



## Let's get active together

We talk about the many ways you can keep moving with MS

**Inside**  
**Research Matters**  
**magazine**

Can we really stop MS?



Issue 132  
**Summer 2019**

**We had cause** to celebrate recently. Thanks to your hard work, ocrelizumab, the first available treatment for early primary progressive MS, is now available through the NHS in England and Wales (read more on page six).

We're confident that many more celebratory moments like this are on the horizon, and are excited to launch our Stop MS Appeal this October. Our aim is to raise £100 million to find treatments for everyone with MS. It's our biggest campaign yet. Read more about what we're doing on page 12 and in Research Matters too.

Our cover story and theme for this issue is physical activity and all the ways you can stay active with MS. Omar, our fitness specialist, offers his top tips (page 16), and we have inspiring stories from people who have tried things including yoga, arm cycling and bowling to stay active. Of course, sometimes exercise isn't an option, which Elaine reminds us of on page 27.

We also have some impressive stories from fundraisers throughout the issue. On page 34, read about the young people who support us, inspired by their family members. And if you're feeling inspired too, there are many ways for you to get involved, from doing an MS Walk (page 31), sponsoring an MS Superstar (page 51), or baking cakes for this year's Cake Break (page 32).

On page 42, we have news of our new strategy, which will launch in 2020, and was made with your collaboration. We're proud to be moving forward with our new vision for the next five years, and are excited to present it at this year's AGM.

Finally, for the early planners among you, don't miss our leaflet with details of our new Christmas card range, which you can order online.

**Nick Moberly**  
Chief Executive



**NEWS**

- 6** The first NHS treatment for early primary progressive MS
- 8** An update on our PIP 20-metre rule campaign
- 9** Campaigns in Scotland and Northern Ireland
- 10** What we did to celebrate Carer's Week 2019
- 11** How you can shape the future of technology for MS
- 12** Stop MS Appeal exhibition at the Houses of Parliament

**INSIGHT**

- 16** Omar Tucker on how to stay active with MS
- 18** **Cover story: Laura Thorne on yoga and MS**
- 25** Jessie Ace on trying Couch to 5k
- 27** Elaine Moore on when exercise isn't possible
- 33** Joanne Chapman on preparing for milestones
- 39** Top tips for bladder issues

Did you know you can help stop MS through your mobile? You can give a regular gift of £3 a month to help stop MS. Just text NOW to 70372 to give £3 each month. Together we can change the future of MS. For full terms and conditions visit [mssoc.uk/mobile](https://mssoc.uk/mobile)



12 Houses of Parliament host exhibition about MS



16 Omar Tucker can help you stay active with MS

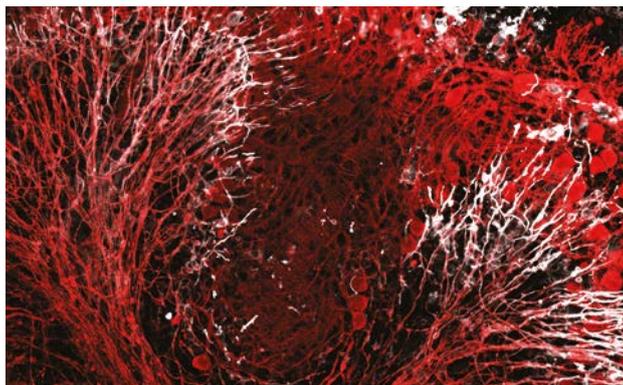


20 Triathlon champion Trish Deykin



31 Organise your own MS Walk

## Research Matters



Turn to the centre of MS Matters to read Research Matters. Hear from our expert scientists about the research that is taking us closer than ever before to stopping MS.

### talk

Need support or information? Call our MS Helpline on 0808 800 8000 or email [helpline@mssociety.org.uk](mailto: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](http://community.mssociety.org.uk)

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

## GET INVOLVED

- 30 Choose your favourite fundraising event
- 31 Organise your own My MS Walk
- 32 Hairy Bikers support Cake Break
- 54 Do our summer raffle bonus crossword

## REAL LIFE

- 20 The athletes who are living with MS
- 29 Debbie Soave: Life as a neuro-physiotherapist
- 34 The young people fundraising to stop MS
- 41 A carer on life with MS

## COMMUNITY NEWS

- 42 Our new strategy, membership model and AGM news
- 47 How the Big Lottery made a big difference in Wales; Janis Winehouse MS Ambassador; What a Nerve exhibit; and our MS superstars.

## COMMUNITY VIEWS

- 53 The trouble with parking space vigilantes

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# We did it!

## Ocrelizumab campaign success

Following months of campaigning, the first available treatment for early primary progressive MS has been approved for use on the NHS in England and Wales

In 2018, the National Institute for Health and Care Excellence (NICE) approved ocrelizumab (drug name Ocrevus) for relapsing MS, but rejected it for early primary progressive MS.

We came together in our thousands to call for ocrelizumab to be available on the NHS for people with primary progressive MS. Twenty one thousand people signed a petition to call for NICE, NHS England and the drug manufacturer Roche to find a deal, and together we sent over 3,300 letters,

reaching 97% of MPs in the UK.

Leading neurologists and other MS charities publicly supported the campaign, and



it was covered extensively throughout the media.

Building on that momentum, we organised a campaign day in the Houses of Parliament in November, bringing together all organisations involved. This included NHS England, the pharmaceutical company, neurologists, MS nurses, charity groups and people living with primary progressive MS to speak to MPs about the campaign.

Our message was heard, and eventually Roche and NHS England agreed to put forward a new proposal

to NICE. In May 2019, NICE changed its decision.

For now, this decision applies to England and Wales, but we expect decisions on access across the UK by the end of the year. We are hopeful that health bodies in Northern Ireland and Scotland will adopt a similar positive decision, and we'll be continuing to campaign on this.

### A landmark moment but not the end

Disease Modifying Therapies (DMTs) are not a cure for MS, but they can slow down



damage that builds up over time. There are over a dozen DMTs for relapsing MS – but ocrelizumab is the first and only one licensed to treat primary progressive MS.

It's been approved specifically for early primary progressive MS, and neurologists will be able to advise patients about who is eligible. They will look for signs of inflammation on recent MRI scans and evidence of the level of disability to make decisions. People who have had symptoms of MS for more than 15 years will not be

eligible for the treatment.

This decision is an important step. But we won't stop until everyone with MS can access treatments. We are continuing to fund research into treatments for secondary progressive MS and more treatments for primary progressive MS.

Look out for more information on research and the Stop MS Appeal in this edition of MS Matters (page 12) and in Research Matters.

**To find out more about our campaigns, join our campaigns community at [mssociety.org.uk/campaigns](https://mssociety.org.uk/campaigns)**

Photo: iStock

## A community speaking together

The entire MS community – from researchers to nurses to people with MS – came together to make this happen. Here are some of your reactions.

### Zoe who has primary progressive MS

“I know that with any treatment there's no guarantee it will be successful. But not having the chance to try anything has been super scary. That's why I supported the MS Society's campaign to make ocrelizumab available for people like me. Now that there's a treatment available that could work for me, I finally have a glimmer of hope for the future.”

### David Martin MS Trust CEO

“This is very welcome news. But we know this is just the start. More treatments for progressive MS are still desperately needed, and we will continue to fight to ensure everyone with MS can access the treatments they need.”

### Joanna Smith MS nurse

“I think further treatments are needed for progressive MS because this is the first one. But I think it definitely gives hope for people that have progressive MS. It will make people feel that they're listened to and that there is at least one treatment option and hopefully more to come.”

### Prof. Gavin Giovannoni Professor of Neurology

“As healthcare professionals, we are now able to offer some people with primary progressive MS, ocrelizumab, the first licensed therapy, which has been shown to slow disability progression in this population of patients. This will give people with primary progressive MS hope in delaying the need to rely on mobility aids, wheelchairs and carers to look after them as their disability progresses.”



## Barbara's story

**Barbara (67) from the Scottish Borders shares her experience of the PIP assessment process.**

Shortly after I was diagnosed I started receiving Disability Living Allowance (DLA). I was given an indefinite award for the highest rate for mobility and the lowest rate for care. In June 2017 I was reassessed for Personal Independence Payment (PIP).

I took my mobility scooter to the assessment centre. I said I could do things once or twice but not repeatedly. I don't think the assessor took this in. If I said I could do something then the box got ticked. I didn't get the chance to explain anything. I don't think the assessor understood MS at all.

I learnt I would only get the lowest rate for mobility and nothing for care. My statements and substantial supporting medical evidence had been largely disregarded. Looking at my report, I had virtually been called a liar by the assessor.

I took this to tribunal and waited six months to be given back the same level I had on DLA.

This process drained my energy more than my MS on its own ever has. I was completely exhausted - there were many days I was so tired and down that I was unable to go out, talk to people or do much of anything at all.



## Raising our voice to #ScrapPIP20m

**W**e know the welfare system isn't working for people like Barbara (pictured right), so we're doing all we can to change it.

Last year, over 36,000 of us signed a petition telling the UK Government to scrap the Personal Independence Payment (PIP) 20-metre rule. And in April, we published new research that found the rule is predicted to cost the UK Government millions more than it saves. The government is reviewing how to spend money over the next few years. So together, we took more action.

As part of the MS: Enough campaign, more than 8,000 of us wrote to Amber Rudd MP, Work and Pensions Secretary, asking her to scrap the 20-metre rule - that's more emails to an MP than we've ever sent before. We said

the 20-metre rule simply doesn't make sense - for people with MS or the government.

Thanks to your support, the UK Government has been talking to us about ways to make PIP better for people with MS. But we won't stop until they scrap the rule.

Look out for more on the MS: Enough campaign in September. Get involved in the campaign at [mssociety.org.uk/campaigns](https://mssociety.org.uk/campaigns)

### PIP in Scotland

In Scotland, we're also lobbying the Scottish Government to remove the 20-metre rule. We used our survey from people with MS across Scotland to shape our response to a recent government consultation on improving disability assistance.

# Politicians pledge to stop MS at this year's MS Week

Scotland's First Minister Nicola Sturgeon was one of 105 MSPs to pledge their support to the fight to stop MS during this year's MS Week.

We held a reception in the Scottish Parliament, which had 140 guests, including 20 MSPs, and the Minister for Public Health, Sport and Wellbeing, Joe Fitzpatrick. The event focused on the positive impact of MS research happening in Scotland and our Stop MS campaign, which is launching later this year (see page 12).

The reception was hosted by George Adam MSP who also held a debate about MS in the chamber the following day, keeping MS research high on the agenda among Scotland's

decision makers.

Across Scotland we got the message out about why research is so important, with coverage in over 40 newspapers and a great buzz on social media.

The MS Society Northern Ireland was also busy during MS Week, hosting MLAs from the five largest political parties at the MS Resource Centre in Belfast.

Politicians heard directly from people affected by MS on the issues that concern them most. One person shared a moving account about the ongoing recall of neurology patients, her own misdiagnosis, and how the health service was failing to meet the needs of people affected.



## Learn more about living with MS

Do you feel like information about living with MS is constantly changing? Are you looking for more opportunities to meet other people with an understanding of MS?

In 2019 we have a number of events taking place across the UK, from research talks to information days.

These events are a great opportunity to get up-to-date information from MS Society staff and professionals, as well as a brilliant chance to meet other people affected by MS.

To find out more about events taking place near you, email [event.info@mssociety.org.uk](mailto:event.info@mssociety.org.uk)



## Neurology recall update

In Northern Ireland, the publication of a Department of Health report on the outcome of last year's recall of neurology patients was postponed in June. The department indicated the delay is due to sensitive, unforeseen circumstances.

In 2018, around 3,500 patients were recalled following concerns about the practice of

consultant neurologist, Dr Michael Watt. The department's report was expected to provide details of the outcomes for patients recalled.

We are committed to representing everyone with MS who has been affected. If you want to tell us about your experience of the recall, contact [nireception@mssociety.org.uk](mailto:nireception@mssociety.org.uk)

# Celebrating Carers Week 2019



## Speaking out in Westminster

“Telling MPs about the reality of having to rely on others for the necessities of life, or of being relied upon and having to make up the shortfall when proper care is not available, felt like I was doing something constructive and moving the debate in the right direction.”

These were Doug’s words after he headed to Westminster with MS Society staff on 10 June as part of Carers Week 2019. This is the annual campaign to raise awareness of the challenges that unpaid carers face, while celebrating their vital contribution to families and communities throughout the UK.

Doug, who lives with MS, was joined by Charley who cares for her dad, along with Rodney, who lives with MS, and his brother Richard. The event was attended by more than 100 MPs and members of the House of Lords, helping to make sure carers’ voices are heard in the UK Parliament.

We know that carers make an amazing contribution to the MS community, but it can also be really challenging, especially without the right support. We’re continuing to call for urgent reform to social care as part of the Care and Support Alliance (CSA), a coalition of more than 80 charities.

## A team of two

During Carers Week, we also celebrated the caring relationship with a song written by singer Jack Frimston from the indie-pop trio The Tailormade. Jack, whose mum lives with MS, met Marie who cares for her husband, our ambassador Stuart Nixon MBE, at the 2018 MS Society Awards. Inspired by Marie’s acceptance speech for the Carer of the Year Award, Jack wrote the song, ‘Our Team of Two’. Jack, Stuart and Marie all appeared on BBC’s Sunday Morning Live, where Jack performed the song.

Stuart says: “Sharing is at the centre of what we do, and Jack’s song picked up Marie’s line, ‘It’s just what we do’. That really sums Marie and I up – we are a team. It’s not a 50-50 split as Marie does far more than I ever do, but we see it as the two of us together. By being a unit, we can take on the world. I don’t have MS, we have MS.”

**Listen to the song at**  
[mssociety.org.uk/team-of-two](https://mssociety.org.uk/team-of-two)



**join**

We’re holding the government to account on their promise to improve social care, so people with MS and their carers get the support they need. Visit [mssociety.org.uk/end-care-crisis](https://mssociety.org.uk/end-care-crisis) to find out how you can join our campaign

# Help develop new health and care technology

**N**ew technology has dramatically impacted our lives, from how we shop, to how we communicate with each other. However, if you're living with MS, there is one area where the pace of technological change has been less rapid – in your health and care.

Last year, we worked with the Nuffield Trust to investigate this. We found that better use of data and technology can make a difference in how people with

MS manage their condition, and it can also improve people's experiences of treatment and care.

We also found that people with MS are not usually involved in the development of new technologies – so we're taking action to change this.

## Taking a lead

This summer, we'll be launching the MS Technology Forum. This will bring together people living with and affected by MS, health professionals, charities, and technology companies, to ensure that new technologies are developed with the input of

people with MS. The forum will also be looking at how to expand the reach of good technologies across the NHS.

Speaking on stage at London Tech Week in June, our Head of Policy, Phillip Anderson, said: "We know that many apps and digital tools fail because they don't engage their users from the start to understand their needs. We want to change this so the priorities of people with MS are driving the creation of new technologies, and the MS Society is determined to take a lead with our new forum."

## Understanding the needs of our community

We are also learning from experts who've done research in this area. Christy Holland, an MS Specialist Physiotherapist in Yorkshire,

has recently engaged with people with progressive MS to understand how technology can help.

Christy said: "Apps could help people with progressive MS, and their health professionals, to improve management of symptoms.

"Using a mix of focus groups and interviews, I spoke to people with progressive MS, a group largely under-represented in previous research.

Whilst people lacked confidence in their abilities to use apps, they were motivated to learn new skills with the right support. People wanted apps that could track changes over time, provide prompts, advice and a link to their health professionals."

## Do you want to be involved?

If you have an experience with technology that you'd like to share, or if you'd like to contribute to the work of the forum, please email us at [techforum@mssociety.org.uk](mailto:techforum@mssociety.org.uk) or find more information at [mssociety.org.uk/technology](https://mssociety.org.uk/technology)



# Get ready for our Stop MS Appeal

This October we're publicly launching something exciting – our biggest campaign ever

**O**ur Stop MS Appeal aims to raise £100 million to find treatments for everyone with MS. It will be launching publicly with a big advertising campaign this October. Research has got us to a critical

point – we can see a future where nobody needs to worry about their MS getting worse. Scientists believe we are close to having treatments for everyone with MS. With the right funding, by 2025 we plan to be in the final stages of testing for a range of new treatments for relapsing

and progressive forms of MS.

Read more from MS researchers about the exciting work that's happening for the appeal in this edition of Research Matters. And here you can read about our exhibition at Westminster and the ways you can involved to stop MS.

## My hope is for a cure

**Kirsty, from Fife in Scotland, took part in the exhibition (see page opposite), sharing her hopes for MS research with MPs. This is an extract from her story that was on display.**



Photo: Julie Howden

“I was diagnosed with relapsing MS when I was a 22-year-old art student. Three years after diagnosis, I started on medication. Since then I've not had any major relapses, although I still experience other symptoms regularly.

“Fatigue is my worst symptom. It affects my ability to think. When I'm extremely fatigued, I get spasms in my left leg. I also have tingling sensations in my hands, feet and across my skin.

“I'm a self-employed designer with my own label, Charcot. I use the nasty lesion shapes of MS damage, taken from MRI scans of my brain, to design prints and luxurious silk collections.

“My hope for MS research would be to find a cure. I'm really excited about research into myelin repair treatments, which could repair the damage caused to the central nervous system. I don't know what my future holds – this lack of clarity is one of the hardest parts of living with MS.”

At our Westminster exhibition, Kirsty displayed a silk scarf that she designed and created from her own MRI scans. She said:

“I chose this object as it is from the first design I created to represent and engage with what MS can do to the body. I'm really proud to not only make MS visible, but to make it wearable too!”

# Our parliamentary exhibition – MS: the research story

As we get ready for the public launch of the Stop MS Appeal, people affected by MS have been raising awareness at Westminster about the progress we're making in MS research.

In June, MPs and members of the House of Lords had the opportunity to come to an exhibition at the Houses of Parliament about this crucial point in MS research and what it's like to live with MS.

The exhibition featured stories from nine people with MS, from across the UK, about their hopes for the future of MS research. And it also included objects from people with MS that represented something important to them. For example, Rebecca Robinson (pictured below), from Croydon, displayed a Scrabble board that she uses to play with her son, along with a card that he made for her. The objects showed MPs how different MS is for

everybody, and reflected the diversity of the MS community.

### MPs across the country listened

The exhibition was well attended by MPs and members of the House of Lords, and gained support from representatives of different parties. Politicians stopped by to read the stories of people with MS, many of them taking to Twitter to share their reflections.

Thelma Walker, MP for the Colne Valley, tweeted: "Fantastic to meet the MS Society today to hear about the research and investment they are putting into treating the condition. They have my full support for their brilliant work #StopMS"



Kirsty Steven's brother Ross and his fiancée Sophie attended the exhibition, wearing one of Kirsty's scarves



Photo: Jon Bradley

## Rodney's experience at Westminster



To kick off the exhibition, we held a launch event in parliament that was attended by ten people affected by MS, many of whom featured in the exhibition. Rodney Ashe, from Belfast, was one of them.

"At the MS exhibition, MPs seemed genuinely interested in what we were doing and saying. Several told me that if they had simply received documents and information on their desk, they wouldn't have taken as much notice – but the exhibition, and people with MS being front and centre, really struck home to them. I think the event was a fantastic way of bringing Westminster's attention to MS, people living with the condition, and the researchers trying to stop it."



## Get involved to stop MS

We're all coming together to stop MS - whether we're volunteers, donors, members, scientists or staff, we can all play a part in the campaign. How you get involved is up to you.

In this edition of MS Matters, you can read about My MS Walk (page 31), Cake Break (page 32), and upcoming events (page 30), which are just some of the ways that you can help to fundraise.

### Joanne's story

Here's a story from fundraiser Joanne Nicholson from East Yorkshire, whose husband Andrew has MS. If we are going to raise £100 million together, we'll need as many innovative ideas like Joanne's as possible, so do get involved.

"On 2 November, we're hosting a fancy dress MonSter Ball, specifically for research into primary progressive MS, as this is the type my husband has. I've found that including people and giving them a good time is better than just asking

them to donate or sponsor me. So there is a comedy hypnotist act, a singer and dancing for entertainment; a carvery and dessert included in the ticket price; and a high-end raffle and chance to win a mini cruise on P&O Ferries with a lottery-type game.

I love organising events and have found that I've become more confident in myself through people telling me how good I am at it. Raising awareness of MS, as well as raising much needed funds for research, keeps me positive and gives me something to focus on.

Andrew and I probably have a better social life now and laugh more than we did before he got ill. It makes you realise what's really important in life."

join

To find out more about the Stop MS Appeal, visit [mssociety.org.uk/stop-ms](https://mssociety.org.uk/stop-ms) or find some great fundraising ideas at [mssociety.org.uk/fundraise](https://mssociety.org.uk/fundraise).

## Look out for our film

We're making an extra special media campaign for the Stop MS Appeal, shining a light on what it's like to have MS. At the heart of the campaign, there'll be a film featuring four people with MS. We're working closely with our pro-bono partner agencies, MediaCom and Publicis, to produce the film and ensure it gets the exposure it deserves. The film will launch in October. Look out for it on our website and social media.

# Keep active with MS

Our expert, Omar Tucker, introduces this issue's fitness special and why being active is a good idea for people with MS

**W**elcome to the MS Matters fitness special. I'm Omar, a physical activity specialist, here to help people with MS to get more active. You can call me on the MS Helpline and I'll help find activities to suit you and work out how to overcome the barriers that might be in your way.

Everyone can benefit from being active. It can help manage your symptoms and improve your mood. And regular activity will keep your body working at its best. People used to be told that exercise would make MS symptoms worse, but we now know there's no evidence that exercise makes MS worse in the long term, or that exercising causes relapses.

That said, I know it isn't easy and that MS symptoms are a challenge when trying to be active. If you're in a situation where you feel as though there's not much you can do, please give me a call and I'll try my best to find something that works. Getting started is often the hardest part, but once the ball gets rolling, things are much easier.

In this issue, we're featuring all sorts of fitness stories, ranging from people like Kate (featured opposite) who made small changes that made a big difference, to stories of sportspeople with MS who have made exercise a big part of their lives (see page 20). Of course we can't all be professional athletes, but I hope these stories might help inspire you to get active in whatever ways you can.

Remember there's nothing to lose by trying and so much to gain from the potential improvements.

**Omar Tucker**  
Physical Activity Specialist

Call Omar for free on the MS Helpline on 0808 800 8000 or email [helpline@mssociety.org.uk](mailto:helpline@mssociety.org.uk). He's available Monday to Friday, 9am to 7pm. And we also have lots of tips and resources on our website at [mssociety.org.uk/staying-active](https://mssociety.org.uk/staying-active)



## “Exercise makes me feel better”

**Kate called Omar for advice and together they made a plan that has produced great results.**

I have secondary progressive MS and am in a wheelchair. This is not what I planned, but that's life for you, throwing a curve ball. For years I was told that exercise would make my MS worse, but when I saw the advice had changed, I decided to make the most of what I've got and give it a go.

I got advice from Omar and now use a small pedal cycle, for my hands, not my legs. The results are addictive. I cycle to my favourite music and have already built my biceps a little. It makes me breathless, which is good for my heart.

I can also do a type of sit-up

in my wheelchair, and I've recently started going to the gym. The first time, I went with a neurophysio who gave me advice on what I can do. I go once a week and exercise for about 20 minutes in total with lots of breaks in between. It's not easy, but it helps my body and ultimately my mind. I feel so much more awake afterwards. And last week, I had leg tingles before I went, but when I did some leg presses, the tingling stopped.

It's not a sudden cure, but exercise does make me feel better. Small victories can make you feel great. I have more



strength to transfer myself and push myself up, and it's given me mental confidence too. Next week, I'm even going to start driving again.

I'm not going to be in the Olympics but I'm determined to maximise my body and live life to the full. I really can't recommend exercise enough.

### Omar's top tips



#### **If you don't use it, you lose it**

If you keep active and use your body and muscles as much as you're able to, this can help you keep as many of your abilities as you can and even make improvements.



#### **Focus on the future not the past**

Living with MS can be one of the most challenging things you'll have to live with, but the body has the ability to get stronger and improve neuro pathways. Look to the future for improvements and you might be surprised by what you can achieve.



#### **Don't let fatigue get you down**

Every day can be different with MS. The key is to manage when to do some activity and when to rest. If you have a busy day ahead, it might be better to exercise or do housework on a less busy day, so you have time to recover.

In the long-run, being more active helps to keep you energised. Think of it as an investment – it will tax you to start with, but if you keep it up, doing a little consistently, you will overall have more energy to spend.

# Yoga and MS

After a sudden diagnosis of MS, **Laura Thorne** faced a long road to rehabilitation. Now a yoga instructor, Laura tells us why yoga is a great choice for people with MS

## How did yoga form part of your journey with MS?

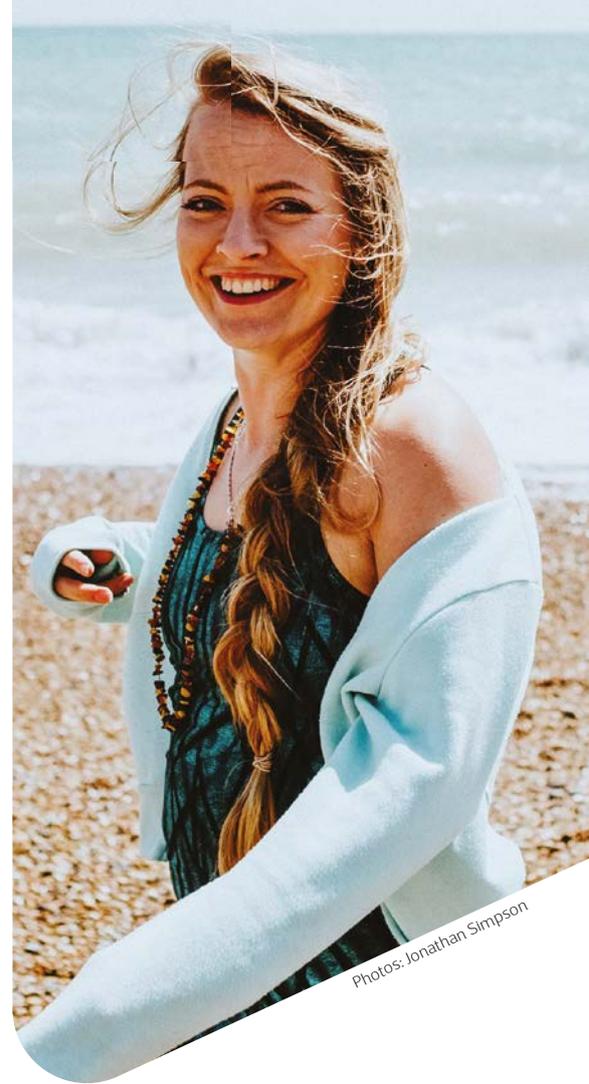
My diagnosis was very sudden. I was on a call at work when I lost the ability to speak, and a few hours later I was rushed into surgery with suspected brain cancer. The results later revealed an aggressive form of relapsing remitting MS. I had significant brain damage and spent two years going through intense rehabilitation.

I've always been passionate about yoga as it's a great way to destress, but after my diagnosis it became an integral part of my recovery and a way to heal myself from the inside out. I even trained as a teacher.

I still have ongoing health challenges because of my MS, but yoga helps me, and I want to help others through my teaching – because when life gives you lemons, you make lemonade.

## How can practising yoga help someone living with MS?

Living with MS can bring you down, so it's important to exercise physically and mentally. Yoga allows you to do both at once. Through the movements, you focus on your body and on what makes you feel better, rather than your ailments. You learn something



Photos: Jonathan Simpson

new every practice, so yoga can also help forge and strengthen pathways in the brain.

Also, the great thing about yoga is anyone can do it and you don't need fancy equipment – you can even do seated yoga from a chair.

## What tips do you have for someone with MS who wants to try yoga?

If you're taking a class, arrive early and speak to the teacher about how your MS affects you, so they can adapt poses to suit you. When I'm teaching, I personalise my classes to each student so we're playing to their strengths. If you're feeling self-conscious (because we've all been there), it's fine to lay down at the back or take regular rests. Practise at your best time of day, mine is the morning. And don't put pressure on yourself, yoga is completely individual – just like your health.

## Try yoga at home

We are currently working hard on our next MS Active Together campaign, which will feature Yoga for MS with Laura. The videos will be accessible to all, so you can have a go at yoga from the comfort of your own home. For more information, follow us on social media.



# We are the champions

With or without MS, we're not all marathon runners or award-winning athletes, but here are some stories of people who have gone the extra mile and achieved extraordinary fitness goals while living with MS

## Dave Phillips, Paralympic archer

Paralympic archer Dave Phillips travels the world to compete for Team GB and is ranked world number seven.

Dave first got into archery at age 13. He excelled in school tournaments and joined the Welsh junior team before stopping in the early 80s to focus on work and family life.

In 1996, Dave was diagnosed with MS. After taking an early retirement at 46, his wife, Angie, urged him to take up archery again, just to get him out of the house.

Before he knew it, Dave started getting noticed for his outstanding scores, and within a year, was selected for Team GB.

Dave says: "I never thought I

with MS, Dave struggles with fatigue and balance.

"Getting back into archery after 30 years was a big learning curve. I often experiment with equipment and techniques to find what works for me. I train hard within my abilities – sometimes I don't do as much as other people, but when I do, I make sure I shoot 100 good arrows rather than 200 bad ones."

Dave, who is from Cwmbran, now volunteers with the MS Society Cymru to inspire people with MS to stay active.

"The better I'm doing at

“I say always do something you're good at and enjoy”

was going to compete in the Rio Paralympics – that was the best experience ever and a career highlight for me.”

In archery, upper body strength counts most, and Dave is fortunate that MS mostly affects the lower part of his body. But like many people

archery, the more I can raise my profile and reach out to people about my experience with MS.

"I say always do something you're good at and enjoy doing. And think about all the things you can still achieve – don't give up hope."



## Trish Deykin, Triathlete champion

**Trish Deykin is a former world and European triathlon champion. In 2018 she clocked up the fastest female overall time at the Triathlon European Championships.**

Trish's remarkable sporting achievements were recently recognised with two top accolades – the Sunday Times Sportswoman of the Year's Helen Rollason Award for Inspiration, and British Triathlon's Peter Holmes Award for Inspirational Performance in International Competition.

While these wins and accolades are confidence boosters, Trish hopes they're helping to change people's perception about what a person with MS can or can't do.

But she remains modest about her successes, attributing them to her own stubbornness.

"I believe that nothing is impossible. With MS, you've got to get your head round it and have a positive mindset. I've chosen not to let my condition hold me back."

When Trish first started getting into triathlons in 2002, she won the first competition she entered, and continued winning over the next two years.

Trish says: "Things were going so well and then MS reared its ugly head. I was absolutely gutted when I was also told to stop competing straight away."

Trish continued training but didn't compete in races until she decided to make a comeback five years later.

"I was bored and needed

goals in life. The thought of competing spurred me on. I love training for competitions

when I have the most energy, and I only do three races a year to allow time for recovery.

**"I believe that nothing is impossible"**

and the adrenaline I get when I'm racing."

Trish has learned to treat MS with respect but not let it rule her life. Being realistic about how much she can push her body is also key to her success.

"I tailor my life around MS – I don't have a coach or belong to a team. I train in the morning

"I never dreamt in a million years that I would achieve what I've achieved. I'm glad I did it – you just don't know until you try."



## Donald Chalmers, National bowler

**Bowler Donald Chalmers has twice represented Scotland nationally and was close to securing a place in the Commonwealth Games in 2014.**

Now 75, Donald was diagnosed with MS in 1982, when he was working as a farmer. He continued farming for twelve years before giving it up. Seeking out ways to keep active, he discovered bowling at Fintry Bowling Club.

Donald says: "Quite a few of my farming friends were bowlers so it didn't take much persuading for me to join them. I started bowling indoors and

was a totally different game. The only power you had to deliver a bowl was in your arm. I had to learn to bowl all over again."

Donald learnt so well that he was spotted by the Scotland Development team. "You feel very proud to be representing your country. I was selected to play in the pairs and it was a bit daunting as my partner was the present Commonwealth champion!"

Doing so well, Donald wanted

**"You feel very proud to be representing your country"**

very quickly decided it was for me."

Initially standing to bowl, over time Donald found this difficult and thought he might have to give up the sport. But by using a special bowls wheelchair he was able to continue bowling. "I discovered wheelchair bowling

to encourage other people to give the sport a go – but more wheelchairs were needed. Through lots of fundraising he raised enough money to buy another five wheelchairs to allow others to bowl too.

Now retired from the national squad, Donald continues to play twice per week at his local club, and competes locally.

"My attitude has always been to go for it, whatever it may be. I think it's important to keep as active as possible."

In our Moving More with MS booklet, we have lots of ideas for how you can stay active with MS, plus details of disability sports organisations you can get involved with. Download the booklet at [mssociety.org.uk/moving-more](https://mssociety.org.uk/moving-more)



## These MS superstars ran the London Marathon 2019

### Abel family

Alex, 26, ran with his Dad, Jeremy, and his sister, Emma. Alex was diagnosed with MS in June 2018.



Alex said: "Everything has changed since I was diagnosed with MS, but I try not to think of the future and want to live in the present. I wanted to show people that MS doesn't have to define you, and there is support out there – that and I can run as fast as my Dad!"

### Josie Hutchings

Josie, 31, who has MS, started training just 12 weeks after giving birth to her daughter.



Josie said: "I felt really emotional when I crossed the finish line, after everything I've been through. I was so proud of what I'd achieved. It's been a fantastic opportunity to raise awareness of MS, particularly in women of my age starting a family."

### Paul Provins

Paul Provins, 36, from Hampshire was given his MS diagnosis when his son, Ollie, was just three months old.



Paul said: "The best thing about the whole marathon process has been the strength it has given me mentally to carry on being active, as well as proving to myself that my life has not changed and that I can still do anything I put my mind to."

# “I have so much more energy now”

**Jessie Ace** tells us how she got started running with a little motivation from her dog, Lucy

**A**round seven weeks ago, I realised I wasn't moving enough. I was taking my dog, Lucy, on shorter and shorter walks. As I sat on my sofa one day, I realised how overweight she was getting and how much energy she was lacking. I decided enough was enough, I had to do something. I had to start exercising. But how? I felt permanently exhausted.

That's when I discovered the Couch to 5k app. The app gets you exercising in a really nice, gentle way. You start by walking for one minute then running for 30 seconds a few times, and then you repeat that three times per week. It reminds you when your next run day is, and you even get a trainer in your ear to give you encouragement and to tell you when to run or walk.

At first I found it hard, but I knew that my body was adjusting, so I pushed on. I

wanted to get myself fitter and I felt I owed it to Lucy to get her fitter too.

I find that MS makes exercising hard because you're always battling symptoms and there's a constant worry that it'll be too much and you'll have a relapse. I think that's why I hadn't exercised prior to this. At first I found the fatigue was overwhelming, but strangely enough, after going running, my recovery time got faster and faster each time. I now have more energy and less symptoms. I don't know how that's possible, but it's true.

Seven weeks on and I ran for 25 minutes straight for the first time the other day. I'd never run before starting Couch to 5k, so this was a massive achievement for me.

I plan on doing a 5k in the next couple of months and then a 10k in November. Who knows, maybe I'll run a marathon one day? I feel like I can do anything!

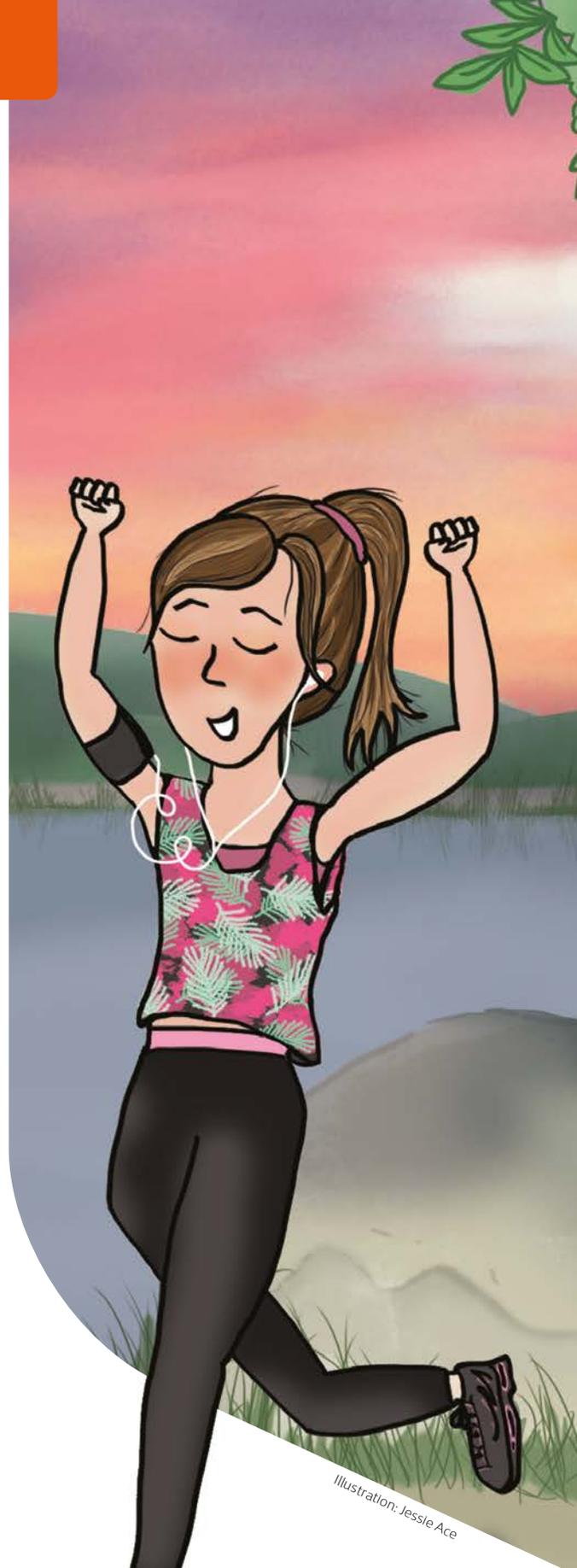


Illustration: Jessie Ace

Find out more about Couch to 5K at [nhs.uk/couchto5k](https://nhs.uk/couchto5k)

And read more from Jessie on the blog at [mssociety.org.uk/authors/jessie-ace](https://mssociety.org.uk/authors/jessie-ace)

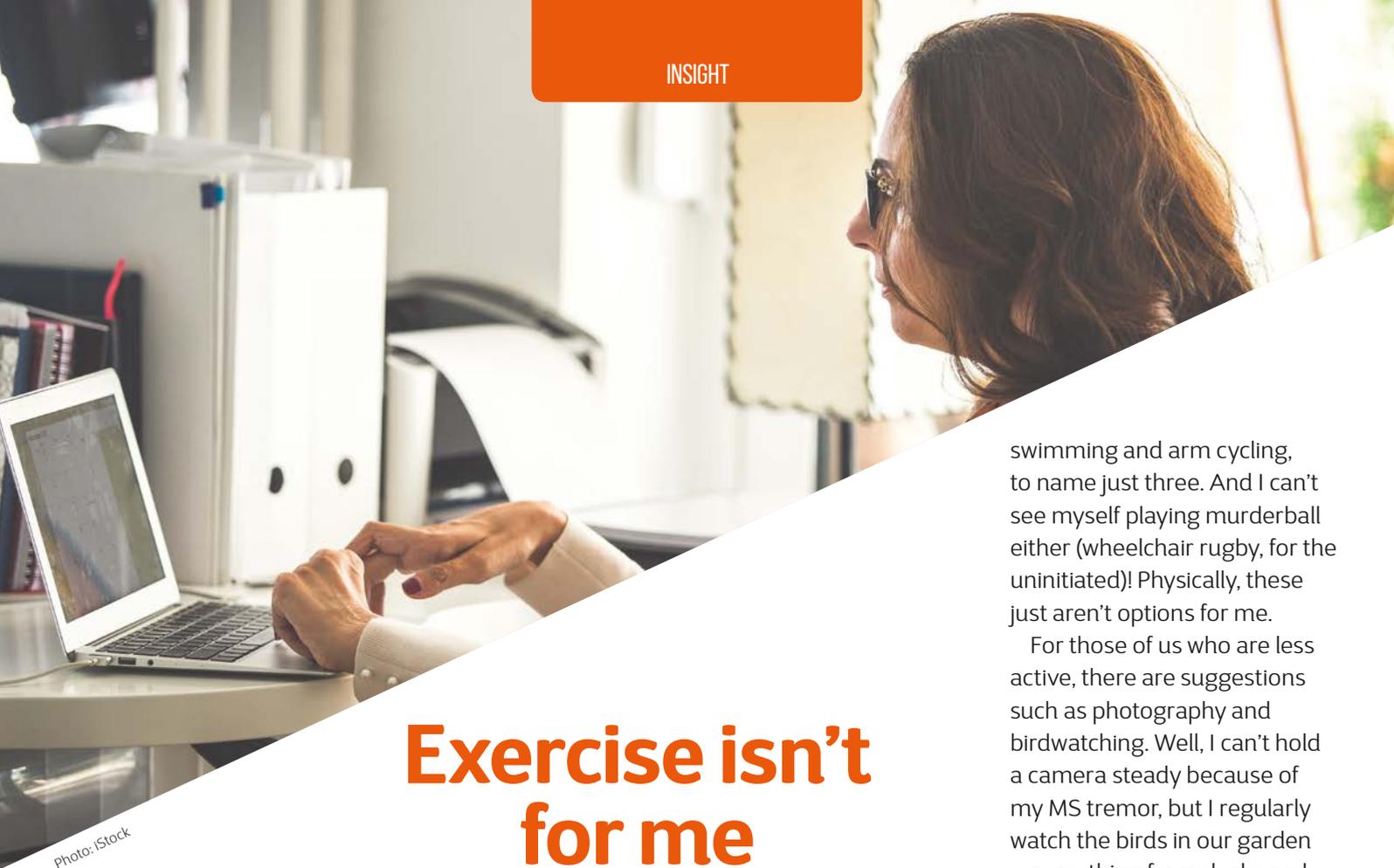


Photo: iStock

## Exercise isn't for me

**Elaine Moore** shares her experience about how exercise isn't always an option with MS

I'm told that exercise can improve my cardiovascular health, core strength, balance and coordination. It can also improve my mood and increase my energy levels. But how does exercise work when one session of even light exercise could leave me in a state of collapse for the rest of the day?

Don't get me wrong, I understand it's important for everyone to keep active. Especially people with MS. For us, the old adage "use it or lose

it" rings particularly true. I see photos of people walking a mile on crutches and I think "good for them". I see people taking part in wheelchair Zumba sessions and I think "good for them". In fact, my admiration is tinged with guilt because I didn't try such things and now it's too late.

So I did some research to see if there's anything I can still do. As MS affects everyone differently, finding the right activity is important. I quickly discounted wheelchair archery,

swimming and arm cycling, to name just three. And I can't see myself playing murderball either (wheelchair rugby, for the uninitiated)! Physically, these just aren't options for me.

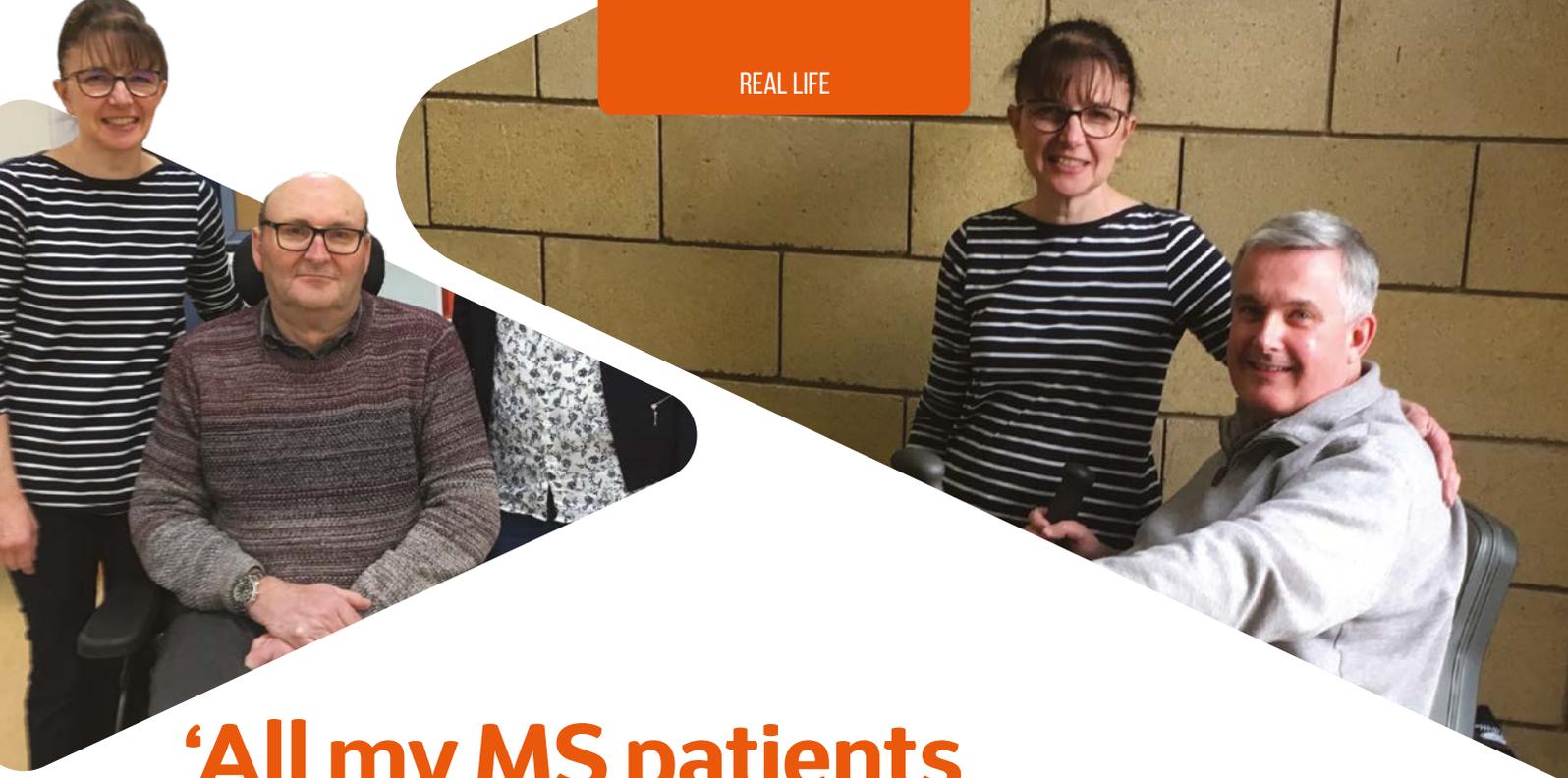
For those of us who are less active, there are suggestions such as photography and birdwatching. Well, I can't hold a camera steady because of my MS tremor, but I regularly watch the birds in our garden – everything from ducks and pheasants to robins and wrens. Do you think that counts?

The only exercise I take these days is typing columns such as this and articles for my website. So at least my brain and my fingers are active. And I can still manage to self-propel my wheelchair a little way and transfer to another seat. Although this is very limited, surely it still qualifies as exercise.

As I said at the outset, encouraging people with MS to keep active is very commendable, but it's not for all of us. It's not for me. And I know I'm not alone. I hope it's enough that we cheer them on from the sidelines.

### Find your movement

Elaine's experience is not uncommon, but even doing small activities, like she mentions, is so important. Our Physical Activity Specialist, Omar, works to tailor programmes of movement across all levels of ability to help you stay active as much as you can. If you're interested, call Omar for free on the MS Helpline 0808 800 8000 or email us at [helpline@mssociety.org.uk](mailto:helpline@mssociety.org.uk)



## ‘All my MS patients inspire me’

Neuro-physiotherapist **Debbie Soave** tells us why she’s passionate about helping people with MS improve their quality of life

“I’ve been working in this field for 30 years. I love the variety of working with people with different needs, building long-term relationships with them and learning from their experiences of living with MS.

“Patients I see can be 18 or 82, and I’ve known some of them for over 20 years.

“All my MS patients inspire me. They never cease to surprise me with the amazing things they do – one of my patients learned how to fly a light aircraft, and recently got her PADI diving certificate. It’s fantastic to see people set and achieve their goals.

“My work involves assessing how MS affects my patients. I work with them to improve their strength, flexibility and balance. We also offer aquatic physiotherapy and neuro-rehabilitation classes in the gym

at Eastbourne District Hospital where I’m based.

“We help people to increase their exercise tolerance and confidence on different gym equipment, and make sure they have a programme they can follow after completing their sessions with us.

“We encourage people to think differently about exercise by making positive lifestyle choices that can help them maintain function for as long as possible.

“Alongside my NHS job, I work with the local MS Society group to provide subsidised weekly MS exercise classes, and I do an annual fundraiser for them too.”

Debbie was recently awarded an MBE for all her work with people with neurological conditions, including the self-help group she helped set up for the local MS Society group.

## Debbie’s top five exercise tips



**1. Find an activity you enjoy** and you’re far more likely to continue doing it.



**2. Choose a time of the day that suits you best.** Don’t leave it to the end of the day when your fatigue is at its worst.



**3. Build up the activity sensibly** and set yourself goals once you get going.



**4. Keep cool** – fans, air-conditioning, iced drinks and cooling garments can reduce temperature-related fatigue.



**5. Use online resources,** MS-specific exercise videos and health apps to help you with your activities at home. Find some at [mssociety.org.uk/staying-active](https://mssociety.org.uk/staying-active).

# Be an MS Superstar

Feeling inspired to take on a challenge?  
Here are some exciting events you can take  
part in – all while helping to stop MS



## Take a big leap

If you're looking for a slightly different, somewhat terrifying challenge, then why not try a skydive? Whether you want to conquer that fear of heights or are already an adrenaline junkie, a skydive is one of the most exciting ways to fundraise.

join

If you or your friends or family are interested in taking on a challenge, visit [mssociety.org.uk/fundraise](https://mssociety.org.uk/fundraise), email [challenge@mssociety.org.uk](mailto:challenge@mssociety.org.uk) or phone 0300 500 8084

### Kiltwalk Dundee (18 August) and Edinburgh (15 September)

Get your friends together and grab some tartan for a fun day out at the Kiltwalk. The Hunter Foundation is adding 40% to everything that's raised – an amazing opportunity to make your efforts go even further.

### Royal Parks Half 13 October

Join our team to discover London's beautiful royal parks and iconic landmarks, all while running one of the capital's most spectacular half marathons.

### London Landmarks 29 March 2020

Discover the grand, the quirky and the hidden side of London on this exciting half-marathon.

### Sunrise Climb 10 August

Join us in August to climb Northern Ireland's highest peak, the spectacular Slieve Donard, just in time for sunrise.

### Ben Nevis Night Hike 24 August

Under the cover of darkness, with just the stars and your head torch leading the way, come join our MS Superstars and climb to the highest point in the UK.

### Arctic Trek January 2020

We're very excited to take our first group of fundraisers to the Arctic in January 2020. Our brave team will be pushed to the limit in freezing temperatures to help Stop MS (read about one of the trekkers, Scott, on page 51).

### Zipslide Zinger April 2020

Coming back for its fourth year is our fully accessible Zipslide Zinger in Perthshire. Sign up now for your chance to fly through the trees before places sell out.

# Walk, roll or stroll your way

**M**S Walk is back for 2019 and it's going to be bigger and better than ever.

This September you can walk, roll or stroll at our MS Walk events in London and Belfast. You can also organise your own event with our new My MS Walk. However and wherever you take part, the money you raise will fund vital MS research, so that together we can stop MS.

## Do it your way: My MS Walk

Have you ever wanted to take part in an MS Walk but not been able to make it to London or Belfast? Well now you can. You can sign up for My MS Walk and organise your very own MS Walk event. It doesn't matter how far you walk, if you take part in a wheelchair, or whether

you walk with old friends, new friends or four-legged friends, every effort takes us closer to stopping MS.

### How to get involved

- Pick a date that suits you.
- Pick a route (whatever the length) that's special to you.
- Invite as many of your friends, family and colleagues as you like to your walk.
- Visit our website and register. We will support you every step of the way and will send you everything you need to hold a fantastic MS Walk.

### Join us in London or Belfast

You can also take part in our fantastic MS Walk events in London and Belfast this September. Choose a distance that suits you, and join us to celebrate with music and fun



for all the family.

Our amazing walkers have raised over £600,000 since the first MS Walk in 2013, and you can be part of our special community.

MS Walk London is on Sunday 22 September and MS Walk Belfast is on Sunday 29 September.

**join**

If you're interested in taking part in MS Walk 2019 or have any questions, call 0300 500 8084, email [mswalk@mssociety.org.uk](mailto:mswalk@mssociety.org.uk) or visit [mssociety.org.uk/my-ms-walk](http://mssociety.org.uk/my-ms-walk)

# My MS Walk



# Take a (cake) break

Our favourite motorbike-riding chefs, the Hairy Bikers, are back to support our sweetest fundraiser of the year

**D**own-to-earth duo Dave Myers and Si King are challenging you to call on some mates and host a Cake Break this October.

Whether you're an expert baker or planning to pop to the supermarket for some ready-made treats, by raising dough you'll be making a big difference to the lives of people affected by MS.

Dave (pictured right and inset as a baby with his mother) was eight years old when his mum was diagnosed with MS. He says: "Within two years Mum was in a wheelchair and Dad and I became full-time carers. It was hard going. Back then there was hardly any support or respite for people affected by MS. But I do remember the MS Society opened so many doors for me as a young lad and my family – it made our lives just that bit better.

"There's been a great deal of

work done to support those with MS, but we still need to raise as much money as possible to make MS a thing of the past. And what better way to get a slice of the action than by hosting a Cake Break? Go on, grab a brew and share your bakes with your mates."

The official Cake Break day is 4 October, but feel free to host yours whenever suits you. To help you rise to the occasion, head to our Cake Break website. There, you'll find exclusive recipes from the Hairy...Bakers, as well as decorations, a collection box and cake-inspired games to help you spread the word.

And don't forget to share your Cake Breaks using [#CakeBreak2019](#).

**Register for your flan-tastic fundraising pack at [cakebreak.org.uk](http://cakebreak.org.uk) or contact the Supporter Care team on 0300 500 8084.**



# “It may sound boring, but I’m more happy that way”

As Joanne Chapman prepares for her son’s first day at school, she reflects on some of the things that having MS has taught her



## Every day is different

Little Man’s and my needs change without notice. I get frustrated and feel guilty when MS impacts life. Spontaneity may have gone out the window, but if I don’t plan for milestones, the brown stuff doesn’t just hit the fan, it clogs it.

Remembering I’m not a superhero, having support and tips, using techniques like mindfulness and counselling, as well as planning “me time”, all contribute to making life easier and keeping spirits high. For example, my notice board will help with cog fog when school starts.

## MS shapes you

Little Man will be entering a new development phase and milestone, but having MS means I have also evolved: the MS journey comes with its own unique milestones. Every symptom, appointment attended, aid used, decision made, and drug taken, shapes my life as an “MSer”. I’ve had to come to terms with many aspects, including a career change. Without becoming an

MS Mummy, I wouldn’t have discovered my love of writing.

## MS affects everyone close

As Little Man grows, I’m thinking about our family’s emotions more and remembering MS affects everyone close, not just the person being diagnosed. I may have accepted I have MS, but not everyone accepts or is on the same time frame as you.

## You need tailored essentials

As MS is an individual, progressive condition, I know what helps and triggers symptoms. A loo that’s close by, appliances like my answer phone and dishwasher, energy-saving parent activities, and aids like my stairlift and scooter, all help. I know stress or fatigue bring out my MS, so instead of ploughing on like before, I try to pace and plan. It may sound boring, but I’m more happy that way. I understand what I’ve learnt from my milestones.

**You can get in touch with Joanne through her blog [poorlyparents.wordpress.com](http://poorlyparents.wordpress.com)**

# Our young heroes

These young fundraisers are inspired by a loved one with MS. Whether it's because of their mum, nan or grandad, they're giving it their all to help people with MS. Here are four stories of young heroes who went above and beyond to fundraise for all of us

## Nicole, 16

**Nicole knows that her nan, Lynda, would do anything for her grandchildren and the feeling is mutual. Lynda has advanced MS, and this summer Nicole is saddling up for a special fundraising event to support her.**

"My nan and I used to go out every Sunday and spend the whole day together," says Nicole. "She used to work two jobs, she drove, and she loved having us grandchildren round for tea."

Recently, Lynda's health has declined due to her MS, which severely affects motor function on one side of her body. "Nan's lost a lot of confidence and she can't leave the house as easily as before. I wanted to organise something that Nan could be

been really difficult for Nan. MS affects both her legs now and she was in hospital six times with infections. It's really brought home to me what she goes through.

"MS affects your mental health and it can be difficult to find things like support groups. Nan often feels like she's the only person in the world who's struggling with MS. This is about giving her the confidence to see that she isn't alone.

**"I'm raising money so people like my nan don't have to do this alone"**

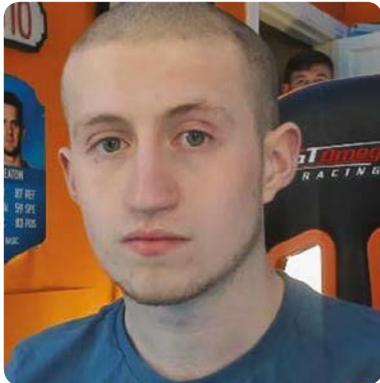
part of too.

"I'm leading a group of horse-riders along an 11-mile route across Oldham, and we've got friends and family walking along with us. Nan's coming to see us off and she'll be driven along the route to meet us at the end."

"The last 12 months have

"Connection is important for everyone. A young girl messaged to ask if she could join the ride because her nan has MS too. We've never met despite living only a couple of streets apart, but now we know we've got something in common and we'll be making a difference together."





## Liam, 20

**Liam Waddington is a professional “YouTuber” who uses his unique platform to raise money for us, the charity that supported his mum. In February, he hosted a 50-hour live video stream on his channel, raising over £6,500.**

Liam, known as Vizeh to his fanbase of 177,000 subscribers, makes football-themed videos for his popular YouTube channel.

Liam is also a vocal supporter of the MS Society. His mum lived with MS throughout Liam’s childhood before she passed away when he was 13 years old.

Determined to help others in the same position, Liam decided to use his YouTube platform to raise money with a 50-hour live video stream dubbed #formum. This is a new way of fundraising where people who are popular online host a kind of modern-day telethon. They broadcast a live show of themselves where they talk about the cause and encourage donations, often in fun and inventive ways.

“I must admit, when I decided to do the challenge I was terrified at the thought of staying up for 50 hours straight! It meant no sleep, no breaks, and essentially speaking to my audience for over two days and nights, all broadcast live online.

“The tone of my videos is about having a laugh, and within my community I’m known as a bit crazy, so the

challenge had to match that. I wanted to make sure there was always something entertaining going on.

“Having a plan helped keep people donating and engaged.

platform for others. I spoke to a 13-year-old lad whose mum was living with MS – he had such an amazing mindset and we received thousands of comments showing solidarity.

“It’s important to talk about your struggles”

For every £100 raised, I would spin a wheel and do a challenge live on air: smashing an egg on my head, for example! I collected donations through my JustGiving page.

“I also used the event as a

“The community that I’m part of on YouTube was hugely supportive, both in terms of donations and proving how important it is to talk about your struggles together.”



## Logan, 9

When Logan decided to raise money in honour of his Grandad, who has MS, he knew the challenge needed to be very special.

“Logan has always cared a lot about his grandad and they share a special bond,” says mum, Jeanette. “When we visit, Logan often asks to help with some of Dad’s care.”

Inspired by their shared love of football, Logan decided to tackle a sponsored walk, beginning at his grandad’s house and ending at their beloved Ross County F.C’s home ground – a whopping 13.9 miles.

The big day soon arrived, and family and friends cheered as Logan, his mum and grandma set

“Every step was for Grandad”

off. “Logan carried an MS Society collection box,” says Jeanette. “And people kept stopping to donate. It felt like an adventure!”

After five and a half hours of walking, Logan reached his goal, and has raised an amazing £1,800 since completing his challenge.

“I know that Logan is inspired by his wonderful Grandad Aly, and we were all thinking of him that day. Every step Logan took was for him.”



## Mia, 10

Mia from Newtownards is an enterprising young fundraiser who sells handmade treasures and trinkets to raise money for the MS Society. Mia’s mum, Cathy, lets us in on what motivates Mia.

“When she first decided to raise money for the MS Society, Mia began by selling anything and everything in our local neighbourhood.

“Recently, she’s sold handmade bracelets and necklaces, little bags of lavender picked from the garden, and keyrings. She enlists help from her friends and they sell to family and neighbours.

“Mia’s Granny Hester has MS and raising money is Mia’s way of helping. They’re very close and spend every Tuesday together, doing homework or an arty activity.

“The summer holidays is a great time for a fundraising project like this, and it’s a great way for Mia to channel her creative side. She watches YouTube tutorials for ideas on

what to make and often gets her friends from school or Brownies to help out. As you can imagine, everyone is always happy to support her!”

A huge thank you to all these fundraisers for their incredible support. If you’re feeling inspired to do your own challenge, you can find lots of ideas and tips at [mssociety.org.uk/fundraising](https://mssociety.org.uk/fundraising)

“As you can imagine, everyone is always happy to support her”



# Top tips for managing bladder issues

**B**ladder problems affect as many as nine in ten people with MS at some point. Many people find it difficult to talk about and may feel embarrassed. We've made a new handy A5-size booklet with lots of information about how it can affect you and how to get specialist help. We've also asked people with MS for their tips to help you plan ahead. Here are some to get you started.

## Food and drink tips

- Flush your bladder by drinking lots of liquid, but don't drink too much. About 1.5 to two litres a day is ideal. And have your last drink no later than two hours before going to bed.
- Switch to decaf tea or coffee as caffeine irritates the bladder.

- Cut down on fizzy drinks, smoking and alcohol as they can also cause irritation.
- Avoid spicy food.
- Watch your weight. Being too heavy puts pressure on your bladder and pelvic floor muscles.

## How to find a toilet while out and about

- Contact our Supporter Care team for a free 'I need some help' card, which explains that you urgently need to use a toilet. Call 0300 500 8084 or email [supportercare@mssociety.org.uk](mailto:supportercare@mssociety.org.uk)
- Download an app to your phone, such as Toilet Finder or Flush, or use Google Maps to find your nearest toilet.
- Join the National Key Scheme. For a few pounds you can get a special Radar key that lets you into over 9,000 locked accessible toilets in the UK. Order yours at [disabilityrightsuk.org](http://disabilityrightsuk.org)

- If you need toilets bigger than standard accessible ones, or you need a hoist, check out [changing-places.org](http://changing-places.org)
- Contact your council to see if there's a Community Toilet Scheme locally. It lets you use toilets in shops, restaurants and pubs without paying.

If you work, you may want to be located near to a toilet. You can ask your employer for this, as the law says this is a reasonable adjustment. Visit [mssociety.org.uk/working-and-ms](http://mssociety.org.uk/working-and-ms) for more information on work and MS.

## How exercise can help

Pelvic floor exercises can help improve your ability to hold on. A physiotherapist or continence adviser can help you to learn how to exercise these muscles. And we have some instructional videos on our website at [mssociety.org.uk/exercises-for-symptoms](http://mssociety.org.uk/exercises-for-symptoms)



We have a wide range of booklets about many of the symptoms that affect people with MS. To order any of our booklets free of charge, including the latest bladder tips booklet, visit our online shop [mss.ecgroup.net/ms-info-leaflet](http://mss.ecgroup.net/ms-info-leaflet), email [shop@mssociety.org.uk](mailto:shop@mssociety.org.uk) or call 0300 500 8084

# “We take a deep breath and deal with the here and now”

Our anonymous columnist shares the bittersweet reality of life as a carer for his wife who has MS

I write as the only carer for my disabled wife. There is no help – my choice.

The day is surely coming when the lifting and laying will finally be beyond my physical capabilities and my own health, precarious and unpredictable, will necessitate calling in the cavalry.

We know all too well how the grip of MS, relentless and unceasing, seems to take hold.

Looking back over one year,

five, or ten, it takes a certain amount of courage to assess the decline and to face the stark reality that, for many folks, things are on a downward path. Sometimes it doesn't do to look too searchingly into the future.

For the carer, as the list of daily tasks grows (I am now cutting up my wife's meals), I have noticed how our lives have become so much smaller. I say this without a shred of self-pity, but it's a challenge to look back to our past shared lives and recall what kind of life we had.

We were lucky. We were a couple who used to do things. And we're still lucky in so many

ways to have the memories of two lives lived as one. Leafing through our many photo albums and reminiscing fills us with joy rather than regret.

We often think, but dare not dwell too long, on the many things we used to do. When was the last time we got dressed up and dined out? Or the last time we managed to go longer than an hour in the car? Or the last time we made love?

These, and so many other shared joys, are now fading in the memory. Our shared life is rapidly shrinking, and my wife, bless her, is determined that I carve out a new life for myself – enrolling for an evening class, going to concerts, meeting friends for a drink.

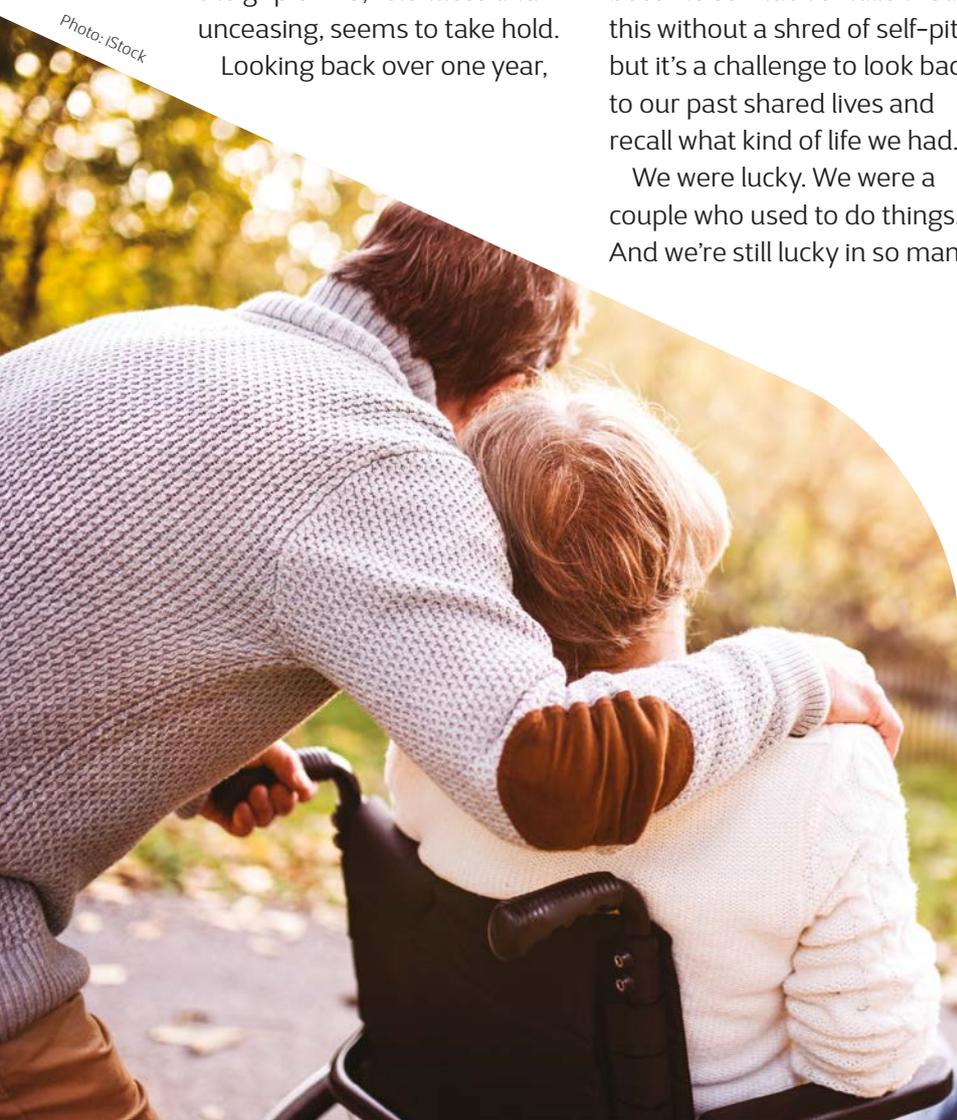
All are perfectly possible were it not for one thing: my hesitation and fear that I will get to love any new life more than the one I have now.

So, for now, possibilities are on hold. I take a deep breath, we take a deep breath and deal with the here and now, as we have done these past fifteen years.

**Find out about the support the MS Society can offer to carers at [mssociety.org.uk/carers](https://mssociety.org.uk/carers).**

**And you can call the MS Helpline on 0808 800 8000 or email [helpline@mssociety.org.uk](mailto:helpline@mssociety.org.uk)**

Photo: iStock



# Shaping our future

We're excited to launch our new strategy for the future of the MS Society and all we do together

In 1953, Richard and Mary Cave were frustrated by the lack of treatments and support available for Mary's MS. So they decided to do something about it. They set up a meeting in west London to discuss how they could improve the situation, and the MS Society was born.

Today, we have a national community network of volunteers running groups and providing support for people living with MS all over the UK. And we play a leading role in MS research and campaigns

for better care. Those founding members would have been delighted to hear the progress and support now available through the MS Society, as well as many other charities and organisations throughout the UK.

## We're building on our successes

Over the years, we've had some significant breakthroughs by funding research to understand more about the condition. And we've also helped increase access to care, treatments, and

services. This fantastic progress didn't happen in isolation – it's the product of careful planning, and listening to what people living with MS want and need.

To continue this valuable work across all aspects of MS, we've developed a new strategy for 2020-24 that builds on these fantastic achievements and directs how we'll focus our energies for the next five years.

We didn't start from scratch, but have built on the progress we've made already. We wanted to ensure that our previous goals were brought up to date and made more relevant for the challenges that face our community today, and that may not have been there before.

## Thank you for all your help

The strategy was built in collaboration with the whole MS community, including our members, volunteers and staff. We also reached out to



MS health professionals, and as many people living with, or affected by MS as we could reach.

Our aim was to streamline our goals and acknowledge where there were overlapping priorities. We took our seven old goals and evolved them into three new goals that encompass the continued needs and new challenges that we'll face over the next five years.

This new strategy is founded on what is important to our community. It's been signed off by our Board of Trustees who want to thank everyone who has fed-in to help us make it the best it can be.



### Launching in 2020

Watch this space for much more information on the launch of the strategy in the new year – and how we can continue to work together to make as much of an impact on and for the MS community as possible from 2020 onwards.

We will be presenting the new goals at this year's AGM where you'll also have a chance to endorse the new strategy by voting for its acceptance.

The AGM will take place on Saturday 21 September. See more details on page 44.

“Those founding members would have been delighted”



# Building a stronger MS Community

**W**e want every member of the MS Society to have an experience that suits their individual needs, so we've been hard at work gathering information from our communities and beyond about how to create a tailored membership model.

We're excited to do something that will help create a stronger MS community. We know you

can help us to highlight new and key challenges. And together we'll create a community that will better support everyone living with MS.

We will keep you up to date with our progress, and any opportunities where we need your guidance or support. In the meantime, if you have any comments you wish to share, you can email us at [membership@mssociety.org.uk](mailto:membership@mssociety.org.uk)



## Vote at the AGM 2019

If you were a paid-up member of the MS Society on 22 June 2019, you're entitled to vote at this year's AGM. Your AGM booklet and voting papers are enclosed with this copy of MS Matters. Please take the time to read the booklet and vote.

The AGM booklet contains information about the resolutions that are being proposed, including endorsement of the MS Society's new five-year strategy, receipt of the Annual Report and Accounts 2018, and the appointment of auditors. It also includes information

about the candidates standing for election as trustees and National Council members.

If you're entitled to attend the AGM or vote, then you have the right to appoint a proxy – someone to do that on your behalf. All the information on attending the meeting and on voting is included within the AGM booklet.

To book a place at the AGM or appoint a proxy, please complete the form at [mssociety.org.uk/agm-2019](http://mssociety.org.uk/agm-2019) where you can also find the AGM booklet, or call 0300 500 8084 (option five). The AGM

will be available live via our website.

### Notice of AGM

The Multiple Sclerosis Society's 9th Annual General Meeting will be held at MS National Centre, 372 Edgware Road, London NW2 6ND at 11am on Saturday 21 September. The agenda will include:

- Review of 2018
- Our new strategy
- The Annual Report and Accounts 2018
- Appointment of auditors
- Elections of trustees and National Council members.

# Big Lottery create a big difference in Wales

**B**ack in 2015, we travelled the length and breadth of Wales asking the MS community about the issues that matter most. This evidence helped us to shape a successful application to the Big Lottery and Masonic Charitable Foundation for the My MS, My Rights, My Choices project. And now, over two years into the project, what a difference it has made. Project Manager Adele Gilmour tells us what's been happening.

"The project originally planned to reach 1,300 people in Wales during the three years it's funded for – but by the end of year two, we'd already reached 1,900 people living with and affected by MS. Working closely with the MS clinical teams, we've reached around

70% of people newly diagnosed with MS in Wales.

"We know from our research that welfare benefits, accessing treatments and care, financial support, and lack of information about MS and self-management, are among the main problems that people with MS are facing in Wales. My MS, My Rights, My Choices is responsive to these issues and is giving our community what they need through one-to-one support and special MS events and activities.

"From our events, new MS support groups have been formed, and the MS community in Wales has become stronger as a result. For instance, following our Newly Diagnosed Day held in March in Swansea,

a group of people living with MS have come together to set up a new group in Carmarthen.

"Many of our volunteers have also benefited from the project, and are now sharing their experience and skills, providing support in their community, arranging information stands in clinics, and helping people in financial need to fill in grant applications.

"In December this year, we'll begin the process of drawing the project to a close, but, in the meantime, we're also preparing a new bid to the Big Lottery Fund for a further grant.

"There's no doubt that My MS, My Rights, My Choices has made a significant difference to the lives of those who have benefited from the project so far, but we know we haven't reached everyone in need. We'll be doing all we can to get further funding so that we can make an even bigger difference to our community."

**To find out more about My MS, My Rights, My Choices and how to sign up to events and activities, email [mymscymru@mssociety.org.uk](mailto:mymscymru@mssociety.org.uk)**



## What a Nerve!

**T**he 2019 Cambridge Science Festival in March featured a special exhibition, What a Nerve, all about MS. Bob Bragger and Jill Merchant, from the Cambridge and District Group, put on a free one-day art exhibition and series of talks from researchers, artists and people living with MS. The event was created in partnership with the Wellcome-MRC Cambridge Stem Cell Institute and Growing Art Partnerships.

Held inside the historic

Cambridge Union debating chamber, What a Nerve explored all aspects of living with MS, and expressed disease, science and cells through acrylic, glass, paper, paint and sound.

Visitors heard from Professor of Stem Cell Medicine Robin Franklin, and Dr Susan Kohlhaas, Director of Research at the MS Society, as well as artists, to discuss MS from scientific, artistic and personal perspectives.

Cambridge local Jo Tunmer

was among four artists who spoke and displayed their work on the day. Jo's sister-in-law Ruth has lived with MS for over 20 years, and Jo captured how the condition has impacted Ruth over time, and the challenges she faces in day-to-day life. Her piece was titled 'Progression and Obstruction'.

**Top:**  
'Progression and Obstruction' by Jo Tunmer

**Right:**  
Sculpture by Kelly Briggs to represent stem cell structure, demyelination and myelination



## Janis Winehouse named MS Society Ambassador

We are thrilled to announce Janis Winehouse as our newest MS Society Ambassador.

Janis lives with MS and is the mother of singer Amy. Over the last seven years she's supported our work and volunteered for us in many ways. This includes giving media interviews to raise awareness of MS and our work, and participating in every MS Walk since it began.

Janis said: "It's such an honour to be named an MS Society Ambassador. I know Amy would have been incredibly proud too. To see me this far along and still going, she'd think it was a real achievement."

# Time to celebrate our MS Superstars

Let's look back at some of the incredible things our supporters have been doing to support people living with MS – and some of the exciting adventures coming up soon



## Walking on wings ▲

Twelve daredevils, including four people with MS and three of our Council members, took to the skies on 25 April to do a fundraising wing walk for MS Wales, raising over £8,000.

Kathryn Foot, who organised the event, said: "My mother and sister both have MS, which drives me to raise money so a cure can one day be found. I really hate heights, so the wing walk terrified me, but pushing myself to do something like that is the least I can do to help."



## ◀ Trek of a lifetime

Amazing adventurer Moira Jones from mid-Wales raised over £14,000 for MS research by trekking Mount Kilimanjaro in treacherous conditions earlier this year.

## ▼ Orange is the new black tie

On 16 March, supporters in Oldham put on a fantastic charity ball, raising over £5,000 for the MS Society and MSA Trust. Called the Mandarin Masquerade Ball in honour of the charities' colours, the event included entertainment from a magician and DJ, and an impressive charity raffle.





### ▲ Cheering on our Edinburgh Marathon runners

We had a fantastic weekend at the Edinburgh Marathon Festival in May. It was our second year as a premier affiliate charity, with 184 amazing runners taking part across the weekend. We even had some of our Scotland Council members and MS Society staff take part, including Trusts Fundraiser Katy Sanford (pictured above) who ran in the Hairy Haggis Relay. Places are now open for EMF 2020. Sign up at [mssociety.org.uk/emf](https://mssociety.org.uk/emf)



### ▲ Run for Research

This year we hosted our second Run for Research event in Northern Ireland with almost 500 runners taking part in either the 10k or half marathon.

Pictured are two of the organisers: Northern Ireland Council member Ivan Prue, and Jennifer Coulter who ran the 10k with baby Callum.

## Amazing adventurers



### An Arctic adventure

Our incredible team are gearing up for our first ever Arctic Trek, pulling toboggans through

icy conditions, in January 2020.

Scott McPhillimy, one of the team, said: "Since being diagnosed with MS four years ago, my motto has always been to "challenge MS" and I can't think of a bigger challenge than the Arctic Trek. Check out how Scott's training is going at [facebook.com/arctictrek2020](https://facebook.com/arctictrek2020)



### 21 miles for 21 years

Forty-five-year-old Christian Knowles from Holmfirth, Yorkshire, was diagnosed with

MS 21 years ago. To mark the occasion, he has set himself the huge challenge of swimming the 21-mile English Channel in August, aiming to raise £21,000. Christian wants to encourage others to push their boundaries. Find out more at [justgiving.com/fundraising/pushyourboundaries](https://justgiving.com/fundraising/pushyourboundaries)



### Rowing the Minch for MS

This summer a team of five hardy highlanders will take on a 15-hour,

50-mile row across the Minch – a stretch of open sea in north-west Scotland – to help stop MS.

The crew, who have a combined age of 292, will pilot a 22-foot rowing boat in unsheltered conditions for this daunting endurance challenge.

Follow their progress on Twitter @MinchRow or [facebook.com/RowingTheMinchForMS](https://facebook.com/RowingTheMinchForMS)

# communityviews

## Parking space vigilantes

In March, blogger **Martin Baum** wrote about how people can be quick to judge people with MS' use of disabled parking spaces.



**Martin's article resonated with many people on Facebook. Here are some of your responses:**

"Although this is the 21st century, attitudes towards people with MS don't seem to have moved with the times. Unless there's a stick or a wheelchair, the burden of having to prove yourself to merit a blue badge to park on a single yellow line - or in a disabled parking space - never goes out of fashion. It never gets old, and that bothers me a great deal.

"Being made to account for myself by complete strangers is nothing new, and over the years I've had my fair share of disabled parking space vigilantes. There is something so righteous about how they stand and stare as if deciding if the man getting in or out of the vehicle looks 'normal'.

"Last year one person claimed to have once been a policewoman and demanded that I explain myself to her. It wasn't until my wife faced her down that she retreated faster than Miss Marple on a bike, peddling like the clappers. I think it was more embarrassing for her than me. Or maybe not."



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](mailto: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](mailto:msmatters@mssociety.org.uk)

f Facebook [www.fb.com/MSSociety](http://www.fb.com/MSSociety)

t Twitter [@mssocietyuk](https://twitter.com/mssocietyuk)

**Paula** "The whole system is a joke. I couldn't get a badge even though some days I struggle to walk and suffer with balance problems and muscle spasms, and fatigue is a major issue for me. But off I go to my appointment, with someone who clearly doesn't care or understand MS, and because I walked around the centre's car park, I'm [considered] absolutely fine."

**Debbie** "I feel now with my MS, if people can't see the pain, there's obviously nothing wrong with you. It's hard."

**Jackie** "I have MS, and one time I put my badge on the car and when I got back to it someone had left a note on my windscreen saying: 'If you can walk don't park in a disabled bay, these bays are for disabled people.' I was so upset about it."

**Andrew** "I've had so many elderly people give me dirty looks. It really makes me so angry. It's not my fault I'm disabled and it's none of their business or their right to try and intimidate or make me feel bad for having it either."

