



Life after lockdown

How does it feel for people living with MS?

Inside
The power of MRI
We look at the latest research and developments in MRI technology



Issue 138
Summer 2021

I hope you're all coping well as we inch slowly from the pandemic.

It's an odd feeling for everyone, so in this issue we talk about life after lockdown and what that means for people living with MS (page 34)

One thing the pandemic hit was our finances. This meant we had to make some difficult choices. For example, you may notice this magazine is slightly slimmer than usual. This will help with saving costs and has enabled us to continue producing MS Matters. We've prioritised the content we know from our surveys is most important to you.

One thing we know you love to hear about is MS research. In this issue, we focus on MRI, looking at how evolving MRI technology is helping clinical trials (page 17), how artificial intelligence can spot patterns in MRI (page 23), and how research into old MRI scans is helping people today (page 20). We also answer your MRI questions on page 28.

Thanks, as always, for your continued support. And I wish you all well as we move into post-lockdown life.

Nick Moberly
Chief Executive



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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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Your Letters

Wayne's partner, Sandra, died earlier this year after living with MS for many years. Wayne sent us a letter explaining how he and Sandra sometimes felt alienated within the MS community. He said:

"My partner Sandra was diagnosed late with MS after many years visiting her doctor. We attended an MS Society meeting for newly diagnosed people. I will never forget arriving at the venue thinking we'd got the wrong date. We had a disability badge and a wheelchair, so parked in a disabled space, but we were the only car in one. All the other people were not as far on as Sandra.

"We always said that most of the information and stories in MS Matters were around people who were still able to get on with daily life with a little help, and with a good close family and care services.

"We did have help from various services and the MS Society, but we always felt we had to constantly keep asking for help. It didn't seem to find us otherwise. And I must admit it beat us both down to read about others where help seemed to knock on the door."

MS Society - We're so sorry to hear about your partner and send our heartfelt condolences. And we're sorry that MS Matters hasn't always featured stories that you can relate to. It's one of the challenges of creating a magazine about such a varied



condition – and trying to balance hope and inspiration with different realities.

We are working hard to put together an inclusive magazine and will take on board your comments. For example, this issue features people living with many different experiences of MS. On page 33, you can read about Marilyn who found community and comfort at our progressive MS wellbeing sessions. And on page 38, you can read about Len and his journey coping with loss.

Many thanks for writing in and raising these issues.



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

We're speaking up for the MS community

How we're raising the voices of people living with MS across the UK and how you can get involved.

#TooMuchToLose

Too often, people with MS can't get the support they need to stay active and independent, such as physiotherapy and occupational therapy. And this only got worse during lockdown. Our Too Much to Lose campaign shone a light on this issue.

In 2020, our community wrote to almost every local health decision maker in the UK to ask them to pledge to take action.

And earlier this year, we teamed up with other neurological charities and arranged a meeting with parliamentarians to discuss improvements to neuro rehabilitation services in England. This joint meeting of the All-Party Parliamentary Group (APPG) for MS, and several other groups, discussed the impact on the community. We heard from people with neurological conditions about how lockdown affected them. And we made the case for a funded national strategy to improve rehabilitation. As a result, we met with the health minister and continue to campaign

together nationally.

Through the campaign, we've made connections with local health decision makers who signed our pledge. We've met with some to discuss their plans, and we've heard about their work to improve access to services like neuropsychology. We'll make sure the voice of our community is represented in this work, and push for these conversations to happen across all of the UK.

We're also engaging with the Scottish Government, who've published their plans for rehabilitation and recovery during and after the pandemic. Their plans give details about how they'll respond to long COVID and provide services to people living with long-term conditions such as MS.

We'll be exploring these issues further throughout the year as part of an inquiry we're carrying out for the APPG for MS.



Working in Westminster

We're keeping busy in Westminster, meeting with MPs to make sure the MS community's concerns are heard.

Each month, we meet with Nadhim Zahawi MP, the minister for vaccinations. We discuss the COVID-19 vaccine rollout and how it affects people with MS,

and we get answers to your questions.

We've also spoken with a committee of MPs who are carrying out an inquiry into the disability employment gap. They're looking at how the government can make it easier for people with MS to get into and remain in work.



LOCAL

ACTION

for MS

Get involved in a local campaign

Our new Local Action for MS campaign programme has had lots of interest so far. Campaigners are using our resources and campaign training to address issues affecting them and their communities.

Local campaigns include calling for more MS nurses, training for medical students about restless leg syndrome, pedestrian crossings, dropped kerbs and more.

Chris Todd, part of a group of Hull campaigners tackling supermarket car parking, is delighted to be involved: "We wanted to make a difference and this has given us the confidence and ideas to get started. The training helped develop my skills and I can't wait to make good use of it."

Anyone can take part in local campaigning. Resources are available on our website, including toolkits and information about how to get more involved. Further training sessions are planned in the autumn, including a session on influencing MPs with Sir Norman Lamb, former health minister for England.

join

To get involved in our campaigning work, contact us at campaigns@mssociety.org.uk or sign up at mssociety.org.uk/campaign-with-us

Our post-election plans in Scotland and Wales

On 6 May, Scotland and Wales went to the polls for the Scottish Parliament and Senedd Cymru elections. Here's how we'll be working with the new representatives.

Scotland

In the lead up to the election, we asked you to contact your candidates to help put MS on the agenda at Holyrood.

This included asking candidates to pledge their support for our MS manifesto asks. These are:

- the creation of a rights-based social security system
- for care, support and treatment to be person-centred
- and for improved wellbeing support.

More than 60 candidates pledged their support, and 19 of them were elected.

Now the next Scottish Government has been elected, our priority will be to engage with MSPs,

old and new, on the issues that matter most to the MS community.

We'll continue to campaign to scrap the 20-metre rule from Adult Disability Payment (ADP) criteria. And we'll work with the Scottish Parliament to support the recovery and remobilisation of health and social care services as we come out of the pandemic.



Wales

It was a Senedd Cymru election like no other. COVID-19 may have prevented us from meeting candidates face to face, but it didn't stop us from putting them on the spot at the five pre-election online hustings we organised.

Before the pandemic struck, access to MS treatments and services were the number one priority for the MS community in Wales. And they remain even more

so now. We want the new Welsh Government to do more than just commit to pre-coronavirus levels of support. Instead we want them to improve capacity within the NHS so everyone living with MS has better access to MS treatments, care and support.

We're hosting an online reception for all Members of the Senedd (MSs) in September. We'd love you to attend and invite your MSs too.



To get involved in campaigns in Scotland, contact scotlandcampaigns@mssociety.org.uk And for campaigns in Wales, contact fiona.mcdonald@mssociety.org.uk or call **07740 753 945**

Join Team **Stop MS**

Our new Team Stop MS campaign film features people living with MS alongside celebrity supporters like Andy Serkis, Kit Harington and Rose Leslie. Here we speak to two of the film's stars.

Sandhia Shah

(pictured with Andy Serkis) lives in Manchester and was diagnosed with relapsing MS in 2014.

Fatigue is my number one symptom. I used to be able to deal with it, but it's getting more and more intense. I also struggle with my cognition and not feeling in the present moment. I feel like my MS is like an out-of-body experience sometimes! I'm so glad I got involved in Team Stop MS. It was so much fun to film and I've never done anything like it before! It was so lovely meeting all the other people involved, and it's given me a sense that I'm part of something much bigger. I feel privileged to be part of something that could help future generations – as well as hopefully all of us living with MS today.



There's still a lot I want to do in my life, but at the moment my health is limiting me and I can't do as much as I want. I've noticed a change over the last 18 months. Not knowing how my MS will progress is a constant worry to me. The fear factor is there all the time, but I hope, with research and funding, we can get to a place where everyone with MS can maintain a good quality of life.

That's why joining Team Stop MS is so important. By raising awareness and funds for research, we have the possibility of making that happen. We could finally stop MS!

Alun Armstrong

became an MS Society ambassador in 2019. His sister Elaine lives with relapsing MS.

Being part of Team Stop MS means a lot to me. Anybody who is connected with MS knows how debilitating it can be. When my sister and I were very little, we had an uncle who lived with MS, back when there weren't any treatments. I remember the impact of it all and I was so fearful for my sister. I just kept hoping some breakthrough would be discovered. Decades later, and we're at this incredible juncture in the fight against MS. From what the scientists tell us, we're on the verge of some really significant breakthroughs and the future for progressive treatments really does look promising.

We all want to help in whatever small way we can. And by joining Team Stop MS – just by getting the word out, or helping to raise some funds – you could be the important piece that takes research to that next stage. It's really exciting.



We need to raise £100 million to find treatments for everyone with MS – and we're over halfway there. Join **#TeamStopMS** today and watch our campaign film at **mssociety.org.uk/team**

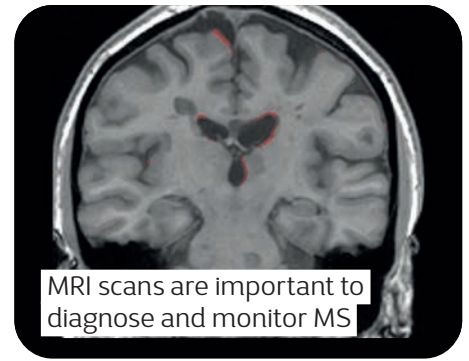
New approach to MRI identifies previously unseen brain changes

MRI scans are routinely used to diagnose and monitor MS, by highlighting areas of myelin damage. But these scans don't pick up everything happening in the brains of people with MS.

We know other changes take place because we can see the evidence in brain tissue donated by people with MS after their death. Researchers have now shown that a new approach, combining several advanced MRI techniques, can detect some of these changes in people only recently diagnosed with MS.

The team from University College London found that people with MS showed changes in the sodium concentration in nerves, as well as to the structure of nerves at a microscopic level.

Interestingly, they also saw a link between the degree to which these changes were evident and subtle signs of clinical disability, like slower walking. The same link wasn't there when they looked at conventional MRI scans.



The researchers now plan to follow people with MS over time, and see whether there's a link between these changes in someone's brain and how their MS develops.

Turn to page 24 to read more about how MRI is uncovering new insights about MS progression.



A shared goal to stop MS

We've committed to raise £3.7 million to fund exciting programmes of work at two centres of excellence over the next five years.

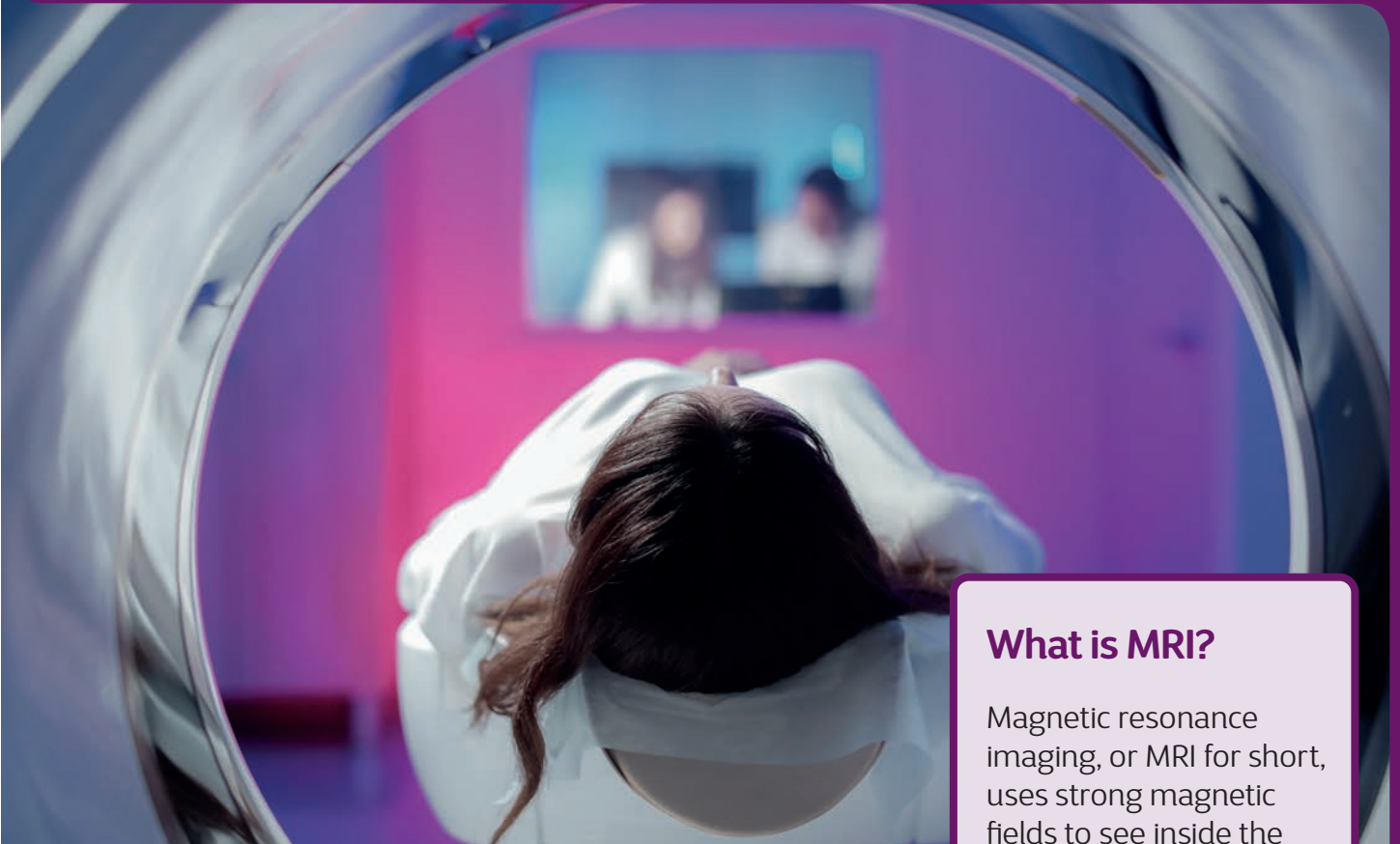
Researchers in Edinburgh will be developing a pioneering drug-testing platform. It will use robots to screen thousands of possible treatments on zebrafish with an MS-like condition. Potential treatments will also be tested on MS cells grown in a dish and on human brain tissue samples. Using these different methods

together will help researchers prioritise treatments with the best chance of success in clinical trials.

The Cambridge team will build on research on the impact of ageing on MS. They will study myelin repair in people with MS of all ages, including children. By looking across the lifespan, the team hope to identify how our natural ability to repair myelin changes with age, and how this could be used to develop myelin repair drugs.

read

Read more research news on our website, including the latest research discoveries and updates on our clinical trials. Read more at mssociety.org.uk/latest-research



Transforming trials with MRI

MRI technology has been evolving. Techniques are faster, more powerful and more detailed than ever. And MS researchers are making the most of this new technology to make trials of new treatments more efficient, so we can stop MS sooner.

The ultimate goal of clinical trials for progressive MS is to see if a potential treatment slows or stops your disability getting worse. But if your MS is progressing, your symptoms usually get worse quite gradually, over many years. So it takes a long time to see whether a potential

treatment is slowing disability progression down.

Frustratingly, this can mean researchers spend years testing a treatment that eventually turns out to be ineffective. Now though, MRI technology is helping reduce that risk. MRI scans can give us an early insight into whether new treatments look promising.

What is MRI?

Magnetic resonance imaging, or MRI for short, uses strong magnetic fields to see inside the body. It's particularly useful in MS as it allows us to measure what's happening in the brain and spinal cord.

How does it work?

It measures how much water there is in the body. Because different parts of the brain have different amounts of water, we can use MRI to distinguish them and build up pictures of your central nervous system.

The protective myelin coating is a fatty substance, so it repels water. This means we can measure how much myelin is present because it looks different to nerves and other brain cells on a scan.

Testing treatments to repair myelin

Researchers at our Cambridge Centre of Excellence for Myelin Repair recently used MRI in a small phase 2 trial to see whether bexarotene, a drug used before in cancer treatment, could help repair myelin.

Researchers used a type of MRI scan called magnetisation transfer ratio (MTR) to see whether the drug was effective. This technique measures changes in the amount of myelin in our brains. It detects a signal that goes down when your myelin is damaged and back up as your myelin repairs. An increase in MTR signal from one scan to another over time tells us that myelin repair is happening.

By using MTR, the researchers could get an answer to whether bexarotene looked promising much more quickly than if they'd waited to see if there was an effect on disability.

The trial showed bexarotene treatment boosted MTR, meaning

myelin repair in people with MS is possible. Bexarotene isn't being taken forward as a treatment because of severe side-effects. But the learnings around MTR are being used in a new myelin repair trial. You can read about this trial at mssociety.org.uk/cambridge-myelin

Testing treatments to protect nerves

Several years ago, Professor Jeremy Chataway, and his team from University College London, ran a phase 2 trial to see whether simvastatin, a common cholesterol-lowering drug, could slow progression in secondary progressive MS.

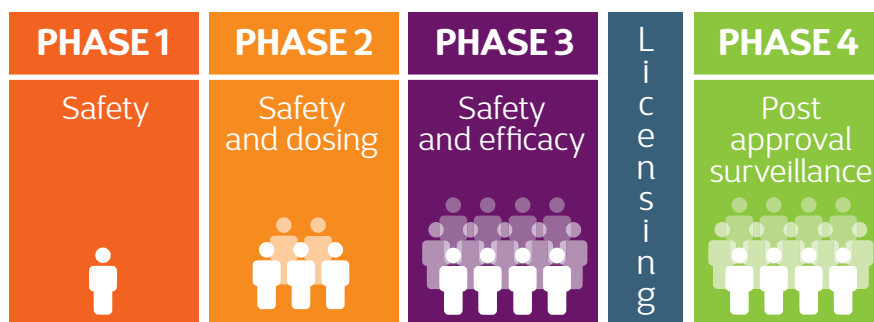
They used MRI to look for changes in the brain that can be early signs your MS is getting worse, like brain atrophy. Brain atrophy is how we describe a loss of nerve cells. It happens to all of us as we age, as well as in MS. And we can track how fast it's happening by using MRI to measure the volume of the brain.

“Octopus will test potential treatments up to three times faster, with a little help from MRI technology.”

The team found people taking simvastatin showed slower brain atrophy than people taking a placebo (dummy drug). Brain atrophy usually happens many months before you see signs of disability progression, such as more difficulty walking. So that was an indication the treatment may have the potential to eventually slow down disability progression.

On the basis of MRI results, we funded the researchers to set up a much larger phase 3 trial, MS-STAT2, to see if simvastatin does slow disability progression. It is now in its third year and nearing its recruitment goal. You can read more about MS-STAT2 at mssociety.org.uk/simvastatin-trial

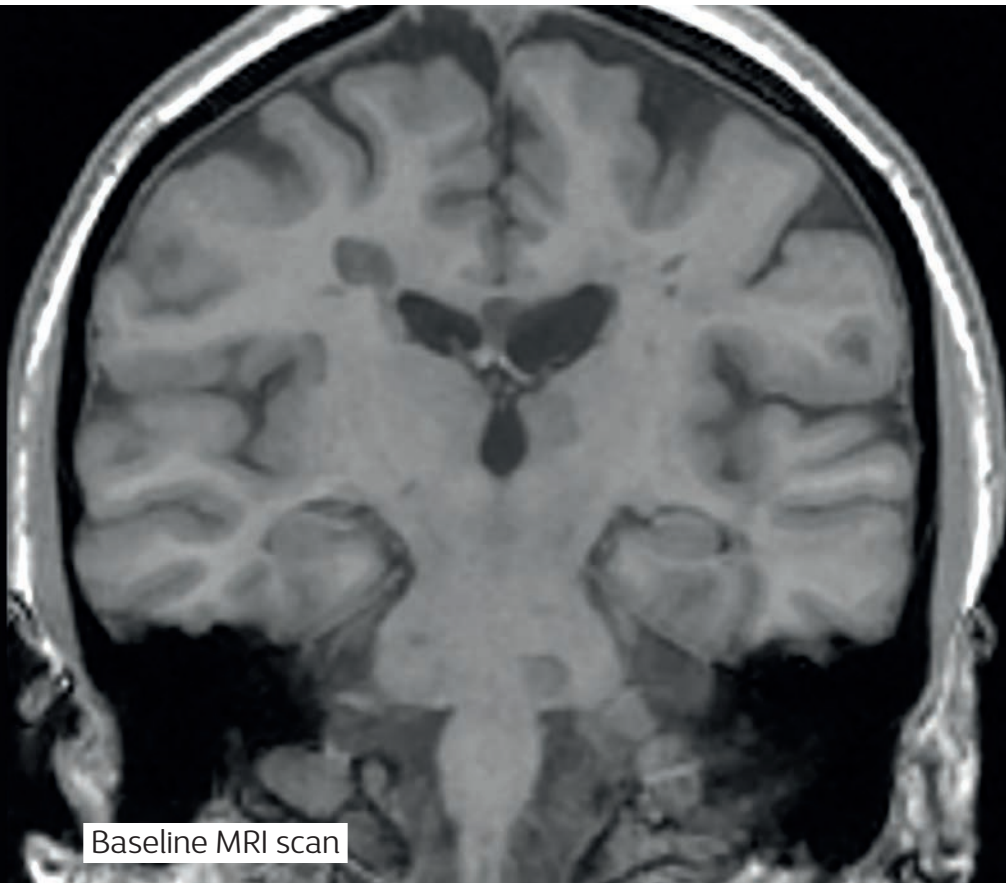
Clinical trial phases



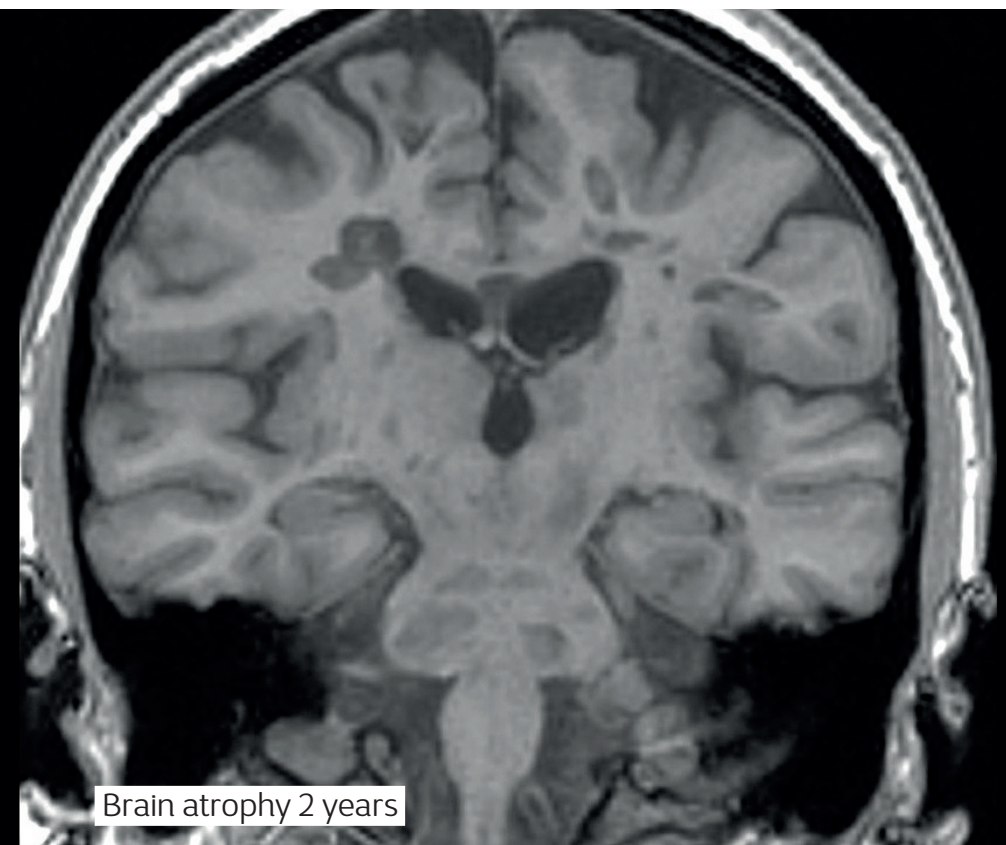
Using MRI to merge two trials into one

We've been using what we've learned about MRI from all of these trials to set up Octopus, our first of its kind mega-trial for progressive MS. Octopus will test potential

What does brain atrophy look like?



Baseline MRI scan



Brain atrophy 2 years

treatments up to three times faster, with a little help from MRI technology.

Researchers will use MRI to get a sneak preview of treatments' potential part way through the trial. So they'll know early on whether a treatment looks promising.

If the results look encouraging, the researchers will invite hundreds more people with MS to join the existing participants to see if the treatment slows disability progression as well.

So they won't have to spend time setting up a new separate phase 3 trial. Instead, phase 2 and 3 will seamlessly merge into one.

If MRI shows the treatment doesn't seem to be helping any better than a placebo, the team will drop it from the trial. This will avoid wasting resources and time on a drug that is unlikely to be successful.

Future of MRI

There are many ways MRI can help us make our search for new treatments more efficient, so that we can stop MS sooner. We're confident it'll help Octopus and other trials set the course to revolutionise treatments for progressive MS. Find out more about Octopus at mssociety.org.uk/octopus-trial

Using MRI scans from decades ago to help people now



Research Network member **Sue Harrison** asked three researchers from University College London what analysing 30 years of MRI scans could mean for people with MS.

It can be one or two decades before you understand what course someone's MS is taking. Therefore, studies that follow people for a long period of time are essential to identify early signs that might allow doctors to predict how people's MS will progress.

Drs Declan Chard, Karen Chung and Wallace Brownlee explained how long-term MRI studies are helping them understand how MS progresses and what the markers are for progression.

Looking back over decades

Thousands of MRI scans from people with MS going back several decades have been saved, and the team have been reanalysing them using new techniques. By using this existing data, they've discovered they can identify patterns in how different people's MS progresses.



Sue Harrison

Karen has been analysing data from a 30-year study. She said: "One of the key findings is that, 30 years following diagnosis, some people have only minimal disability and worked until retirement age or are still working. And crucially, even as early as one year following the first MS symptoms, brain scans could predict who might follow this course."

Wallace has been working on a 15-year study looking at scans of the brain and spinal cord. He found early

spinal cord damage was a sign that people were much more likely to go on to develop the secondary progressive form of MS. A simple MRI scan could help to predict whether someone has a 50% or 5% chance of needing a walking stick 15 years later.

Working towards personalised care

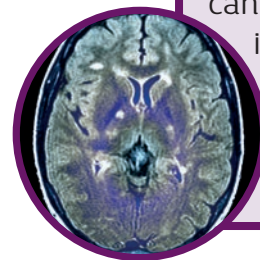
It is hoped that key data emerging from these long-term studies could contribute to the personalisation of care. Many factors influence decisions about treatments and symptom management therapies. These might be side effects of a treatment, or whether it's given via tablet or infusion. Information on likely progression should also form part of the conversation.



Looking into grey matter

Previous analysis of these MRI scans has focused on white matter. White matter is made of the part of nerves called axons. The white colour comes from the fatty covering around axons - myelin, which is damaged in MS.

Grey matter is made up of the main parts of nerve cells – the cell body. It is the outer, wiggly brain tissue you see in brain images. Technological advances mean the researchers can now analyse changes in the grey matter as well, which may provide markers for MS progression.



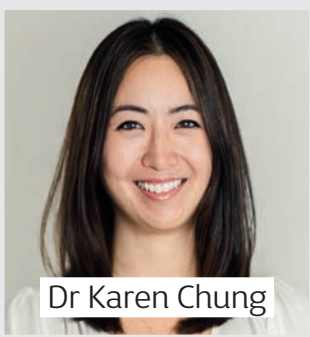
Dr Declan Chard

Knowing how someone's MS is likely to progress in the long-term would also offer people much-needed certainty. So people living with MS can plan for their lives in the future.

Future research

The researchers are excited about the places their research can go next.

Although they've made great progress on predicting how someone's MS will progress, there are still no definitive techniques that neurologists could use in the clinic. The researchers hope, with more advanced analysis, they can identify specific MRI markers that individual neurologists could use to personalise their patients' care.



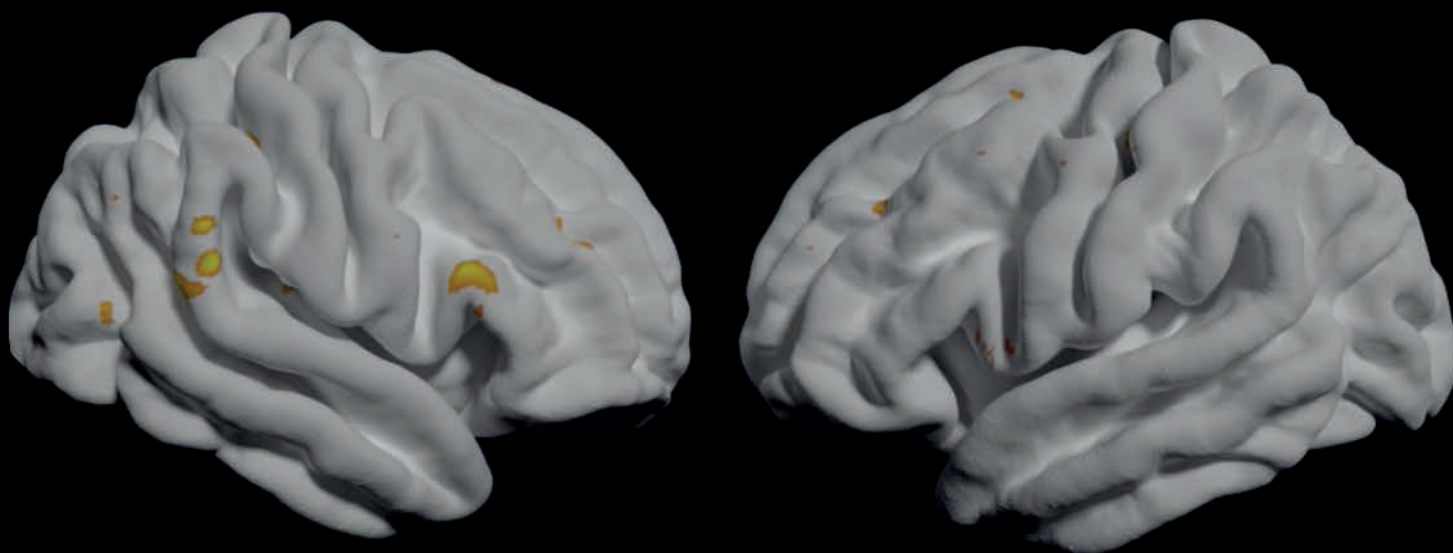
Dr Karen Chung



Dr Wallace Brownlee

Making a difference

The researchers emphasise that progress would not have been possible without people with MS participating in their studies. People who joined 30 years ago, when there were no treatments for MS at all, volunteered just to try to improve things for people with MS in the future. And the researchers are so grateful for their help!



Artificial intelligence spots new patterns in MRI

Dr Arman Eshaghi from University College London used artificial intelligence to analyse thousands of MRI brain scans in MS. Research Network member **Dominic Shadbolt** spoke to Arman and tells us what it revealed.

In the last 30 years, we have come from a phone attached to the wall with a wire, to a small, battery-powered device that has significantly more power than the computers that ran the Space Shuttle. And this incredible technological change is also affecting MS research.

Have you ever wanted to see into the future? Well, I can't offer you the winning

lottery ticket numbers, but soon we might be able to predict some things about MS. Artificial intelligence (AI) is not sci-fi anymore.

What is AI?

AI uses computers to do things that would normally rely on human intelligence. The use of computers greatly reduces the time it takes. In MS, clinical trials can include hundreds or thousands of participants. It



Dominic Shadbolt

would take a human a really long time to analyse all those scans! This is why we get a computer to do it for us.

What has the AI analysed?

Recently, Dr Arman Eshaghi used computers to look at an astonishing 9,000+ brain images. Arman said: "It was nine solid months of a

university supercomputer working 24/7 to analyse the images.”

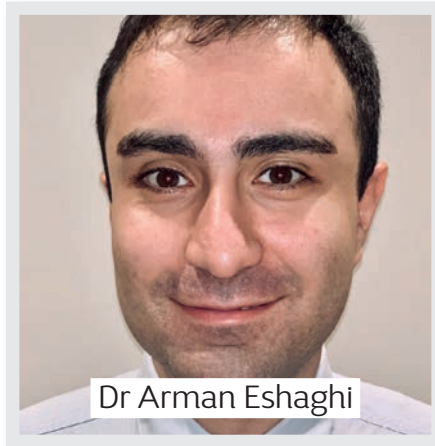
To analyse the scans, the AI had to learn how to play 3D chess with brain images. When someone has an MRI scan, you get a series of images of slices of the brain. So the AI had to look at each flat image and link them back together to look at the whole brain.

From there, it learnt to spot changes in the brain caused by MS, and any patterns in these changes that might tell us more about MS.

What did it find?

By comparing more MRIs than any neurologist will see in their life, the computer has learnt to spot patterns that are very hard to see.

This huge dataset has allowed the AI to identify different sub-types of MS based on where the brain changes are and how they evolve over time.



Dr Arman Eshaghi

“It was nine solid months of a university super-computer working 24/7 to analyse the images.”

By analysing so many brain scans alongside clinical data, the AI was also able to predict how people with these different sub-types are likely to progress and even how they may respond to treatment.

More research is needed but Arman tells me this study

could turn the traditional two-way distinction between relapsing and progressive MS on its head.

How could this help people with MS in the future?

There are lots of ways this technology could make a difference for those of us with MS.

In the future, AI could give recommendations to neurologists potentially by predicting the most suitable treatment for each individual person. It'll hopefully ensure you are getting care that's more about you and your MS, not just MS in general. I hope this will be possible for both relapsing and progressive MS in the future, as more treatments emerge.

AI could also give the neurologist your MRI scan with its observations, highlighting early signs of progression that may be brewing, that a human can't necessarily spot yet. This could allow you, and the doctor, to make better decisions or give you a bit more certainty about your future.

Arman is hopeful we'll see this technology moving from clinical trials into clinical practice in the next five years. And in ten years, it could become a pretty standard part of how our MRIs are analysed. Personally, I can't wait!

Three new MS subtypes

The researchers describe each subtype by the first changes visible on MRI scans:

1. Changes in the volume of brain tissue in the outer part of the brain.
2. Changes in nerve cells' ability to send messages in the inner part of the brain.
3. Areas of myelin damage concentrated in lesions, occurring early on in the condition .

Magnets could hold the clues for cognitive symptoms

Research Network member **Rabiah Coon** spoke with **Professor Rob Dineen** about using magnets to understand cognitive symptoms of MS.

About 60% of people living with MS report cognitive issues, including memory problems, difficulties with language or feeling slow. You can learn techniques to help you cope better with these problems. But there aren't treatments that tackle what's causing them.

Dr Rob Dineen's research is using two types of powerful magnet to understand more about the areas of the brain



Rabiah Coon

that, when affected by MS, can lead to cognitive problems.

Tracing changes that may lead to cognitive problems

In 2014, after studying medicine and radiology, Rob pursued his PhD at the University of Nottingham. He set out to answer the question: "Can we use imaging to get a better understanding of the causes of cognitive problems in MS?" Rob used a specific type of MRI analysis that can show us connections between different areas of the brain.



Professor Rob Dineen



He found MS damage could make it harder for nerves in different areas to talk to each other. The amount of disruption was associated with the severity of cognitive problems in MS. These disruptions weren't seen in the brains of people without cognitive problems either.

Rob thinks there may be a way to boost these connections.

Developing a therapy to address cognitive problems

In his current research, he is studying how scientists can interact with these



connections and impact them using transcranial magnetic stimulation (TMS).

TMS is already widely used to treat depression and has been shown to be safe. Rob believes TMS could also be used to activate brain connections that impact cognition, hopefully reducing symptoms.

He is focusing on a region near the front of the brain. This area has strong connections with deeper structures of the brain. It is important for several cognitive functions including working memory (information you're actively processing).

MRI vs TMS

Many people with MS visit the inside of an MRI scanner as part of monitoring the condition's progression. MRI also plays a crucial role in research.

TMS also uses an external magnet, but in a different way to MRI. The magnet stimulates a small area of the brain by exciting and activating nerve cells near the surface of the brain. This in turn can activate other brain structures connected with these cells. It is hoped that this activation improves the functioning of the cells. To receive TMS, the participant sits in something like a dentist's chair. The stimulation is delivered via a coil placed on the outside of a person's head.

Testing TMS in a trial

Rob and his team are doing a study to test whether TMS can improve the cognitive symptoms that people with MS experience.

For each participant, an MRI will first identify the exact location of the part of the brain the researchers want to activate. TMS only affects a small area of their brain, and the researchers want to make sure they're activating the right spot in each individual.

Participants will complete cognitive assessments and questionnaires before and after TMS, to see if there's an improvement.

The researchers will also see if any positive effects last when they follow up three months later.

What could this mean for people with MS?

Effectively addressing cognitive issues can keep someone employed longer and improve their quality of life.

Rob hopes these results will lead to and inform a larger trial in the future. If TMS is effective, it could help many people with MS with their cognitive symptoms.



Find out more about Rob's TMS study at mssociety.org.uk/tms-study

Ask the expert

What do you want to know about MRI scans?

Magnetic Resonance Imaging (MRI) plays a vital role in how we diagnose and monitor MS. MS nurses **Razia Khan** and **Jennifer McNeil** answer your questions.



Q I'm waiting for a scan. Usually, does the patient get detailed feedback to understand the findings of the scan and what that means for their own diagnosis?

Helen

Your consultant will give you the results either face to face or over a telephone call, and follow up by letter. They'll be able to tell you where lesions are located and the number of lesions found. They might also be able to advise you if there's any active inflammation, but that depends on the type of MRI scan that's

been carried out.

A common kind of scan that's done is a 'T2-weighted MRI scan'. It shows the total number of lesions, old and new, in the brain and spinal cord. A technique called FLAIR can make it easier to spot those lesions.

As well as a T2 scan, they might do a T1 scan to look for new lesions. A T1 scan checks for current inflammation and activity. With that scan, a technique called 'gadolinium enhancement' shows up the areas of active inflammation.

So, using both kinds of scan,

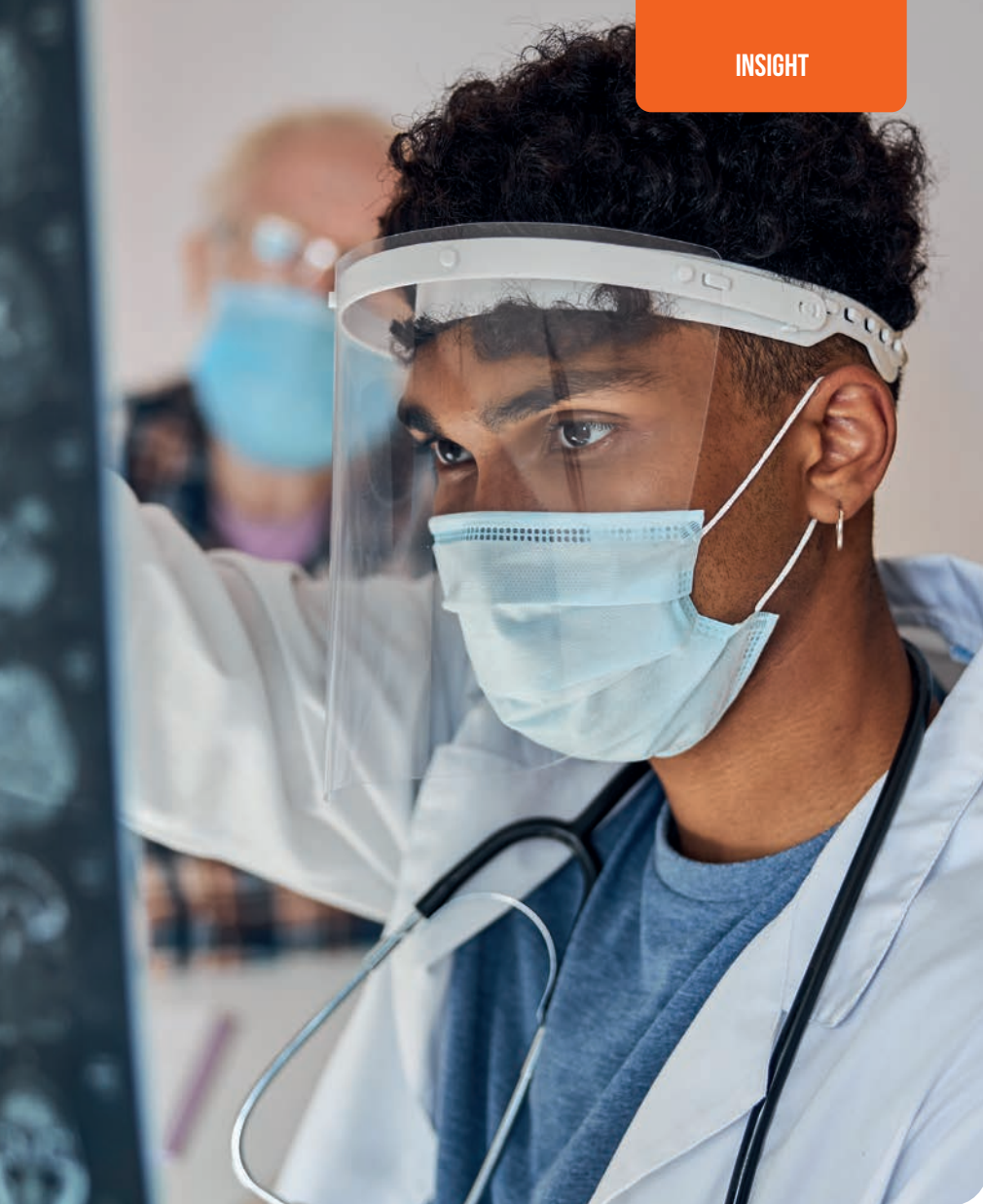
they could see old lesions, new lesions, and any lesions that have got bigger.

Q I've had some scans with contrast dye injections, and some without. What exactly does the dye enhance in the images, and how do the MS team decide when to request its use in scans?

Ross

That contrast dye is also called 'gadolinium enhancement'. It's used in about 1 in every 3 MRI scans. It makes the images clearer on the MRI scan. In MS, gadolinium makes it

“Your consultant will give you the results either face to face or over a telephone call, and follow up by letter.”



“In MS, gadolinium makes it possible to tell the difference between active MS lesions and older areas of scarring.”

possible to tell the difference between active MS lesions and older areas of scarring. Your neurologist will decide which MRI scan to carry out.

Q I'd like to know if there's a chance of having an allergic reaction to gadolinium contrast dye because I have multiple allergies.

Eiona

patients, an itchy skin rash might appear a few minutes after the injection. This appears to be due to a mild allergy. It usually settles down by itself within an hour or so, but rarely it might be a warning sign of a more serious allergic reaction developing.

Severe allergic (anaphylactic)

reactions to gadolinium contrast medium have occurred, but are extremely rare. These severe reactions, which might involve difficulty breathing and swelling of the lips and mouth, occur in approximately 1 in every 10,000 people who have gadolinium. These severe reactions generally respond very well to standard emergency drug treatment, similar to that given for other severe allergic reactions.

Q My husband had his scan and diagnosis in 2008, never had a scan since!

Helen

Same here. Got one in the end in 2019, but they flatly refused prior as didn't fit the criteria? No-one, when questioned, could answer what that criteria is?

Sheila

The National Institute for Health and Care Excellence (NICE) recommends that all people with MS have a comprehensive review of all aspects of their care at least once a year, including an assessment of their MS disease course and any relapses. It should be carried out by healthcare professionals with expertise in MS. But there are no set criteria for MRI scans.

learn

Find out more about MRI at mssociety.org.uk/MRI or call the MS Helpline on **0808 800 8000**

In approximately 1 in 1000

Spotlight on treatments

The latest updates on treatments for MS and what we're doing to make sure your voices are heard.

Ofatumumab approved for relapsing MS in England

In April, the National Institute for Health and Care Excellence (NICE) approved ofatumumab (brand name Kesimpta) for people with active relapsing MS. The drug should be available to people living in England by July. The treatment is one of many disease modifying therapies (DMTs) that can make relapses less frequent and severe, and slow down how fast someone's MS gets worse.

Ofatumumab is taken as an injection under the skin. After initial guidance from a healthcare professional, ofatumumab can be self-injected. This makes it the first DMT in the 'highly effective' class that can be taken at home.

NICE decisions are reviewed by governments in Wales and Northern Ireland and are usually adopted. The Scottish Medicine Consortium (SMC) will publish a decision on whether or not to recommend ofatumumab this summer.

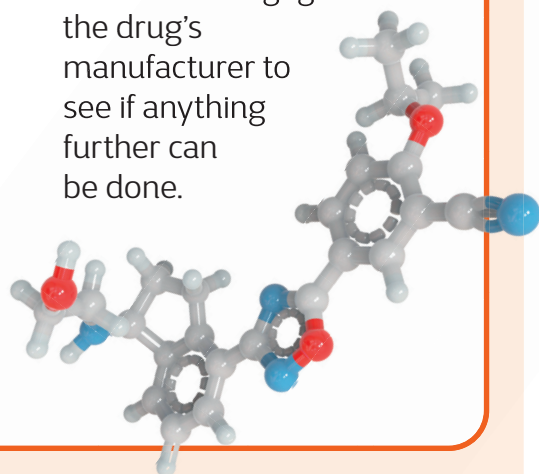
Ozanimod for relapsing MS rejected by NICE

In May, NICE made a final decision not to recommend another disease modifying therapy called ozanimod (brand name Zeposia) for people with active relapsing MS on the NHS in England.

NICE made an initial decision to reject ozanimod back in January. Following a further review of the evidence, including a submission from the MS Society, NICE decided that the treatment was not cost effective enough to be recommended. They thought it wasn't clear what effect ozanimod had on how fast people's MS gets worse.

Back in February, the Scottish Medicines Consortium (SMC) approved ozanimod for people with active relapsing MS, meaning it should now be available on the NHS in Scotland.

We are disappointed by this NICE decision. We'll continue to engage with the drug's manufacturer to see if anything further can be done.



You can read about available DMTs at mssociety.org.uk/disease-modifying-therapies
For more information about upcoming treatments, visit mssociety.org.uk/emerging-research
Or you can contact our MS Helpline on **0808 800 8000** or helpline@mssociety.org.uk

Understanding progressive MS

What is progressive MS?

With progressive MS, symptoms and disability get steadily ('progressively') worse. That's different to relapsing MS where symptoms suddenly get worse, then usually get better until the next relapse.

Progressive MS is diagnosed as either:

Primary Progressive: called 'primary' because, from your first symptoms, disability slowly gets worse. You get few, often no, relapses. And doctors see very little, often no, inflammation on your scans.

Secondary Progressive: called this because the progressive stage comes second. The first stage had inflammation and relapses.

Progressive MS with relapses (active progressive MS)

Some people with progressive MS also get occasional relapses. Or scans show inflammation is still happening. This is called 'active progressive MS'. It happens because MS damages nerves in two ways – and in these people both happen together:

1. The immune system attacks nerves in the brain or spinal cord by mistake, stripping away their protective coating (myelin). This stops nerves

working properly. On MRI scans, doctors see inflammation in the shape of lesions, which are areas of nerve damage. A relapse in symptoms is another sign that the immune system is causing inflammation in these nerves. MS with inflammation or relapses is called active MS.

2. When there's no inflammation (or only a little), something else must be causing symptoms and disability to steadily get worse. Research is trying to find out what's making the nerves break down and die. This is what's causing most of the damage in progressive MS.



Treatments for active progressive MS

If you have active secondary progressive MS, two disease modifying therapies (DMTs) might help: Extavia (a beta interferon) or siponimod (brand name Mayzent).

If you're in the early stage of primary progressive MS, and it's active, there's ocrelizumab (Ocrevus) – or you might get HSCT, a kind of stem cell therapy.

What if your progressive MS isn't active? A DMT won't help as there's no inflammation for it to dampen down. Instead you'll need drugs to repair myelin or protect nerves from damage. These aren't available yet. But trials are now testing several promising drugs. Until then other treatments will help manage your symptoms.

talk

To talk to someone about your type of MS:

- Speak to an MS specialist.

Ask your MS nurse or neurologist at your yearly review (official guidelines say all people with MS should have one). You don't have to wait for your review to ask to speak to your neurologist.

- Call our MS Helpline on **0808 800 8000**

- Chat to other people with MS on **mssociety.org.uk/ms-forum**

And you can read more in our updated booklet, 'Understanding progressive MS', available to order or download at **mssociety.org.uk/understanding-progressive-ms**

Join our progressive forms of MS wellbeing sessions

Our virtual wellbeing sessions for people living with progressive forms of MS start on 7 September on Zoom. You'll get the chance to meet others living with a progressive form of MS, and to chat, share and reflect. Each week, we cover a different topic tailored to the group, including self-compassion and managing fatigue.

Marilyn joined our previous wellbeing sessions where she felt as though she had finally found her people. She said: "It was a breath of fresh air to be with others who truly understood me – and being part of the group empowered me to know it was completely acceptable to not be okay when I'm not."

"When I joined the wellbeing sessions, I was in a dark place, but the sessions and the group gave me perspective and brought me out of that place, for which I am really grateful."



join

Sign up to the wellbeing sessions at **mssociety.org.uk/progressive-ms-sessions** or contact **selfmanagement@mssociety.org.uk**

Life after lockdown

After a year of lockdowns, it looks like we're starting to emerge from tight restrictions. But how does that feel and what does it mean for people living with MS?

“I need to take one moment at a time”

Rebecca lives with relapsing MS and has a six-year-old son.

I'm a bit apprehensive about coming out of lockdown. I'm excited to see people more, but I also think we need to be cautious.

Lockdown has shown me how important it is to put my wellbeing and health first. I'll prioritise self-care even more now because that's what's helped me during these times.

I need to take one moment at a time, but still plan ahead because it's important to look forward to things and have goals.

Lockdown made me think about the importance of spending time with loved ones and friends. I really appreciated the time I could spend with my son, and how I have found ways to keep him entertained.



I'm concerned about surrounding myself with so many people so soon, so coming out of lockdown in gradual steps is more suitable for me. I'll start with my family members and begin branching out from there. I'll think about how to space out my time between seeing people and venturing out to places. I'm not comfortable being around large groups of people just yet.

I do think about how returning back to the way things were could affect my health, as my body isn't used to it anymore. I'd like to do it in stages and mindfully – a bit at a time.

Just because someone opens the gates doesn't mean you have to run through them.



Alex Grace

Lockdown and out

Martin Baum is an author, blogger and influencer who lives with progressive MS.



It's odd that when it was announced lockdown restrictions were to be eased, I was somewhat reluctant to reclaim my freedom. There was a feeling of wariness along the lines of a form of Stockholm syndrome where I, as a hostage to COVID-19, have bonded with my lockdown captors.

There have been many occasions over the past year or so where I emotionally hit a wall thinking: "Will this isolation never end?" Now, instead of merely dreaming about life's simple pleasures, such as a trip to the cinema, hairdressers, the theatre or flying abroad, it's now possible to live the dream if I want to.

Reintegration into society has a familiar ring to it. There were so many occasions in my past where I couldn't cope with MS and would shut myself away. I enjoyed that as much as I have lockdown, which has been miserable. That's why I now know it's time to once again emerge from hibernation and trust that life will return to normality.

I may be slow to embrace public transport which, from memory, was no great shakes at the best of times, but from here on in, I will not be avoiding people and places any longer than I must. There is a risk of getting it wrong by acting in haste. But I've had both my injections and there has to come a time to draw a line and move on.

My mantra and hashtag before COVID-19 was to 'Live life not MS'. Nothing has changed.

Read more from Martin at martinbaum.co.uk

Tom's tips for coping with post-lockdown life

Tom lives with MS and runs a volunteer counselling service for us in Northern Ireland.

We've been through a strange and traumatic time. We've been told to live differently, to shield, to keep away from people and to curtail our lives. Isolation has increased and social interaction has been restricted. That's not natural. What's natural is to have had anxiety about that and to have concerns about those restrictions lifting.

Some of us won't be able to simply flick a switch and go back

to the way things were, or to go and do everything that we're now "allowed" to do again. Here are some tips to help.

- Go at your own pace, no one else's. But do give yourself helpful nudges. Every couple of days do something that challenges you.
- You don't need to do everything at once. Make a plan, set objectives and achieve something new every week. For example, meet friends in the park one week and in a restaurant the next.



- Write things down if you can. Noting what you did, what you achieved and how it made you feel can help you reflect and progress to new things.
- Diet, exercise and sleep might have all taken a hit during lockdown. Take some gentle exercise. Endorphins are critical to good mental health. And if you exercise outside in the sun, the vitamin D will be good too.
- Be nice to yourself.

ask

If you do feel anxious, you might find breathing techniques, grounding exercises and counselling services helpful. Learn more about dealing with anxiety at mssociety.org.uk/mental-health. And find ways to get help at mssociety.org.uk/getting-help or call our Helpline on **0808 800 8000**.



Keeping you safe at work

Your employer has a duty to take reasonable steps to protect you and others from coronavirus. To do this, they must carry out a COVID-19 risk assessment. This means identifying situations that might cause the virus to spread, then acting to remove the situation or, if this isn't possible, control the risk.

The steps employers need to take vary depending on the type of workplace. At the time of writing, general guidance covered social distancing, frequent cleaning, and handwashing requirements.

What are my rights?

Everyone with MS is included in the clinically vulnerable group. This means employers must be especially careful and take extra steps to protect you.

If you're concerned that your employer isn't doing enough to keep you safe, you should discuss it with them and contact your trade union if you have one.

If you're worried about returning to work, or want to know more about your rights, contact our MS Helpline on **0808 800 8000**, email helpline@mssociety.org.uk or visit mssociety.org.uk/work-and-coronavirus

Istock

MS groups meet face to face again

After over a year of being online, our local MS groups are now starting to meet in person again and provide face-to-face services.

We've put new processes in place so activities can happen in a COVID-safe way. And we ran Zoom sessions for volunteers so they could find out what they needed to do and ask questions.

Dot Fisk, Group Coordinator for our East Kent Group, said: "The Zoom sessions really helped me to feel confident that we could go ahead and arrange our regular massage sessions safely."

Groups are starting in-person activities at their own pace. Find out what your local group is doing at mssociety.org.uk/groups-local



Photography saved my life

Len Williamson, whose wife Karen had secondary progressive MS, talks about how photography enabled him to cope during her illness and after her death.

View
Len's photos
lenandtheowl.com

Trigger warning: this article discusses suicidal thoughts and assisted dying.

Karen and I had 40 years together. I adored her. She was my soulmate. She was everything and it was so tough watching what she was going through. The last five years were impossible, but we still loved each other so much.

By January 2019, Karen was very, very ill. The thing about being a partner to someone who is very ill is that you have to keep yourself in good shape. I had to have therapy and keep myself strong enough to deal with everything. I had to keep myself occupied.

When I discovered an online Masters' course in photography, I thought it would be a good distraction. I love landscape photography and I was going to do a piece on nature. Then, one day, my supervisor asked if I had any pain in my life. She said if you can feel strong emotions about your work, it will resonate with other people.

We started with the idea of trying to photograph Karen's illness, but I had to stop because it became too painful for me. Then I thought about using my own pain as a trigger for a project to understand what I was going through. That became quite therapeutic.

When I was helping Karen, I'd be almost euphoric trying to find solutions and make things better. Then, all of a sudden, I'd crash. I tried really



hard to fix her illness and, because I couldn't, I saw myself as a failure. That's what led to suicidal episodes.

I think, for me, my project saved my life. It made me look at myself from the outside, through my camera, and face into what I was experiencing. Inside I was black as hell, but it made me see that I was much stronger from the outside than I felt.

Karen was into art – she was a painter. The project became something we did together – she worked with me to organise the photographs. I think it was good for both of us because it gave us an opportunity to talk about the situation in an independent way. I can think of lots of moments of us laughing together as we did it.



As paralysis moved through her body, in July 2019, Karen made the decision that she wanted to die. In January 2020, we went as a family to Switzerland, where she was helped to end her life. It was beautiful, in a way, but completely tragic.

It's been incredibly difficult, but somehow I've survived. I look back at my photos of Karen and increasingly remember the happy times. I feel very privileged to have had her as my companion in life. She was incredibly strong, right to the end.

Information and support

If you are affected by any of the issues raised in Len's story, our MS Helpline can provide emotional support. Call **0808 800 8000** or email helpline@mssociety.org.uk. You can also find advice on looking after yourself as a carer at mssociety.org.uk. And for bereavement support, see our booklet mssociety.org.uk/bereavement

What I've learned about fatigue

MS Mummy Joanne Chapman shares her tips for dealing with fatigue.

I'm constantly fatigued, which affects my other symptoms. I feel like I'm unable to get out of a bath of thick chocolate (if only!). Here's what I've learned over time.

Knowledge is power

By keeping a fatigue diary, I can spot patterns. I record secondary factors that aren't unique to MS (such as sleep, exercise, mood, infection or medication). And I plot my energy levels and activities, so I understand my fatigue. The

MS Society's online fatigue management course can help with this.

Don't fight it

MS can feel like having a failing battery. Pacing myself, resting and prioritising helps to avoid guilt, frustration and burn out. I set a timer to stop me ploughing on. Activities can be physical or mental, or both. If I need some time for clear thinking, I plan ahead – for example by using my power chair so I have more energy.

Know your energy zappers

I have strategies for when I know my energy will be low. For example, to fight heat-driven fatigue, I make sure my bath water isn't too hot, and I dry in a towelling robe. And I keep cool and hydrated if I'm in the sun.

Only superheroes wear pants outside of their trousers!

I've learned to swallow my pride and not struggle on. I ask for and accept help from others. And I use gadgets and aids – for example, stairlift and mobility aids, blue badge parking, work adaptations and flexible hours. I also use things designed for convenience, like a lightweight cordless vacuum cleaner, and a stool so I don't have to bend when doing the laundry.

Ultimately I try and be kind to myself and practise self care.



Getting to know you...

Kadeena Cox MBE is a Paralympic sprinter and cyclist who lives with MS. She is an MS Society Ambassador.

Why did you get involved with the MS Society?

I wanted to help make a difference in the lives of those with my condition (and those supporting them). And also to highlight the amazing things that can still be done with MS.

What's your greatest achievement?

Having the courage and resilience after my diagnosis to get up and get moving after two months of being housebound. And becoming world champion and world record holder 12 months later.

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

Own the situation you're in and prove the doubters wrong.

Where's your favourite place you've travelled?

Jamaica. It's my mum's home country and I just love the food, the vibes and the sun.

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

My great grandmother who raised my mum. Mum speaks so highly of her and I love the stories.

Kobe Bryant. He seemed like an amazing person on and off the pitch. I think I could have learnt a lot from him.

And Daniel Radcliffe. I'm a massive Harry Potter fan.

When were you happiest?

When I completed my historic double in Rio. The podium dancing said it all!

What is the most important lesson life has taught you?

Your life can change in a heartbeat, but how you deal with the situation shows your true character.

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

Being invisible. Some days I'd just like to go unnoticed and not have to communicate.

What or who is the love of your life?

Jesus. I couldn't have done anything I've achieved in my life without him.



Head over to our website to sign up to **For you**

For you is your own personal space on our website where you can choose what you see, and when you see it.

Create an account and you can:

- get your own page on our website, tailored to your interests, location and type of MS
- control what you see – news, tips, stories, latest research, ways to manage MS – the choice is yours
- save pages on our website so you can find information that's important to you in one handy place when you need it

- join the conversation on our new forum, find support and connect with people who understand
- pop in your postcode and easily find events and services in your area.

It only takes a few minutes to sign up. All you need is an email address.

To sign up and find out more, visit mssociety.org.uk/new-for-you



Volunteer spotlight:

Kirsty and Jane

Kirsty Bennett and Jane Gentleman are both living with relapsing MS. They teamed up to create the 1953 gin to help raise funds to support other people living with MS across the UK.



Jane is co-owner of Selkirk Distillers. She and Kirsty created the gin with the help of Jane's sister and newly qualified distiller, Emma. The gin is named after the year the MS Society was founded.

Jane said: "The idea to create the 1953 gin came about when Kirsty's husband, Scott, and I couldn't take part in the fundraising events we had planned last year.

"The pandemic has made fundraising much more difficult but we still wanted to do something. Kirsty and I thought, 'Why don't we create a gin?'"

Ten pounds from every

"It makes me feel very proud that I was part of it. It's a great way to raise funds and awareness of the MS Society."

50cl bottle is donated to the MS Society, and another £2 goes to our Scottish Borders local group. For a 20cl bottle, £2 is donated to the group. So far, the gin has raised over £4,000.

Kirsty said: "It was a great experience helping develop the gin and then seeing it in a real-life bottle. It makes me feel very proud that I was part of it. It's a great way to raise funds and awareness of the MS Society.

"We did an online gin

tasting event at Christmas to launch the gin. The event sold out and we had to add more places, which was fantastic!"

Jane and Kirsty are both volunteers at our Borders Group and are part of the group's committee.

Want to try?

The 1953 gin costs £30 for a 50cl bottle, and £15 for 20cl. Buy a bottle at selkirkdistillers.com





Walk, roll or stroll to stop MS in 2021

MS Walk is back for 2021 and it's going to be bigger and better than ever. With five walks happening across the country, wherever you are, you can walk, roll or stroll for life-changing MS research.

After the year we've all had, we can't wait to see you all in person again at walks in Manchester, Bristol, London,

Belfast and Cardiff. There'll be 1, 5, 10 and 20km routes for all abilities, fantastic views of iconic landmarks, and fun for all the family.

MS Walk Manchester – 22 Aug
MS Walk Bristol – 5 Sept
MS Walk London – 19 Sept
MS Walk Belfast – 26 Sept
MS Walk Cardiff – 17 Oct



Our events may look a little different this year but, as always, the health and safety of our participants, staff and volunteers is our top priority. You can find out more and sign up at mssociety.org.uk/ms-walk-2021 or email mswalk@mssociety.org.uk



This year, anything goes for our 100k Your Way challenge.

Skate it, roller blade it, scoot it, cycle it, run it, roll it, canoe it or even do it on a horse!

You can complete the challenge yourself or split the 100k distance between your family, friends or work colleagues. Do it in days, weeks, or take your time. You don't even have to set a distance – just take inspiration from 100.

You could:

- bake 100 cakes and buns and sell to friends and neighbours
- complete 100 laps of the garden
- grow your beard for 100 days
- plant 100 seeds or bulbs.

Find out more and sign up at mssociety.org.uk/100k

“I never imagined that moment would happen”

After trying out a special MS exercise programme, **Merlin Curtis**, who lives with relapsing MS in South Wales, took his first steps in 28 years.

“I had previously tried physiotherapy to help with my symptoms, but I was unsure about the idea of an exercise programme.

I decided to sign up for the free MS Cymru Active Together course after learning of it through friends at our local Rhondda Cynon Taf & Merthyr MS group.

The course took place over 16 weeks. It was a mixture of circuit-style sessions that incorporated upper body and lower body movements, core exercise and cardio.

I relied on a wheelchair at the time, but, after four months, my strength grew and I was able to go from standing to taking my first steps using a

walking frame.

After 28 years of not walking, I never imagined that moment would happen. My wife was by my side and couldn't believe it either. And the first time my children and grandchildren saw me taking steps, their eyes were like saucers.

Coronavirus had a huge impact on me. I was spending a lot of time sitting around watching TV or doing quizzes. I started to undo all the progress I'd made with the exercise programme. Then in November, the realisation hit me that I needed to get active



again. I found out that MS Society Cymru were running classes online, so I started doing two zoom classes a week – and got back walking again!

It's completely changed my life. I feel far more optimistic about the future”.



learn Find out more about staying active with exercise that suits you at mssociety.org.uk/keeping-active