MS Society msmatters

Spring 2020 · Issue 134

When it's more than MS

Top tips and stories from people living with **multiple health issues**

Inside

Research Matters magazine

Tech and MS, plus much more

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msmatters
UK

Issue 134
Spring 2020

I hope you're all looking after yourselves while we're in the midst of the COVID-19 pandemic. At the time of writing, we're in a rapidly changing and unprecedented situation. None of us have ever known anything like this before, and it's meant we've all had to make significant changes to the way we do things.

Along with the rest of the UK, we're monitoring the coronavirus situation closely, following the latest government guidelines to help keep our community safe.

We want to ensure we're providing the best possible information on coronavirus and are regularly updating our website with the latest news and advice for people living with MS. This includes information from our scientific community about DMTs, and details about how to self-isolate.

Unfortunately, the situation has also meant we've asked for all face-to-face contact of MS Society groups to stop for the foreseeable future. And we've also postponed all of our forthcoming events (see page 49). The uncertainty surrounding coronavirus is unsettling, but please remember that nobody has to face MS alone – we're all in this together.

We know that you like to hear information on living well with MS, and this is especially important during the coronavirus pandemic. We're continuing with our regular treatments update on page 28 and have tips on managing fatigue on page 26. And on page 22, we have real life stories about managing multiple health conditions. Also turn to page 9 for tips on how to deal with self-isolation.

Much of the content in this edition of MS Matters was agreed before the coronavirus situation changed so rapidly. We went to print on 23 March, so things are likely to have moved on even further by the time you read this. Please check **mssociety.org.uk/covid-19** for the latest updates. Or if you can't get online, call our MS Helpline on 0808 800 8000. But please bear in mind there may be delays at this busy time.

Nick Moberly
Chief Executive

10 Our campaigning during the first 100 days of Boris Johnson's government

NEWS

INSIGHT

Make your donation go further
Did you know that giving direct from your salary is one of the easiest and most tax-efficient ways of donating to our work? Because your donation is taken out of your wages before tax, if you donate £5 to us, it actually only costs you £4, or even less if you're a higher rate taxpayer. Find out more at **mssociety.org.uk/payroll**

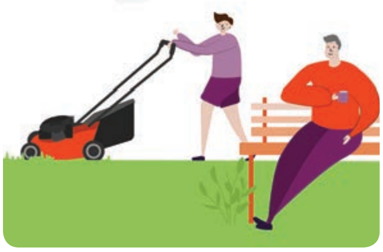
CONTENTS

14 How many people are living with MS in the UK?

18 Meet our Stop MS champions

47 The mystery shoppers helping to improve fitness facilities in Wales

26 We have a new online course for managing fatigue



Research Matters

Turn to the centre of MS Matters to read Research Matters. Find out more about the potential that technology holds for MS, hear from our experts on hormones and cognition, and meet the researcher living with and researching MS.

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

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

REAL LIFE

COMMUNITY VIEWS

COMMUNITY NEWS

GET INVOLVED

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Your Letters

In response to ‘Time to take a break’, Autumn/Winter 2019

Last year, I made a long desired trip to Andalusia. I checked with the airline's call centre to find out what the procedure for the wheelchair was. I got one story that didn’t tally with what the travel agent had said. Then I got more conflicting information from the airline’s customer service team, the airport’s customer service, and the airport’s disability department.

In the end, I wrote directly to the chief executives of both the airline and the airport saying I really didn't mind what the process was, but would they please make sure everyone was singing the same song. In due course, the flight went smoothly and we were treated royally.

Airlines and airports help thousands of wheelchair-using passengers, more often than not with no problems. But problems do occur. When they do, it’s usually down to poor communication or carelessness. Advice: plan, plan, plan. And expect that there might be glitches.

- Anne

We’re sorry your booking process was so fraught. Thank you for the tips and we hope you had a wonderful holiday! You can find out more about traveling with MS at **mssociety.org.uk/accessible-transport**

iStock

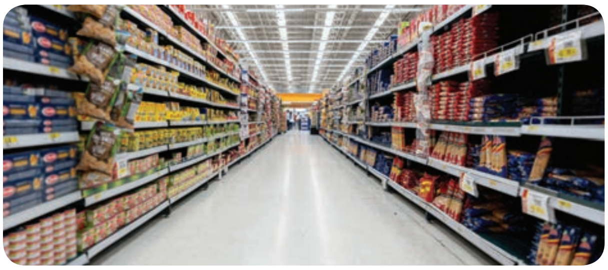
In response to ‘We are Undefeatable’, Autumn/Winter 2019

In this article, Nick Moberly asserts that: “It is a common myth that people with MS will make their condition worse if they exercise.”

I agree that exercise in moderation is good for you. But I went to a very good course recently run by the Southampton Hospital MS Nurses and their advice was to consider your energy as a battery and only use 70% at any one time. So, if you do exercise with MS, don’t push yourself, keep 30% of your energy in hand.

- Norman

Exercise is beneficial for people living with MS so long as it’s not overdone and enough rest is provided after. This is the same for anyone as we all have different fitness levels. The important thing to remember is that you should go at your own pace and listen to your body.
Read more about exercise and MS at **mssociety.org.uk/exercise**



I have found that I can walk fast and a long way in our huge local Sainsbury’s with my walker. The floor is flat, the aisles are wide and I go up and down each aisle at speed and get my exercise that way.

I don’t have the same confidence on the paths near our house as they are uneven, so thank you Sainsbury’s for my own private gym!

- Penny

What a great idea for exercise! We hope we can all get back to the shopping aisles soon.

We love to hear your feedback on the magazine and the articles you’ve read. Do share your thoughts by writing to us at **msmatters@mssociety.org.uk**

Coronavirus and MS

At the time of writing, the COVID-19 coronavirus pandemic is a rapidly changing situation. Due to the nature of print (we are writing this on 23 March), we can't provide the most up-to-date information in the magazine. We therefore urge you to find the latest details and advice on MS and COVID-19 on our website at **mssociety.org.uk/covid-19**. If you don't have access to the internet, you can also call the MS Helpline on 0808 800 8000, but please be aware there may be delays during this particularly busy time.

Our CEO, Nick Moberly, has written more on the pandemic on page four. And you can read an update about our events on page 49.

Coping with social distancing and self-isolation

Here are some ideas to keep the mind and body active while you're staying at home during the coronavirus pandemic.

Stay active

Keeping active can help us stay as healthy as possible – physically and mentally. We've got a range of online exercise videos for people with MS that you can do at home. Visit **mssociety.org.uk/ms-and-exercise**

Relax

If you're feeling anxious or stressed, there are lots of things you can do to look after your mental health.

- Try mindfulness. See page 53 and **mssociety.org.uk/mindfulness**. Or give our relaxation yoga video a go (see our exercise page link above).
- The mental health charity MIND has helpful information at **mind.org.uk**
- If you want to chat to someone, call our MS Helpline on 0808 800 8000. We're here Monday to Friday, 9am to 7pm except bank holidays.

Be connected

- Keep in touch with family and friends with phone and video calls. For online video calls try Skype, Zoom or Google Hangouts.
- Join the conversation online at our MS forum: **mssociety.org.uk/ms-forum**
- Check out our online wellbeing and time to chat sessions at **mssociety.org.uk/wellbeing-sessions**
- Most big supermarket chains do online shopping. And online pharmacies like **pharmacy2u.co.uk** can deliver prescriptions free of charge. It's important to make sure you register with a legitimate pharmacy. Search 'dangers of buying medicines online' at **nhs.uk** for what to watch out for and a link to a register of authorised online sellers of medicines.

Be entertained, learn something new, get creative

- You could try talking books, podcasts or online channels like Netflix. And BBC, ITV, Channel 4 and Channel 5 all have free on-demand services.
- Check out online courses from sites like **futurelearn.com** or **open.edu/openlearn**
- Express yourself by writing, making a photo diary, getting creative with food, or doing some art.

See more tips at **mssociety.org.uk/distancing-and-isolation**

MS in the UK Parliament
The first 100 days

The general election in December 2019 ushered in a new UK Government and meant that a host of new MPs entered Westminster for the first time. Since then, the new Government has spent its first 100 days setting out plans for the coming years.

Devolved assemblies and the Parliament in Scotland, Wales and Northern Ireland have also seen an action packed few months, particularly with the Northern Ireland Assembly sitting for the first time in three years and the Scottish Parliament gearing up for an election.

The changing political times have been an opportunity to push MS onto politicians' agendas, and MS campaigners have been doing just that. Hear from them about how, together, we've been raising our voice for people with MS.

Janis Winehouse, MP Fabian Hamilton, and Ashley handed in our open letter on PIP at Number 10

iStock

Our team of campaigners, staff and MPs walked to Number 10 to deliver our petition

Demanding change on PIP at Downing Street

Ashley, 29, from Leeds, is one of thousands of people campaigning to change Personal Independence Payment (PIP). She tells us why she got involved.

The MS Society's PIP campaign came to my attention at a crucial point for me. I had just been through my second PIP assessment and was really struggling with the ordeal and stress of it. Going through the complaint was causing me such anxiety.

I saw the campaign on Facebook first. And then I shared my experience with the campaigns team at the MS Society so they could use it in the campaign. I had to help, for everyone who has been affected by the unfair and unjust process of applying for PIP.

On 23 January, I went to London to join a team of MS Society staff and supporters to hand in an open letter to Downing Street. It called on the Prime Minister to make changes to PIP assessments and was signed by over 21,000 people. I was so proud to be part of this – I knew it was going to be a long and tiring day for me, but I wanted to be the voice of those who are less able and less supported than me.

My local MP, Fabian Hamilton, was one of several MPs who came to support too.

I really enjoyed the day and I also met Janis Winehouse who is such an inspiration.

The whole experience has made me realise that we are not alone, others are going through this daily and we have people on our side.

I really hope that the government act on this, and that the PIP process is one less stress that chronically ill and vulnerable people have to go through. We've got this!

Read more on PIP on page 38.

People with MS, MPs and Peers come together in Westminster

In March, the first meeting of the All-Party Parliamentary Group for MS (APPG) saw three people with MS – George, Philippa and Susan – come together with MPs and Peers to campaign on issues affecting the MS community.

The APPG is a group of MPs and peers from all parties who work to help put MS on the political agenda.

Philippa, 27, from Belfast, was there speaking up for people with MS.

She said: "I feel that the voice of people with MS in Northern Ireland needs to be heard in the UK Parliament and brought to light. People with MS face issues across the UK but there might be issues that are specific to Northern Ireland too. I want to make sure they're represented.

"It was important for me to be there to show that MS can be different for everyone. And that all areas of our community have a voice and that MPs can hear the real life experiences of people with MS rather than just look at numbers on a page.

"The key point is to raise awareness and have the most important issues talked about throughout the year. These include welfare and access to treatments, and I hope that we can raise the importance of these issues."

A bold manifesto for MS in Wales

This month we've launched our manifesto for Wales ahead of next year's Senedd Cymru election.

Wales lags behind England, Scotland and Northern Ireland on access to vital MS treatments, care and support. We're asking the Welsh Government to improve the NHS infrastructure and invest in a workforce that meets the needs of everyone living with MS.

Access to social care services and support is inadequate for many people affected by MS in Wales. We're asking the Welsh Government to take urgent action to change this.

Poverty affects many people living with MS in Wales, and there is inequality in access to services for people who are poorer. We're asking the Welsh Government to address the poverty and hardship that people living with MS face, and to hold the UK Government to account for the humiliating and degrading system of welfare that is failing disabled people.

As the election looms, we'll be speaking up for MS and campaigning for candidates to take MS issues seriously.

Speaking up for MS across the UK – will you join us?

Too many people affected by MS in the UK have to fight for the treatments, services, care and support they need. Together we can change that.

Ashley, Philippa and Mary are part of a community of thousands of us speaking up for MS. Will you join them?

To get involved, visit **mssociety.org.uk/campaigns**

Campaigners and staff at the #20sNotPlenty demonstration

Keeping the pressure up in Holyrood

In Scotland, MS campaigners headed to the Scottish Parliament to raise their voices on PIP. Mary Douglas, chair of our Scotland Council, was one of the organisers.

She said: "We held a high profile #20sNotPlenty demonstration outside the Scottish Parliament in February, including members of the MS Society Council, groups and staff.

"Before the event, we invited MSPs to talk to us on the day about the 20 metre rule and how it impacts so unfairly on people affected by MS. As a result of our interventions, a Labour MSP asked about the PIP 20 metre rule in First Minister's Questions immediately before our demo. First Minister Nicola Sturgeon said: 'People with MS are badly failed by the UK benefits system.' Result!"

The Scottish Government will assume responsibility from the UK for new PIP claimants in spring 2021 and for current cases in 2025. The SNP has pledged to introduce a fair replacement for PIP.

With a Scottish Parliament election in May next year, we will continue to campaign to keep the PIP issue high on the agenda and encourage MSPs to keep their word.

Working with new MLAs in Belfast

The Northern Ireland Assembly is back. After almost three years without a devolved administration in Northern Ireland, an agreement was reached in January to bring an end to the political deadlock and for the NI Assembly and Executive to return.

It is fantastic news that political accountability and decision making have returned and we've been quick to respond. Our team in Northern Ireland have been briefing and engaging with MLAs from all parties on things like waiting times, problems facing the neurology service, developments around medicinal cannabis and on the ongoing issues with PIP.

We've already met with the new Minister for Health, Robin Swann, and are in the process of re-establishing our All Party Group on MS. We'll continue to work alongside people affected by MS to ensure the Northern Ireland Assembly works for them and delivers for the MS community.

Rise in number of people estimated to be living with MS

More than 130,000 people are living with MS in the UK – around 20% more than previously thought.

The UK MS prevalence figure, which estimates the number of people believed to be living with MS at any one time, was previously thought to be 110,000. The estimated number of new cases of MS identified each year has also increased from 5,000 to 6,700.

This means one in every 500 people in the UK is living with MS, with about 130 people diagnosed every week on average.

The results estimate that the number of people with MS in all four UK nations has increased, with Scotland seeing the biggest rise from 11,300 to 15,700.

Where do these figures come from?

We worked with Public Health England (PHE) to produce the new figures. Using 2018 patient information taken from a GP database, PHE applied the number of people identified as having MS to the population of England as a whole. We used the same research method to estimate UK-wide figures.

But the new figures don't mean the risk of developing MS has increased. The rise is likely to be due to a number of factors. These include improvements in the way MS is diagnosed, better recording of medical data, and the fact that people are living longer with MS.

"Too many people are struggling"

Dr Susan Kohlhaas, our Director of Research and External Affairs, said:

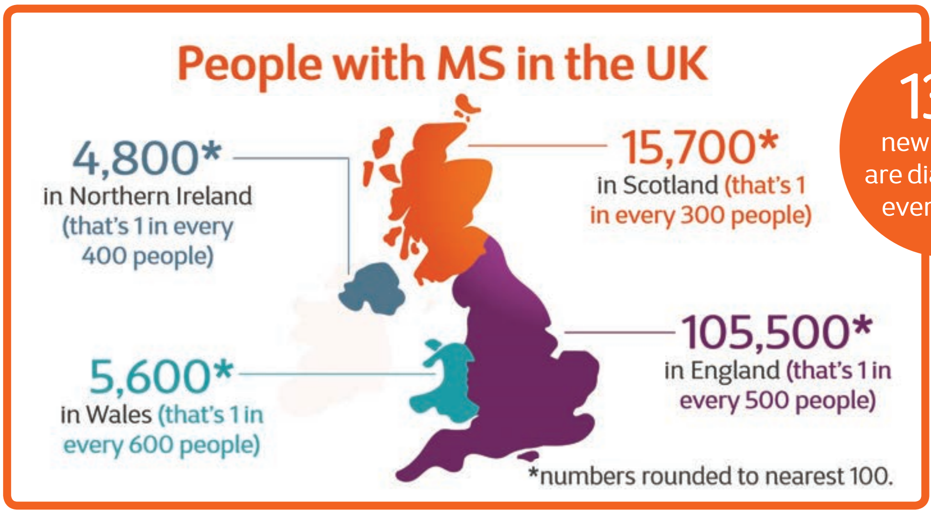
"While the NHS is getting better at diagnosing and recording cases of MS, in many ways society is getting worse at supporting people with the condition.

"Compared to just a few years ago, fewer people with MS receive social care support and key welfare payments. And we hear far too many stories of people struggling to stay in work without the adjustments they need.

"The Government needs to step up and create an expanded and sustainable social care system, overhaul the way benefits are assessed, and strengthen rights for employee support."

130 new people are diagnosed every week

Read the full report at **mssociety.org.uk/ms-in-the-uk**



Win £3,000 in our Spring Raffle

After the success of our Christmas Raffle, which raised over £120,000 to help stop MS, we're back again with our new Spring Raffle 2020. This time we're offering more prizes than ever before.

First prize is £3,000, and there are lots more smaller prizes to be won, including food hampers and 100 M&S gift vouchers for £25.

Take part by going to **raffleentry.org.uk/mssociety**. All funds raised go towards our work, from help and support to research.

MS ballet residency at the Royal Opera House

In January we partnered with the Royal Ballet for a three-month residency with people from our MS community. The group – many of whom had never danced before – developed a response to award-winning choreographer Cathy Marston's new ballet, The Cellist.

Inspired by the life and work of acclaimed musician Jacqueline du Pré, who lived with MS, The Cellist premiered at the Royal Opera House in February. Our MS collaboration will culminate with a 'Live at Lunch' special performance at the Royal Opera House later this year.

The weekly dance workshops were delivered by choreographer Bim Malcomson. They encouraged participants to find their own response to The Cellist while exploring the principals of ballet technique.

Bea Pulco, 43, has relapsing MS. She lives with symptoms including fatigue, pain and balance problems, but leapt at the chance to join the Royal Opera House project.

Bea said: "When I was diagnosed with MS 15 years ago, I became very depressed as I didn't know what it would mean for my future. But now, to be able to dance somewhere like the Royal Opera House is truly a dream come true."

For Bea (pictured centre) dancing at the Royal Opera House was a dream come true

HSCT advised for consideration in Scotland

At the end of October 2019, the Scottish Health Technologies Group (SHTG) advised that HSCT should be considered as a treatment for MS on NHS Scotland.

It said that HSCT should be considered for people with relapsing MS who haven't responded to disease modifying therapies (DMTs). And it said there should be equal access across Scotland to the treatment.

What is HSCT?

HSCT stands for haematopoietic stem cell transplantation. It's an intense chemotherapy treatment for MS. It aims to stop the damage MS causes by wiping out and then re-growing your immune system, using your stem cells.

It's most effective for people:

- with signs of active inflammation, as seen by frequent relapses alongside new or active lesions on an MRI scan
- who are early on in their disease course
- without significant disability (EDSS score of less than 6.5).

It's currently available to a limited number of people living with MS in England.

Together with the Scottish HSCT Network, we made the submission to the SHTG to consider HSCT for the treatment of MS. Their advice is welcome news and could help broaden treatment options for some people living with MS in Scotland.

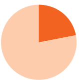
Read more about HSCT at **mssociety.org.uk/hsct**

Over 8,000 of you shared what it's like living with MS in the UK today

My MS My Needs is one of the largest surveys of people affected by MS in the UK. In 2019, an incredible 8,369 people living with MS responded to it – a huge thank you if you were one of them. Here are some of the key findings and what we're doing about them.

Care and support

There is a big impact on people with MS who are struggling to get the care and support they need.



22%

of people **don't get the help they need** to move about their home safely.

14%

of people **don't get the help they need with washing, bathing or personal care.**

This has a wider impact on people's health and wellbeing:

●●●○○

3 in 5

people who aren't getting the care and support they need are **feeling lonely or isolated.**

●●●○○○○○○○

3 in 10

have had their **work impacted.**

●●●○○

3 in 5

reported **deteriorating health.**

What we're doing

We're campaigning for a fair, effective and sustainably funded care system across the UK. We recently published a report demonstrating the impact of the care crisis on families and carers.

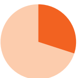
Access to professionals and therapies

Most people have been able to access an MS specialist nurse and neurologist when they needed to in the past 12 months.

However, some people were struggling to access services that support people to live well with MS.

44%

had not been able to get the emotional support they needed in the past 12 months.



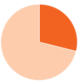
30%

hadn't been able to get **physiotherapy if they needed it.**

What we're doing

We work with local health and care systems to help services improve. In the past year we've made several successful cases for hiring new MS nurses.

Employment support



29%

of people who responded to the survey **retired early due to ill health**, showing that people may not be getting the support they need to stay in employment.

67%

of those who needed support to find employment **didn't get it.**

What we're doing

We're calling on the UK government to improve the provision of support for people to stay in employment. And for employers in the UK to promote inclusion and opportunity for disabled employees.

Making welfare make sense

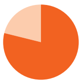
The financial support people receive through benefits isn't sufficient.

36%

Only a third (36%) of PIP recipients say they feel **comfortable on their household income**, compared to 47% of people receiving DLA.

What we're doing

Making welfare make sense for people with MS continues to be a top priority. This includes campaigning to overhaul the assessment process for PIP and scrap the 20 metre rule.



79%

The majority of people (79%) who are receiving one or more benefits, and whose annual household income is less than £25,000, say that **struggling on their income has caused them to feel stress or anxiety**. The same proportion said their **MS had become worse due to their financial situation.**

What next?

We'll use the findings to give a strong backing to our campaigning work over the next few years and to develop our services so that they best support you. We'll continue to campaign for change on issues around welfare, social care and treatments, so that people living with MS get the support they need.

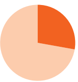
We're also launching our new organisational strategy, which you can read more about on page 40.

Improving access to treatments

Our 2013 and 2016 surveys found that around half of all people eligible to take a disease modifying therapy (DMT) weren't. This led to our Treat Me Right campaign calling for the right treatment at the right time for people with MS.

60%

of people with relapsing forms of **MS who may benefit from a DMT are taking one**, although there is variation across the UK.



28%

Over a quarter of people said they **haven't been provided with enough information** about available treatment options from health professionals.

What we're doing

We're tackling this unfairness in access. Most recently we made the case for ocrelizumab to be approved for early primary progressive MS in Scotland, as it is in England. It was approved in January and the decision endorsed in Northern Ireland and Wales too.

See the full findings from the My MS My Needs survey 2019 at **mssociety.org.uk/my-ms-my-needs**

Meet our Stop MS Champions

Our Stop MS Champions are at the heart of the Stop MS Appeal. They're raising awareness, growing our network and inspiring others to fundraise. Here three champions talk about why they got involved and their plans for promoting the appeal.

Bob Bragger ▾

Group Coordinator for Cambridge and District Group

I'm a carer for my wife, Ruth, who's had progressive MS for 21 years. I've always done a little bit of fundraising for the MS Society, but when we moved to Cambridge four years ago, and I had to stop full time work, I decided to get more involved.

I was part of a team that organised a music festival raising £2,500, and the first-ever MS Society motorcycle show. And I had a team of people manning the Cambridge Rock Festival carpark last year.

For the last 18 months I've been working with the Stem Cell Institute and MS Society Cambridge Centre for Myelin Repair. Last year, we did an art project where people with MS each made a ceramic tile. These were turned into wallpaper, which is now on the wall at the Stem Cell Institute, and we made a film about it.

This opened a lot of doors for me. One of the researchers does talks with me and I can see that the money we raise through the Stop MS Appeal is being put to good use. Although it's unlikely to benefit my wife at this stage, it might benefit future generations.

I've got a lot planned for Stop MS. We're working with a street artist and people with MS to design graffiti walls across the county to raise awareness. I'm also organising a coast-to-coast motorcycle relay from Lowestoft to the Welsh coast.

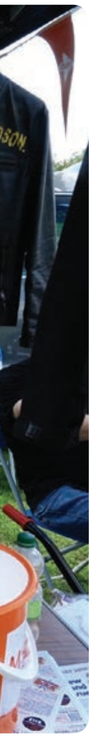
I talk about MS nearly every day. It's mainly awareness raising, but my view is that if you raise awareness, it's easier to raise funds. My last talk was to a mix of people with MS, researchers, a professor, MS nurses and the general public.

> **"I can see that the money we raise is being put to good use"**

My next talk is to the heads of public engagement for the stem cell institutes across the country. Then I've got another one at the National Council of Voluntary Organisations. It's not specifically for Stop MS but, if they give me chance, they'll find out all about it!

Marion Riley ▸

Group Coordinator for Chorley and Leyland Group



I was diagnosed with relapsing remitting MS in 2012. My grandma – my Dad's mum – also had MS. I look at the difference between what we have now, compared to what treatments and support she had then, and it's come such a long way. We are so close to being able to offer treatments for all forms of MS and that is crucial for those who currently have limited options.

I think Stop MS is such an important campaign and the more awareness we create about it the better. That's why we need people to go into the community. I think you need that personal touch, so people don't miss out on hearing about it.

> **"I think you need that personal touch, so people don't miss out on hearing about Stop MS"**

In 2018, it was the 40th anniversary of our group, so we came up with the idea of doing a Top 40 challenge. We asked people to challenge themselves to do something they wouldn't normally do. We aimed for a target of £4,000 and ended up raising about £7,000.

I turned 40 in 2018 and I thought, come on, let's tick a few of these things off my list. I did the Snowden zipwire challenge with my mum, who had just turned 60, and I also recently did a skydive. We had grandchildren doing sponsored swims, and one of our exercise groups and our hydrotherapy group also got involved. It was overwhelming what people did for us.

I've got lots of ideas for Stop MS. I've attended a couple of business networking events to get a feel for what they're about, and have picked up contact details for those wanting to support us. We have quite a few business estates locally and lots of distribution centres. I know they fundraise, so if I could get in and give a talk, that would be brilliant.

I'm planning to reach out to community groups. I've got my name down for a local farmers' discussion group, lady famers and the WI. And we've got a volunteering event coming up at the further education college where I used to work, so hopefully we can encourage the students to raise money.

What is the Stop MS Appeal?

The Stop MS Appeal is our biggest ever fundraising appeal. By 2025, we want to be in the final stages of testing treatments for everyone with MS. Treatments that slow or stop disability progression.

We believe £100 million could take us to a future where no one has to worry about their MS getting worse.

Find out more at **mssociety.org.uk/stop-ms**

Danah Kazim ▲

Member of the Lambeth and Southwark MS Group

I started volunteering with the Lambeth and Southwark Group when I moved to the UK, about four years ago.

My mother, who lives in Germany, has secondary progressive MS. She's had it since before I was born. Then five years ago, my best friend, Negin (pictured right), started experiencing some odd sensations up and down her leg. When I shared her symptoms with my mum, she thought it sounded like MS and suggested she should see a neurologist. It turned out she was right.

Growing up, I found that any help I could give my mum – whether it was emotional or physical – was greatly appreciated. It made her happy. Now I volunteer because I want to help other people with MS and fundraising is one way to do that.

With the Lambeth and Southwark Group, I've been helping to organise events. Sometimes I set up little fundraising programmes on the side at work and I ran the Royal Parks half marathon in 2017, raising £1,000. I wanted to do more running and I thought it would be great to do it for the charity.

> “Stop MS is one of the biggest things I've seen the MS Society do”

The Stop MS Appeal is one of the biggest things I've seen the MS Society do. It's not just about the fundraising but also about awareness. I want people to know about MS, and how serious it is, and be more tolerant towards people who are living with it.

From where my Mum was, to where we are today, treatments have made MS so much more manageable. I'm optimistic for Negin. Almost straight away, she went onto medication and she hasn't had any attacks since.

I've got lots of ideas for the Stop MS Champion role. I'm thinking of doing a Cake Break, as I know it can be quite successful. And I'll be talking to as many people as I can, such as community groups and social groups. It is about raising awareness so as many people as possible know what the MS Society is doing and how they can take part.

Champions wanted

We welcome more Stop MS Champions. To find out more about the role, contact **sian.dorward@mssociety.org.uk**

Heather fought cancer alongside living with MS

Living with MS and other health conditions

Many of us will need to manage more than one health condition during our lives. Three people with MS share their experiences, and we suggest some tips for how to cope.

"It's nice to talk to people with different conditions"

Heather Hockin was diagnosed with MS in 2004. Following a routine mammogram in 2017, she was diagnosed with breast cancer.

"I was coping pretty well with my MS when the cancer was picked up. Being diagnosed felt earth shattering. It's something that consumes your thoughts.

"It was a lot to be going on at the same time, but my friends, family and husband were very supportive. I also found it surprising how many

Heather’s top tip

Don’t Google things. Get information from websites like the MS Society, Cancer Research or Macmillan.

people I knew had had breast cancer and were able to reassure me.

“I had surgery to remove the tumour and then radiotherapy every day for three weeks. Getting there and back every day was exhausting. A big challenge initially was getting on and off the radiotherapy table, and into the right position once on it. I found this very difficult as I have a rigid spine (due to scoliosis) and a right leg that goes into spasm because of my MS. However, the two radiologists were fantastic and able to help me.

“The cancer has been successfully treated and, three years on, thoughts about it don’t consume me anymore. I’m screened once a year to check all is clear at an accessible mobile screening unit, where I get a longer session to dress and undress. That’s a big help.

“I get a lot out of complementary therapies, physio and yoga at a local centre. They help me relax and keep me mobile. And it’s nice to talk to people who’ve got different conditions.”

8 tips for living with several long-term conditions

1. Ask for help.

If you’re struggling, tell your GP or MS nurse. And don’t forget our MS Helpline, online forum and local groups. If you’re feeling depressed, learn what can help at **mssociety.org.uk/depression**

2. Cut down on hospital visits and travel.

If possible – and if you’re treated at the same hospital – ask to have your different appointments scheduled for the same day.

3. If you live in England, make prescriptions cheaper and easier to get

(prescriptions are free in Scotland, Northern Ireland and Wales).

Save money with a Prescription Pre-Payment Certificate. Buy one at **apps.nhsbsa.nhs.uk/ppc-online/patient.do**

For other ways to save, including getting free prescriptions, search ‘prescription costs’ at **nhs.uk**

Repeat prescriptions can be delivered across the UK for free through **pharmacy2u.co.uk**

4. Get a review of your meds.

Ask your pharmacist for a Medicines Use Review. They’ll answer your questions about what you’re taking, and make sure you’re taking them in the best way. They can check if taking these drugs together might cause side effects, or make one of your conditions worse.

In Scotland, ask for a Medicines Care Review. If your pharmacist doesn’t offer this, ask at a different chemist.

In England, you can also access the free New Medicine Service for help and advice if you’re starting a new drug for common health conditions. Search ‘new medicine service‘ at **nhs.uk**

5. Have a system for all your meds.

Things that can help you keep track of your meds include:

- getting a pill sorter or ‘dosette’ box (plastic boxes with different compartments for each day and time of day)
- writing on a chart the days and times when you should take your medications. Mark off each time you take them, so that you don’t forget a dose
- having set times to take your meds
- setting alarms on your mobile phone.

6. Get the social care you’re entitled to.

This is help you, or your carer, can get from your council (or, in Northern Ireland, your trust). See **mssociety.org.uk/socialcareservices**

7. If you’re going for a screening or treatment,

contact the unit beforehand to discuss what help or information you might need. For example, they may be able to give you more time or provide transport.

8. If you have an unplanned admission to hospital, let your MS nurse or team know,

even if it’s for something not related to MS. They’ll want to know as they can help you avoid delays in treatment and discharge from hospital.

Read more at **mssociey.org.uk/multiple-conditions**

"My health conditions don't define me"

Ronnie Green (pictured right with his brother) lives with type 2 diabetes, high blood pressure and MS. In the last three years, he's also had surgery for oesophageal cancer and a brain tumour. He's currently undergoing treatment after a small tumour was found on his liver.

"I try and proactively deal with my health conditions, learning about each one. Being open to discussing things with my health professionals has helped me make informed choices.

"My GP is my main touchpoint. I can also go directly to any of the specialist nurses or consultants. I'll ask about things even if I feel they sound silly – they're happy to listen and help. I've also had support from a 'living well' team, which includes regular appointments with a dietician to make sure I'm managing my diet.

"I ask questions about how my medications interact. For example, I discussed with my oncologist how the side effects of medication for my second cycle of chemotherapy might affect my MS. That led us to look into different drugs.

"The hardest thing about my health conditions has been losing my job and driving license. However, before my current round of treatment, I got a bus pass and was very active, doing courses and getting out to meet different people.

"My health conditions don't define me. I try to be positive and focus on the here and now."

Ronnie's top tip

Prioritise your different health conditions – don't take everything on at once.

"My struggles have built my resilience"

Liz Sheils lives with type 1 diabetes (T1) and MS. She also lives with mental health challenges: depression, anxiety and complex-PTSD.

"MS and T1 are both chronic, unpredictable, and challenging. There are daily ups and downs. Mental health challenges can make the physical conditions feel more overwhelming and less manageable.

"It can be difficult to figure out the cause of a symptom. Sometimes it's a combination of my different health conditions. I begin a process of elimination: firstly I check my blood sugar levels, then I think about factors that can flare my MS symptoms, or if they are new MS symptoms. Then I check my mental health – is something making me feel extra anxious or depressed? It's exhausting!

"My care is very disjointed. It gets tiring having to explain each of the conditions to each of the services. It would be helpful to have a service that joined the dots.

"The biggest challenge is the enduring nature of my health conditions. There is no holiday. Despite this, living with them has strengthened me as a person and built my resilience. My struggles have made me determined to help others."

Liz's top tip

Allow yourself to talk about how you are feeling – health conditions are hard and it's understandable to feel down or overwhelmed.

Manage your fatigue with our new online course

Fatigue - an overwhelming tiredness - is one of the most common symptoms of MS. So we've developed an online course that will help you find ways to manage your MS fatigue and explain it to other people.

The interactive, online course is easy to access and was created with the help of people living with MS. It uses strategies and techniques to help recognise and overcome unhelpful thought patterns.

The course is based on fatigue management workshops (called FACETS) that were developed at Bournemouth University with members from the Bournemouth MS Society group. We translated their face-to-face courses into six accessible online sessions, each around 20 minutes long.

The sessions cover:

- the daily reality of life with MS fatigue
- its practical and psychological aspects
- and useful tips and strategies to manage it.

Putting the course online means we can reach more people. We

5 tips for managing MS fatigue

Rachel Flinn is a neuro-physiotherapist working for the MS Society in Belfast, and Sheena McBriar was a participant on a fatigue management course. Together they came up with five practical, real world tips.

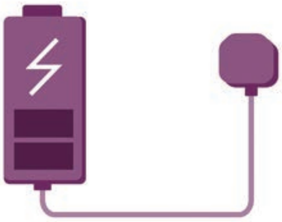
1 Try to be prepared for statements such as: “You look so well” or “How are you?”

Simple questions and remarks can be challenging to deal with.

How you talk about your fatigue affects your mental wellbeing. Many people don't understand what fatigue is. Have some replies ready, such as: “It's great to be here”, or “Today I'm 5 out of 10, tomorrow could be 9 out of 10”, or “I'm going with the flow”.

2 Pacing – use the ‘12 spoons approach’

Imagine you have 12 spoons of energy each day. Each task uses a number of spoons up. You have to plan how you use these spoons of energy each day and over the week.



can also cater for people with access needs, or who don't feel comfortable in groups.

"I have the tools to make my life better"

We developed the course with two test groups. Over 25 people gave us invaluable feedback, which helped shape the whole course.
Here's what people had to say:

"Very professional and polished without being patronising. Provided the course is easily accessible, it will be very useful for everyone with MS."
– Barry

"Through following the guidance in the modules, I now feel better prepared to cope with fatigue and will no longer feel guilty about having to change plans if I've overstretched myself. I will certainly make use of the delegate tool. I would definitely recommend this to anyone struggling to cope with fatigue."
– Ann

"The pressure at work is the hardest thing to overcome, but I have the notes from the course to help me. Thanks to this course, I have the tools to make my life better."
– Katherine

Access our online fatigue-management course at **mssociety.org.uk/fatiguecourse** And watch this space for new online courses in 2020.

3 Use the 'four D's' to decide how you plan a day or week

Dump! Does this task have to be done at all? Just because you always do it doesn't mean it has to be done.
Delay! Does this task have to be done today? For example, can you leave tidying that room to another time?
Delegate! Don't be too proud to ask for or accept help when needed.
Do! Do the task and build in rests.

4 Be prepared to do things differently

Think creatively – for example sitting down to prepare vegetables or maybe deciding on a few items to iron rather than doing all of them.

5 Write an activity diary

Record what you do each day and how your energy levels are related to this. This can help you understand your body, and to plan and pace yourself better over time.

Spotlight on treatments

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

Siponimod (Mayzent) licensed for secondary progressive MS

The European Medicines Agency (EMA) has licensed siponimod, making it the first and only oral treatment licensed in Europe specifically for people with active secondary progressive MS. This is a landmark moment the MS community has waited a long time for. Siponimod has been shown to reduce the risk of disability progression by 21% compared with a placebo. The next step is for UK health bodies to decide whether siponimod should be available on the NHS. We'll be working hard to make sure this happens as soon as possible, but we don't expect a decision until the middle of 2020.

Sativex approved on NHS in England

NICE approved the use of Nabiximols (Sativex) to treat moderate to severe spasticity (muscle stiffness and spasms) for NHS patients in England in November. Sativex is the first cannabis-based medicine to be licensed in the UK.

If you live in England, have moderate to severe spasticity, and other treatments haven't helped, you can ask your MS specialist for Sativex. However, it may still not be easy to get, because the NHS in some regions might not agree to pay for it or local prescribers might decide not to give it to people. And while Sativex is already available in Wales, the decision won't apply to Scotland or Northern Ireland. We won't stop campaigning until everyone with MS who could benefit can access it on the NHS.

Fampridine (Fampyra) approved in Wales

Fampridine is a treatment that can help some people with MS to improve their walking speed. In December, the All Wales Medicines Strategy Group (AWMSG) recommended it for use on the NHS. Wales is now the first country in the UK to recommend Fampyra. People with MS in Wales should no longer have to pay for the drug privately. It's now up to health boards in Wales to make sure people can access it, and we'll be working with them to ensure this happens.

Ocrelizumab (Ocrevus) approved in Scotland

In January, ocrelizumab was approved as the first treatment on the NHS in Scotland for adults with early primary progressive MS. This followed approval in England last year. We expect ocrelizumab to start becoming available in Scotland from April. The treatment is also approved in Wales and Northern Ireland, but it may be some time before it's available.

We'll continue to work to ensure ocrelizumab is made available to everyone across the UK who could benefit.

For more information about upcoming treatments, visit **mssociety.org.uk/emerging-research-and-treatments** or call the MS Helpline on **0808 800 8000**.

Alamy

Ask the expert: Steroids

Steroids are anti-inflammatory medicines that may be used to treat an MS relapse. Neurologist **Dr Gillian Ingram** answers your questions on all things steroids.

Q Is there a point at which steroids are not beneficial for someone with MS even though it looks like they're having a relapse?
Clive

The most important thing to consider when you have new MS symptoms is: what is causing this change? Not all changes in your MS symptoms are caused by a relapse. Many other things can cause a change in MS symptoms, and other medical problems can also mimic a relapse.

After other causes have been ruled out, the next question is how best to treat the relapse. Not all relapses need to be treated with steroids. Some trials have shown that high-dose methylprednisolone (a type of steroid) can improve symptoms quicker than a placebo – but other studies have shown that relapse symptoms tend to improve to the same extent whether steroids are used or not. And steroids do not change the long-term course of your MS. They also need to be started within two weeks of a relapse beginning.

Steroids can have significant side effects, such as infections or psychosis. You won't be given them to take long-term because this can cause osteoporosis, diabetes and other issues.

Therefore, if a relapse isn't causing you too many problems, it may be better to avoid the side effects of steroids and let the relapse settle down naturally. This decision needs to be made with your MS specialist so they can advise you on your individual risk.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Could you explain the pros and cons of oral versus IV steroids?

Ron

Trials have shown no difference in the outcomes or side effects between the two. It's therefore a question of personal choice and convenience. Most centres will offer oral steroids first to avoid the need for going to hospital. But if you're being admitted to hospital anyway, you may be offered an IV (where you take steroids through an infusion or drip).

(The two questions below have been answered together)

Why are steroids not beneficial for primary progressive MS, even after a relapse?

Andrew

Can steroids still be helpful for someone who has secondary progressive MS if they are no longer relapsing but are showing obvious progression?

Vanessa

Steroids only have an effect in MS by reducing the length of a relapse – they have no effect on the underlying condition and will not affect progression in MS. They're therefore not recommended outside of relapses.

Relapses, caused by new inflammatory lesions within the brain or spinal cord, are rare in primary progressive MS, although they can happen. Patients with progressive MS can often experience a change in symptoms caused by infections or other life events, and it's important that these problems are looked for before steroids are considered.

Should GPs prescribe steroids or should the decision be left to MS specialists?

Beth

Steroid prescribing in MS varies across the country. In our local practice, we prefer to see people in our multi-disciplinary rapid-access clinic. This allows us to make a full assessment and consider if the changes in symptoms are due to a relapse or something else. You should try to avoid having more than two courses of high-dose steroids per year, so prescribing steroids from one centre avoids multiple doctors prescribing multiple courses of steroids. Importantly, if there are signs of active MS, a disease modifying treatment (DMT) needs considering and this can only be done from a specialist centre.

I suffer really badly from withdrawal effects. Why aren't we given a tapering dose to reduce these effects?

Heather

The "steroid roller coaster" can be very difficult to manage and that is one of the things to consider when you're deciding whether to take steroids for a relapse. Remember that relapses will improve anyway and, if your symptoms are mild, it may be better to manage them without steroids and then consider DMTs to prevent future relapses. In general, tapering the dose of steroids is avoided to limit the total dose of steroid that is given (and limit the side effects). There are some individual situations when a tapered dose could be considered. You can discuss this with your local MS specialist.

The steroids I had for a recent relapse helped lots of other symptoms, such as my psoriasis, bloating and acne. These came back as soon as the steroids were stopped. Could I micro-dose with steroids for these?

Owen

You are right that steroids are used for lots of other inflammatory conditions like psoriasis. However, we try to avoid long-term use of steroids due to the side effects. You should speak to your GP about ways to manage your other symptoms alongside your MS.

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

Real life stories: living with MS

Three people share their experiences of living with MS

Joanne Chapman on managing stress.

Stress makes me feel worried, overwhelmed, teary, short fused, low in mood and depressed. It can make my MS symptoms feel worse. I can't think clearly. My fatigue increases as my sleep is often disturbed. And my mobility and balance worsens, increasing falls and severely impacting my life.

Having MS is stressful

On diagnosis, a tidal wave of emotions came over me. Attending a pity party and ploughing on caused increased stress.

And having MS meant there were many stressful decisions to make. To take a drug? To endure side effects? To try for a family? And there were feelings of guilt too. Can I be a good mum (whatever that is) when I have MS? I don't want my husband or son to be my carers.

> "There were many stressful decisions to make"

Everyone deals with what life flings at them in different ways, but with unpredictable symptoms in the mix and stress as a mummy with MS, I needed to take back control.

How I limit stress

Eliminating stress totally is impossible, but having strategies in place helps with unplanned eventualities. My support network is essential. Me-time, whether it's time out to rest and meditate, or having treats like a new nail colour, ensures my personal sanity. And future-proofing is key, whether it's adjustments for my home or purchases to help with symptoms.

Planning for known events and advance planning is also a priority. For example, booking for Little Man to see Father Christmas, or planning in downtime before and after I go away.

Little changes

With your mind saying one thing, your body doing another, and symptoms rearing their ugly head, stress is inevitable. It's not good for you, your relationships and those who rely on you, but these little actions and a bit of planning can help make life easier.

Read more from Joanne on her blog: **poorlyparents.wordpress.com**


Joanne and her son

Dave Hamson, who was diagnosed with MS when he was 19, talks about why he decided to join an MS Walk in London to help stop MS.

It was a big step for me. Even though I've organised and taken part in many different charity events, I've never done an event for MS before. This time the focus would be on me.

I'm not embarrassed to have MS. I have an Instagram account with thousands of friends with MS around the world, and I've posted about my struggles, fears and insecurities.

But when it came to fundraising, asking the people around me to part with their hard-earned cash in support of my personal fight against MS had been too much for my brain to process.

But stopping MS would mean waking up feeling good and refreshed for the first time in 10 years. It would mean not worrying about the future as much, and whether I will be able to walk my girls down the aisle, if and when then get married. Stopping MS would give back the piece of me that MS unforgivably stole.

My event might not raise a huge sum of money, but it has been an important, personal step for me. And I hope it will lead to many more charity events.

> “The focus would be on me”


Dave and his two daughters

In the end, Dave was unable to do the walk in London due to ill health, but he set up his own My MS Walk instead. Read more from Dave at **mssociety.org.uk/daveblog**

When Rachel Cooper was coming to terms with her MS diagnosis, one of the most difficult stages was telling other people.

In the beginning, I hardly told anyone about my diagnosis except on a strictly ‘need to know’ basis. I didn't want to be treated differently or for people to feel sorry for me.

I was most afraid of the reactions of people I worked with. I didn't know what they knew about MS or what they would assume it meant for me.

At first, I only told my boss, and I thought I'd get away without telling anyone else. That was fine for a year or so. But then I found myself feeling resentful that I couldn't explain why I yawned my way through meetings. Or why I sometimes had slurred speech in the afternoons, and had to write down every conversation so I didn't forget the details.

I thought keeping my secret was safer than telling the truth. But my worries were unfounded.

> “I thought keeping my secret was safer”

I learned a lot about the people I work with from the way they responded to my diagnosis. And I was pleasantly surprised with their kindness and understanding.


Rachel was surprised by her colleagues' reactions

Telling my colleagues what I was going through took an immense weight off my shoulders. And with their support I was able to think about having a career again - something I thought I would have to give up on.

Nowadays I work part-time, sometimes in the office, and sometimes from home. This means I can manage my fatigue and do my best at work. And I'm more focused, which means I work better.

Moreover, MS is part of me whether I like it or not. If I keep it hidden, I'm hiding part of myself. And that is a stressful thing to do.

Read more from Rachel at **mssociety.org.uk/workblog**

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"Grieving applies to all sorts of loss"

Our anonymous writer shares his experience of grief for the loss of his old life.

In a previous life, part of my job was to offer advice to all sorts of folks facing difficult situations. Fast forward twenty years and I find myself, as a carer, in need of the same support that I was so used to doling out to others.

My wife encourages me to live a life away from the daily routine of 'caring' but I am so reluctant to embrace this. Sometimes I found my guilt overwhelming.

Recently, a colleague told me that what I was experiencing was not guilt, but grief. This was a light-bulb moment!

Dealing with grief

Working through grief is more usually associated with the aftermath of the death of a loved one and learning to cope with loss and rebuild a different sort of life. But 'grieving' applies to all sorts of loss – in my case, loss of dreams and the mourning for a past life.

There are five classic stages of grief: denial, anger, bargaining, depression and acceptance.

The idea of grief counselling is to help the 'patient' work through the five stages and put the broken pieces back, not in the same way as before, but in a different way.

Sadly, some folks never get past stage one, pretending that the loss does not exist. For them, denial minimises the risk of drowning in their own grief.

Anger and bargaining

Adjusting to a new reality (after a diagnosis of MS perhaps) can lead to anger, which can be a cover for our fear.

Looking back over past perceived mistakes leads to bargaining: "If only we had got you to the doctor sooner" or "If only I hadn't said those hurtful things." We wish we could go back and behave differently. Realising our own human helplessness, some look to a higher power to influence outcomes. This gives back a perceived measure of control over something that feels so out of control.

Feeling depressed

Depression can set in when the stark reality finally hits home: How are we going to cope? What does the future hold? We might find ourselves retreating into ourselves and becoming more isolated.

When we come to a place of acceptance, it's not that we no longer feel the pain of loss. But we're no longer resisting the reality of the situation or struggling to make it something different. Sadness and regret may still be present, but the emotional survival tactics of denial, bargaining and anger are less likely to be present.

This is all very well in theory, and I do not overlook that my pain may be different from yours. But it may well be that more of us, as carers or people living with MS, are more caught up in this grief drama than we realise.

Find out more about coping with feelings of grief at **mssociety.org.uk/grief** You can also call our MS Helpline for support on 0808 800 8000.

iStock

Every issue we ask you a different question about living with MS. This time we wanted to know: **What helps you to live well with MS?** From your answers, it seems there are a lot of furry friends out there who like to help...

What helps you to live well with MS?

Shutterstock

"Being by myself"

Debbie

My two girls are my main source of living well. I also started to eat vegan food almost two years ago, with one day a month where I have a non-vegan day. And almost one year ago, I started mindfulness.

Rebecca

"My two dogs and my horse keep me going. My new puppy has turned me from an ill person living with MS to a well person living with MS."

Sarah J

My two dogs are what help me to live with my MS. I can't say I live 'well' with it, but Louis and Luna give me reasons to smile every day, no matter how hard I try to be miserable! In fact, they crack me up with their antics and yet always seem to know when I need some TLC too. They are nature's best antidepressant and I couldn't live without them.

Mandy

"Removing stressful things and thinking of myself more. I feel so much more relaxed and able to get through the day."

Louise

Knitting was my lifesaver when I had a relapse

Charmain

My family....and wine!

Sarah B

Mindset 100000000%

Jessie

"Being able to continue working despite becoming a wheelchair user. At work, I'm still 'me' – my MS and wheelchair are largely irrelevant. I also have a role in my employer's disability network, helping to make life at work better for all employees with disabilities."

Marie

"Accepting what I can no longer do."

Caroline

My Basset Hound was my MS counsellor. He would listen to every moan and gripe I had, and would be rewarded with a treat at the end. To be honest, I think the treat was his favourite part.

Tony

Painting stones and giving them out to children in the family or hiding them in local parks for others to find. I have no skill but it's nice to do. Plus I attend a community cafe at my local Salvation Army [where there are] lots of activities and a cooked lunch. [It's a place to] make friends and have a giggle.

Kerry

I run a therapeutic crochet and knitting flock for people with chronic health conditions. It's proven to be a good source of self-help for pain, and for meeting people and feeling part of something. We do charity projects sometimes, and giving back really boosts people's well-being.

Yolanda

"My husband and my family are the ones that help me through the day. I don't know what I would do without them."

Lindsay

"I find painting and drawing beneficial as they help me deal with stress and anxiety. While the final picture might not be that great, it's what you obtain from simply making the picture that is important."

Clive

For our next issue, we're asking: What's your best achievement while living with MS? Send in your answers to the MS Matters inbox at **msmatters@mssociety.org.uk** or keep an eye on our Facebook group, **facebook.com/mssociety** where we'll be posting the question later this year.

“Wasting a year of my life going through this process was soul-destroying”

Ben has been living with secondary progressive MS for 15 years. When he applied for PIP, he was initially rejected and had to go through a lengthy appeal process to get the support he needed. He told us his story on our blog.

When I was on disability living allowance (DLA), I was given an indefinite award for the higher mobility rate. This meant I could get a Motability car - meaning I could stay in work full-time and get to my medical appointments.

In April 2018, I was reassessed for PIP. Afterwards, the DWP decided I was no longer eligible for mobility support and I’d have to return my Motability car.

When I saw my report, I could tell it had been written by someone who’d never met me. It had no reference at all to the information I’d provided from my GP or consultant neurologist. The report said I could walk between 50-200 metres, but the PIP assessor didn’t even see me stand.

I submitted an appeal and had to wait eight months for my tribunal hearing. I won the appeal and the doctor on the panel even apologised for what I had to go through.

Having to prove myself to the DWP made me feel awful. Wasting a year of my life going through this process was soul-destroying.

Are you a budding blogger?

If you’d like to write for our online community, get in touch with us at **msmatters@mssociety.org.uk**

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

✉ Email **msmatters@mssociety.org.uk**

Facebook **www.fb.com/MSSociety**

Twitter **@mssocietyuk**

Ben’s article struck a chord with many of you on Facebook. Here are some of your responses:

Ian

I attended my son’s PIP assessment and it’s one of the most degrading things I have experienced. The assessor was at pains to tell us she was medically qualified, but surprisingly not in MS. As others have said, continually repeating the same questions, to which we kept referring her to the questionnaire completed before we attended. Yet again, final report was not reflective of the discussion.

Billy

I was on DLA but didn’t get PIP. Just the thought of another application is soul-destroying. My worst symptom is fatigue. I lose entire days to it. However, it’s not a symptom you can see. It’s more a case of ‘climbed the stairs, had to lie down for four hours afterwards’.

Kathryn

The whole process was deeply destructive as you focus on all the things you can’t do. The negative mental impact is lasting.

Find out about our MS: Enough campaign and what we’re doing to improve welfare for people living with MS at **mssociety.org.uk/ms-enough** And for advice on benefits, contact our Benefits Advisor through the MS Helpline on 0808 800 8000, or email **msbenefitsadvice@dls.org.uk.**

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Huw skydiving to help stop MS

Volunteer spotlight: Huw Roberts and Naomi Manton

Huw Roberts and Naomi Manton are incredible champions for the MS community in Wales. They've recently stepped down from the MS Cymru Council, which Huw volunteered on for six years and Naomi for five.

Naomi has led campaigns to improve access to treatments and services in North Wales. She's used her own experience of living with MS to raise awareness of the condition among health and social care professionals. They are both prolific fundraisers, and Huw is one of our new Stop MS Champions (read more on page 18).

Naomi said: 'It's been a pleasure to help keep the channel of communication between people affected by MS and those at all levels within the MS Society open. It's enabled me to give a voice to everyone affected by MS in my area, giving their feedback and comments to the council."

Naomi received one of our Shining Star awards in 2019

Huw said: "I've travelled around Wales attending the volunteer forums, MS Society events and have spoken at a variety of functions. Importantly, my role has included raising awareness of MS and the work of the MS Society wherever I travel. It's been a privilege."

Huge thanks to Huw and Naomi for their wonderful contribution. Diolch yn fawr i chi gyd!

Behind the scenes

Living well with MS

CEO Nick Moberly explains one of our new MS Society goals.

One of the three new goals in our MS Society strategy is: People living well with MS. Here's a little more about what that means.

Supporting people living with MS

We want people to live well with MS. We'll continue to expand our range of services that help people to understand their rights, manage their condition and do the things in life that are important to them.

Supporting carers, families and friends

We know that MS is tough on carers, families and friends. We'll provide the best quality information to help people understand MS and their rights as carers. And we'll keep developing the support we offer, to help everyone's health and wellbeing.

Guaranteed access to responsive treatments, care and support

We'll be fighting to make sure everyone can access the treatments, care and support they need, wherever they live in the UK.

We want the policies made by governments, and the health care people get, to reflect what people with MS, their family and friends go through day to day.

Find out more about our strategy at **mssociety.org.uk/strategy**

A new approach to membership

We're revamping what it means to be a member of the MS Society.

We believe that together we can create a world free from the effects of MS, and to do that we need to reach as many people as possible within the MS community. One of the main ways we do that is through membership of the MS Society. And if you're reading this, you're likely already a member, paying £5 a year for the benefits that come with that, including MS Matters. But membership numbers are declining, and feedback suggests being a member isn't as attractive as it could be.

We want to grow the MS community, so we've been speaking to members and non-members to find out what you'd like from membership and how we can best deliver that.

Here are some of the things you told us...

You want information that's relevant to you

You told us you'd like information that's tailored to your individual needs and personal experience of MS. This includes receiving information in your preferred format, whether that be in print or electronically.

You want to communicate with us in a way that's accessible and open to all

Some of the ways that we communicate with members aren't working for everyone. For example, only a very small number of members attend the AGM every year. And only 14% of members vote.

You want to help shape what we do and how we achieve our goals, but without the formal responsibilities of being a legal member

Currently, one of the key features of being an MS Society member is that you are a legal member of the organisation. This means you have legal rights to attend our AGM, elect directors (our trustees) and vote on resolutions. Your feedback has let us know that you want to play a part in shaping our future and how we best serve the MS community. But you're less concerned with formal responsibilities. You don't always think they're the best way to have your say.

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What are we going to do about it?

A refreshed MS Matters
Thank you for sharing your views on MS Matters in our survey. We're delighted that our members find it upbeat, inspiring and easy to read. We received over 600 responses and you've given us some great feedback on what you like about the magazine, what you want to see more of, and what you're less interested in. We're already taking that feedback on board and you'll start to see more changes in future editions. We'll be working to create the best possible magazine for everyone.

A better online experience for members
We're developing exciting plans for how we communicate with you online, to give you easier access to information that matters and is relevant to you.

Changing legal responsibilities
We're proposing a change to the membership model so that the responsibilities of being a legal member would be transferred to the trustees and the chairs of our national councils. The trustees and chairs are accountable to the whole MS community, so they'd still be representing your views and making sure your voices are heard on constitutional and governance issues.

Retaining the right for the community to elect trustees
Although the majority of members don't currently vote to elect our trustees, we know that some of you highly value this important right. We also want to keep the democratic principles that underpin us. Therefore, all supporters, whether or not they're members, will be able to choose to be part of an electorate who'll elect new trustees to the board. They'll also vote on other key issues, such as our strategy.

We're developing new ways to hear your views and take them on board
Instead of formal votes for resolutions at the AGM, we'll create other ways for you to feed into our work and decision-making. For example through surveys, focus groups, and co-production groups. This way our community can work directly with our staff and volunteers on specific ideas and projects. Most importantly, you'll be able to choose how much you engage with these opportunities and through which routes.

Have your say on the changes

Because the current membership model means you're legal members, we can't make these changes without you voting for them at the 2020 AGM. We'll be sending out more details on the proposals to make sure you have the information you need to make an informed decision. The AGM will take place on Saturday 19 September and voting forms will come out to members in the summer. This year, we'll be sending these to you by email to reduce the cost of printing and posting. However, if we don't have an email address for you, we'll still send you a hard copy.

If you have any questions about this change or anything to do with membership, please email **membership@mssociety.org.uk**

Emily

Polly

Getting to know you...

We interviewed our two new trustees, **Emily Revess** and **Polly Williams**, who both live with MS, to find out more about their lives.

What's your day job and what does it involve?

ER: I'm a civil servant in the Cabinet Office. I work on building partnerships between business and government to tackle the UK's biggest social and economic challenges.

PW: I work for the Royal Academy of Engineering, leading a programme to improve diversity and inclusion across the engineering profession.

Why did you apply to become a trustee for the MS Society?

ER: Having volunteered with several charities and campaigns since I was a student, I wanted to make a more meaningful long-term contribution to a charity close to my heart. I'm committed to creating a more inclusive society that realises the potential of all individuals.

PW: I found the MS Society's information and guidance really helpful when I was first diagnosed, so I wanted to contribute my skills and experience. The MS community is hugely diverse, with a range of lived experiences and needs. I want to help the MS Society reach out more widely and engage with everyone living with and affected by MS.

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

ER: My parents used to always tell me: "Fire in the belly, ice in the mind." I love the idea of keeping that passion and drive burning inside you whilst maintaining a cool head and a clear focus.

PW: Focus on things within your control and don't sweat the small stuff.

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

ER: Emmeline Pankhurst, Ruth Bader Ginsburg and Michelle Obama.

PW: I'd invite Agatha Christie, Jane Goodall and Amal Clooney. And I'd try and join up with Emily so I could meet her guests too!

What is the most important lesson life has taught you?

ER: I believe that you can achieve anything you set your mind to. The biggest lesson I've learnt is that the journey to achieving your goals may not look like what you first imagined it to be, but that doesn't take anything away from the result.

PW: Take time to enjoy the little moments in life.

On page 36, we asked people for top tips for living with MS. What are yours?

ER: Listen to your body. Take a break when you need to. Sometimes you just need a gin and tonic.

PW: Take it one day at a time, be good to yourself, and remember there's a great community out there who can support you.

Join our Board of Trustees

We're looking for talented people to join our Board of Trustees and National Councils for Cymru/Wales, England, Northern Ireland and Scotland. Our trustees play a vital role in creating our strategy and making sure we do the best we can for all people living with MS. And our National Council members provide a crucial link between those who manage the MS Society and the wider MS community. For more information, visit **mssociety.org.uk/people** or contact Danielle Walker at **governance@mssociety.org.uk**

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Our mystery fitness shoppers

In South Wales, people living with MS have developed MS-friendly criteria to rate local gyms and leisure centres. And they're visiting as mystery shoppers to assess what's on offer.

The initiative is part of our Big Lottery-funded Active Together pilot project, which promotes fitness and friendship for the MS community.

Here, some of the people involved share their experiences.

Hayley Driscoll trying out a climbing wall in Cardiff

Hayley Driscoll was a mystery shopper at Boulders indoor climbing centre in Cardiff.

"I went up and down the climbing wall because I knew I was safe. I had someone at the bottom who was supporting me and operating the specialist hoist. And all the staff were friendly and encouraging.

"It's hard for someone with a disability to think they can do an exercise like this. But you can, and I did. And it filled me with power like I haven't felt for a long time.

"The MS mystery shopper survey is invaluable. There is nothing worse than being disabled and getting to a leisure centre, all prepared mentally, and then you can't get through the door, there's no ramp, no rails, the doors aren't electric. From the front door onwards, you've got a lump in your throat and it fills you with anxiety. You think, 'why do I bother?'"

Andrew Swinfen and Hayley Driscoll are part of the mystery shopper project

Andrew Swinfen was involved in designing the mystery shopper survey.

"The survey means that people with MS can say exactly what we want, what we need and what benefits us. Going to a leisure centre and knowing that it's accessible, and the staff knowledgeable and helpful, gives us peace of mind. It has a massive impact on our independence and means we can have the same opportunities as people without a long-term condition or disability."

Hayley Jones can no longer use the swimming pool at her local leisure centre.

"I was going swimming three times a week. But now I'm not at all because I can't get in the water. Since I stopped going, my muscles have seized up, I can't lift my leg up high, and my arm strength is going. Having MS shouldn't stop me from exercising in my local community centre. It was built around the Aberfan community, but now it isn't serving us."

For more information on the Active Together project, contact **bethan.moss@mssociety.org.uk**

Celebrating our MS superstars

Unexpected outcome for polar trek challenge

In December, Michael Mitten attempted the incredible feat of trekking 111km to the South Pole on foot, all in aid of the MS Society. It was in memory of his mum, Christine Mitten, who passed away in 2016 after 18 years living with MS.

Unfortunately, due to a suspected chest infection, subsequently diagnosed as pneumonia, Michael had to cut things short just three days into the 10-day trek. Despite this, he has still raised almost £20k for the MS Society, with more fundraising efforts planned.

He said: "I think it's fair to say the trek did not go to plan, and I'm gutted it had to be cut short. But it became clear that to attempt to continue in those conditions would be a serious risk to my health.

"My pain and frustration only pales in comparison to what people with MS experience every day. I know how difficult it is to want to continue but know that my body won't let me, and that's a feeling that people with MS are all too familiar with."

You can find out more about Michael's challenge and see photos from the trek at **PolesApart2019.com**

Amazing Arctic explorers

A huge thank you to our amazing 10-person team of Arctic Trek fundraisers, who have raised over £40,000 so far to help stop MS. The intrepid explorers set off from Scotland in January for our first ever three-day trek in the Arctic Circle, taking on adverse conditions, frozen lakes and long climbs.

Carols by Candlelight

Our annual Carols by Candlelight concert raised £22,000 for our Stop MS Appeal. Actors Kit Harington, Rose Leslie and Nicola Walker, comedian Paul Merton, Paralympian Kadeena Cox MBE and Dragon's Den's Deborah Meaden joined 300 supporters for the festive gathering.

Comedians stand up for MS

Comedian Ivo Graham hosted a show to raise funds for the MS Society at London's Comedy Store. Stars including Alan Carr and Russell Howard raised lots of smiles and £7,500 for our Stop MS Appeal.

Stop MS Dinner

On 21 November, our Stop MS Dinner at the Principality Stadium in Cardiff raised £7,500 for the Stop MS Appeal. The event was opened by Mark Drakeford, First Minister for Wales, and included a talk by rugby legend JPR Williams whose daughter has MS.

Fundraising events during the COVID-19 pandemic

A note from our CEO, Nick Moberly, on our fundraising events during the COVID-19 pandemic.

As a result of the coronavirus outbreak, many events have had to be postponed.

As a charity, this has a huge impact on us as we rely heavily on the funds generated from these events to carry out our work. Indeed, I was due to be joining you on the streets of our capital for the Virgin London Marathon later this April.

We are talking regularly with other event organisers and will be in touch with you directly if any of our events need to be postponed or cancelled. We'll update individual event webpages with new information as it comes in, so please do check those pages regularly.

And you can also check for updates at **mssociety.org.uk/covid-19-events**. If you have any questions about our fundraising events, contact us on 0300 500 8084 or **challenge@mssociety.org.uk**

Welcome to MS Sessions

A festival of friendship and MS

Hilary Freeman reports from MS Sessions, a festival for young people living with MS across Europe.

In a hotel dining room in Bucharest, Romania, a large crowd of young people are chatting as they queue for the lunch buffet. They may come from 35 different European countries, but they have something important in common: they all have MS.

Some have invisible symptoms, while others use crutches or wheelchairs. The atmosphere is palpable, with a real buzz of excitement and sense of camaraderie. Eavesdrop, and you'll hear people talk about their personal lives, their symptoms, and which MS drugs they've been prescribed, or – in the case of the Eastern Europeans – their lack of access to drugs.

MS festival

This is MS Sessions, the world's only 'festival' for people with MS. The two-day event, organised by the online MS charity, Shift MS, is both a conference and a party. It has a packed programme of seminars and talks from neurologists, therapists and patient advocates, as well as music, dinners and late-night bar sessions. A total of 170 people, aged 20 to 40, attended the 2019 festival in October, which was the second of its kind.

Talks on MS

The sessions included a talk on how to look after your brain and counter cognitive decline by neuropsychologist Dr Sabina Brennan, and advice from neurologist Dr Jeremy Hobart on becoming a key player in your own healthcare. This included the suggestion that everyone with MS keep their own 'blue book' documenting their condition and treatments. Neurologist Sarmilee Gnanapavan gave participants the low-down on the latest MS research, while sex therapist Moira Tzitzika talked about sex, relationships and MS. The experts' talks were interspersed with first-person testimonies from people living with MS across Europe.

At MS Sessions, people find support, forge lasting friendships and, sometimes, form romantic relationships (there's even been an MS Sessions baby). They also gain knowledge about their condition and how to manage it, plus, many attendees say, a newfound sense of empowerment.

Get involved

The next MS Sessions conference is pencilled in for 2021. In the meantime, there are also MS Society events that happen throughout the year. And you can join your local MS Society group for friendship, support and information about MS. Find your local group at **mssociety.org.uk/local-support** And for more information on MS Sessions, visit **shift.ms**

Staying positive with MS

When **Caroline Millar** was diagnosed with MS, she decided quickly that a positive mindset would be key to how she lived her life. She is now passionate about spreading that message.

I was diagnosed with MS as a sports-mad and competitive 22-year-old. I think I realised that if my mindset was negative, it could have been a life sentence.

For me, mindfulness and a supportive network are vital for good mental health and achieving what you want to do in life. I think that applies to everyone to be honest, whether you're living with MS or not.

I sometimes think my friends get sick of me going on about mental health, but it's vital and it links with social interaction and physical activity. Depression is often linked to social isolation, and that can be a vicious circle with something like MS. If you stop going out when mobility is an issue, it can cause problems.

I'm part of an MS Society group. Together with other groups in Northern Ireland, we wanted to provide an emotional support and wellbeing service. We all worked really hard and secured over £150,000 from the National Lottery for the Mind my MS project to provide counselling and mindfulness sessions to people living with MS, and to organise and host community cafes to keep people connected and engaged.

It's so important to keep in touch with people who understand you. It's about sharing what's worked for you and learning from others.

If you live with MS in the Mid and East Antrim area, find out about Mind my MS at **mssociety.org.uk/mindmyms** or email **mindmyms@mssociety.org.uk**

Activity corner

Mindfulness

Each issue, we feature a tip on staying active with MS. This time we're talking about mindfulness.

Fans of mindfulness say it helps them pause and take notice of the world around them and the way they feel. It could even help with MS symptoms like fatigue and pain.

The idea is to notice what's happening in the present moment. How do you feel in your mind and your body? What are your surroundings? By focusing on these details, people can find stillness and calm. Some tools that can help you develop mindfulness techniques are:

- a mindfulness podcast or book
- guided meditation videos
- gentle yoga, which often includes mindfulness
- or a mindfulness course.

You can then use these techniques to create moments of stillness in your life. For example, you could:

- listen to the podcast on your phone wherever you are
- take two or three minutes to watch a bird in the garden
- or read a poem.

To find out more about mindfulness, visit **mssociety.org.uk/mindfulness**

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"The choir brings a bit of sunshine into my day"

Choirs in Wales are spreading joy and helping to combat loneliness in the local MS community.

Wales is known as the land of song and, with two choirs made up of people affected by MS, the MS community is doing us proud.

The choirs are called aMaSing: one in North Wales and the other in the South. They sing to raise awareness of MS and spread joy to the wider MS community, helping to combat isolation and loneliness.

A Big Lottery grant helped set up the choir in South Wales, and it now has over 40 people regularly taking part. They'll soon be recording a CD at the Shabbey Road Studios in Caerphilly to help with fundraising.

Rachelle's story

Diagnosed in 2009, Rachelle Ledsom from Caerphilly lives with secondary progressive MS. Rachelle is part of aMaSing South Wales. Here she describes what it means for her to be involved.

"I struggle every day to do basic tasks and my husband does the majority of housework. I have definitely worsened since diagnosis and now use a rollator all the time as I have no balance. If I'm going out I will either use my scooter or wheelchair.

"My good friend Hayley was in the choir so I decided to give it a try.

"I find the choir lifts my mood. Everyone is so happy and we have such a laugh. It's so lovely, not just for the singing but to meet everyone, feel a part of the group, have a cuppa and a chat.

"When you have MS, you can spend too much time housebound, and having the choir is something to look forward to. It really lifts my spirits.

"I'm so glad to be part of it, and Sianny, the MS Society's Local Network's Officer, makes the most gorgeous cakes! Life with MS is so difficult and the choir brings a bit of sunshine into my day."

Rachelle (right) and Hayley are members of aMaSing South Wales

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