vital step in our mission to stop MS. Here we shine a spotlight on a few of the people who are making these trials happen.

Thanks to research there are already over a dozen licensed treatments for people with relapsing forms of MS, and some emerging for progressive MS. But there are still tens of thousands of people without treatment. That's why we're supporting clinical trials that test a range of treatments to slow or stop disability progression in MS, as well

as trials that help us understand more about the best way to treat MS relapses. We're even planning a new efficient clinical trials platform – a new way of running trials that will help test potential treatments for MS more quickly and cheaply.

The success of clinical trials relies on the contribution of many different people: from neurologists and nurses, to people with MS who take part in

trials, and those who help shape the trials. And, of course, our incredible supporters whose generous gifts provide the funding for our research programme.

2020 has been a tough year for everyone but together we're still determined to reach our goal of being in the final stages of testing a range of treatments for everyone with MS by 2025.



Professor Klaus Schmierer

Klaus is leading a new trial called ChariotMS,* which we're part-funding. He and his team will be testing whether cladribine can slow down the worsening of hand and arm function for people with advanced MS. This drug was developed for cancer and is already being used to treat relapsing MS.

Until now, people who use wheelchairs have been unable to take part in most MS trials because walking is often one of the

key measures of how effective a drug is. There are currently no disease modifying therapies available for people with MS who aren't able to use their lower limbs.

The trial is kicking off this year and Klaus is excited to get started: "We've had to develop a whole new way of testing and collecting data as MS trials for wheelchair users are not very common. If successful, the trial will play a huge role in helping people who use wheelchairs carry on living independent lives."

*ChariotMS is funded by the Efficacy & Evaluation Mechanism Programme – a Medical Research Council & National Institute for Health Research partnership, along with Merck Serono, Barts Charity, the US MS Society and ourselves.

Christine Chapman

Christine has active secondary progressive MS and was diagnosed nine years ago. She works with the MS research team at Barts Hospital in London to help shape research projects and clinical trials and make sure they reflect the needs of people with MS. As someone with a lived experience of MS,

Christine has been involved in designing the ChariotMS trial to ensure it has the needs of people affected by MS at its heart.

A former filmmaker, Christine also helps to communicate research in a way that's accessible to everyone.

"Helping shape MS research is so rewarding. Many of the people with MS I speak to are so pleased and relieved that we are beginning to see drug trials for wheelchair users. I believe no one with MS should ever be left out – that's why the ChariotMS trial is so important."



Lucy Hopkins

Lucy was diagnosed with relapsing MS in early 2019. She's taking part in the DELIVER-MS trial, which is testing whether starting intensive therapy early after diagnosis is better than starting with a less intense treatment and only escalating if it doesn't control your relapses. Although her MS doesn't affect her that much now, taking part in the trial keeps her and her family positive and helps researchers learn more about the best way to treat MS.

"My neurologist suggested the DELIVER-MS trial at one of my first appointments. It seemed like a no-brainer to me. And I also get more regular MRI scans and blood and urine tests. My hope for the trial is that it helps people with MS get the most suitable treatment for them. Research is hugely important in helping us stop MS in its tracks."



Jacqueline Krarup

Jacqueline is one of 1,050 people taking part in our MS-STAT2 phase 3 clinical trial. It is testing whether an existing cholesterol drug called simvastatin can slow disability progression for people with secondary progressive MS.

"When I was first diagnosed there were very few treatments. Now, thanks to research, people with relapsing MS have a range of options. But treatments for progressive types of MS are still very



limited, and there are still thousands of people like me without any treatment at all.

For me, getting involved in MS research helps me stay optimistic about the future.

If research can find ways to slow down my disability progression or stop MS getting worse, that would be incredible. My involvement in the MS-STAT2 trial has convinced me that stopping MS really is within our grasp."

Turn the page for a look behind the scenes of this trial.



Our Stop MS Appeal needs to raise £100 million to find treatments for everyone with MS. Coronavirus has slowed down our progress, but it won't stop us from stopping MS. Find out more or make a donation at mssociety.org.uk/withinreach

A day in the life of a clinical trial

We go behind the scenes with the team working on MS-STAT2.

MS-STAT2 is our phase 3 clinical trial testing whether a cholesterol drug called simvastatin can slow the build up of disability for people with secondary progressive MS.

Clinical trials are the only reliable way to find out if a new treatment is safe and better than what's already available. Even if a treatment looks promising in laboratory testing or in an individual it must go through clinical trials before its benefits and risks are really known.

When MS-STAT2 finishes in 2024 we will know definitively if simvastatin can slow MS progression and protect nerves from damage. If so, it could become one of the first oral treatments licensed for secondary progressive MS, following siponimod, which was recently approved in England, Wales and Scotland (see page 21).



8.45am: Neurologist Dr Tom Williams is on his way into University College London Hospital (UCLH), the lead site for the trial.



9.30am: Trial lead Professor Jeremy Chataway chairs a weekly team meeting to review progress.



11am: Tom and research nurse Sarah head over to the hospital site

to prepare for the afternoon with MS-STAT2 participants. Some people are starting on the trial for the first time and some are coming in for their regular six-monthly check up to review progress. Half of the participants are taking simvastatin tablets daily and half are taking a placebo (dummy drug). To avoid bias neither the participants or the trial staff know who is taking what.

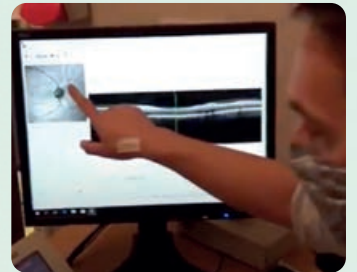


1pm: We know that MS can lead to brain shrinkage as nerve cells die off in the progressive phase of the condition. Some people on the MS-STAT2 trial have MRI scans to see what effect the drug is having on brain size.

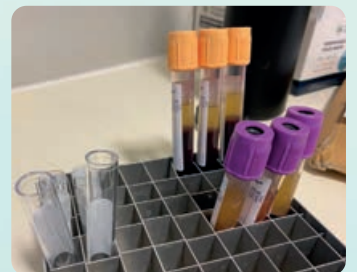
2.30pm: Participants take part in tests to see what effect the trial drug is having, including tests of cognition, finger dexterity and walking ability.



Some participants at UCLH also have eye scans to see how the trial drug is affecting nerves in the eye.



4.30pm: It's important to make sure that the drug simvastatin isn't causing any side effects, so all participants have a blood test every year. The blood samples are analysed in the lab at UCLH.



6pm: The team write up their notes and head home!

Facing up to the financial challenge

Chief Executive **Nick Moberly** explains the impact COVID-19 is having on our finances.



The coronavirus crisis has turned all our lives upside down, with many people in our MS community severely affected. It's hit us hard as an organisation, too.

Our fundraising income has dropped significantly as community fundraising events, marathons, skydives and more have been cancelled.

The blunt truth is we're expecting to lose around 30% (£10 million) of our income this year and around 15% (£5 million) next year. Though we hope the situation will improve, the outlook continues to be very uncertain.

The Board of Trustees, Executive Group and I have reviewed our financial position in detail. We've had to conclude we have no choice but to spend £4 million less each year going forward.

Working out how to make savings of this magnitude has been hard. Our guiding principle has been to minimise the impact on our MS community.

Changes to the organisation

At the start of July, we proposed to our colleagues and volunteers plans to restructure the organisation in two phases. Sadly, these plans mean we've had to make some of our colleagues redundant.

The changes also include pausing our national grants programme for two to three years and closing our high dependency day care service in Northern Ireland. We simply can't afford to run them at the moment. We're also changing:

- the way we support local groups – bringing

together support for volunteers offered by different departments into one central team

- how we influence local MS healthcare services, by establishing a smaller UK-wide engagement team
- how we fundraise in the community – creating one national team to increase consistency in our work.

At the time of writing, we were still working through phase 2 of the restructure. We'll report back with the latest information on our blog:

mssociety.org.uk/blogs

Committed to stopping MS

Our absolute priority is making sure we can continue to be here for people affected by MS for the long term.

Our MS Helpline, webinars and online services are running as normal. We're still making sure our community's voice is heard by governments across the UK. And our research programme is still rolling. Some projects had to pause and some planned new projects have been postponed, but we remain committed to stopping MS together. And, now more than ever, we need your help and support to get there.

If you have any questions please contact me on nick.moberly@mssociety.org.uk or our supporter care team on **0300 500 8084** or supportercare@mssociety.org.uk

Taking local action to say we have **#TooMuchToLose**

Thousands of people with MS rely on rehabilitation services, like physiotherapy, occupational therapy or continence support, to do the everyday things many people take for granted.

A new report we launched in September showed that too often, people with MS can't get the support they need to stay active and independent – and this has only got worse during lockdown. Our research found that since lockdown began, 7 in 10 people with MS (69%) couldn't speak to a rehabilitation professional when they needed to.

Without this support, people with MS are losing their mobility, their confidence and their independence. That's why more than a thousand of us across the country came together to tell local health leaders that this is too much to lose.

Susan, 42, from Morayshire in Scotland, was one of them. She lost out on physiotherapy during lockdown:

"Before the pandemic, I'd been going to physio. At one stage I was even out of the wheelchair and walking. We were really making headway. But everything has gone downhill again as my physio has stopped.

"Since I've not been going, my MS has got worse. The pain in my legs is worse, and I'm noticing pains I've not had for months. I'm getting pains in the joints now that I haven't had for such a long time. It's almost like I've taken a big step backwards.

"I need more help to move my legs when I transfer from the wheelchair to the toilet or to a different chair. Even when I'm getting in and out of the car, I can't get my left leg moving. I need a lot

more help than I did before. I live with my parents and my 12-year-old daughter. She's registered as my carer, so she has to do a bit more to take care of me since the physio closed."

Everyone with MS should get the support they need, during the pandemic and beyond. And we've been speaking out about this together. During October, almost every local health leader in the



Susan's MS has got worse during lockdown




UK heard from one of our campaigners, who asked them to pledge to make sure everyone with MS can get the support they need.

Find out more at mssociety.org.uk/rehab-campaign

Local action for MS

Join our campaigns community at mssociety.org.uk/campaigns or take action in your area with our brand new campaigns toolkit.

We've launched new tools and templates to support you to campaign on issues that matter to you.

This includes a local campaigning toolkit, downloadable templates like a campaign planner and posters, and easy online tools that allow you to send an email to decision-makers such as your local councillors or health bodies.

So whether you're angry about hospital parking charges, concerned about cuts to local MS services, or want to improve access to local leisure facilities, you can make a difference.

Visit our Local Action for MS hub to download our campaigns toolkit, find out more, and get in touch if you need support: mssociety.org.uk/campaigning-locally

“Everyone with MS should get the support they need, during the pandemic and beyond.”

Speaking up across the UK

In England, we've been in touch with all local clinical commissioning groups (responsible for rehabilitation services in their area). We also contacted all MPs, and many of them have raised it locally and shared the campaign with their constituents. Meanwhile, Shadow Disabilities Minister Vicky Foxcroft MP and Lord Dubs, Vice-Chair of the parliamentary group for MS, wrote to Health Ministers on our behalf. We're also working together with professional bodies and other charities, as part of the Community Rehabilitation Alliance and the Neurological Alliance, to keep raising the issue in the UK Parliament and with NHS leaders.

In Wales, the MS community has got behind **#TooMuchToLose**, calling on local health boards to pledge to protect and improve rehabilitation services. We've asked Members of the Senedd and MPs to support our campaign, and we'll be highlighting why rehabilitation is important in the run-up to next year's Senedd Cymru (Welsh Parliament) election. We're also part of the cross-organisation "Right to Rehab" campaign in Wales.

In Northern Ireland, we've been asking local health trusts to prioritise rehabilitation services and raising awareness of the damage caused while these services are unavailable. We've promoted the campaign in the press and briefed Members of the Northern Ireland Assembly and MPs. We hope to have a debate in the Northern Ireland Assembly on the need for a comprehensive rehabilitation plan.

In Scotland, we got in touch with all MSPs and we're pleased that there was cross-party support for a motion by Beatrice Wishart MSP supporting the campaign. We've contacted health boards and asked our "Right to Rehab" partners to share **#TooMuchToLose**. Our campaign has been covered in the Edinburgh Evening News and the Press and Journal, and we've promoted it widely on social media.

Speaking up for you in the workplace

COVID-19, shielding and employment – no one should have to choose between their job and their health.

As the pandemic has spread, many people with MS have faced challenges getting the support they need to continue to work safely. It's been difficult for some employers to make workplaces COVID-secure. With COVID-19 cases rising in recent weeks, the furlough scheme winding down and no clear replacement for people who may be high-risk, many people who were shielding feel they face a choice between their job and their health.

Throughout the pandemic, we've been working with a broad coalition of charities including Age UK, Diabetes UK and National Voices to call on the UK government to make sure people with MS get the right financial support, now and in the future.

In July and August, more than 22,000 people across the country signed a petition calling on the UK government to extend the furlough scheme for those who were shielding. With the support of MPs and Peers, we've been continuing to raise this issue with the UK government.

We know that for many people who have been working from home, the pandemic has brought additional challenges. Others have been concerned about taking public transport to work.

We've been working closely with the Department for Work and Pensions (DWP) and other charities to call for better support through the Access to Work scheme for people with MS in employment.

In response, the DWP has extended the Access to Work scheme to offer new help for disabled people working from home during the pandemic.

Disabled people can now also receive support in paying for taxis to work if they cannot safely use public transport. People who are employed or self-employed and on certain benefits may also be eligible for a support payment of £500 if they are asked to self-isolate.

Throughout the pandemic we've been advocating for more support for people with MS. We've been raising awareness of issues around shielding, benefits and the end of the furlough scheme across TV, radio and print media, receiving coverage on Sky News, the BBC and in the Mirror, among many other outlets.

We know that as the pandemic continues to affect the whole country, we need to continue to speak up so that no one has to choose between their job and their health. Join our campaigns community to campaign with us at mssociety.org.uk/campaigns



Requesting reasonable adjustments

We've provided information and support through our virtual webinars and Time to Chat sessions, on employment, your rights within the workplace, and how to request a reasonable adjustment at work.

Jennifer Hardie was diagnosed with MS in 2018 and works as a teacher in East Renfrewshire. She joined our Time to Chat on reasonable adjustments.

"I was feeling anxious about returning to work and whether the protocols in place would keep me



safe. Joining the Time to Chat session helped me to feel more confident and informed about asking my employer for reasonable adjustments.

"Thankfully my school has been very accommodating of my MS and the adjustments I've requested have been put in place.

"One concern of mine was how I would be able to lead my class outside safely, in the event of a fire alarm going off, as this would mean I wouldn't be able to socially distance from students.

"The solution put in place for this is that another member of staff will lead my class outside and I will wait a few minutes for the corridor to clear.

"Having these adjustments in place has made me feel safer and more comfortable with being back at work."



Webinar helps employers protect staff

Employers need to be especially careful and take extra steps to protect anyone in their workforce who is in a vulnerable group. But we know that this is not always easy to do.

Our webinar in September brought employers and HR professionals together to help them support their employees during the pandemic and adjust to how we are now working. Our thanks to the people living with MS who took part in the webinar to share their experience of shielding and working during the pandemic.

It is vital that employers discuss with their employees living with MS what reasonable measures could help them to be safe at work.

People living with MS in Wales can get support with their employer from the Pontio team (see page 19). Contact them at pontio@mssociety.org.uk

Find out more

For the latest information on work and coronavirus visit mssociety.org.uk/covid-and-work. You can also call our MS Helpline on **0808 800 8000**.

Our interactive webinars and Time to Chat online sessions cover a range of different topics. Find out what's coming up soon at mssociety.org.uk/connect-online



Here for you

We've launched several services in different parts of the UK to help improve your wellbeing and provide some practical support.

Staying connected in Scotland

Our new Wellbeing Hub has been connecting people living with MS in Scotland with vital services during the coronavirus pandemic.

Since launching on World MS Day (30 May), our Wellbeing Hub has supported more than 300 people affected by MS across Scotland to access one-to-one

counselling, physiotherapy sessions, as well as free online exercise classes, financial wellbeing sessions and creative workshops.

The Wellbeing Hub was initially funded until the end of September. However, thanks to its success, the service has secured £68,123 of funding from the Scottish Government's Neurological Framework Fund. This means people living with MS can continue to benefit from the service until March 2021.

Kirsty Stevens is living with relapsing MS and has been accessing virtual physiotherapy sessions from our Wellbeing Hub.

She says: "I'd been doing exercises but wanted to speak to a physio directly, so the Wellbeing Hub was a great resource. It was a bit unusual doing this kind of thing remotely but they're so insightful and being able to speak to someone was really beneficial."

Find out more by emailing wellbeingscotland@mssociety.org.uk or calling **0131 335 4050**.



Kirsty Stevens is living with relapsing MS

Photo: Julie Howden



We offer a range of online and telephone services that are available across the UK. You can find out more at mssociety.org.uk/never-alone

Getting online in Cambridgeshire

A new service is helping people with MS in Cambridgeshire to exercise and attend clinical appointments online. Set up in response to COVID-19, the service provides tablets, internet access and online exercise classes for people who were previously not connected.

Bob Bragger, Cambridge, Ely and Newmarket MS Society Group Coordinator, says: “We wanted to enable people to take part in virtual exercise classes on Zoom and join video calls for their clinical appointments

with Cambridgeshire and Peterborough NHS Foundation Trust. Patients and clinicians get to see each other, and their carers can also join the call. And by offering classes online with instructors they know and trust, we can help people exercise and keep in touch.”

The service is funded by Living Sport, Perkins Engines and two charitable trusts administered by Buckles Law in Peterborough.

Contact bob.bragger@groups.mssociety.org.uk to find out more.

Mind My MS in Northern Ireland

The Mind My MS project in Northern Ireland, funded by the Big Lottery, launched online in May 2020. This project helps people living with MS in the mid and east Antrim area look after their mental health. Services include:

- **Online MS Connect Cafes** – informal online coffee and chat sessions, with a volunteer host.
- **Online mindfulness** – six-week programmes on Zoom, facilitated by a mindfulness



practitioner from Aware, a mental health charity.

- **Counselling therapy** – up to six one-to-one counselling sessions delivered online or over the phone by a qualified counselling therapist from AMH New Life Counselling. Nicola, who is taking part in the project, says: “The mindfulness sessions allowed me to switch off for an hour and gave real practical skills to use in everyday life. Balancing work, a family and my MS can be challenging, especially during a pandemic. Mind My MS really helped.”

Find out more at mssociety.org.uk/mind-my-ms



Photo: Shutterstock

Pontio builds bridges in Wales

We're delighted to announce that the Big Lottery is continuing to support people living with MS in Wales.

Our Big Lottery funded project “My MS My Rights My Choices” came to an end this year. This supported people living with MS to access welfare benefits, health and social care services, employment support and improve wellbeing.

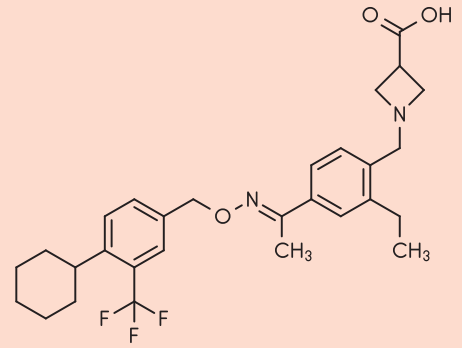
Pontio, which means “bridge” in Welsh, is a new three-year project designed by a group of people living with MS in Wales. It will support our MS community to:

- make informed choices about health and treatment options
- improve emotional wellbeing and social connections
- improve financial, employment and housing/accommodation security.

We'll also be improving people's understanding of MS by delivering awareness training from volunteers with experience of living with MS.

For more details contact adele.gilmour@mssociety.org.uk

Spotlight on treatments



The approval of siponimod is a huge step forward in the treatment of active secondary progressive MS.

Siponimod (brand name Mayzent) has been approved as the first-ever oral treatment for people living with active secondary progressive MS on the NHS in Scotland, England and Wales. A decision is expected in Northern Ireland in the coming months. This is a huge step forward in the treatment of secondary progressive MS and the MS community played an important part in making this happen.

One trial found that the treatment reduced the risk of disability progression by 37% compared with a placebo (dummy drug). Siponimod also significantly reduced the rate of brain atrophy (shrinkage) and the number of relapses people experienced.

Until now, there's only been one other licensed treatment for active secondary progressive MS in the UK (Extavia (interferon beta 1b)), which must be injected. Siponimod is a more effective and convenient option that could help thousands of people take control of their MS.

Siponimod will be available to adults with "active" secondary progressive MS. This means you still have relapses, or your MRI scans show signs of inflammation (new or growing lesions). If your

healthcare professional thinks that it's the right medicine for you, you should be able to have the treatment on the NHS in Scotland, England and Wales. Treatments approved by the National Institute for Health and Care Excellence (NICE) must be made available in England and Wales within three months, and the timeframe is similar in Scotland.

Thank you to everyone who shared their stories which helped us to make an effective case to urge NICE and the Scottish Medicines Consortium (SMC) to make siponimod available. We know that siponimod isn't suitable for everyone with secondary progressive MS. We'll continue to invest in research until the day everyone has treatments, and we stop MS.

Jacqueline, who has MS and gave evidence to the NICE Committee, said: "I am ecstatic with the outcome. It provides a welcome ray of sunshine for people with active secondary progressive MS. Knowing that it could slow down the deterioration of my walking, seeing, doing and very being allows me to make plans for the future with greater confidence."

HSCT approved in Wales

Haematopoietic stem cell transplantation (also known as HSCT and AHSCT) has been approved for people living with previously treated, relapsing MS, following an appraisal by Health Technology Wales. This means that people in Wales who have a recurrence of symptoms, despite previous treatment with disease modifying therapies, may be eligible for treatment with HSCT on the NHS. This one-off procedure aims to reset a person's immune system to stop the inflammation caused by MS.

Fampyra: access restricted in Wales

Fampyra (fampridine) is now available in Wales. But because of COVID-19, right now there are no face-to-face assessments to check if someone's eligible. MS teams are working hard to resume services. We're also asking Local Health Boards in Wales to make sure the teams are properly resourced to make this happen. Contact fiona.mcdonald@mssociety.org.uk if you have experienced problems accessing Fampyra.

Read more about getting MS treatments, including COVID-19 information, at mssociety.org.uk/treatments

Why identity matters

Three people from the LGBTQ+ community who have MS talk about Pride and being open about all aspects of their identities.

Tomas Ince

was diagnosed with MS aged 22 and has shared his experience on our blog and with the Gay Times.

When I was around 15, I wished I could see into the future and get a glimpse of what my life would be like at the age of 25. I can't be the only person to have day-dreamed about the infinite prospects of the future.

Not once did I think by that age I would have already had optic neuritis, balance difficulties and lower limb numbness.

I was diagnosed after waking up after the Notting Hill Carnival and struggling to see. It wasn't in my plan – something that doesn't have a cure at the moment, is unpredictable and would affect my future. I'll be honest, it was heart-breaking.

I am now a 30-year-old gay man, living in central London with MS and fortunately able to do the things I want to do. I'm at a good place in my career, live in a fabulous apartment with my classically good looking and caring husband, Ed. What more could my teenage self have dreamed of?

I don't tend to tell people I have MS, but MS is part of my identity. It's led me to live far more in the present, do more with my life and say yes to things I might

not have previously. I want to focus on the positives, so a few years ago I got in touch with the Gay Times about telling my story and they ran a feature on me. That had some good feedback from the LGBT community.

Now I want to see another 10 years into the future. On my 40th birthday am I going to be walking around or using a wheelchair? What's going to happen?

I thought Selma Blair at the Oscars made such a statement. I don't need to use a walking stick like her at the moment, but I'm sure if I did it would be a fabulous one.

I'd love to keep doing well in my career, to travel a lot and to do more fundraising for the MS Society.

I'm trying not to focus too much on the future though – I'm focusing on the present.



Tomas (left) with his husband Ed



Susan Crane

MS Society Trustee and Fundraising Volunteer, shared her three experiences of coming out for our online celebration of Pride 2020.

The first time I “came out” was easy. My mother was a volunteer at the Brooklyn Junior League, a kind of urban WI group, that had a black-tie winter ball every year. It was essentially a debutante, or a “coming out”, ball. My mother thought presenting her daughter at this fancy ball was a wonderful idea. I had three escorts and a fun night out partying until dawn!

The second time I came out wasn't pre-planned or well-timed. I'd come to the realisation I was a lesbian during my second year at university and was about to take a gap year in London. My mother found out inadvertently when she read a postcard I'd left out to post to my newly “out” cousin.

She sat me down and lectured me for ages about the immense damage I was doing to her, my father and myself. My father and I didn't really

speak for six years after that night, when my parents redeemed themselves by inviting my partner – who I'd met in London – to Christmas.

The third time I came out was about my MS.

Although I was diagnosed 2005, I didn't really come out about my diagnosis until 2019.

I've thought about all the reasons I didn't face my MS “coming out” earlier. There's a definite stigma with any disability and it's hard to explain an invisible one. I hated being pitied, getting the cocked head and “oh dear” response.

I had a little breakthrough when the company I worked for did some work with shiftMS. It was great to see others who were facing MS like me. Then I had a few encounters with

strangers who commented on my balance issues thinking I was drunk.

My response was to get badges made saying, “I'm not drunk, I have MS”.

I've now been an active local volunteer for two and a half years and a MS Society Trustee for two years.

I had the chance to merge my LGBT world and my growing MS world in 2019, when I heard the MS Society was marching with Pride. I'd marched with other groups for more than 25 years but had assumed my marching days were over. It was lovely to march proudly with my new tribe.



Susan as a debutante and (above) with her partner Karen



“I'm not drunk, I have MS”



Jess Mansel

Engagement, Involvement and Empowerment Officer, explains why it's important to recognise the different facets of people's identities.

As a Queer mixed-race person with MS, it's important I see my whole self reflected somewhere. My identity being reflected back to me hasn't always been easy to find.

Last year I took part in the Pride march with our MS Community in Wales. There were disabled people and disability groups along the march. It was inspiring, to see them claim their place in the Queer community. It felt like a loud reminder: disabled people do exist within the LGBTQ+ space. It was empowering to be fully visible. But at the same time, the march was disempowering too. On one of the hottest days of the year, there was nowhere to stop and sit, no toilets on route, and road closures that meant lots of extra walking.

“Our community has diverse needs and it's important those are reflected and met by the MS Society”

Queer spaces and events are often inaccessible, with physical and attitudinal barriers that mean disabled people are alienated, “othered” and excluded. This compounds the sense of discrimination running through our lives as intersectional people – people marginalised on multiple fronts like not being able, not being straight and not being white. When we can't access these spaces, and we're not there, we become invisible.

This year Pride went digital. With online events and discussions, in some ways, it made the event more accessible for disabled people. But will it stay that way? And is there more we can do, especially for people with MS who aren't online?

Last year research from Stonewall found LGBTQ+ people faced widespread discrimination when accessing health care. One in seven LGBTQ+ people avoids seeking help due to the fear of discrimination.

Recognising a person living with MS as having a multifaceted identity means

Jess (right) with MS Society colleagues Iestyn and Julie



we acknowledge and can meet their needs as a whole person – not just a set of symptoms. One size does not fit all. Our community has diverse needs and it's important those are reflected and met by the MS Society.

Having a voice

The Experts by Experience Network is an online community who share our experiences of MS. We help shape and design information and support services at the MS Society. This means everyone in our community can have a voice, make sure our work reflects the whole community and meets people's needs.

You can sign up to join at tinyurl.com/ExbyExMS

Digital technology can help us stay connected, but sometimes it can be hard to get to grips with the virtual world. We spoke to two people about what's helped them get online.

What would help you get online?

Hazel lives on a farm near Omagh, Northern Ireland, and was diagnosed with MS in 2004. She's an active member of her local group.

When it comes to going online, in the past I always thought "Oh, I could never do that." My daughter lived in Australia for a while so I got used to emailing her, but not things like video calls. My brain can sometimes be like scrambled eggs and it always felt a bit too much for me.

But after lockdown I missed the interaction with other members. So I've joined the online Zoom MS group "Coffee and Cheer", which meets every Friday. Local Network Officers Susan and Charlotte sent me the link and it was very easy. My granddaughter

helped me and gave me confidence saying, "Granny, you can do this!"

I enjoy it, we have a bit of banter and a quiz and get up-to-date information. I've definitely got more confidence from using Zoom.



Hazel receiving an award for volunteering

Peter's wife Naoko has had MS for about 10 years. The couple live on Shapinsay, one of Orkney's inner north isles.

I've tried to learn computer skills in the past, but I couldn't pick it up. I've never been very good at reading and writing, and after an accident my memory has been terrible. So I found it hard.

But now there's things happening online, because of coronavirus, that we used to enjoy – like our local group's art class. Our group coordinator, George, got some iPads from a Scottish Government fund and gave me one. I can do things on it now I couldn't do a few months ago. I'm learning, but bit by bit, taking my time.

Naoko is better at it than me and has her own laptop. We enjoy doing the online art class. I also read the news, play games and check the MS Society accounts online. The more I pick it up the more I might use it.



Peter and Naoko

How can we help you?

There are lots of reasons getting online might be difficult, such as MS symptoms, confidence or trouble buying and using equipment. We'd like to find out more about how we might support you.

For an informal chat, call Jessica Mansel on **020 3872 8732** or **07900 983 120** or email jessica.mansel@mssociety.org.uk

Ask the expert:

How important is the flu vaccine for people with MS?



This year, all UK nations are expanding their influenza (flu) vaccination programmes. People with MS should be offered free immunisation against flu as in previous years. **Razia Khan, MS Nurse**, answers your questions.

Q Does having MS mean I have a greater risk of catching flu, or that I would have it more seriously than someone else?

Sarah

Having MS doesn't increase your risk of catching the flu, but if you have MS, catching the flu can make your MS symptoms worse. By having the flu jab, you reduce your risk of having flu. If you do catch the flu after having the vaccine, you're likely to have a milder illness. Having the flu jab also means you're less likely to have flu and COVID-19 at the same time, which could make you more unwell.

Q Will an MSer be adversely affected if they choose to have the flu jab? Will it provoke a relapse?

Claire

The flu jab given to adults is not a live vaccine, so it's safe to have it. Vaccines in general are not associated with an increased risk of relapse.

Q Is the flu jab the same at the GP, the chemist and the supermarket pharmacy?

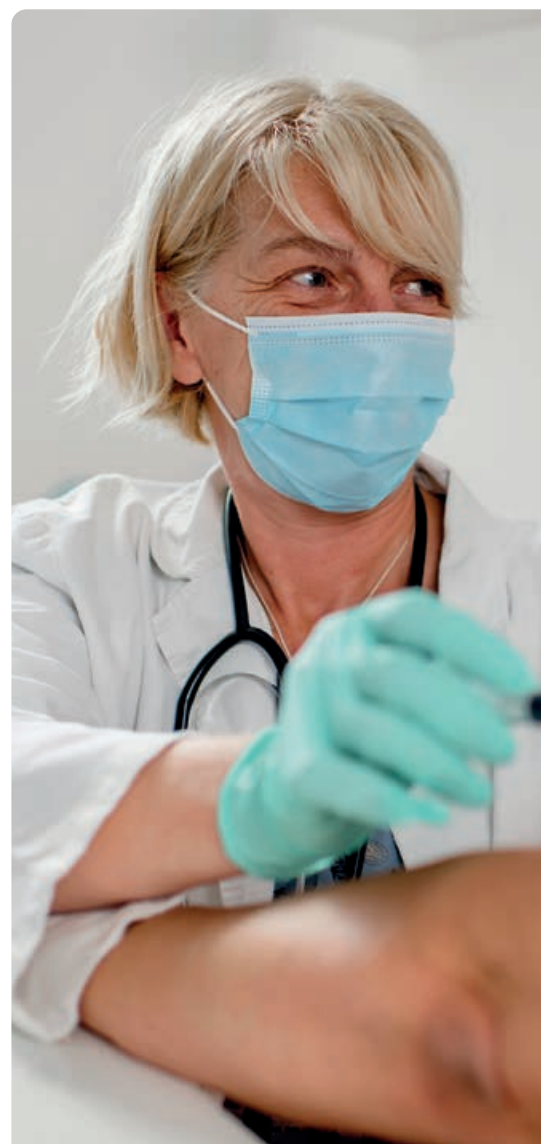
Sarah

You can have the NHS flu vaccine at your GP surgery, a pharmacy offering the service (including supermarket pharmacies), or at your midwifery service if you're pregnant. You will get the same kind of flu jab whichever pharmacist or GP you see. There are different types for different age groups, but none of the injected flu vaccines for adults contains live viruses.

Q Can I safely take the flu jab while I am taking a disease modifying therapy (DMT), which already suppresses part of my immune system?

Scott

A study reviewing all the research into flu vaccination and MS found that vaccination was effective in people with MS and offered them protection



from flu infection. Although disease modifying drugs affect the immune system, most did not stop the vaccination from being protective against flu infection. If you've recently taken certain DMTs or high-dose steroids, many neurologists would suggest avoiding any live vaccine. (The adult flu vaccine is not a live vaccine.) Your MS team will have a record of which DMT you have had and can give you specific advice.

Q Can you have the jab after Lemtrada?

Victoria

It is recommended that patients

“By having the flu jab, you reduce your risk of having flu.”

complete all their immunisations at least six weeks before starting treatment with Lemtrada. The ability to generate an immune response to any vaccine following Lemtrada has not been studied, so your MS team will need to advise you on whether you should have the flu vaccine in this case.

Q We have a 20-month-old daughter who is going to nursery and bringing home all kinds of bugs. As she lives in the same house as someone with MS, will it pose a risk to them if she has the nasal flu spray vaccine?

Edward

The advice varies depending on whether you take a DMT and what DMT you take, so please speak to your MS team. You may be advised to avoid changing your baby's nappy for two weeks after she receives the vaccine. This is because the nasal flu spray for children uses a live attenuated (weakened) influenza virus. But although vaccinated children can shed the virus for a few days after vaccination, this is normally below the levels needed to pass on the infection to others.

Q I phoned my GP's surgery today and was told I wasn't eligible, despite being 60 and caring for my partner who has MS. Is that the case?

Julia

This certainly is not the case. People

who should be offered the flu vaccine this year includes:

- adults aged 65 and over
- people with some medical conditions, including MS
- the main carer of an older or disabled person
- people on the NHS 'extremely clinically vulnerable' list – and anyone they live with
- pregnant women
- people who are in long-stay residential care
- children aged from 2 to 11 or 12 (depending on where you are in the UK)
- health and social care workers

This year in England, Wales and Northern Ireland, for the first time, the flu vaccine will be offered free to people aged over 50 (over 55 in Scotland) once it has been given to those in the list above. However, those most at risk (in the list above) are being prioritised first. If you're not in one of the groups listed above, and you're aged 50-64, you may be asked to have your vaccine later in the year.

Look out for our call for questions for the next MS Matters on our Facebook page at [facebook.com/mssociety](https://www.facebook.com/mssociety)

You can find out more about the flu vaccine, other vaccines and MS at [mssociety.org.uk/vaccines-and-ms](https://www.mssociety.org.uk/vaccines-and-ms)

Tips for coping with bowel problems

Up to seven in ten people with MS can have either constipation or bowel leakage (incontinence). Here are some tips from our new bowel booklet.

Have a regular routine

If you get constipated, have a set time to go to the toilet. The urge to poo is strongest within half an hour of waking up and after eating. This makes breakfast a good time to try, so don't skip this meal.

Keep moving

Moving, eating and drinking stop bowels becoming sluggish. We have exercises for all levels of mobility at mssociety.org.uk/being-active

A continence nurse can explain how to do special exercises to strengthen the stomach muscles that push poo through your bowel.

Food and drink tips

Avoid constipation by drinking six to eight glasses or cups of fluid a day (more in hot weather or when exercising). Eat more fibre to bulk up your poo. It'll then move through your bowels more easily. Leakage is also less likely when poo is firmer. Increase fibre slowly as



too much too soon causes bloating and wind.

Treatments

Your MS nurse or local continence service can advise you about the many treatments and products available for bowel problems. This includes which laxatives to use (and how) if you get constipated.

Finding a toilet

Our free "I need some help" card explains that you urgently need a toilet. Order it on

0300 500 8084 or email supportercare@mssociety.org.uk
Download a phone app



like Toilet Finder or Flush or use Google Maps to find the nearest toilet. For a few pounds, the National Key Scheme gives you a key that lets you into over 9,000 accessible toilets. Order one at disabilityrightsuk.org (search for RADAR).

For a hoist or toilets bigger than standard accessible ones, check out changing-places.org

Ask your local council if there's a Community Toilet Scheme, which lets you use toilets in shops, restaurants and pubs without paying.

If you're in work, would being close to a toilet help? The law says this is a reasonable adjustment you can ask your employer to make. Visit mssociety.org.uk/working-and-ms



Our bowel booklet is one of many about MS symptoms. Download them free at mssociety.org.uk/publications or call 0300 500 8084 for printed copies.

Our webinar on 2 December at 7pm is all about the bladder, bowel and your MS. Noreen Barker, a consultant MS nurse, will answer your questions. Register at <http://bladder-bowel-ms.eventbrite.co.uk> or by calling 0131 335 4071 (Mon-Thurs, 10am-4pm).

A journey towards acceptance

Two women living with MS talk about the long process of accepting their diagnosis.

After 15 years of living with primary progressive MS, **Jo Tame** talks about why it's time to look ahead.

I'm 52. I have loved working in a school and still do – it's a dynamic environment that I thrive in.

I've been lucky that my symptoms have progressed steadily over the years, allowing me to adapt as they got worse. I've never really considered the need to come to terms with my diagnosis, until recently.

With my mobility decreasing, I'm now using a walking stick and I've bought my first mobility scooter. But the most daunting part is the prospect of early retirement. And that has got me thinking more about my illness.

I've arrived at a point of



change. I feel I'm now able to completely accept my reality – that I have MS and working full time is not going to be possible for much longer.

Sense of bereavement

I currently teach business studies but when I was first

“I believe the strongest bond we have is with ourselves and it takes a long, slow process of cutting through that bond to allow new growth to happen.”



Chandra Ruegg explains how opening up about her MS has helped her to “own” it.

diagnosed, I was Head of PE. I was very active and sociable, and I played hockey twice a week. I remember feeling like I had suffered a bereavement. I cried a lot and was grieving for the life that I thought I would lead but I wasn't able to anymore. I was in shock and denial.

We all form different attachments throughout our lives. I believe the strongest bond we have is with ourselves and it takes a long, slow process of cutting through that bond to allow new growth to happen. Looking back, I've come to understand now that it was OK, and indeed important, for me to grieve for the life that I've had. Only by doing so was I able to get on with my new life with MS.

Through my illness, I've also discovered the enormous pleasure I get from enabling others to develop because of my personal experiences with MS.

I've realised how far I've come and how far I still have to go. I'm still here, still myself and an important part of other people's lives. Now, the only choice I have is how I move on and I'm excited about that.

It's now five years since I began my MS journey (and it is a journey, an ever-evolving one). I have come to a point where I am able to accept my MS. But I want to go further than just acceptance – I want to own it.

It's been difficult to do this and the steps have sometimes felt small and laborious. But a big moment for me was coming out with my illness on social media.

I am an incredibly private person and have not shared my condition with many people. Even with friends, it felt like a drip-feeding process of telling various friendship groups. But I got to a point where I felt: why am I hiding this?

I guess it has to do with not wanting to be seen as different, or as having an ailment, and of how people might perceive me. But that really shouldn't matter.

Inspired to write

After catching sight of my reflection walking and not particularly liking the gait I now have, I was inspired to write a poem about my illness. I then shared the poem and shared my MS with the public.

The words are very personal and raw but also accessible. From sharing my poem I was asked to do a podcast which enabled me to delve further into my experience. I feel a great sense of relief having been so open and honest.

Although I have no control over the illness, I can attempt to take a hold of how I react to it. So that's what I mean when I say I am taking ownership of my MS and in doing so, not letting it own me.

“Anger lingers inside of me,
the unfairness of it all

Darkness overwhelms but I'm careful not to fall
into a state of depression

This is my life's lesson and somehow, with
persistence, this MS I'll over-rule.”

From “Me, My MS and I” by Chandra Ruegg

Listen to Chandra read her poem in full at:
mssociety.org.uk/owning-my-ms

“Lockdown has taught me to be more kind”

Joanne Chapman reflects on the challenges of being an MS Mummy while shielding.

At the time of writing, this “new normal” feels harder despite increased freedoms like Little Man returning to school and his Daddy to work. We lived with an even playing field while staying at home but, knowing my vulnerability, the situation now feels like a ticking time bomb.

Wind back time to March, I felt more prepared to stay at home. As the months went by, I often thought “welcome to my world” as everyone had to remain in their house. But independence is valuable, especially to MSers, so when you’re told to shield it can make you want to leave the house even more.

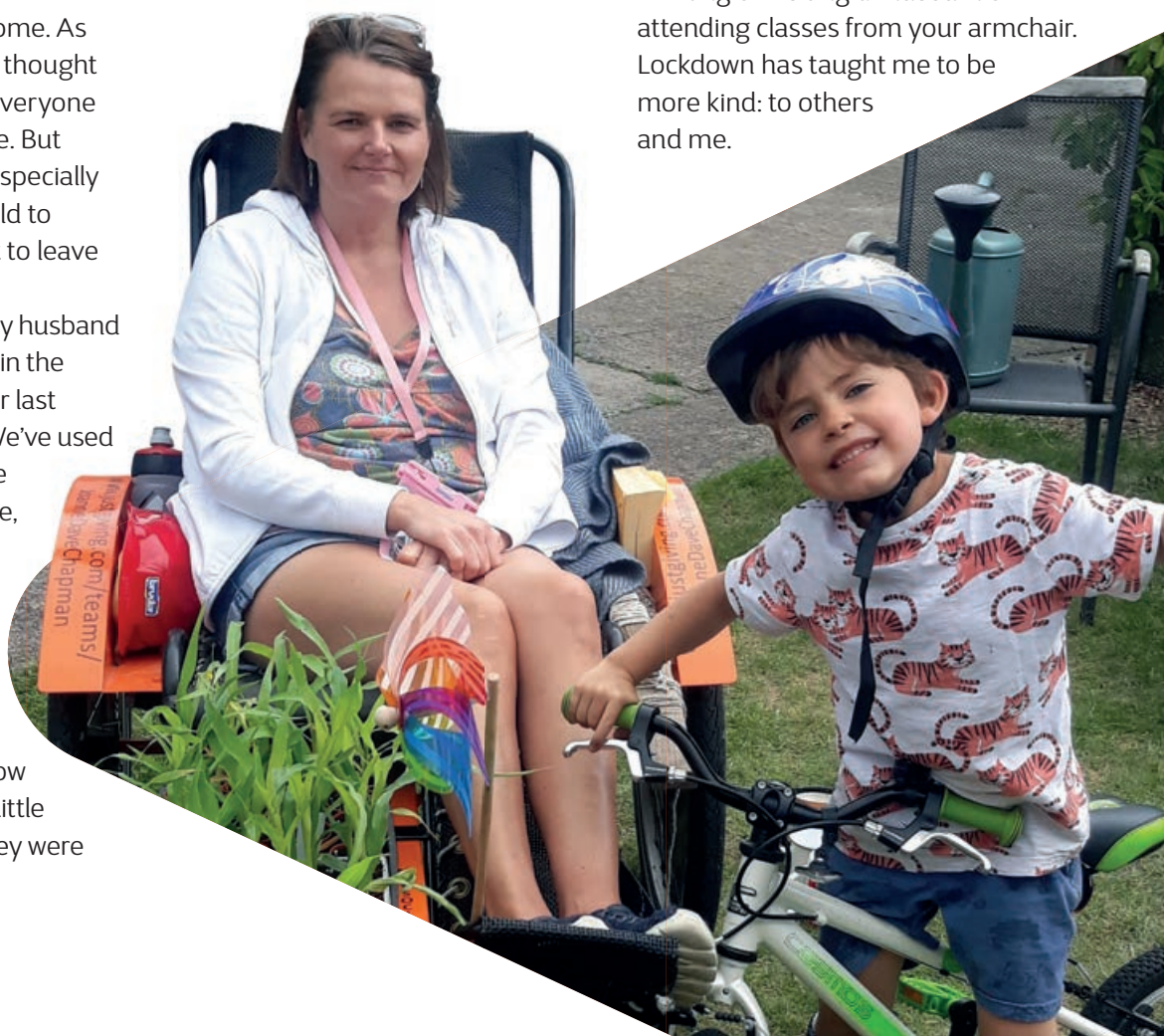
My running chair, which my husband made so we could take part in the Yorkshire Marathon together last year, has been a godsend. We’ve used it for visiting friends, for Little Man and his Daddy’s exercise, and for simply getting me out after shielding. During shielding, Little Man and his Daddy went to our allotment. I often reflected on protecting emotions, handling progression and how my MS was more visible to Little Man and his Daddy, since they were at home more.

Lockdown has led to new symptoms and made others worse. The cog fog due to home schooling and fatigue was crippling. With cancelled appointments and my MS nurse deployed elsewhere, I felt alone. Isolation was stemmed by sharing opinions with other like-minded people and making friends by connecting online with a

local group. It was so important to interact with others.

As I was moving less, my muscles weakened, affecting my mobility, so I fell more often. To strengthen my muscles, I attended online chair exercise and, like Captain Tom, walked the garden, with Little Man joining in. After weeks at home, I knew the importance of exercising and also calming my mind. I downloaded a language app to try and expand the grey matter by learning Spanish. To help me relax, I did meditation. This was my “me time” – time off from being an MS mum. I also had to think about what to say about MS to Little Man. He’s grown up around MS, but lockdown made talking about emotions even more pertinent.

No one knows how long this “new normal” will last. When this virus is tomorrow’s chip paper, I hope it unlocks a more accessible world, whether through more remote working or visiting a museum or attending classes from your armchair. Lockdown has taught me to be more kind: to others and me.



Life with MS can throw many challenges at us – we thought we'd ask for your stories, experiences and thoughts on overcoming some of them. From marathons to bellringing, here are some of your responses.

What's something you've done which you thought you couldn't do because of MS?



"A flying lesson, hopefully some more when this pandemic over."

Amanda

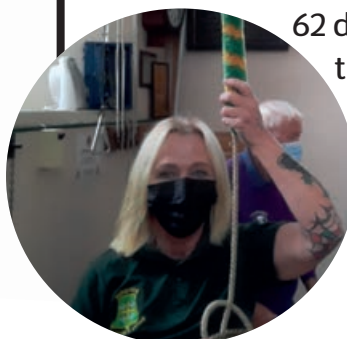
"I climbed Snowdon, albeit on the train, but I still got up there and experienced something I thought would be impossible now I'm mostly confined to a chair."

Emma

"Abseiling from the Civic Centre in Walsall back in 2000. I'd had MS for two years at the time."

Deb

I started to learn to ring church bells three years ago. It's incredibly challenging one-handed. My first quarter-peal was a challenge of physical endurance, mental exhaustion and repetitive posture core-controlled movements. I've rung in 62 different towers now and there is no running out of new methods to perfect.



Michelle

“I took up the aerial hoop. It was life changing. I’m so rubbish on the ground, but I can dance in the air!”

Iain

Being from a sporting background has allowed me to explore para sports. My best achievement is coming third at the para cycling national championships in the C3 category only 18 months after being diagnosed with MS.

Colin

My son and I walked Hadrian’s Wall and camped along the way. It took seven days, dragging my right leg as it decided not to work, but excellent memories for us and raised over £2,300 for MS.

Anthea

“Walked a half marathon through London for charity. Trained for six months, walking every weekend.”

Suzie



I went to Athens on my own and got up the big hill to sit at the Parthenon. I’ve done that more than once and, although it’s extremely difficult,

the seat at the top is spectacular.

April



“I cycled 50 miles with my husband on our tandem. I was diagnosed with relapsing MS two years ago.”

Jo

I’ve lived in another country, become a school governor and, most recently, taken up running (couch to 5k) and can now run/jog for 30 mins without stopping. I recognise not all of us in this community are able to do so, but I have enjoyed discovering what I am capable of despite MS.

Kristina

“Scaling Uphill Hill, Weston-Super-Mare. From the bottom to the top it took me about 40 minutes, but it didn’t defeat me and my trusty old powerchair! The view was fantastic.”

Russ



Thank you to everyone who shared their thoughts. In the next issue, we’d like to ask you: **What are your top tips for technology that you use to help you?**

Email mismatters@mssociety.org.uk or keep an eye on our Facebook group, [facebook.com/mssociety](https://www.facebook.com/mssociety) – we’ll post the question in early 2021.



Working as a paramedic and having MS

“As a Paramedic Clinical Advisor at East Midlands Ambulance Service, my job is to look at the 999 calls coming in,” writes Jackie on our blog.

I was diagnosed with MS following an MRI scan in February 2019. I was absolutely devastated. I put it to the back of my mind and continued to work hard.

In August 2019 I had to go for a lumbar puncture. After this procedure, I was having severe headaches, and this is when it all hit me. I had got MS and there was no hiding away from it anymore. I also started with severe depression and ended up on anti-depressants.

By October 2019 I wanted to return to work but I didn't feel confident enough to return to my job due to the anxiety about dealing with patients. After speaking to my managers about it, I was able to work in a different role.

At the beginning of March, I returned to my role as Clinical

Advisor, but was soon medically stood down because of COVID-19 as there was no way for me to social distance whilst at work.

Then EMAS provided me with computer equipment, which enables me to continue to do my job fully and effectively from home. Working from home has helped massively with my MS. If I'm having an off-day, I no longer need to worry about driving to work, which has really helped reduce my anxiety.

 **Nicola**

I'm a mental health nurse and working from home has definitely helped my MS. Doing video and telephone consultations rather than driving to the office and to home visits has definitely helped reduce my fatigue.

 **Clair**

I have worked from home since March and I have found my fatigue has been halved and my symptoms are manageable. It has made me rethink what I had been doing and what I need to be doing. I have always worked through my bad days and dealt with it when I get home. But I have realised what I have been doing to myself is not healthy for a normal person and even worse for someone with MS.

 **Lea**

I work for the ambulance service so it's really reassuring to see other options available without having to leave the service.

For more information on working and MS visit mssociety.org.uk/work-and-ms

 share

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](https://twitter.com/mssocietyuk)



Not “only” a spilled jar of coffee

Our anonymous columnist talks about looking for small victories.

It all started with a jar of coffee. Insistent that she make the 11 o'clock cups of instant, my wife's fingers and hands, not great at the best of times, failed her completely. With one deft and unintended move, jar, contents, spoon and mugs all crashed to the floor. The jar was not in the space where she thought it was, her jerking hands knocking everything in sight off the worktop.

Then the tears came, great gulping sobs, eyes stinging with anger, all leavened with some choice language.

My immediate role was to console and comfort, to tell her she wasn't useless, to tell her it wasn't her fault and, in the scheme of things, not a great tragedy. It was “only” a jar of coffee.

But we have been there before and we all know it is not “just” about a spilled jar of coffee, or a broken plate, or a knocked-over plant. These incidents all represent a failure of control and the constant fight to live a “normal” life. It represents a brokenness within that will not be healed.

The post-mortem took on the same shape as all the previous ones: “I'm just getting worse”, “I'm just becoming a burden and you are having to do more and more”, “How will this all end?” These are words which are despairing and unsettling enough to listen to, but a thousand

times worse to be the one actually voicing them.

There are so many more positive aspects to daily living and this, surely, is the challenge. Sharing in the small but precious victories, maximising every opportunity for pleasure and fun, to encourage and support at all times. These are the mighty, daily challenges to be faced

“When my wife feels she has reconnected with the world she used to inhabit, there she celebrates a small victory”

by both parties.

When my wife feels she has reconnected with the world she used to inhabit, there she celebrates a small victory.

We all break plates and upset vases of flowers and clearing up is just what we do. But those simple tasks can be almost out of reach for someone whose balance is poor, whose eyes cannot focus.

Imagine the sense of achievement when my wife marshals every fibre of her being, steels her resolve, nerves her will and sets to with brush and pan. She will not always be beaten!

That constitutes a small victory, but in the moment, it is a huge win.



Getting to know you...

Dr Sarah Rawlings joins the MS Society this November as our new Executive Director of Research and External Affairs.

Why did you join the MS Society?

Mainly for the opportunity to work for such a fantastic charity. I'm passionate about research, policy and campaigning, as well as communications. The opportunity to have a role that works in all these areas was one I couldn't pass up. I also have friends who are affected by MS, so it was something I was personally very keen to work on. My focus will be on making sure our vital research continues, and the changing needs of our MS community get the attention they deserve in government.

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

For a very long time I wanted to be a vet. At some point, that changed into wanting to be a scientist – I'm interested in biology and chemistry and how things work. I did work as a scientist for a while, but I discovered quite quickly that I was probably more successful working with people than petri dishes.

What or who is the love of your life?

My family. I've been with my husband for nearly 25 years now – we met at university – and we have two boys who are 11 and seven. They're wonderful.

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

Just before I had my first son, my then boss said, "when you have your son and you come back to work, it's OK to feel conflicted". I think what she meant was that we all make different life choices and we're not going to get it right all the time – and that's OK. It's stuck with me over the years.

If you could have a superpower what would it be?

One would be fluent in every single language. I speak English and that's it! I'd love to be able to speak all kinds of different languages because

communication is really important. The second superpower I'd have is to be able to fly. It would be incredibly helpful, especially on the school run!

What is the most important lesson life has taught you?

To believe in people and to believe in kindness. People are our greatest asset – whether it's our friends or family, or people at work. A lot of that is around how teams work together and how people can achieve things and make a difference. I think kindness and how you treat people is so important.

Sarah replaces Dr Susan Kohlhaas, who left the MS Society in July. Find out more about her career by visiting: mssociety.org.uk/getting-to-know-you



It's time to vote!

Trustee **Susan Crane** and Northern Ireland Council Chair **Catherine Doran**, who both live with MS, explain why we're asking you to vote on the proposed legal changes to our membership.

Why are you proposing this change?

CD: For me, the reasons why we want to make this change are clear: it's about building our community, having a bigger voice and making more impact. It's also about giving people a choice, rather than saying: "Here's your membership. This is what you get." It will allow people to be involved in the way they want to be.

SC: I'm a volunteer in the West Central London Group, as well as being a trustee. My group is relatively new, and we're trying to get a lot more people involved. But the current membership experience puts up barriers, for example by asking people to fill in forms and sign up for a direct debit. We want to remove those barriers and reach out to as many people as possible.

CD: Yes, and the more people who join us, the

more clout we'll have when we talk to policymakers and stand up for people with MS.

What are you asking me to vote on?

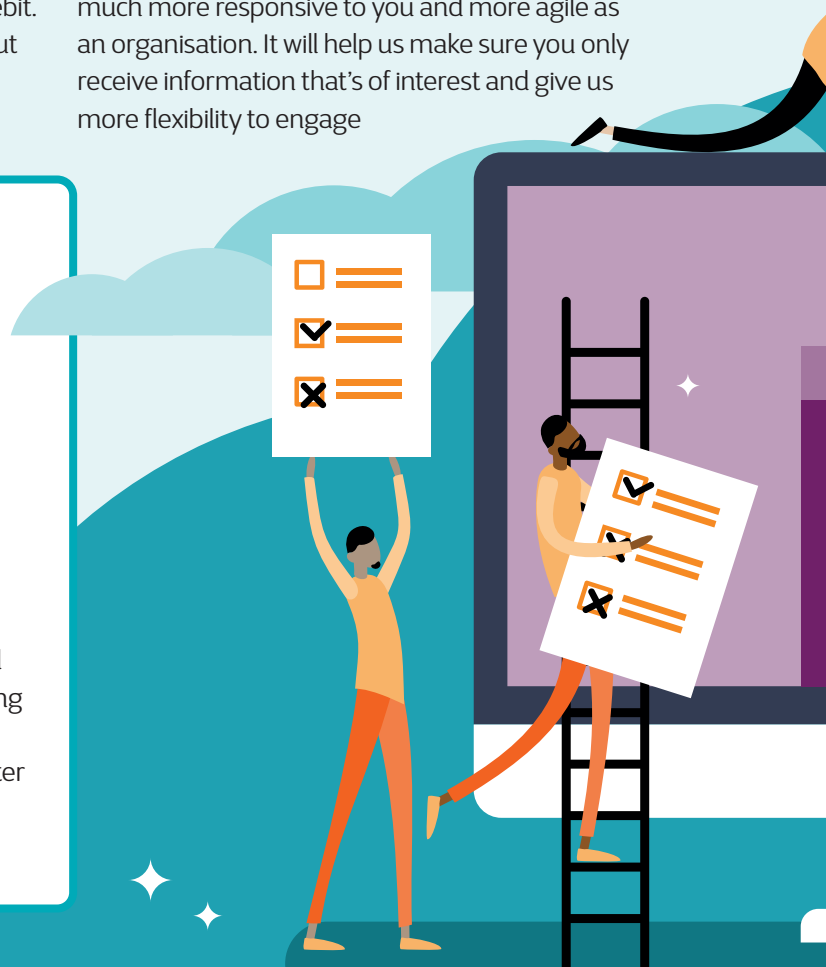
CD: We're asking you to vote on a special resolution to adopt a new Articles of Association (our constitution), which will transfer the legal member status from members to trustees and the four National Council chairs.

What does the proposed change mean for me?

SC: The proposed change will enable us to be much more responsive to you and more agile as an organisation. It will help us make sure you only receive information that's of interest and give us more flexibility to engage

Will I still get MS Matters?

Yes, you can still look forward to receiving MS Matters three times a year. There will be an annual £5 fee to receive it by post. So, if the resolution is passed, your annual £5 membership fee will be transferred to an MS Matters subscription. You can of course choose not to receive the magazine. If that's the case we hope that, wherever possible, you will be happy to continue your annual contribution to help fund our services and research. If you don't want to continue with your existing payment, then you'll need to cancel your direct debit prior to its annual renewal. Please contact our Supporter Care Team on **0300 500 8084** or **supportercare@mssociety.org.uk** who will be happy to help.



with members throughout the year, not just at the AGM. And because all members can choose to join the electorate and will retain the right to vote for trustees, you'll still be able to have your say. As your representatives, we'll actively seek your feedback and our new online space will help us to do that.

On a personal level, the biggest thing I've learned as someone with MS is that you need to be your own advocate and look out for your own MS care. Our new membership offer will support you to do that by providing information that's relevant for your MS.

If the resolution is passed and you're already a member, you'll be transferred to the new membership. You'll be able to access the new offers, without having to do anything.

What does the proposed change mean for my group?

CD: We're committed to maintaining groups' income from membership for the future. After three years, we intend to review how the arrangement is working in consultation with local groups,

making sure that this total income is being fairly divided between our groups. We think our new membership offer will attract more people to join our groups by making them even more vibrant and representative of the communities they serve.



CATHERINE DORAN

What will my new membership experience be like?

CD: You can choose to engage online or offline, and we'll still be producing a printed copy of MS Matters. On the website, there will be a personalised space you can tailor so it's relevant to you. For example, you'll be able to choose whether you want to connect to your local group or not, and what topics you're most interested in hearing about. You'll be able to link up with forums and connect with people who are going through the same thing as you. For me, it's about finding your people – and that's what the MS Society is all about.

SC: The new membership experience will give you a unique way of interacting with the information and services that are available. Because everybody with MS experiences it differently, with a different prognosis and a different interaction with their treatment. There are so many perspectives – and we're trying to provide a membership experience to reflect that and to give people the choice as to what they would most like to hear about.



SUSAN CRANE

How and when do I vote?

In October, we sent you the AGM booklet, including the meeting notification, by email or post. This has all the details of how to vote on changes to the legal membership. You can vote by post or online until 11am on 3 December. The results will be announced at the AGM on 5 December. You can sign up to attend or watch the event online at mssociety.org.uk/agm

There's much more information on the changes in the AGM booklet and on our website. Visit mssociety.org.uk/membership-developments

Tentative steps towards meeting face to face

We're very grateful to our local group volunteers for all they have done during lockdown to support their local MS communities.

With members and service users at increased risk of isolation, many volunteers embraced unfamiliar technology to keep them connected and moved group services and activities online. This has been a success and enabled some people who can't attend activities in person to take part – but those without internet

access have been disadvantaged.

With the gradual relaxing of lockdown, some of our groups told us they were keen to restart face-to-face services. We've been looking at how we can support them in this.

At the time of writing, we were working with a small number of groups to test new paperwork and procedures (based on government guidance) that could enable some activities to restart. The trial ran until the end of October and we're working on timings for a wider roll-out, subject to the COVID-19 situation in each nation. In taking this

tentative first step, our priorities are to make sure volunteers feel comfortable with the additional responsibilities placed on them, and that everybody stays safe.

The recent increase in social restrictions and local lockdowns emphasises that restarting group activities face to face will not be a straightforward process. We'll continue with the roll-out wherever possible, while following the most up-to-date health regulations.

For more information visit mssociety.org.uk/local-groups

Volunteer spotlight: Emma Johnston

Volunteer Counsellor, Northern Ireland

I used to work in a nursing home but had to leave my job after my MS diagnosis in 2014. I found the physical parts of the job difficult. After my diagnosis, I reached out to the MS Society in Northern Ireland and received counselling from their team in Belfast. It was absolutely fantastic, it really helped me understand what I was going through, accept MS was part of my life and rebuild.

I had gotten so much from my counsellor Tom, who also has MS. Speaking to a counsellor with the same condition was unique and even more useful. I wanted to help people in the same way, so I started retraining to be a counsellor in 2016. I started providing sessions to people affected by MS in 2018.

As a recipient and now as a practitioner, I find that counselling provides the emotional support people need when they need it. It is a place people can get true empathy, freedom to speak freely, to be themselves and a place totally lacking in judgement. When



my clients find out I have MS they open up quicker, there are fewer barriers and there is a certain understanding.

I think people often find it difficult to talk about their MS with friends and family or feel people struggle to understand what they are going through. Living with MS can be a lot about acceptance, but things can change all the time which is challenging. I love being able to offer support to people and help them make a positive difference in their lives.

If you're in Northern Ireland, you can access the counselling service at nireception@mssociety.org.uk

My MS, My Way: Tayside expands

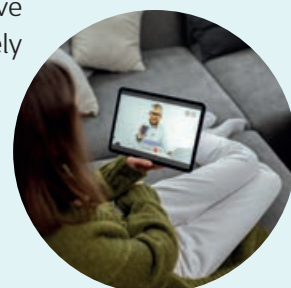
Our “My MS, My Way: Tayside” support service for people living in Dundee, Angus and Perth and Kinross is reaching out to more people in its second year.

The project has already helped 83 people newly diagnosed with MS to access support, counselling and information.

The service was initially designed for people diagnosed with the condition in the last five years but will now be open to anyone affected by MS in the area.

People can access free one-to-one counselling, peer support and exercise classes, all of which have been delivered remotely since the beginning of the lockdown.

One participant says: “My counsellor was very encouraging and reassuring. She made me realise that I’m coping well, and am stronger and doing a better job than I realise, which I remind myself still if I’m having a bad day.”



Find out more at mssociety.org.uk/tayside-support

Need a listening ear?

Our UK-wide MS Helpline offers emotional support and information to anyone affected by MS. We can also let you know how you might find counselling near you. Call **0808 800 8000** or email helpline@mssociety.org.uk

BLACK
HISTORY
MONTH

Celebrating Black History Month

As part of our renewed commitment to equality, diversity and inclusion, this October we marked UK **Black History Month** for the first time. Karen, a member of our Experts by Experience Network, shared her perspective on our blog.

My parents are Jamaican and I am Black British. I did not know anyone with MS at the time of my MS diagnosis and my knowledge of MS within the Black community was non-existent.

My health professionals were kind, compassionate and helpful. It is important to me to appreciate their expertise then and now, for how they help me cope in ways that suit me. Over the years I became an expert too with my MS.

Having a strong family network is very important to me. And there was no judgement within my family circle. When I've been

judged by others, it has been hard to tell what the real issue was – my disability, my colour, both or something else.

When challenged, people imply that an issue may be related to my disability rather than colour. However, this has been questionable in the past. Stereotypes about disabled and Black people definitely exist. Wrongs cannot be made right if people are not made aware, able to admit it, or be accountable for their thoughts and actions.

Windrush, BAME (Black, Asian and Minority Ethnic), Black Lives Matter and Black History Month are familiar terms of reference

for Black people. And recent happenings in 2020 have helped Black collective voices and other voices to come together more.

This can be positive, helping us speak up together to improve services for Black people with MS.

I have been involved with the Experts by Experience steering group as a volunteer since it started two years ago. My role is to help involve a more diverse range of voices. Our group want to represent the MS community in real terms with their different voices and experiences.

In the words of Martin Luther King Jr: "If you can't fly then run, if you can't run then walk, if you can't walk then crawl, but whatever you do you have to keep moving forward." ('What is Your Life's Blueprint', 1967)

Very apt words for our MS community too.



Read more on Black History Month at mssociety.org.uk/blog

To join our Experts Experience Network, visit: tinyurl.com/ExbyExMS

GAME OVER for MS



Xander Booth

In 2020, many people have learned to use digital technologies that are new to them to stay connected. But the gaming industry has always been one step ahead.

Worth over £5.7 billion to the UK economy, gaming is one of the fastest-growing industries. It's helped create massive online communities of like-minded people who come together, share a passion and communicate through different platforms in a virtual world.

Many gamers are now using their online connections to raise money for the charities that are close to them. We wanted to get in on the action too, which is why we're really thrilled to launch Game Over for MS!

One of our supporters Liam Waddington, or Vizeh as he is known in the gaming world, has raised over £16,000 in three years for us through his gaming streams.

Xander Booth, whose father lives with MS, has supported us for several years and dreams of becoming a professional gamer.

Xander says: "Gaming is a great way

to help fundraise for the MS Society. Due to the lockdown it has boomed, and more and more gamers are watching other gamers stream live. If you can build up a good following of other game lovers, it's possible to get donations and help fundraise for good causes."

Ahmed Khan, our Senior Community Fundraiser, says: "Game

Over for MS is a new fundraising activity for us, but we're so excited about its potential to engage and reach new audiences for whom gaming is a way of life. There are loads of ways that you or someone you know can get involved."

Find out more at mssociety.org.uk/gameover

How do people raise money through gaming?

- A gamer is someone who plays interactive video games on a games console, such as an Xbox or PlayStation, or a tablet, computer or mobile phone.
- Gamers often watch each other's "streams", which is where you play in front of a live audience online and record it.
- Gamers can ask friends and family to sponsor them to take on a challenge, such as gaming for 24 hours non-stop. People can watch their stream as they play.
- Gamers can also raise money by getting a group of friends together to play online. Everyone pays an entrance fee to the charity of their choice.

A big thank you for walking, running and cycling 100k Your Way

Although we missed seeing MS Superstars because we couldn't run our usual events this year, we were delighted that over 430 people from across the UK took part in our virtual 100k Your Way challenge. Over the summer, you walked, ran and cycled in your own time, raising funds to help make sure no one faces MS alone.

Wendy (pictured, centre), who was diagnosed with relapsing MS two years ago, took part. She says: "The symptoms I noticed when I was running – dizziness and vertigo – led to my diagnosis. I hung up my running trainers and got myself a bike hoping to stay fit. That's the best

part of 100k Your Way. You can decide what exercise to do according to your body on that day.

"Every day is different with MS. Sometimes I feel like I couldn't manage a walk, so sitting on a bike and getting wind in my face on a ride is perfect and keeps me cool!"

We're delighted to have raised over £193,000 so far! 100k Your Way will be back in summer 2021, so look out for more details on how you can take part.



Dates for your diary

Join us for one of our exciting fundraising events in 2021. To find out more visit mssociety.org.uk/fundraise or email challenge@mssociety.org.uk

11 April

Royal Parks Half Marathon

13.1 miles through London's scenic parks.

23 May

London Landmarks Half Marathon

Run past the capital's highlights at this unique event.

29-30 May

Edinburgh Marathon Festival

The biggest Scottish event of the year, with distances to suit all abilities.

29-30 May

London 2 Brighton Challenge

Walk, jog, or run from capital to coast.

30 May

The Big Leap

Soar from over 10,000 feet for a truly unforgettable experience. (And if you don't want to wait until May, you can skydive at a time and airfield that suits you. See our website for more details.)

June

Cake Break

The sweetest way to help stop MS!

Please note that details are correct at the time of going to print. Due to COVID-19, events may be subject to change. Visit our website for the most up-to-date information.

Fantastic fundraisers

It's been a challenging time to fundraise – but that hasn't stopped you from stepping up to the mark. Thank you so much for all your amazing efforts!

Going beyond one million steps in just one day

In 2018, Amy Thompson was diagnosed with relapsing MS aged 21. Last year, she set up MS Together, a support group that brings together people aged 18 to 35. The group connects online and sometimes members meet face to face when it's possible to do so.

Now with more than 200 members from across the UK and Ireland, the 1 Million Steps for MS was the group's first fundraising effort.

Amy says: "We aimed to collectively complete one million steps in one day by walking, running or using a wheelchair. We split the steps so everyone felt comfortable with what they could achieve. That's why this challenge was so perfect."

On 26 July, 56 members of MS Together successfully completed 1,227,385 steps (that's over 600 miles) to raise over £20,000 to support our work.

Amy says: "Everything exceeded our expectations. Everyone was

so proud of the extra steps we managed, and the overwhelming support we received.

"Some of us met up for this challenge, some did it on a

"We were keeping in touch throughout the day and working together towards the same goal"

treadmill and others went out for walks or runs locally. A few of us got lost and ended up doing more steps than we needed!

"Best of all, even though we were all over the country, we were keeping in touch throughout the day and working together towards the same goal."

Find out more by emailing mstogether@outlook.com, visiting [facebook.com/groups/mstogetherofficial](https://www.facebook.com/groups/mstogetherofficial) or following the Instagram feed [@mstogetherofficial](https://www.instagram.com/mstogetherofficial)





All sewn up

During the lockdown, Kay Simpson turned her sewing hobby into a brilliant fundraiser from her home in Glossop.

It all started with a few face coverings that Kay made for her daughter's kickboxing club. Encouraged by the positive response, she decided to make more in support of the MS Society and her local hospice.

Kay says: "MS has had a huge impact on my family. Both my niece and late mother-in-law were diagnosed with it. I've had MS for 30 years. Now I can't walk or stand up for long, but sewing is something I enjoy and can do by myself."

Kay's fundraiser quickly became a family affair. Her husband helped with cutting fabric and her daughter helped spread the word on social media.

Incredibly, Kay ended up making 500 face coverings, raising £1,800.

Kay says: "We had orders from everywhere. People's generosity and lovely comments have given me a great boost."



Reach for the stars

Over the past few months, most of our events have unfortunately been postponed as they simply can't go ahead safely.

However, thanks to increased measures to keep our supporters safe, we're delighted our Ben Nevis Night Hike was able to go ahead.

On 22 August, 24 MS Superstars climbed the UK's highest peak under starlight and raised over £24,350 to help stop MS. This is the first fundraising event we've been able to hold since the UK went into lockdown in March.

Safety measures included temperature checks on arrival, staggering start times to allow social distancing and providing

hand sanitiser to all participants.

Matthew Thorne was diagnosed with primary progressive MS in September 2019. He was part of a team that took on the challenge.

Matthew says: "Taking part in the Ben Nevis Night Hike was a wonderful experience. I definitely found the challenge tougher than expected, but my brother and friends stayed with me and our guides Dan and Jack were amazing. Raising more than £14,000 towards stopping MS has been incredible."



Tour de UK tops £2,200

Supporters Stuart and Paul took on their very own cycling challenge in August, which they called Tour de UK. Cycling 1,057 miles over 12 days, travelling to all the capital cities in the UK, they managed to raise a massive £2,229.

Stuart says: "With all our holidays, social activities and events cancelled, Paul suggested doing our own challenge. We are in our mid-40s and we keep relatively active but are definitely not athletes in any shape or form. We wanted to push ourselves to achieve something in this very strange year."

The pair choose to fundraise for us as a close friend had lost her mother



to MS during lockdown and they wanted to raise funds in her memory. Along the way they were spurred on by the huge support from family, friends and supporters who were donating.

Visit mssociety.org.uk/fundraise for up-to-date information about our fundraising events and ideas for holding one of your own. You can also contact your local Area Fundraising Manager for more support at myfundraising@mssociety.org.uk

Will making made easy



If you're thinking of making or updating your will, our Legacy Manager **Adam West** can help.

More people than ever have contacted us this year for help with making their will. We have a number of services available to anyone affected by MS.

The National Free Wills Network

The National Free Wills Network has solicitors throughout the UK

who can help you make or update your will for free. We can put you in contact with them.

The Goodwill Partnership

Through The Goodwill Partnership you can get a low-cost solicitor-written will made in the comfort of your own home. Visit thegoodwillpartnership.co.uk/ms-society for more details.

Farewill Online

For a limited time you can get a will made online, through our friends at Farewill, for free. Please visit farewill.com/MSMATT to get started. (The Farewill service is only available in England and Wales.) For more details about these services, contact Adam on **020 8827 0374** or legacies@mssociety.org.uk



WIN
£5,000

Play the Christmas raffle

You'll have the chance to win £5,000 or another fantastic prize. Enter online at mssociety.org.uk/raffle or by phone on 0300 002 0267 (Monday to Friday 9am-5pm).

Send some festive cheer

With Christmas just around the corner, why not get ready for the festive season and buy your Christmas cards today? Check out our new designs for 2020 and buy your favourites at mssociety.org.uk/xmascards

Festive ways to fundraise

By buying our Christmas cards and playing the Christmas raffle, you can support people affected by MS and help fund vital research to stop MS for good.

A perfect pair of socks for Christmas

Monkey Sox has launched an exclusive sports sock for the MS Society, designed to coordinate with our events kit.

James and his wife Lianne created Monkey Sox after James was diagnosed with MS. The company donates 50% of its net profits equally to MS charities, including the MS Society. It will donate an extra £5 directly to us from the sale of each pair of these

exclusive socks.

Monkey Sox are always odd, designed to represent how the left and right sides of the body can act and feel differently for those living with MS.

James and Lianne are committed to inspiring an active lifestyle to help the

symptoms of MS. Made with breathable mesh, a supportive rib arch and a comfortable double cuff, these socks perform like no other!

Shop online at monkeysox.org/mssociety or call 0208 943 9016 to order by phone.



Getting active at home

Physiotherapist **Rachel Flinn** offers some tips on exercising at home.



Regular exercise improves health, physical functioning and overall wellbeing. It's recommended for everyone, including people with MS.

During lockdown, it's been more difficult to get out to exercise. Many places where exercise takes place have been closed, such as swimming pools, gyms, leisure centres, community centres and parks.

There's been an increase in online exercise classes for those who have mastered Zoom or other video calling software.

For others, it's been difficult to manage exercising at home. But our homes offer plenty of opportunities for exercise. It may be step-ups at the bottom of the stairs, balancing at the kitchen worktop, deep breathing exercises in the chair or lifting some weights using a few tins of beans from the cupboard.

It can be difficult to motivate yourself to exercise regularly at home. Here are a few ideas to help:

- Choose a time during the day, even

for 10 minutes, to set aside for exercise. Mornings after breakfast are often a good time before the day's activities start.

- Set some goals to work towards. For example, to do five minutes of stretches, then five minutes of aerobic, then five minutes of strengthening exercises.
- Share your goals with someone who will check in with you to make you accountable for your exercise plan.
- Increase your enjoyment by exercising to your favourite music.

Remember to keep exercise within your limits. Start at a reasonable level and then gradually increase the amount of exercise. The exercises on our website can be a good starting point.

For more information visit mssociety.org.uk/staying-active or order our exercise booklet by calling **0300 500 8084**.

Chair exercises

Here are three exercises you can do while sitting down.

Tummy breathing

- Place your hands on your stomach. As you breathe in, try to breathe in deeply to the base of your lungs and let your stomach move out.
- This allows the diaphragm to lower and lets more air into the bases of the lungs.
- Try to breathe in through the nose and out through the mouth.
- Relax shoulders down during the breathing exercise.
- Try to do it 10 times.

Chest opening

- Start with arms down at the outsides of the chair.
- Then move palms to face outwards and take both arms back behind the body.
- As you do this, the front of the chest opens up and the shoulder blades come together.
- This exercise particularly benefits those sitting at a computer for long periods.
- Repeat 10 times.

Seated marching

- While sitting on a chair, march your feet on the spot and swing arms back and forwards with elbows bent.
- You can try 10 marches fast and then 10 marches slowly, and repeat the sequence.
- Aim for 30 seconds, rest, and repeat up to five times.



Fighting back with a paintbrush

Jenny Ferguson on how art brings purpose to her life.



I was diagnosed with MS in 1994. I was in neonatal nursing and determined to carry on for as long as possible. To cut a long story short, I retired in 2012, still loving my work and very sorry to leave.

I've always been interested in art. My house was full of pictures. So when I finished work I joined an

adult education art class, which I thoroughly enjoyed - it felt so natural.

Since then I've hardly stopped. They say it takes 10,000 hours to become an expert in anything, so at first, I aimed for those lofty heights. Now I spend three or four hours a day on art. I'm a long way off 10,000 hours but with practice, you keep getting better and better.

Art allows me to immerse myself in an activity that brings me satisfaction and purpose in the face of the dreaded MS. It helps fill my time with something that inspires me, and it's been a great mood elevator.

I love colour and shapes and am always on the lookout for things to

paint. They could be on the internet or around me in the house or garden. My three dogs are good models and my iPad is an invaluable source of reference material.

My husband and I are avid charity shoppers, where we find plentiful art materials and frames. I post my finished pieces on social media and look daily to see how many likes they attract, which I find good for my self-belief. And it puts me in touch with other artists.

Art keeps me sane and gives me an identity as an artist, as opposed to the one who is in a wheelchair, who has MS. Never underestimate the need for good mental health when facing something so enormous as MS. People find enough excuses to leave you isolated, but rather than getting down I fight back with a paintbrush.

Jenny's tips for budding artists

- **Where you paint is important.** Make sure it's warm, near the loo and near food! For me it's the kitchen.
- **Join a group if you can,** then you've really got to do it. While we can't meet in person, I'm part of a group that meets online.
- **Don't forget YouTube** – it's an invaluable learning resource. There's lots of tremendous artists on it sharing their work and how it's done.

You can see Jenny's art at [instagram.com/jen_ferguson_bettebravo_art/](https://www.instagram.com/jen_ferguson_bettebravo_art/)

