

## Cost of living crisis

Our community speaks out

**Plus**

Latest news about our clinical trial, Octopus

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Issue 144  
**Summer 2023**

I've been editing features and interviewing people for MS Matters since I started at the MS Society in November 2021. In that time, I've met some amazing people from the MS community. And I feel so proud of the magazine and the journeys it highlights.

But hearing about people's experiences of the cost of living crisis has been hard. There's no way to sugarcoat the current situation. And knowing that many people in our community are sacrificing essential care and treatments just to afford to live infuriates me. So we've used this issue to help people voice their frustrations. But also to offer hope and some joy during a difficult time.

Turn to page 22 to hear from four people about their perspectives on the cost of living crisis. On page 18, we interview celebrity chef and activist Tom Kerridge. And on page 26 we look at some research that could help people with MS stay in employment for longer.

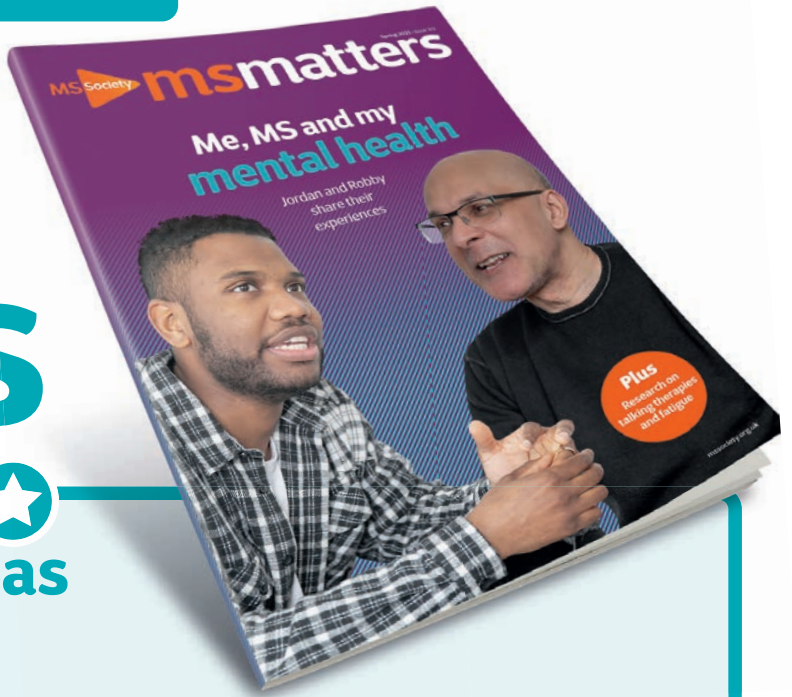
I hope you find some comfort in this issue. If you're struggling, or want to talk about any of the topics in the magazine, our MS Helpline can offer support. Call for free on **0808 800 8000**.

As always, we'd love to hear from you. Please send any comments, feedback or suggestions to **msmatters@mssociety.org.uk**. And if you're interested in helping create MS Matters find out about our new MS Matters engagement group at **mssociety.org.uk/co-pro**

*Claudia*

**Claudia Knight** Digital Editor

# Your Letters



## Mental wellbeing ideas

After reading the spring issue of MS Matters on mental health, I'd like to share some ideas I use to support my wellbeing.

I keep my brain active by playing Mah-jong online and doing the free crossword and competition in the weekly Waitrose newspaper. I also get cooking ideas from here. I use a mindfulness app on my Apple watch and love to listen to the sounds of the seabirds, as I live by the sea. This helps me focus and divide my day up.

From a practical point of view, I've moved to a place with a lift by the front door. I also asked if it's OK to use my own disabled parking triangular cone in one of the bays.

I bought the cone from the online motorway shop. In the past, I've found

people have been prejudiced about me using it and have tried to trash it. But it survived and people are better about it where I live now.

I have pauses to feel good about life here and now. I enjoy listening to the radio and TV, following sport and keeping up to date with current affairs, especially the latest MS and neurological research.

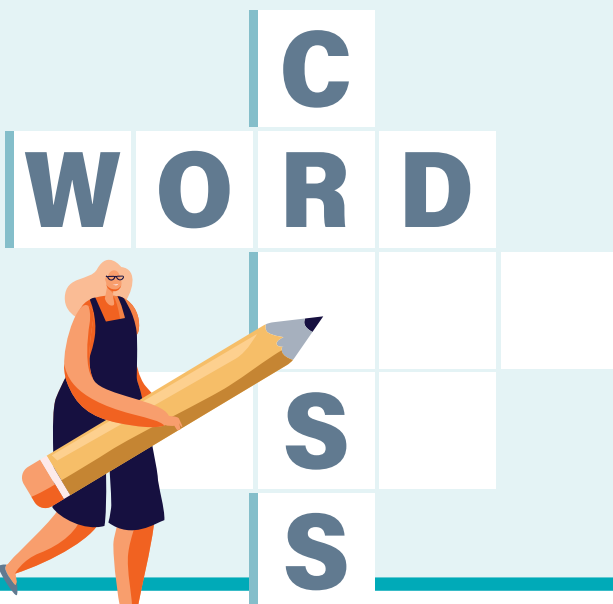
I also use lots of methods I've learned online through an MS Society fatigue management course, such as pacing and reframing. I organise myself with lists and accept that sometimes I need help.

I try to predict what sort of day I'll have while also trying to be flexible and keep positive. After all, it's a new day.

**Sharon Lawrence**

- Learn about fatigue management at [mssociety.org.uk/fatigue-management-course](https://mssociety.org.uk/fatigue-management-course)

**share** Let us know your thoughts at [msmatters@mssociety.org.uk](mailto:msmatters@mssociety.org.uk) Or use the hashtag **#MSMatters** on your social media channels. You can call the MS Helpline for support on **0808 800 8000**.



“Being part of this campaign gives me power”

Last year our **#BreakingPoint** campaign called for better support for people with MS through the cost of living crisis. Thousands of people signed our petition and hundreds wrote to their MPs.

Following the campaign we were pleased to see:

- a new cost of living package
- an extension of the Energy Price Guarantee
- benefits increasing in line with inflation

But we know these changes weren't

enough for lots of people.

Becky Sim, who lives with MS, shared her experiences of the cost of living crisis and helped shape our campaign last year. Becky explained why she got involved.

“As a person living with a disability I can't ignore, I feel ignored and forgotten about by the Government. I feel they're not listening and don't seem to care. It's all about massive profits for big companies – wealth for the few and growing poverty for the many.

“The support the Government has said it'll provide won't go far enough. I'm asking the politicians to sort this out. They've got the power to do that. I don't feel I've got any power.

“But being part of this campaign is giving me some power.”

People with MS were

reaching breaking point last year, and we know that things are now even worse for many. The UK Government has recently announced big changes to benefits. So we'll continue to campaign to make welfare work for people with MS throughout the year.



Would you like to take part in our campaigning? We're looking for people to share their experiences with the benefits system and help guide our campaign. Please email **campaigns@mssociety.org.uk** to get involved.



# Campaign updates

We're campaigning to make disability benefits like PIP work better for people with MS

## Campaigning on Adult Disability Payment in Scotland

Last year Adult Disability Payment (ADP) replaced Personal Independence Payment (PIP) in Scotland. Despite our campaigning, ADP kept many aspects of PIP, including the 20-metre rule.

In response to our campaign, the Scottish Government committed to consult on the rule and the 'moving around' part of ADP. This will form part of their review of the benefit.

We've continued campaigning against the 20-metre rule. Our

campaigns highlight how the ADP and PIP criteria discriminate against people with conditions that can vary day to day, like MS.

We asked our community to respond directly to the consultation and over 100 people took part. We've also handed in a response from the MS Society and one from the Cross Party Group on MS (which is led by MSPs). We've also raised the issue with a Scottish Parliament Committee.

## Access to Sativex can be life-changing

In March we launched the second phase of our campaign for access to Sativex. This is a cannabis-based spray for use in moderate to severe spasticity when other treatments haven't worked.

Newcastle resident Michael shared how Sativex changed his life. He says "Since taking the drug my spasms are reduced considerably. I now regularly get a full night's sleep, a godsend for not only me but my wife too."

Unlike many people living with MS, Michael can access Sativex through his local hospital. We believe everyone who's eligible should get a chance to try Sativex, if their doctor thinks it's right for them.

- Find out more on our campaign at [mssociety.org.uk/sativex-blog](https://mssociety.org.uk/sativex-blog)

## How the Government plans to change disability benefits

In March the UK Government announced their biggest planned changes to disability benefits in a decade.

Their plans include testing the use of specialist benefit assessors and automatically sharing assessment reports with people who apply for PIP. We've campaigned for these changes for years, so this is a big win!

However, we're concerned by their plans to replace the Work Capability Assessment (WCA) with the Personal Independence Payment (PIP) assessment in 2026. Under this plan, the PIP assessment will decide if people on Universal Credit get extra financial support for a health condition. We know many aspects of the PIP assessment don't work for people with MS, including the 20-metre rule and informal observations.

In response, over 3,000 people in our community emailed their MPs to ask them to support a review of PIP. We'll continue campaigning to make disability benefits work for people with MS later this year.

## Back the 1 in 6

An incredible 19,000 people signed the Neurological Alliance's petition calling on UK governments to **#BackThe1in6** of us living with a neurological condition. The petition was delivered to the Department of Health on 5 June. And MPs met with people with neurological conditions in Parliament to hear how they can support the campaign.



## Dates for your diary

### Thursday 17 August, 6.30pm Movement, motivation and MS webinar

Find out how movement benefits your physical and mental health with one of our MS Helpline physical activity specialists and a physiotherapist.  
[mssociety.org.uk/movement-webinar](https://mssociety.org.uk/movement-webinar)

### Monday 4 September, 6.30pm Progressive forms of MS wellbeing course

In this three-week course we'll look at ways to support you to live well with MS. We'll also connect you with other people living with progressive MS.  
[mssociety.org.uk/progressive-ms-course](https://mssociety.org.uk/progressive-ms-course)

### September – various dates MS Walk

Walk, roll or stroll to stop MS this September! MS Walk is coming to Glasgow (9 September), London (16 September) and Cardiff (23 September).

Wherever you take part, you'll take in the iconic sights of each city while raising life-changing funds for MS research. Don't miss out on a special day in London as we celebrate the 10-year anniversary of MS Walk London!

[mssociety.org.uk/ms-walk](https://mssociety.org.uk/ms-walk)

Find more fundraising events at [mssociety.org.uk/get-fundraising](https://mssociety.org.uk/get-fundraising). And see our programme of webinars and information events at [mssociety.org.uk/virtual-support-events](https://mssociety.org.uk/virtual-support-events)

# Octopus is here!

We're excited to announce Octopus has now started recruitment in London, Edinburgh and Southampton.

This means the first people with primary and secondary progressive MS have begun taking part. There'll eventually be up to 30 sites around the UK, including in:

- Scotland
- Wales
- Northern Ireland
- Yorkshire
- West Midlands
- South England.

## Can I take part in Octopus?

If you're interested in taking part in Octopus, you can register your interest through the UK MS Register.

You'll be asked some questions about your MS to see if the trial is right for you. And you'll be asked where you live, so the closest trial sites can get in touch when they start recruiting.

For most people, this won't happen for quite a while. This is because trial sites are still getting set up and over 1,700 people have already registered their interest.

## What is Octopus?

Octopus is the new clinical trial we've committed to fund. And it's designed to transform the way treatments for progressive MS are tested. It's the first multi-arm, multi-stage trial for MS. A smarter way of testing potential treatments, it could deliver life-changing new treatments up to three times faster.

- Find out more about Octopus at [mssociety.org.uk/octopus](https://mssociety.org.uk/octopus)

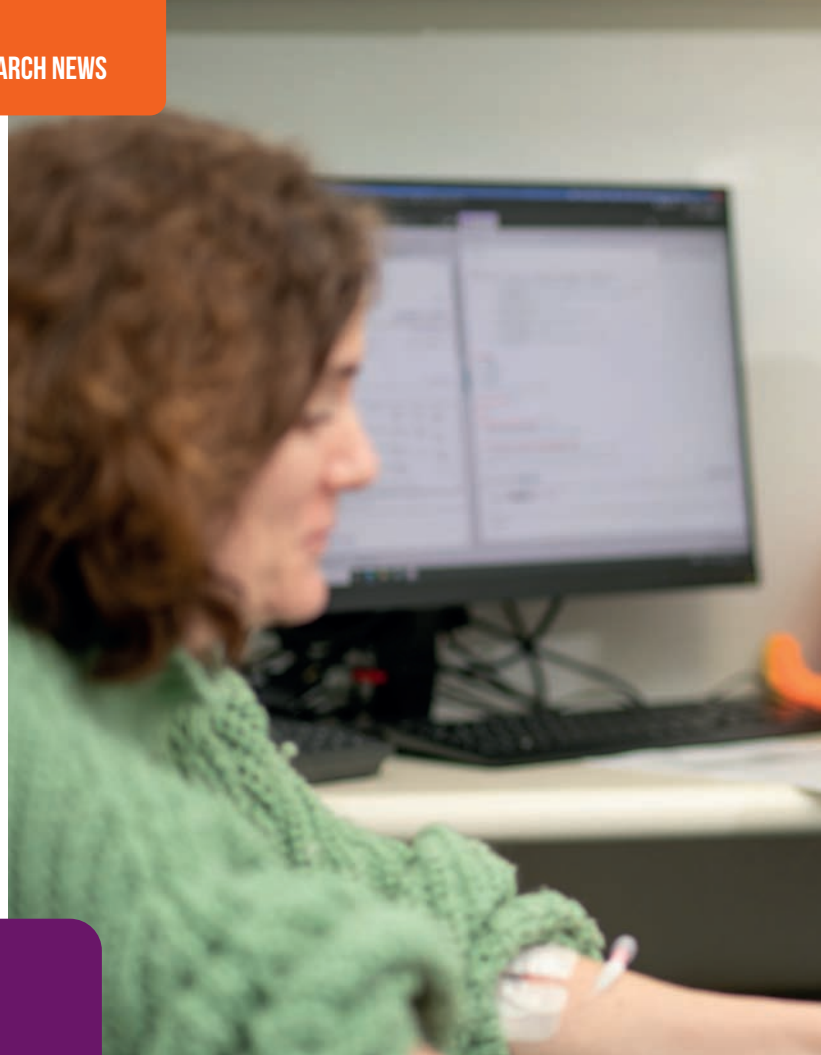


"It wasn't a difficult decision in my mind to sign up – the trial

is fantastic! I firmly believe medical science can and will evolve if people are involved in trials.

Octopus definitely gives me hope. It's a massive sense of hope and delight. You don't know what's going to happen when you have MS, you don't know what the future will hold. You have to try things and see if they work. And there's a 66% chance I'm on one of the two actual drugs and not a placebo."

**Alykhan Kassam, Octopus participant**







**“The multi-arm, multi-stage approach to trialling emerging medications has been utterly transformative in other conditions.**

**So I’m thrilled we’re now able to apply it to progressive MS. Ultimately, Octopus will lead to more treatments for progression becoming available to people living with MS sooner.”**

**Professor Jeremy Chataway, Lead Researcher for Octopus**



**“This is a major moment for MS research – Octopus could change the landscape for neurological clinical trials around the world. It’s thanks to all the wonderful**

**participants that trials, like Octopus, can happen. We won’t stop until we have treatments that transform the lives of everyone with MS.”**

**Dr. Clare Walton, Head of Research**



## **Trial shows no effect of high dose vitamin D in relapsing remitting MS**

Research shows vitamin D plays a role in your risk of developing MS. But a new clinical trial from the United States showed a high dose of vitamin D may not be an effective treatment for relapsing MS.

In the trial, 172 people with relapsing remitting MS took either a low or high daily dose of vitamin D for nearly two years, alongside a disease modifying therapy (DMT). The low dose was 600 international units (IU), slightly above what the NHS recommends. The high dose was 5000 IU, which is above what the NHS says could be harmful.

The results showed no difference in the number of people who had relapses when comparing the low and high dose of vitamin D. The researchers also didn’t find a difference in the number of new lesions or in brain shrinkage on MRI scans.

### **Why is this important?**

These new findings suggest taking a high dose of vitamin D, on top of a DMT, may not have an impact on your MS.

But our bodies do need vitamin D to help absorb different nutrients. It’s produced in our skin in response to sunlight. And because of the UK’s climate, the NHS recommends everyone living here takes a daily vitamin D supplement to support bone health.

● Read more about vitamin D and MS at [mssociety.org.uk/vitamin-d-news](https://mssociety.org.uk/vitamin-d-news)



## Genetics research shows we need more diverse data to understand MS

We know lots of genes are linked to making a person more likely to develop MS. But most of our understanding about these genes comes from studies with white people from European ancestral backgrounds.

Researchers from Queen Mary University of London used genetic information to predict MS risk. They looked at whether the accuracy of these predictions was affected by ancestry. The predictions suggest how many people in a population or group are likely to develop MS, rather than if an individual will.

They used genetic information from:

- 500,000 people from white European ancestral backgrounds. 2091 of these developed MS.
- 50,000 people from South Asian ancestry. 42 of these developed MS.

They found that predicting MS risk was more accurate when they used genetic information from the same ancestry. The same genes are important in MS regardless of ancestry. But the versions of those genes may differ slightly between ancestries.

### Why is this important?

Genetic information has the potential to improve how we think about diagnosis, treatment, and progression in MS.

But without fully understanding the relationship between ancestry, genetics and MS, there's a risk some of the benefits won't apply to everyone with MS. Especially for people from under-represented ancestral backgrounds.

- Read more about ongoing research into MS risk and ancestry at [mssociety.org.uk/adams-study](https://mssociety.org.uk/adams-study)

# Survey reveals impacts of financial hardship



**O**ur 2022 My MS My Needs survey has shown that financial hardship is having a significant impact on some people with MS.

Of the 6,697 people who responded to the survey, 14% told us they're "struggling" or "really struggling" on their current income. This is affecting every part of their lives and making it difficult for them to manage their MS effectively.

The impacts of financial hardship include going without food and heating, seeing friends less often and feeling anxious. Some people said they were going without care and support.

The survey also showed that people with MS in financial hardship are less likely to access the specialist healthcare they need.

And 30% of people with MS who are struggling financially said their MS had got worse because of this financial hardship.

## What is the My MS My Needs survey?

My MS My Needs is the largest survey in the UK of people living with MS. Every three years, we ask you to tell us if your needs for treatment, care and support are being met.

Thank you to everyone who took part in our 2022 survey. You're helping us raise awareness of the challenges people with MS face. We've presented some of the findings to members of an all-party parliamentary group – MPs with a particular interest in MS. We'll also use this research in campaigning work. This could involve, for example, campaigns about low incomes and the effects they can have on someone's experience of living with MS.

## My MS My Needs survey results

Of the people with MS who told us they're facing financial hardship:

**23%**  
are going without care and support

**30%**  
said their MS got worse

**40%**  
are going without essentials like food and heating

**72%**  
feel stressed and anxious

talk

Call our MS Helpline on **0808 800 8000** for information and support on financial matters. Read about the survey at [mssociety.org.uk/my-ms](https://mssociety.org.uk/my-ms)

“Cooking can have such a positive effect on people”



We spoke to our new Ambassador, **Tom Kerridge**, about his work, his connection with MS and why he supports us.

**Can you tell us about your personal connection to MS?**

The work the MS Society does is incredibly personal to me. My father was diagnosed with MS when I was six years old. He sadly passed away when I was just 18. I've seen the devastating effect it can have on a person, but I know it can be different for everyone.

**Do you think many people know about MS?**

I think a lot of people have heard of it, but may not know more than the name. But awareness is growing, which is why it's so important to talk about it.

**Why do you support the MS Society?**

I saw what my dad went through and how his mind

and body were affected. It was heartbreaking. So, if my support can make a bit of difference for families, I'm all in.

**What was it like presenting our BBC Lifeline Appeal in 2022 and your cook-along during the pandemic?**

It was great to present the Appeal and to see the

Turn to  
page 20 for a  
healthy low-cost  
recipe from Tom's  
Full Time Meals  
campaign

just physically by eating well,  
but also mentally.

**Tell us about supporting key workers with Meals from Marlow and kids and families with Full Time Meals.**

Meals from Marlow was born out of the sheer kindness of the local community. Key workers were working extremely long hours, often missing lunch and or dinner, with limited access to a full meal.

So we decided to create meals for them, funded by the local community, and it really took off. Everyone was so generous. We've given away over 100,000 meals – and it's still going strong.

Myself and footballer, Marcus Rashford, created Full Time Meals. It's an ongoing campaign to help end child food poverty. We created a bank of easy-to-make recipes for families and it's going from strength to strength.

**Why is food accessibility so important to you?**

Everyone deserves access to healthy, nutritious food. Sadly,

with the cost of living crisis, there are thousands of people living in food poverty. Parents are skipping meals so they can feed their children.

It's unforgivable. And it's why I'm working with the Food Foundation and Full Time Meals to help end child food poverty. It's also why access to free school meals is so vital.

**What does it mean to become one of our Ambassadors and support the MS community?**

Raising much-needed funds to keep world-leading research going is important. But I also want to help raise awareness of MS.

I'm proud to be an MS Society Ambassador and champion the amazing work being done in local communities.

**Do you have any hopes for the MS community and the future of research and treatments?**

You always have to have hope – it's what drives progress. With a positive attitude you can honestly achieve so much, I really believe that. I trust the MS community to continue with the amazing work they do. And, one day, I hope there'll be a cure.



For information about healthy eating and MS visit [mssociety.org.uk/eat-drink](https://mssociety.org.uk/eat-drink)

difference it made to the community.

And the pandemic was such a strange and uncertain time for everyone, especially people with serious conditions. So the cook-along represented an escape, helping people to cook simple meals from staple ingredients.

It really helped bring people together, which is one of the biggest reasons I love food and the hospitality industry. Cooking can have such a positive effect on people, not



Serves 4, done in 20 minutes

# Carrot and courgette spaghetti

A quick and colourful pasta dish packed with goodness. Deliciously melted cheese makes this a bowl full to fill up on!

## Ingredients

- 1 x 500g packet of spaghetti
- 1 large carrot (or 2 small)
- 1 large courgette (or 2 small)
- 1 tbsp vegetable oil
- ½ small tub of light cream cheese
- 1 small block of Red Leicester cheese
- Pepper
- 1 clove of garlic

## Method

**1** Bring a large pan of water to the boil. Add the spaghetti and cook for 10-12 minutes, or according to the packet instructions. Once cooked, keep back ½ a mug of the pasta water (to use later), then drain the spaghetti and set aside.

**2** While the pasta is cooking, peel the carrot, and then use the vegetable peeler to peel long wide strips (a bit like ribbons) along the length of the carrot and courgette. Peel and roughly chop the garlic.

**3** Heat the vegetable oil in a large non-stick frying pan over a medium heat. Add the garlic, and then the carrot and courgette ribbons. Stir it all together and cook for a couple of minutes until softened.

**4** Add the ½ mug of pasta water to the pan, and then add the cream cheese. Grate the Red Leicester and add this to the pan too. Mix it all together and let everything warm through gently until the cheese starts to melt.

**5** Add the drained spaghetti to the pan with the vegetables and cheese, tossing it together so the pasta is coated in the sauce. Divide it between 4 plates or bowls and season with a bit of black pepper. Now tuck in!



Find out about the Healthy Start Voucher Scheme at [endchildfoodpoverty.org](https://www.endchildfoodpoverty.org)



# How the cost of living crisis is affecting people with MS

Three people from the MS community share their perspectives on the cost of living crisis and the impact it's having on their MS.

## “It’s frustrating not being able to get out much”

Disability rights campaigner Rachael lives in Yorkshire with her dog, Baloo.

My main challenge is that every single thing has gone up. Even budget products are more expensive now.

I try and cook as much as I can in bulk. But because MS affects my hands, I have to buy pre-chopped vegetables which are so expensive.

When I shop online I use apps like Honey and Dealfinder that search discount codes for the best deal. And I've got a price tracker on my phone for things I buy regularly on Amazon, like hair dye.

### Asking for support

If you're struggling with bills, ask the company providing the service if they offer any support for vulnerable

people. For example, lots of broadband providers supply a lower rate to customers who claim benefits. They don't advertise it, but if you ask, you might find it's there.

It's frustrating not being able to get out much – because of MS and because of the cost. I used to love swimming to de-stress, and it's something I really miss.

Recently I became a volunteer Ambassador for East Riding Leisure. In return, I can use their facilities for free for three months. After that, there's a low-cost pass. They've said they can support me to access their pool – I hope I can start swimming again.



### Having an influence

Despite not being able to get out much, I've found ways to meet people and have an influence. I do a lot of volunteering online with campaigning organisations like End Social Care Disgrace. I speak at online events, attend meetings with politicians and edit videos for YouTube and TikTok.

Plus, I've got my own social media channels. I love creating. I'm very proud of what I've achieved – but I haven't really started yet!



## “Everyone deserves to stay independent”

**Rhianna lives with highly-active relapsing remitting MS. She lives with her partner and their dog, Figgy.**

I think more about paying for things that support my wellbeing. And paying for something essential, like dental care and a new pair of glasses. I looked into going to aqua-fit classes and massage therapy to help ease my MS symptoms. But they're so expensive, I currently can't justify spending money on them.

My partner and I work full-time, and he earns a decent salary. But I've never wanted to rely on someone financially. Currently, my earnings just about cover my portion of the rent, bills, necessities and the dog.

I'm living pay check to pay

check and I don't have a good amount to put into savings. This means I can't afford to save for a deposit for a house or luxuries like a holiday, or even a wedding.

### Put off by PIP

I don't claim PIP - I've always been put off by the process. The scoring system and the 20-metre rule seem to work against people with dynamic disabilities like relapsing remitting MS. I'm worried they'd assume because I can walk unaided some days, I don't need the support. And that stops me from applying, even though I know I'd benefit from it.

### Finding joy for free

We used to go out for a drink and to concerts, but now we have to ask ourselves if it's worth the cost. Instead, my partner and I explore the outdoors for free. When my mobility's fairly good, we'll visit national parks and heritage spots.

It'd be great if there was better support in place for disabled people. Everyone deserves to stay independent, mobile and happy.





# “I’m worried about this winter”

**Simon**, aged 43, from Northern Ireland, has relapsing remitting MS. He had to give up work soon after he was diagnosed in 2012.



As prices skyrocketed, the main issue last winter was how often I could put on my central heating. I have constant pain in my left leg which gets worse with the cold. And then fatigue jumps in.

I’m also sensitive to too much heat. I keep my blinds down when it’s hot and use fans. They use a fair amount of electricity – but summer is less expensive.

I’ve contacted all the companies I get services from and asked them what they can do for me. I got an extra payment from my electricity company towards my winter electricity, which was brilliant.

But I’m worried about this

winter. There won’t be the same government support and prices will still be high.

### **Saving money and energy**

My diet isn’t as healthy as it used to be because fresh food is so expensive. But batch cooking has been a godsend. I use my slow cooker, microwave and air fryer – I don’t know when I last put the oven on. As well as saving

money, it’s about being a friend of the environment. I don’t like wasting energy.

I’ve also got an electric car now – I use my PIP mobility payment for it through the Motability scheme. I charge it two or three times a month. Although my electricity bill has gone up, it’s much cheaper than a petrol car. That’s saved me money and it’s better for the environment.

### **talk**

If you’re worried about the cost of living, you can call our MS Helpline on **0808 800 8000** for information and support. You can also find out more about financial help by visiting [mssociety.org.uk/financial-help](https://mssociety.org.uk/financial-help)

# Helping people with MS **stay in work**

Two-thirds of people with MS in the UK experience problems at work. We've committed to fund two projects which focus on finding how best to help people with MS stay in work as long as they'd like.



**Dr Blanca de Dios Pérez is a postdoctoral Research Fellow at the University of Nottingham. Her programme offers advice on different aspects of staying in work.**

I'm passionate about MS research because, since I was a child, I've known several people living with MS. But I never truly understood what 'living with MS' meant until I started studying how health conditions can affect a person's quality of life.

Over the last eight years, I've worked with people with MS on a wide range of topics. I noticed

a recurrent theme. It was 'work'.

Work not only offers financial security but can be an essential part of our identity and a human right. Many of the people with MS I spoke to for my research were truly passionate about their work. Conversations frequently centred around their jobs. But I came to understand people living with MS face specific challenges staying in work.

## **A personalised programme of support**

In my PhD I developed a vocational rehabilitation programme, to help people with MS remain at work for as long as they wish.

People received a personalised package of support over three months. It addressed the topics most relevant to helping





## What is vocational rehabilitation?

This is anything which helps someone with a health condition to stay at, return to, or remain in work.

It can have many positive benefits for people with MS, like helping them:

- identify and tackle barriers to staying in work
- return to work after time off for sickness
- stay financially independent for longer

Organisations and employers also benefit from this type of support, by having a more diverse workforce who feel good about their workplace. And it improves their awareness of MS and how to better support their employees.

At the end of the programme, the 15 people who took part achieved their work-related goals. They also reported feeling more confident and knowledgeable about their MS, particularly in how to explain their needs to others.

### Making the programme accessible

Now I want to know how that programme could be included in NHS services for people with MS. I'm working with occupational therapist Professor Kate Radford on a research project funded by the MS Society to find this out. We want to know how best to train NHS professionals, such as occupational therapists, to deliver the programme. And how to tell people with MS about the programme. For example, if it should be shared

at their annual appointment with their neurologist or MS nurse.

We've recruited 15 people already and we hope to have some findings to share by the end of the year. We hope to shed light on how everyone with MS can be offered advice to manage MS at work. And how to manage difficult conversations with their employer or co-workers. If we can understand more about the current barriers, in the future we hope our programme can be routinely offered and delivered in the NHS.

them remain at work. We know generic information can be hard to apply to your personal circumstances. So I used my specialist training as a psychologist and held one-to-one sessions on the phone or online.

The programme included help with:

- empowerment to self-manage their symptoms at work
- learning ways to tell employers or co-workers they have MS
- navigating difficult situations, such as understanding their legal rights



Learn more about Blanca's project at [mssociety.org.uk/preventing-job-loss](https://mssociety.org.uk/preventing-job-loss)



**Dr Charlotte Wicks is a postdoctoral researcher at Leeds Teaching Hospital. She'll use a particular type of talking therapy in her project.**

**W**e know people with MS are more likely to stop working earlier, often before they would like. And we know psychological factors play a key role in this. We think a type of talking therapy called Acceptance and Commitment Therapy (ACT) could help people with MS to stay in work for longer if they choose to.

ACT can help people to stay in work because it can

increase people's self-belief in their ability to succeed. It encourages them to embrace their thoughts and feelings. And to seek solutions to difficult situations. ACT has also been shown to protect against things like burnout.

So, with the help of people with MS, we've co-developed an ACT-based programme to help people stay in work. It's online so people can choose when they want to access it, but it's supported by a healthcare

professional who makes scheduled calls to check in.

Our pilot study showed the programme could reduce the risk of job loss for people with MS. Now, we'll trial with more people to find out if we can make this work on a much larger scale, so it's accessible for more people who need it.

We hope it could offer a widely available option to help people with MS stay in work, without extra NHS resource. And we know ACT can also improve a range of psychological factors which impact quality of life in MS.

## What is Acceptance and Commitment Therapy (ACT)?

ACT is a type of behavioural therapy. It combines mindfulness skills with the practice of self-acceptance, to help people address negative thoughts or feelings directly.



Learn more about Charlotte's project at

[mssociety.org.uk/act](https://mssociety.org.uk/act)

# Deciding which treatments get funded – the value for money issue

The National Institute for Health and Care Excellence (NICE) provides guidance on which treatments get to be funded on the NHS. **Dr Annie Hawton**, Senior Research Fellow at the University of Exeter, tells us about her research, funded by the MS Society, investigating how well this process works for people with MS.

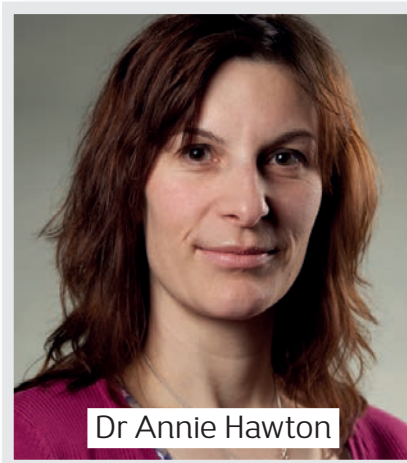
**T**he NHS has to work within a certain budget. That's why NICE tests if a treatment is good value for money – this is known as cost-effectiveness.

As Health Economists we look inside the black box at how NICE does this. It has a massive influence on the types of treatments people can get.

## Being impartial

To decide if the NHS would be getting good value for money, NICE weighs up the cost of a new treatment with how much it'll affect someone's life. They look at how many years you're likely to live and what your quality of life will be during this time.

NICE's job is to be as objective and fair as possible. So they work out the effect of a treatment on



Dr Annie Hawton

quality of life using a standard questionnaire, called the EQ-5D.

It looks at aspects of health that are important to people in general, like mobility and pain. So it hopes to be suitable for any health condition.

## Does it work for MS?

But what if different things matter to people with MS compared to other conditions?

For example, the EQ-5D doesn't ask a lot about fatigue. So if one of the effects of a

treatment is to improve fatigue, this might not get picked up by the EQ-5D. And it might not get taken into account when NICE considers cost-effectiveness.

Another example is wellbeing. Some treatments might not have a direct impact on standard measures of health. But they might do wonders for someone's wellbeing. For example, doing the things in life that you'd like to do. And being able to be who you'd like to be. It's about weaving your own course. But the EQ-5D doesn't look directly at this.

## How fair is it?

This is where my work comes in. I'm researching how well the EQ-5D works for MS. Working with the UK MS Register, we asked

people with MS to complete these questionnaires every six months:

- The EQ-5D
- Three wellbeing questionnaires
- A MS-specific questionnaire called the MSIS-8D

We recorded any changes in their life related to their MS. For example if they changed employment due to MS, or had

more symptoms of anxiety or depression. We then tested how well each questionnaire picked up these changes.

### Our results

We found the MSIS-8D and the wellbeing questionnaires were better at picking up changes related to someone's MS than the EQ-5D. So they might detect benefits of a treatment that would be overlooked by the EQ-5D.

There's a strong argument

for using MS-specific and wellbeing questionnaires when deciding if a treatment is good value for money. If benefits are found, treatments are more likely to become available on the NHS.

### Hopes for the future

In the future, I hope there'll be more treatments, especially for people with progressive MS, who so far haven't had so many treatments. And I hope we'll have the right tools to help NICE detect all the benefits of these treatments.

We're now working with the organisation that developed the EQ-5D to test how responsive a newer version is in relation to MS. And we're publishing our results, speaking at conferences and we're still working with people with MS to get their input about what's important to them.

## MS-specific questionnaire

The MSIS-8D is similar to the EQ-5D. But it has some extra categories important to people with MS that aren't in the EQ-5D, such as:

- social activities
- fatigue
- cognitive function
- emotional wellbeing



## Ask the experts

# Benefits and financial support

**Julian and Rachel**, our MS Helpline benefits advisers, answer your questions.

**Q** I'm really struggling with the cost of living and energy bills. Can I get any financial support? Are there any benefits I can claim if I have MS?

If you claim certain benefits, you may be eligible for Cost of Living Payments.

If your MS means you can't work, or you work less than 16 hours a week, you may be entitled to Employment and Support Allowance.

If you're not getting Disability Living Allowance, you may be entitled to Personal Independence Payment (PIP), or Adult Disability Payment (ADP) if you live in Scotland.

If you're on a low income, you may be entitled to Council Tax Support and Universal Credit. But if you're already getting other benefits or Tax Credits, applying for Universal

Credit could end these. So we recommend you seek advice before applying. You can check how much you might be entitled to online at [gov.uk/benefits-calculators](https://www.gov.uk/benefits-calculators)

There may be other benefits you can claim if:

- you have children
  - you're a carer
  - you're over State Pension Age
- Call or email us for advice on your own circumstances.

**Q** What if my MS affects my ability to work? How can I find out which benefits apply to me?

You may be entitled to

Statutory Sick Pay (SSP) if you're too ill to work. It's paid by your employer for up to 28 weeks. You may get more sick pay than this, depending on what's written into your contract. There may be other benefits you can apply for, depending on your circumstances. Before deciding to give up work or reduce your hours, get some employment advice on your right to reasonable adjustments at work.





### Q Should I apply for PIP? How should I fill in the form?

If your MS symptoms affect your ability to do daily activities, you may be entitled to PIP or ADP. Your symptoms have to affect your ability for at least 50% of the days of the year. Daily activities include preparing food, washing, dressing and moving around. You should explain on the

form if you use any aids, like a perching stool in the kitchen or a shower seat. You should also explain how doing these activities impacts you:

- Is it painful?
- Does it cause you a lot of fatigue?
- Does it take a very long time?
- Can you do the activity safely?

We've produced a booklet to help you fill in the form at [mssociety.org.uk/pip-booklet](https://mssociety.org.uk/pip-booklet)

### Q I get PIP or ADP and my condition has worsened.

#### Can I get a higher rate?

PIP and ADP are points-based benefits. In the assessment, points reflect the difficulties you have with different activities. You need to get eight points for the standard rate and 12 points for the enhanced rate, which is a higher payment.

If you get the standard rate of PIP or ADP, and your condition has got worse, you may get enough points for the enhanced rate. You should tell PIP or ADP if your condition has got worse. If possible, provide supporting medical evidence showing how you meet the points needed for the higher rate.

### Q I recently applied for PIP or ADP and was turned down. Can I challenge the decision?

Yes, you can challenge the decision. First you'd request a 'mandatory reconsideration' for PIP or a 'redetermination' for ADP. If this is unsuccessful, you can appeal. It may be useful to get extra medical evidence and a supporting letter from anyone who helps you with daily activities. 68% of PIP appeals are successful, so don't assume you're not entitled to PIP if you're turned down.

#### Benefits info online

- You can search for any benefit by name on the [gov.uk](https://www.gov.uk) website to find out more.
- For Adult Disability Payment visit [mygov.scot/adult-disability-payment](https://mygov.scot/adult-disability-payment)
- Visit [mssociety.org.uk/benefits-guide](https://mssociety.org.uk/benefits-guide) for more information on benefits, including guides on how to complete forms.



For information tailored to your situation, call our MS Helpline on **0808 800 8000** and ask to speak to one of our Benefits Advisers. Or email [msbenefitsadvice@dls.org.uk](mailto:msbenefitsadvice@dls.org.uk). We also offer a legal advice service in England, Wales and Scotland on issues like employment.



# Grants to support your independence

You can apply for grants to pay for things like home adaptations and equipment to help you live better with MS.



## Social care services

Your local council may pay for equipment and adaptations to help you live independently at home. You can ask the council to carry out a home and financial assessment. This will decide how much, if anything, you'd need to pay towards the cost. Find out more at [mssociety.org.uk/about-social-care](https://mssociety.org.uk/about-social-care)

If you live in England, Wales or Northern Ireland you could apply for a Disabled Facilities Grant at [gov.uk/disabled-facilities-grant](https://gov.uk/disabled-facilities-grant). If you live in Scotland, you can apply for

grants from your local council.

## MS Society Groups

We have a number of volunteer-led groups who raise income and spend it on services and support for the local MS community. Not all MS Society Groups provide grants, but you can check with your local group to see if they do. Find them at [mssociety.org.uk/local-support](https://mssociety.org.uk/local-support)

## Other organisations

Home Improvement Agencies (HIA) can provide information and advice on home

adaptations, including accessing grants. Visit [findmyhia.org.uk](https://findmyhia.org.uk)

The MS Research and Relief Fund offers grants for aids, adaptations and services. Call **01670 505829** or email [info@ms-researchandrelief.org](mailto:info@ms-researchandrelief.org)

Independence at Home offers grants for adaptations, goods and services. Call **020 8427 7929** or email [iah@independenceathome.org.uk](mailto:iah@independenceathome.org.uk)

## Search for a grant

There are websites you can use to search for particular grants.

- Disability Grants: [mssociety.org.uk/disability-grants](https://mssociety.org.uk/disability-grants)
- Turn2Us: [mssociety.org.uk/turn-2-us](https://mssociety.org.uk/turn-2-us)
- MoneyHelper: [mssociety.org.uk/money-helper](https://mssociety.org.uk/money-helper)

## Our information

We've got free information on a huge range of topics. New web pages include tips for talking about HSCT, the DMT decision tool, and Sleep and MS. We've also fully updated our information on managing the cost of living, social care services, hearing problems, swallowing and speech, and tremor. All our information is created with people affected by MS and other experts. See the full range, including free booklets and downloads, at [mssociety.org.uk/resources](https://mssociety.org.uk/resources) or call **0300 500 8084** to order.



Contact our MS Helpline on **0808 800 8000** for support and to speak to our benefits advisers.

# How I'm coping with rising costs

As prices remain high, we asked you about your coping strategies.

## “Setting goals is important”

I go out on my mobility scooter (when the weather allows) to benefit my mental health. My brain is constantly working to make sure I don't run into or over things. I also talk to random people, even if it's just to say hello. But mobility scooters need to be charged – so I do have to think about the cost.

When I can't get out, I use internet games that test memory, attention, flexibility, speed and problem-solving. Exercising my brain like that not only keeps it active but gives me personal goals that I can work on achieving. Setting goals is important as I can focus on something other than my condition. This keeps my mind off it and allows me to progress, not stagnate and worry. - **Craig**



## “We've found different ways to do things”

I'm a single parent living with MS and I now work part-time because of my symptoms. I've had to create and stick to a budget and find deals on things like our monthly food shop.

Now the weather's improving, I can take my son to parks and be outdoors. But we've had to find different ways to do things. For example, we've been visiting friends at their homes and sharing takeaway orders instead of selecting individual orders which costs more.

I'd like to see more support for people living with MS who are on part-time salaries and for single parents. - **Rebecca**

## “My running friends are a source of support”

Most of the electrical appliances are turned off in my house and the heating's been on low. I've also had to change my diet completely. I used to eat lots of oily fish and vegetables. Now I look for discounted items mostly.

I'm an avid park runner and used to be part of a running club, but I can't afford that now. My running friends are still a source of support though. I'm also a medical adviser for MS Warriors, which has connected me with other people living with MS. And I try to go for park walks to meet others and get out there. - **Vince**



## “I've found strength among fellow MSers”

The last couple of years have been difficult for everyone. My first impression was 'I'm not coping. It's not possible to cope with MS and extra worries about the rising cost of living.' But the more I thought about it, I realised I am coping.

After COVID-19, I learned that tomorrow isn't guaranteed. So I've had to make the most of today. I prioritised what was vital and that's what I spent money on.

I started using a budget and drastically reduced impulsive purchases. I also started Pilates, which put me in a better frame of mind. I wish I could tell you I haven't got money worries. But at least I'm not panicking about the future.

I found strength in attending meetings with my fellow MSers and joining online communities. Every time I start to worry, there's

someone I can discuss my burning issues with. That's made a huge difference.

- **Yinka**



## “I've simplified my life”

To try and keep costs predictable, I've simplified my life. Mostly I work, eat and sleep - that's about it!

I've explored free ways to get fit (I have trainers, a bike and some lovely countryside). When I get the chance, I meet friends for walks or invite them to my house. I love to read, but instead of buying books (even second-hand books) I'm using informal lending libraries. These are often village bus shelters and I can swap the ones I've finished for 'new' ones. Not knowing what you might find adds to the fun! - **Sarah**



Our MS Helpline supports anyone affected by MS, even if you just want a chat. Call **0808 800 8000**. To find out about support in your area visit [mssociety.org.uk/local-support](https://mssociety.org.uk/local-support)



## What low-cost or free things have brought you joy during the cost of living crisis?

Our community on Facebook and Instagram share their ideas.

I enjoy reading Kindle books, having online meetings, and sustainable fashion. Now, as the World Health Organization (WHO) has declared the official end of the COVID emergency, I need to think about new low-cost activities. From my point of view, no COVID-related deaths would mean the end of the emergency. But, according to the WHO, it's different.  
**ms.my.strategy**

Going for a walk in the countryside with my girls watching them run and gather sticks on a beautiful sunny day.  
**Adrian Cunningham**

Going into town on my scooter. I love it.  
**Ann Bell**

Seeing the seasons shift with my beautiful dog Coco. She loves taking me for a walk!  
**Christina Waters**

I've got myself bird feeding stations from the RSPB. Bird watching is a great way to relax on days when I don't feel good, have no motivation, or have fatigue. On days I do feel good I go out to refill the feeders. I see blackbirds, wood pigeons, collared doves, robins, magpies and starlings.  
**Lee Fearnley**



For our next issue, we're asking: **If you're caring for someone with MS, what support do you need the most that you're not getting?**

Send your answers to our inbox at **msmatters@mssociety.org.uk**. Or keep an eye on our social media at **facebook.com/mssocietyuk** and **instagram.com/mssocietyuk**. We'll also post the question there.

Me too! We have blue tits nesting. We also have daily visits from greenfinches, goldfinches and a squirrel. Not bad for a small-town garden.  
**Jo Cottingham**

# How is the cost of living crisis affecting the MS Society?



Our community is facing some difficult financial pressures that'll continue to impact many people affected by MS in the future.

**T**he cost of living crisis is leading to more people needing support to survive. And we want to make sure we can continue our support for everyone living with MS.

There's more demand for our services. But people are having to cut back on charity donations with the rise in living costs.

We saw incredible support for us in 2022. And this helped us continue our vital work to support people with MS.

But, unfortunately, our donations did fall by £1 million (2021 to 2022). Despite this, we continued to provide as much help as possible to people in the MS

community. Our local volunteer-run groups awarded over £238,000 in support grants to people affected by MS.

Our MS Helpline responded to over 25,000 enquiries.

Our MS Helpline also helped people in our community claim an estimated £723,209 in benefits.

## Research grants

As well as supporting the community, research remains a top priority. In 2022 we funded over £4.9 million in research grants. These were to:

- find and test

treatments to slow or stop disability progression in MS

- help people manage their symptoms
- develop new services

Ed Tait, our Executive Director of Engagement and Income Generation, says "We know our community needs support more than ever. We've witnessed this through a rise in calls to our MS Helpline, and we'll do everything we can to keep our services running. But we can't do it without the continued donations from our supporters."

## MS Society in numbers (2021-22)

The Helpline responded to over

**25,000**

enquiries. We also helped people claim an estimated

**£723,209**

in benefits.

We funded over

**£4.9 million**

in research grants.

Local volunteer-run groups awarded over

**£238,000**

in support grants to people affected by MS.

give

We know times are hard. And demand for our services is high. So, if you can, please donate today. Our wonderful supporters help us provide our services, fund research and campaign for better support. Please call **0300 500 8084** or visit **donate.mssociety.org.uk**

# What are **social determinants** of health?

Everyone's experience of MS is different. People have different symptoms. Some have more relapses or their MS progresses faster. Recent research suggests these differences are influenced by more things than we thought.



**W**e don't fully understand why everyone's MS is different. But we do know that someone's experience of MS, and the impact this has on them, can be affected by many things, including:

- disease modifying therapies (DMTs)
- other health conditions
- lifestyle, especially smoking
- genetics

Other factors are also important across health and illness. These factors shape how we experience the world, and they influence lots of different conditions.

Because they're relevant to everyone, we call these factors "social determinants

of health". They include:

- sexuality
- ethnicity
- education
- employment
- ability to access food and social support

These don't always stay the same and are often impacted by external forces, which individual people might not have much control over. For example, COVID-19 had a big influence on employment and social networks. And new factors are emerging, like confidence using digital systems.

Research shows we can improve health by influencing some of these circumstances, but we don't yet know exactly how they impact MS.

## **Social factors and MS**

Dr Ruth Dobson and her colleagues recently published a new research article exploring the evidence in MS so far. They believe social factors could play a major role, for example:

### ● **Social support**

Financial and emotional support comes from family, friends, colleagues, charities, and even pets. But MS can affect all of this, and evidence suggests social isolation caused by MS can worsen mental health and quality of life.

### ● **Education**

Several studies have suggested higher education levels may protect against MS progression for some people. But these studies have limitations. They



who weren't working 10 years after diagnosis. They had worse physical functioning and said they took part in daily activities less. Another found more stress and less life satisfaction in unemployed people with MS.

#### ● Socioeconomic status

Socioeconomic status uses things like income, occupation and where we live to give an overall measure of how privileged or deprived someone is.

Most studies focus on the effect of socioeconomic status and the risk

of developing MS. But some research suggests a link between being more deprived when you're diagnosed with MS, and later disability (like reaching secondary progressive MS faster).

#### ● Race and ethnicity

Research suggests people from minoritised racial or ethnic groups may have worse MS outcomes. For example, one study showed Black Americans had faster disability worsening than White Americans.

These differences are likely the result of racism across health and other services. But there are still gaps in our understanding of MS in diverse populations.

For some factors there hasn't been any research done for

people with MS. For example, more and more households in the UK are struggling with food poverty, but no studies have examined the effect on MS.

Many social factors are closely linked or can be influenced by having MS. So it can be very hard to untangle all the separate effects.

#### Improving health

We think many social determinants may affect people with MS partly through their experience of healthcare, rather than through direct effects on MS. That doesn't make it any less important to tackle these where possible.

Being aware of each person's circumstances is likely to improve care. So we need to help neurology teams recognise people who have social factors that might make their MS and quality of life worse.

If we address some of these factors, alongside using DMTs and symptom management therapies, we could make living with MS easier. We've seen this in other health conditions, but urgently need research to help us understand how to do it in MS.



Dr Ruth Dobson

don't look at the quality of education. Also, experiencing early signs of MS could make it more likely that people leave education, not the other way around.

#### ● Employment

Studies show unemployment can affect MS outcomes. One study looked at people with MS



Find out about MS Society-funded research exploring social factors and MS at [mssociety.org.uk/improving-ms-services](https://mssociety.org.uk/improving-ms-services)

# Impact Awards

## Help celebrate our volunteers

The MS Society was founded by volunteers 70 years ago, and they're as important to the MS community as ever. We can't do what we do without volunteers.

Last year, we launched our Impact Awards to recognise how volunteer activities contribute to our strategy and help achieve our mission. This led to our first live-streamed award ceremony, hosted by DJ Scott Mills, one of our Ambassadors.

We're getting ready for this year's ceremony to celebrate more amazing volunteers. At the ceremony, the winners in our impact categories will be announced. They're chosen from everyone who gets an Impact Award throughout the year.

So do you know a volunteer who's made a real difference to the MS community? Someone who deserves to be recognised for their commitment and achievement?

- Please nominate them for an Impact Award at [mssociety.org.uk/volunteer-impact-awards](https://mssociety.org.uk/volunteer-impact-awards)

### Did you know?

We have **3,066** volunteers

Their average age is **42**

**389** new volunteers joined in 2022

There are **232** active local groups



## Thinking of starting a group?

Mike, from Greater Manchester, has set up a group for younger people in his area. To help others do the same, he's joined our co-production team to develop some useful resources.

"When I first reached out to the local MS community, there wasn't anything aimed at 'people like me'. But by networking at clinical appointments and volunteering with my local group, I started gathering contacts of people around my age. And that's evolved into a network that's been meeting up for seven years now.

"To help people get started and run their own networks, a team of us have got together as a co-production group. There, we share the knowledge we gained from beating that path ourselves. We've helped build guides around what works and what to avoid – so that people can make independent peer support work best.

"For my group, it's always been about empathetic connection. People with MS seem to have an affinity with one another – and relationships are quick to form everywhere."

**learn** Find resources and support on how to grow your own community at [mssociety.org.uk/start-a-group](https://mssociety.org.uk/start-a-group) or email [socialconnect@mssociety.org.uk](mailto:socialconnect@mssociety.org.uk)







“I don’t  
have MS  
in the  
water”

Linda discovered the benefits of sea swimming when she took a dip in the chilly North Sea during lockdown. In a blog post, she explains how this helps her MS.

The first time, I did ask myself what on earth I was doing. But the benefits far outweigh the downside. I just feel so wonderful. And I got addicted to it. I only do it from May to December because it’s too cold for me during the other months. When I’m not doing it, I really miss it.

I have problems sleeping. I have problems with my bladder and have to get up in the night to go to the toilet. But after my first sea swim I slept virtually all night.

My walking and balance are absolutely dreadful. But in the water, because I’m not having to balance, my MS goes – I don’t have MS in the water.

I never go in on my own. That’s really important. I always go with friends. And I’ve got one of these flotation devices attached to me. They all know me so well and they look out for me.

• Read Linda’s blog in full at [mssociety.org.uk/swimming-blog](https://mssociety.org.uk/swimming-blog)

Linda’s blog resonated with our community on Instagram.

 **cockbill5**

After a severe relapse recently, I can no longer ride my bike. But I’ve found the right electric trike for me. It means I can still get out in the fresh air and get to the beach. Beginning to enjoy life again.

 **fionab55**

Used to love swimming but drop foot and severe spasticity in my left leg stops me. Great to hear how swimming helps.



If you’d like to write for our blog, get in touch at [stories@mssociety.org.uk](mailto:stories@mssociety.org.uk)

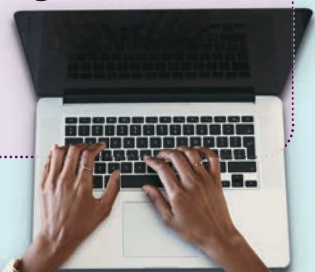
Do you have a comment on something you’ve read in MS Matters or on our website?

✉ Email [msmatters@mssociety.org.uk](mailto:msmatters@mssociety.org.uk)

Facebook [fb.com/MSSociety](https://fb.com/MSSociety)

Instagram [@mssocietyuk](https://@mssocietyuk)

Twitter [@mssocietyuk](https://@mssocietyuk)



## Volunteer spotlight

# Maria Frangeskou

Maria marched with us at Pride in London in 2022. She's also volunteered for an MS Walk and is part of Talks with MS, a group in London.

Last year was the first time I'd walked the parade with a charity. I'd normally go and watch it. But being part of it with the MS Society was amazing.

The best moment was when we set off, seeing and hearing the crowd's reaction, cheering us on. We knew we were doing something really brilliant and helpful for the MS community and the people seeing us.

I feel it's important to have that representation. Not just for people with a disability and not just for queer people – but both communities together.

Sometimes people with a disability can be seen as only one thing. People forget there are so many more parts to us. That's why it's so important for the MS community to be at Pride.

It's about being treated as a whole person, not just someone who's LGBTQIA+, and not just someone who's disabled.

When I was diagnosed with MS, and I had to explain it to people, I lost people in my life. But I also gained people. It really reminded me about when I was first open about my sexuality. It

was that same process of people seeing another side of you and having a different opinion of you.

So that's the nice thing about the two groups being together at Pride. Both can see how much we have in common and that we should be working together.

**join** We've already marched at Pride in London and other events this year. But you can still join us at Black Pride on Sunday 20 August at the Queen Elizabeth Olympic Park in London. Keep an eye on our Instagram at [instagram.com/mssocietyuk](https://www.instagram.com/mssocietyuk) and Twitter [@mssocietyuk](https://twitter.com/mssocietyuk) for updates.



# Getting to know you...

**Dr Tarunya Arun** is Consultant Neurologist at the University Hospitals of Coventry and Warwickshire. There, she's the joint lead for the MS service and the Research Lead for neurology.



Tarunya

## What led you to MS research?

As a medical student, I liked the fact neurology was complicated! And also it involved lots of work in the clinic. I started extra research projects as a junior doctor.

I was particularly interested in MS. Many of the people with MS were the same age as me. I felt I could join them on the journey, helping them throughout.

## What's the most exciting thing you're working on at the moment?

I'm excited we're now looking at finding treatments for people with progressive MS. I'm lead investigator here for clinical trial MS-STAT2 and

I'm involved in DELIVER-MS.

One of the hardest things as a clinician is telling people with progressive MS they have to stop treatments. Now I can offer them more options through clinical trials.

## What's the best thing about your job?

I always wake up and think 'when I go to work today I can make a difference.' Whatever the size of that difference might be. I think it's a privilege to be part of people's lives in this way.

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

I did competitive sports when I was younger. And my grandfather would say 'don't look at what the person on your right or the person on your left is doing. Just focus on yourself, and being a little better than you were last time.'

And I think this is true for everything in life. I give this advice to my children – I must say it to them three or four times a week!



Find out more about some of the clinical trials Dr Tarunya Arun is involved with at [mssociety.org.uk/deliver-ms](https://mssociety.org.uk/deliver-ms) and [mssociety.org.uk/cholesterol](https://mssociety.org.uk/cholesterol)