

## Me, MS and my mental health

Jordan and Robby  
share their  
experiences



**Plus**

Research on  
talking therapies  
and fatigue

# The truth is:

7 in 10 people with Multiple Sclerosis, suffer bladder issues at some point<sup>1</sup>.

*If you are experiencing them you are not alone.*

## Are you experiencing bladder problems?

*Do you ever get leakage, urgently dash to the toilet, or get up more than once in the night to urinate? Do you sometimes feel that you need to go but can't, or go but never feel empty?*

If you answer yes to any of these questions, or experience any other bladder issues, they could be linked to MS. Don't let bladder issues control you. There are management options available to you.

More than 80% of people with MS have neurogenic bladder dysfunction, which means a decreased ability to control the bladder. The bladder, which stores urine, is controlled by the nervous system. Because MS can cause nerve damage in the areas of your brain and spinal cord that control your bladder function, the symptoms experienced will depend on which areas have been affected. Some people may get occasional urinary incontinence. Some find that they need to urinate more frequently or urgently (*over-active bladder*), whereas others may find difficulty emptying the bladder or a feeling of incomplete emptying (*bladder retention*).

## Don't put off seeking help

It is natural to put changes in bladder function down to normal aging or childbirth, but if you are experiencing any of the symptoms in the box, now is the time to reach out to your MS health care professional to discuss your bladder function, as it could be linked to your MS.

*I find it difficult to start urinating when I get to the toilet, or I need to lean forward or strain to start.*

*My urine flow is weak and slow.*

*My bladder doesn't feel completely empty when I've finished urinating.*

*I often get urinary tract infections.*

*I need to use pads or other ways to protect my clothing from leakage.*

*I'm planning my daily activities around my bladder symptoms or avoiding doing the things I enjoy because of them.*

It is easy to put off talking about bladder issues. Not knowing who to talk to or feeling embarrassed can be factors, but there are simple management options available that can make a real difference.

## Why is bladder health important?

Healthy bladder function is essential for long-term kidney health, prevention of infection, personal independence, self-confidence and overall quality of life. Untreated bladder issues can cause:

- Urinary tract infections, which can cause the body to mimic symptoms of a relapse, as the body tries to fight the infection.
- Kidney damage, as a result of back flow or pressure build up.

- Challenges with work, relationships and social activities.
- Loss of independence, self-esteem and self-confidence.

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- “ *By using a catheter – I gained a world of freedom*” Liselotte
- “ *It's incredibly important to get help. There is help out there. I struggled with it for nine years for no reason at all*” Monika
- “ *Catheterisation has given me back a big chunk of my life. I can live my life the way I want*” Fabiola

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Eva, SpeediCath® Compact Eve user

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My catheter size is  CH

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**10** Updates on our clinical trials



**14** Celebrity interview: pro athlete Lina Nielsen

**NEWS**

- 9** MS Awareness Week
- 10** Updates on our clinical trials
- 11** Research news: CBT study and StarMS
- 12** Campaigns news and dates for your diary

- 32** Our MS nurses answer questions on mental health
- 41** What to expect from counselling
- 43** A sceptic's guide to wellness

**RESEARCH**

- 17** Talking therapies and fatigue
- 20** When MS and mental health is professional and personal

**INSIGHT**

- 14** Celebrity interview: pro athlete Lina Nielsen



**20** When MS and mental health is professional and personal



**43** A sceptic's guide to wellness

**45** How drugs are chosen for Octopus trial

**REAL LIFE**

- 23 COVER STORY:** Robby and Jordan on mental health
- 26** Challenges and joys of parenting with MS
- 31** A carer's perspective on mental wellbeing
- 34** How do you keep a healthy mind?

**COMMUNITY NEWS**

- 7** Your letters
- 38** Our services to support your wellbeing
- 47** Blog spotlight: supporting Black men with MS
- 49** Hope Reborn and volunteering at an MS Walk
- 50** Meet our two new trustees



Issue 143  
**Spring 2023**

**I've been working on MS Matters for several years, as part of the editorial team.** I'm the first of a few new faces you'll see in this column.

We feel it's important to make sure this magazine is overseen, written and created by people from the MS community. And we want to help people with MS to work with us and co-produce our services and support. That's why we're launching our MS Matters engagement group soon. This group of readers will help us decide what's important to cover in the magazine. We'll be inviting guest editors from the group to introduce themselves here. Find out how you can get involved at [mssociety.org.uk/co-pro](https://mssociety.org.uk/co-pro)

In this issue, we focus on mental health. After a winter of soaring costs, people in the MS community have told us they're struggling in many ways. Maintaining your mental wellbeing at this time is more important than ever. So we've asked lots of different people for their perspectives.

Read an interview with Lina Nielsen, a British sprinter, hurdler and yoga teacher on page 14. And on page 20, two researchers living with MS talk about their research into mental health and MS.

We hear about mental wellbeing from men with MS (page 23) and parents talking about family life (page 26). If you need to talk to someone about any of the topics we cover, please call our MS Helpline for free on **0808 800 8000**.

**Miriam**

**Miriam Jones** Editor

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Or visit: [www.manfred-sauer.co.uk](http://www.manfred-sauer.co.uk)

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# Your Letters

## Cost of treatments

I'm confused that your #BreakingPoint article (MS Matters Autumn/Winter 2022) says people can't afford treatments. We all pay for prescriptions but disease modifying therapies (DMTs) are free on the NHS.

Also, wouldn't it be a good idea to inform readers about the NHS prescription prepayment certificate? You pay a fee once a year (or monthly) and don't pay for individual prescriptions. This can save you money.

I now get free prescriptions. All you need is a note from your GP to say you can't get to the chemist to pick up the prescription under your own steam. For example, if you can't get out of the house or have to ask a friend, carer or relative to pick it up.  
**Julie Bradley, Whitley Bay**

### Phil Anderson, our Head of Policy and Evidence, responds:

As part of our #BreakingPoint campaign, we surveyed people with MS about how the cost of living crisis is affecting them. Looking at the cost of treatments, some people told us they couldn't afford:

- symptom management treatments like fampridine (Fampyra) that aren't available on the NHS in all the UK nations
- therapies like physio and counselling, which people can often struggle to access on the NHS



- transport to a hospital to get treatment
- prescription charges in England

You're absolutely right to say some people with MS can get free prescriptions. For people who can't, they can save money using the NHS prescription prepayment certificate.

But this only applies to NHS prescriptions. Many people with MS are forced to use private prescriptions if a medicine that could help them isn't available on the NHS in their area (like fampridine). Such prescriptions tend to be much more expensive.

For more about saving on prescription charges visit [mssociety.org.uk/prescriptions](https://mssociety.org.uk/prescriptions)

See our #BreakingPoint campaign at [mssociety.org.uk/breaking-point](https://mssociety.org.uk/breaking-point)



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



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\*T&Cs apply. See website for details.







## #MSMakesMe

This year, MS Awareness Week will run from 24–30 April. For the first time ever, we're joining forces with six other MS charities:

- MS Trust
- Overcoming MS
- MS Together
- Shift.ms
- MS-UK
- MS Therapy Centres

We're coming together with a common goal – to raise as much awareness about MS as possible.

We want to make this year's MS Awareness Week bigger and better than ever!

MS is unpredictable and different for everyone. So we worked with an incredible group of volunteers from the MS community to develop this year's theme, #MSMakesMe, to reflect everyone's unique experience.

Throughout the week we'll be encouraging you to use our hashtag

#MSMakesMe to tell us how the condition makes you feel. You might feel angry, strong, anxious or positive. Whatever it is, we want to shine a light on the diversity of living with the condition. Everyone in the MS community can

get involved, however MS affects you, and whether you're online or offline.

In the press, we'll be sharing a huge range of MS stories from across the UK.

Throughout the week, the charities will be running virtual events to help you connect, learn or try something new. Keep your eyes peeled on our website and social media channels for more.

We'll also be signposting people to information, stories and resources from all the charities involved.

join

How does MS make you feel?

Search **#MSMakesMe** on social media or email **pressoffice@**

**mssociety.org.uk** to join the conversation.

We'll share some of your comments in the next issue. Find out more about

**#MSMakesMe** at **mssociety.org.uk/msweek**

## Stop MS Annual Lecture

You can hear about the latest MS research at our 2023 Stop MS lecture, presented by Professor Helen Ford. Our panel of scientific ambassadors will answer questions from the audience

on the night.

If you can't make it along, it'll be shown live on YouTube, where you'll also be able to ask questions. Find out how to join at **mssociety.org.uk/annual-lecture**

**Date:** 25 May 2023

**Time:** 6.45pm to 9pm

**Location:** Royal College of Physicians, London, NW1 4LE.

The venue is fully accessible.

● To register, email **special events@mssociety.org.uk**

# Clinical trials updates

To help people at every stage of MS, we need to stop MS from getting worse. Researchers are looking at three ways to do this. And trials we support in all three areas are making fantastic progress.



ChariotMS uses a test of arm and hand function.

## 1 Preventing immune damage

ChariotMS is testing whether cladribine (a cancer drug) can help people with advanced MS maintain the use of their arms and hands.

Professor Klaus Schmierer, who's leading ChariotMS, says "We've now recruited over a third of the people we need to

make the trial a success. We're really proud of this progress, but we're still looking for lots more people to take part. There are hospital sites open all round the country!"

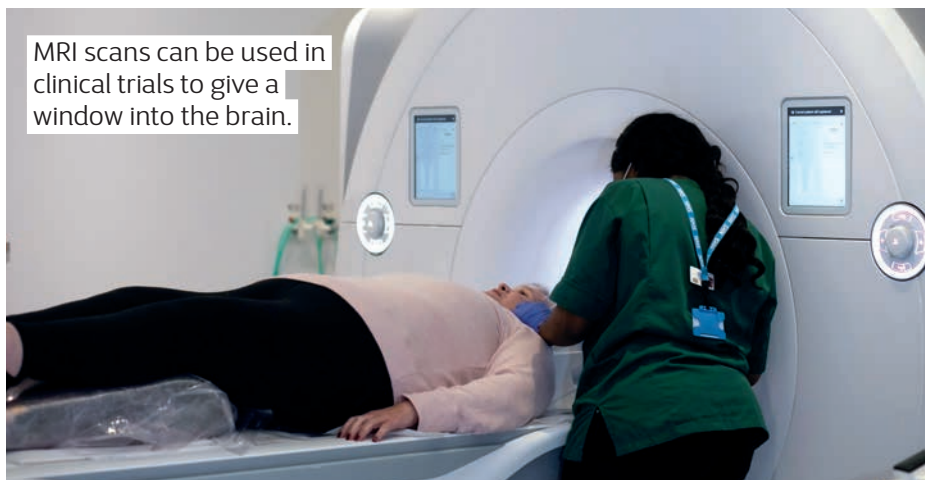
## 2 Promoting myelin repair

Two drugs, metformin and clemastine, have both shown promise for boosting myelin

repair in early studies. They're both already licensed for other conditions. Now they're being trialled together. The team are recruiting people with relapsing MS. And they're over halfway to their recruitment goal. Each person stays in this trial for six months. And we're hoping to get the results in 2024.

## 3 Protecting nerves from damage

MS-STAT2 is testing whether a common cholesterol-lowering statin can slow progression in secondary progressive MS. Last year, the team reached an important milestone – they enrolled all their participants. So people will be finishing their time in the trial over the next couple of years. And then we'll be able to see the results.



MRI scans can be used in clinical trials to give a window into the brain.



Read how treatments are selected for Octopus on page 45

## Plus... speeding up clinical trials!

Octopus is our revolutionary mega-trial. Its unique design is transforming the way we test potential treatments to slow or stop disability progression in MS.

Right now the trial team are working hard to get hospital sites around the UK ready for people with primary and secondary progressive MS to take part.

# Octopus

read

Find out more at  
[mssociety.org.uk/  
clinical-trials](https://mssociety.org.uk/clinical-trials)

## HSCT trial opening at hospitals around the UK

Haematopoietic stem cell transplantation (HSCT) aims to stop immune attacks. It works by wiping out and then re-growing your immune system using your stem cells.

StarMS is a new trial comparing the safety and effectiveness of HSCT for MS with four other very effective disease modifying therapies.

Professor Basil Sharrack is one of the StarMS leaders at Sheffield University. He

said “If you go back 10 years, HSCT wasn’t being talked about by the neurological community. Now with StarMS we should find an answer to how it compares to other really effective treatments. I hope it’ll help make HSCT become more widely available in the UK.”

The team are now enrolling people with highly active relapsing MS.

● Read more about HSCT at [mssociety.org/hsct](https://mssociety.org/hsct)

## Making mental health support for MS more accessible

Every year we commit to raise funds for new research projects. This year, one project will focus on a new treatment for distress for people with MS.

Research shows psychological treatments like cognitive behavioural therapy (CBT) can effectively treat anxiety and depression in MS. But there aren’t enough NHS therapists to meet the demand.

So researchers have developed an online CBT programme called COMPASS. In a small pilot study, the team found it was effective for people with

long-term health conditions.

Now they’ve adapted COMPASS specifically for people with MS. The online programme is supported by six therapist sessions. And it’s designed to be part of your existing NHS care.

The researchers will gather evidence on how effective the programme is for people with MS. And how it works for healthcare professionals. They’ll recommend how it could be delivered by the NHS so more people with MS could access it in the future.

● Read about COMPASS at [mssociety.org/compass](https://mssociety.org/compass)

Handing in our #BreakingPoint petition



## Campaign updates

### Back the 1 in 6

Over 17,000 of you added your name to the petition supporting the 1 in 6 people in the UK living with a neurological condition. Later this month, we'll join other members of the Neurological Alliance in Westminster to hand in the #Backthe1in6 petition to the UK Government.

- Find out more on our campaigns page at [mssociety.org.uk/one-in-six](https://mssociety.org.uk/one-in-six)

## “Many voices are stronger than one”

We know people living with MS need more support with the cost of living crisis. So last autumn, we launched our #BreakingPoint campaign.

Since then, we've handed in our petition at Downing Street. We were joined by Martin and Vince, who both live with MS.

Martin said “Although leaving my house is difficult, it's so important for me to represent the 14,000 people who signed the MS Society's petition. I want to be one voice as part of

a collective – many voices are stronger than one.

“Why should I be forced to choose between heating my house, paying for a carer, and my vital MS medication? It's an impossible situation.”

Thank you to everyone who supported the campaign. We'll continue campaigning about the cost of living crisis and disability benefits in 2023.

- Find updates and our campaign wins so far at [mssociety.org.uk/breaking-point](https://mssociety.org.uk/breaking-point)

## Carers' Leave Bill set to expand rights

In April, the Carers' Leave Bill will go through its final stages in the UK Parliament and should become law.

This important Bill will give unpaid carers the right to take up to one week's unpaid leave for the very first time. Our ultimate goal is for carers to get up to two weeks' paid leave. But this Bill is an important step. It'll help people with caring responsibilities in the UK get help balancing their work and caring for loved ones.

The Bill will give new rights to all unpaid carers. And, for the first time, employers will have to think about their employees with caring responsibilities.

We'll keep campaigning for better support for friends and families who care for people living with MS this year.

- Stay up to date at [mssociety.org.uk/carers-leave-bill](https://mssociety.org.uk/carers-leave-bill)

## Sativex campaign

This year, we're speaking up again on the unacceptable postcode lottery in England for Sativex. Since launching our campaign in August 2021, we've seen some great results. Sativex is a cannabis-based treatment for moderate to severe spasticity (muscle stiffness and spasms). And the number of health bodies routinely funding Sativex has increased by 45%.

But we want it to be available to everyone who's eligible. So the second phase of our campaign is targeting the remaining health bodies not yet prescribing Sativex routinely.

- To get involved or read about availability in the rest of the UK visit [mssociety.org.uk/sativex](https://mssociety.org.uk/sativex)



## Dates for your diary

### Thursday 18 May, 6.30pm Mental health webinar

We'll be joined by counsellor Tom Hunter who'll talk about the importance of looking after your mental health when living with MS.

[mssociety.org.uk/mental-health-webinar](https://mssociety.org.uk/mental-health-webinar)

### Saturday 15 July Round the Harbours

Cycle around the Hampshire harbour towns of Havant, Southsea, Fareham and Gosport to raise funds for MS research. Choose between a 32 or 54-mile circular route and enjoy at your own pace. Suitable for all abilities.

[mssociety.org.uk/round-the-harbours](https://mssociety.org.uk/round-the-harbours)

### Various dates Peer Support Groups

Our monthly Peer Support Groups are led by volunteers. Here, you can share experiences and tips, and get motivated with other people living with MS.

[mssociety.org.uk/virtual-support-events](https://mssociety.org.uk/virtual-support-events)

### Various dates MS Walk

Walk, roll or stroll to stop MS by joining an MS Walk near you. MS Walk returns to Manchester (13 May), Bristol (20 May), Glasgow (9 September), London (16 September) and Cardiff (23 September).

[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)

# “I’ve always believed in the power of movement”

**Lina Nielsen**, 26, is a British sprinter, hurdler and yoga instructor. She shared her MS diagnosis publicly last summer after relapsing just before competing in the World Championships. We spoke to Lina about how she supports her mental wellbeing.



## What was it like experiencing MS symptoms at 13 and being diagnosed at 17?

I didn't think too much about it when I was 13. But relapsing at 17 took a big toll on my mental health. It probably took me three to five years to process everything.

## How did you feel when you were diagnosed?

I think I was in denial. I didn't want to understand the condition. Instead, I used the internet to read stories from other people with MS. I was also pitied by the few people I told, which I hated. That stopped me from sharing because I didn't want a pity party.

## How did it feel sharing your MS with the public?

I always pictured myself having my athletics career and then telling people about my MS. But announcing it during the World Championships felt right because my relapse happened at such a crucial moment.

I felt vulnerable for a long time, which is something I'm not used to. I'm quite a private person, so it was a bit weird!

Luckily, I had people to look up to like parasport athlete Kadeena Cox. And

so many people reached out on social media which was great. I'm really proud of myself for doing it.

## How do you protect your mental wellbeing while in the public eye?

I reached a point last summer where I realised I hadn't had time to properly heal from the World Championships. I was doing interviews about what happened. It was like reliving the trauma every time. So I started saying 'no'. I felt like

a bit of a diva, but I had to protect my space and peace.

### Where do you get support from?

The love from the people closest to me. Especially last summer. I don't think I would've got through that period without it.

But there aren't many people who understand exactly what you're going through. And experiences and symptoms vary so much from person to person. I realised my main source of support had to come from myself.

### How has exercise helped your wellbeing?

I really believe in the power of movement. For me, stopping moving when I'm going through a relapse means I'll take longer to feel better. So I always try to move my body in some way.

### Tell us about your yoga practice.

I'm a qualified yoga teacher, but it's taken a bit of a backseat at the moment because of training. I believe in making adjustments and moving in a way that suits you.

That's what I love about yoga. There are so many forms and it teaches you to be patient with yourself and do what feels right. You don't need a fancy mat – you can just do it on your living room floor or in a chair.

### Lina's wellbeing tips

Try and keep your body moving and listen to it. If it tells you to stop, then do. And try not to compare your new self to your old self. You might not be able to do the things you used to, but there's always a way to move forward.

**“I always pictured myself having my athletics career and then telling people about my MS.”**



learn

Find out more about exercise and

MS at [mssociety.org.uk/ms-and-exercise](https://mssociety.org.uk/ms-and-exercise)



# Make the most out of life

to become or stay active while living with the effects of Multiple Sclerosis

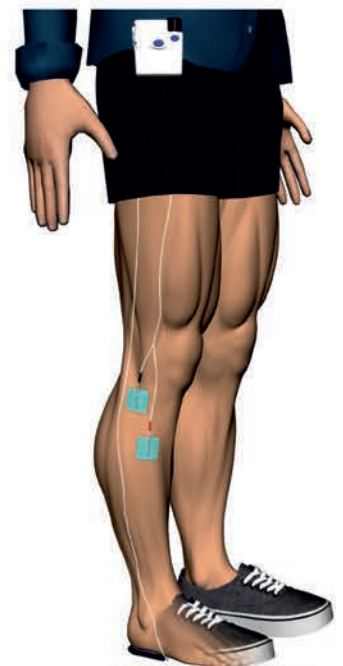
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Contact your local Healthcare Professional for advice on the right combination for you. If they are unaware of FES and would like to know more, please ask them to contact Odstock Medical Limited on

01722 439540 or [enquiries@odstockmedical.com](mailto:enquiries@odstockmedical.com)





# Talking therapy to help manage fatigue

Research has shown a type of talking therapy can offer relief for people with MS experiencing fatigue.

**F**atigue is more than just tiredness. It can make even small tasks feel unmanageable. The majority of people with MS experience it in some way. And research suggests it's more severe in MS than in other long-term conditions.

Yet UK MS Register data revealed only around 30% of people with MS are being offered any treatment for their fatigue. So finding better and more accessible solutions is a top priority.

## Current options for treating fatigue

In the UK, a drug called

amantadine can be offered for fatigue. Some people find it really helpful. But in clinical trials, the current drug treatments for fatigue don't give a significant benefit.

Over 100 studies have investigated non-drug interventions for fatigue. Researchers at King's College London and Queen Margaret University reviewed these studies. They found cognitive behavioural therapy (CBT) showed one of the most significant improvements.

## It's not 'all in your head', but talking about it can help

CBT for fatigue is different to the more well-known CBT for »

## What is CBT?

CBT is a type of talking therapy. But it's not one specific treatment. It's actually a combination of techniques. And the techniques differ depending on what you're trying to address. Like mental health, pain or fatigue. You'll work with a therapist to discover how best to tackle the problem together.

It combines two key therapy approaches to help you feel better:

- Cognitive therapy helps you address unhelpful thoughts and difficult emotions.
- Behavioural therapy helps you change behavioural patterns.

CBT is often one-to-one with a therapist, but it can be in a group setting. More recently, apps and websites have been developed to deliver CBT.



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» mental health. Scientists think inflammation and other biological factors trigger fatigue. Our thoughts, feelings and behaviours can then make it worse.

For example, research has shown ‘boom and bust behaviour’ can make fatigue worse. When you have lots of energy one day you might take advantage of this. But this can be followed by a ‘crash’ where you then find yourself avoiding activity as much as possible. This can create feelings of frustration, anxiety and distress about falling behind.

CBT for fatigue focuses on initially reaching a consistent level of daily activity and good sleep patterns, and then increasing activity over time. It’s also important to learn to be self-compassionate and to learn about managing difficult emotions.

### Exercise and CBT - a winning combination?

The review of non-drug interventions also found some types of exercise significantly reduce MS fatigue. It found a combination of exercise which increases heart rate, strength and balance showed promise.

There’s still not a fatigue programme that can easily be delivered on the NHS. So last year the King’s College team started the REFUEL-MS project. Guided by input from people with MS, it’s combining exercise and CBT into one intervention. People can choose what they want to focus on. And there’ll be an app supported by healthcare professionals. This is the first time this has been done for fatigue.

REFUEL-MS is based on NHS requirements so, hopefully, it can be delivered to everyone with MS who needs it.

Read more about COMPASS-MS on page 11

## Using CBT for mental health

More than one in three people with MS experience psychological distress, like anxiety and depression. Research consistently shows CBT can effectively help people with MS manage it. For example, tackling low moods by recognising negative feelings early on. And learning to understand what’s fuelling them.

The NHS recommends people with MS should be offered psychological treatment. They’re often advised to try CBT. But accessing support is often challenging.

One barrier is there aren’t enough trained therapists to help the number of people experiencing psychological distress. So we’re supporting a new project called COMPASS-MS. It’ll test a digital CBT intervention for anxiety and depression in MS.



# When psychological support is personal and professional

**PhD student Hannah Morris-Bankole** and psychologist **Dr Laura Allen** both live with relapsing remitting MS. They met and discussed how different therapy styles could be beneficial for people with MS at different times.

**“W**ithout my own training, I’d have been in a difficult position,” says Laura. She wasn’t offered psychological support when she was diagnosed with MS. But she was already a trained psychologist and counsellor working with people with long-term health conditions.

Hannah was diagnosed with MS while studying for her psychology degree. She remembers she was handed “a load of booklets” by a healthcare professional. There was information about psychological support, but more focus on physical symptoms. So her research now focuses on MS.

Both Hannah and Laura found their psychology studies supported them with the uncertainty of an MS diagnosis. Now their lived experience continues to influence their research.

## What stops people with MS from seeking professional support?

In her PhD research, Hannah’s found only around half of the people involved were seeking professional mental health support. Some people don’t seek any support at all and she wants to find out why.

Hannah remembers being overwhelmed with worry when she was diagnosed. She says “I wish I’d known when I was diagnosed, you

do need professional support. It’s just not offered.” She didn’t think about her emotional needs or know where to go.

Her research shows one barrier is the stigma some



## What styles of therapy can people use?

Two of Laura’s examples are ACT and CBT. Included in both of these approaches are mindfulness skills. ACT includes noticing thoughts as they come up, without attaching emotions to them.

And CBT is about changing negative thought patterns.

Hannah’s research indicated CBT could be even more effective when combined with other approaches, such as group therapy.

people feel around therapy. Some might be embarrassed to admit they need professional help.

She explained another major barrier is not knowing what therapy options you have. Laura sees the same thing in her clinic. Many clients don't know the types of therapy they could try.

### Overcoming stigma and exploring therapy options

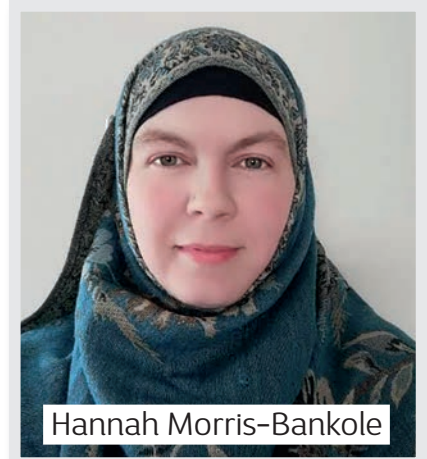
Hannah found once people overcome the barriers and access one type of support, they're keen to explore other

sources. Even opening up to people close to them makes it easier to seek support from professionals.

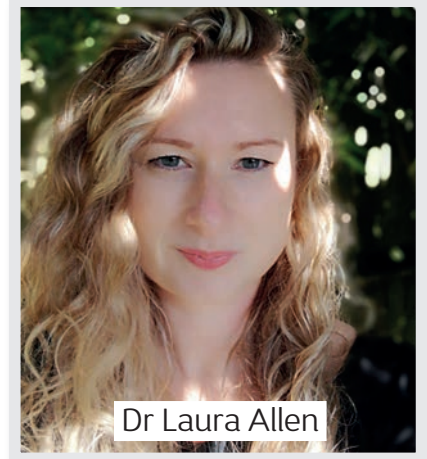
Laura thinks trying therapy for the first time creates "open-mindedness". She says "in a first session, everyone's nervous". And once her clients start to benefit, they're more open to embracing possibilities of other types of therapy.

### The right approach at the right time

Hannah's findings suggest people living with MS can benefit from different therapy



Hannah Morris-Bankole



Dr Laura Allen



For some people, peer support in a group helped normalise their feelings. But people's experience of group therapy was mixed. Laura adds she "often meets people who struggled with

group dynamics."

Trying different styles of therapy could help find the right type of support.

- Read about one of our ongoing projects using ACT at [mssociety.org.uk/act](https://mssociety.org.uk/act)

styles at different times.

She found people were often advised by professionals to use CBT. But their experience was often more positive when it wasn't the first therapy style they tried.

Her research aligns with Laura's clinical experience. When Laura has a client who's newly diagnosed with a long-term health condition, her tactic is to start with something called Acceptance and Commitment Therapy (ACT) and move on to techniques like CBT later.

Laura sometimes approaches the stage of diagnosis similar

## How do you carry out mental health research?

There are different ways to study psychological interventions.

During her PhD, Laura used a course based on compassion and mindfulness. She asked people to score their feelings of anxiety, fears of compassion and stress before and after the course. She later created a course using ACT for individuals living with MS.

Hannah's PhD is designing an MS-specific psychological intervention. To do this, she needed to find out what support people already use. This was so she could understand where it'd be most useful to deliver.

She collected responses from 565 people with MS in the UK using an online survey. She also did a smaller number of in-depth interviews. Her survey gave an overview. And she's analysed her interviews to look for common ideas.

to how she'd approach grief. She says "Grief doesn't have to be about death, but about transitions in life, or about a loss of something."

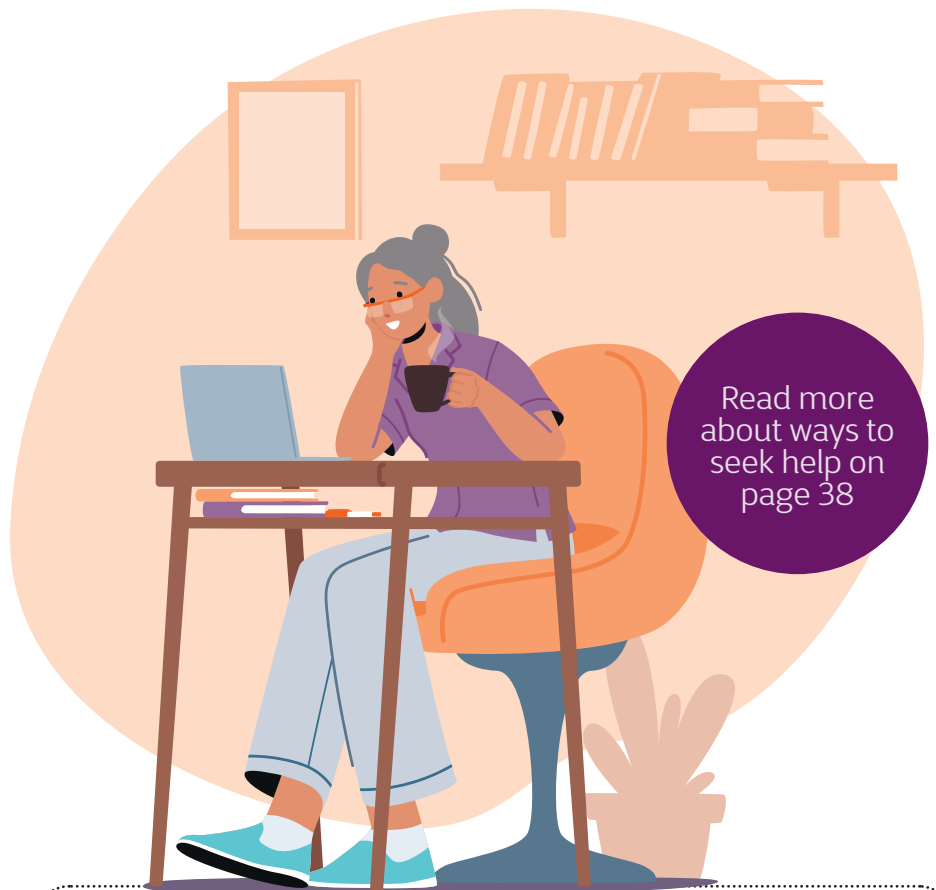
They both agree finding what works best for an individual is the right approach.

### Sharing experiences to help others

Hannah and Laura want to find ways to help others overcome

barriers to getting the right support for their mental health. And to share that it's okay to need help.

They're both determined to make sure more people with MS have access to the right support. And they hope to combine their personal and professional experience to make an impact for the whole community.



Read more about ways to seek help on page 38

#### help

Hannah's PhD is exploring how to overcome barriers to seeking mental health support. But we also know lots of people who do seek support can't access it. Many people with MS are waiting a long time for help. If you're struggling with your mental health, one of the resources you can contact is our MS Helpline which gives emotional support and information to anyone living with MS. Freephone **0808 800 8000**. Confidential email [helpline@mssociety.org.uk](mailto:helpline@mssociety.org.uk)

# Me, MS and my mental health

**Jordan**, 29, has relapsing remitting MS and **Robby**, 53, has secondary progressive. They shared their experiences with MS and their mental health.

## Tell us a bit about your diagnosis.

**Robby:** I went interrailing when I was 18 and my left leg became weak. When I got home, my GP referred me to a consultant neurologist. It took four years to get there. I was diagnosed in 1992.

**Jordan:** I noticed a tingling down my spine when I flexed my neck. This was followed by pins and needles in my feet.

After many trips to the GP, I saved up to see a neurologist privately. With the help of an MRI machine, they confirmed I had MS.

## How was your mental health during that time?

**Robby:** My mental health was okay. My consultant didn't seem too concerned, so I didn't research MS. And I hadn't heard of it because I couldn't access the internet back then.

**Jordan:** I had a positive outlook until my father passed away, 16 weeks after my diagnosis. I couldn't believe I'd been diagnosed with an incurable condition and I'd just lost my father. Now, I'm happy knowing he'd be super proud of me and the decisions I've made.





Robby

## “I think men have pressure from society to ‘man up’ and just deal with it.” – Robby

### How did people react when you told them you had MS?

**Robby:** I didn't tell people for a while. I was still trying to process having a progressive, sometimes debilitating, and incurable disease. When I told my friends, they were great. They didn't treat me differently – they just made adjustments when I was going through a relapse.

**Jordan:** I get a mixed reaction when I tell people about my

MS. People can't believe I've kept smiling and achieved the things I've achieved. But having MS doesn't change me.

### How did their reactions impact your own mental wellbeing?

**Robby:** The support I had from my friends was important. It stopped me from feeling alone.

**Jordan:** Dealing with people's reactions is part of having the condition. It's become easier to handle now I've accepted it myself.

### Have society's attitudes towards disability affected your wellbeing?

**Robby:** I used to be cynical of people, but being disabled showed me the kindness in others. The Paralympics in 2012 normalised disability a little and things became more accessible.

**Jordan:** I'm aware of changes people make for the right reasons and changes people make just to say they've done something. Changes have to be genuine.



### Do you think men find it hard to talk about mental health?

**Jordan:** I sometimes feel men believe the stereotype of 'men don't cry'. This makes it harder to address the problems we're facing.

**Robby:** I think men have pressure from society to 'man up' and just deal with it. Not expressing your emotions isn't helpful. You need release, otherwise things fester.

### How do you look after your own mental health?

**Robby:** I stay in frequent contact with family and friends. And volunteering is important. It gives me a sense of purpose.

**Jordan:** I reflect on things going on around me and things I'm grateful for. I take time every day to think about all the positives.

### Do you have any advice for others in a similar situation?

**Robby:** Engage with life. Being alone with your thoughts can

be hard sometimes, so find things to occupy your mind.

**Jordan:** I've always said "The journey still continues. This

is just a hurdle you weren't expecting." Sometimes just accepting things can make your journey easier.

**"I get a mixed reaction when I tell people about my MS. People can't believe I've kept smiling and achieved the things I've achieved." - Jordan**



Jordan



Find out more about MS and mental health at [mssociety.org.uk/mental-health](https://mssociety.org.uk/mental-health). You can also call our MS Helpline for support on **0808 800 8000**.



# The challenges and joys of parenting

Three parents with MS talk about how they look after their mental health in the midst of family life.

**“My relationship with my wife and children is stronger than ever”**

**Mike Spencer**, who has four adult children, was diagnosed in his mid-thirties. He now has secondary progressive MS.

worked in a major bank for 15 years, eventually in their marketing team. I then moved to a new job with a company owned by the bank, which sold computers to large companies. I tripled my income, which I needed with a growing family. I was given Wales as my area to look after.

My first problem was in my eyes. I was diagnosed with optic neuritis as I doubled up the numbers of cars travelling towards me. After quite a long

time I seemed to have problems with walking and speaking.

I was then diagnosed with MS. My four children were aged between one and six at the time. Rachel is my oldest, then Anna, then Richard. Sophie is my youngest. They're all over 30 now. I'm a granddad times six, with the seventh on the



way, which is fantastic.

For me, one of the worst things about having MS as a parent was not being able to drive. I couldn't be the person to say, "Let's go somewhere," and then just do it. I still find it frustrating.

In the earlier days I used to meet my youngest daughter from school on the mobility scooter, which was difficult for us both at the time. Openness and understanding were the way forward.

Over the years, my MS has reduced my ability to make decisions, which I've also found very difficult. What's kept me going is my hobby. I love

to paint. It's helped me cope psychologically. Humour is very important.

I've had more time for my wife and children because of having MS. It makes you slow down so you can listen.

My wife Chrissy is the security of my family. I'm so fortunate and she helps me during every single day.

## "It helps to talk to mums with MS"

**Emily Hall is mum to two-year-old Lola. She was diagnosed with relapsing remitting MS in 2016.**

I love Lola and everything she brings to our lives. But after she was born, I put a lot of pressure on myself. I wanted to give her my breastmilk because research has suggested some people who breastfeed also experience fewer relapses after giving birth. But breastfeeding didn't work very well, so I was up all hours pumping my milk. When she was eight weeks, I had a relapse anyway.

Around this time, I experienced a mini-psychotic episode. It was an uncommon side effect of some steroid tablets I'd been put on. I was out walking with Lola and lost all touch with reality. It only lasted a day, but it was so scary. I also struggled with not working and the lack of routine. It was during lockdown, so I wasn't going to baby groups. And I'd been made redundant.

I think all these things contributed to me getting post-natal depression. I'd never had mental health issues



before, and I didn't want to acknowledge how numb and empty I felt. Then my MS team said "Remember, depression can be a symptom of MS." That helped a lot.

I did some cognitive behavioural therapy (CBT). Then I was referred to a neuro-psychologist. It was great because I could just talk. She gave me practical things to do, like a 'self-check-in'. A lot of it was writing things down.

I was also prescribed anti-depressants. And getting a new job – which I love – made a massive difference.

I'm very thankful to my husband Rich for his support. And it helps to talk to other mums with MS. I've got a friend with MS who has young children. Our MS nurse put us in contact. It's brilliant because we can really relate to each other.

# “You can always find ways of doing things together”

**Nina Campbell** has three adult daughters. She was diagnosed with MS in 1995 when her second child was a baby.

**W**hen my daughters were very young, I managed fairly well most of the time. Soon after I was diagnosed, I decided to give up my work as an occupational therapist. It was a hard decision. I loved my job and, financially, it was tough. But I wanted to use my energy to be a mum.

I've never regretted my decision. It meant I could take them to nursery and do things with them. When they went to school, I'd take my time doing the cooking and washing during the day. That meant I wasn't exhausted when they came home. Then I'd take them to their dance classes, gymnastics and swimming.

I have an absolute rock of a husband. I've always given him credit for his contribution to their upbringing.

My daughters are 25, 28 and 30 now. They're very close to each other and close to me. And I have a

grandson who's three and a half, and another due.

My grandson's a lovely little boy. He calls my walking sticks “Nana's magic sticks” because I can make them really small. Nana has a wheelchair named Elmo. Nana plays with Lego and can read a story. She's not going to run around the garden. But she's got a motorised scooter and we can terrorise everyone on that.

My tip for parents living with MS is to concentrate on the things you can do, not the things you can't. You can always find ways of doing things as a family where you're very much part of it.



**read** Find out more about managing family life and MS at [mssociety.org.uk/family-and-relationships](https://mssociety.org.uk/family-and-relationships)





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# Talking things out is never a waste of time

Our anonymous columnist, who cares for his wife with secondary progressive MS, talks about mental wellbeing.

**K**eeping a firm grip on one's mental health, especially since COVID and cost of living pressures, is challenging for the best of us.

The carer hasn't only their own personal welfare to consider. A large part of 'caring' involves looking after not just the physical needs of another person, but their mental health needs as well.

We might see a change of mood as 'simply' the rollercoaster MS ride of having good, better, bad or worse days. Or we might miss the signs completely.

What would we, as carers, think if there was a sudden run of 'bad days'? Often manifesting itself in physical decline, temporary or otherwise, there might just be a more serious underlying mental health issue. The carer has to be on high alert. So what's our role in all this?

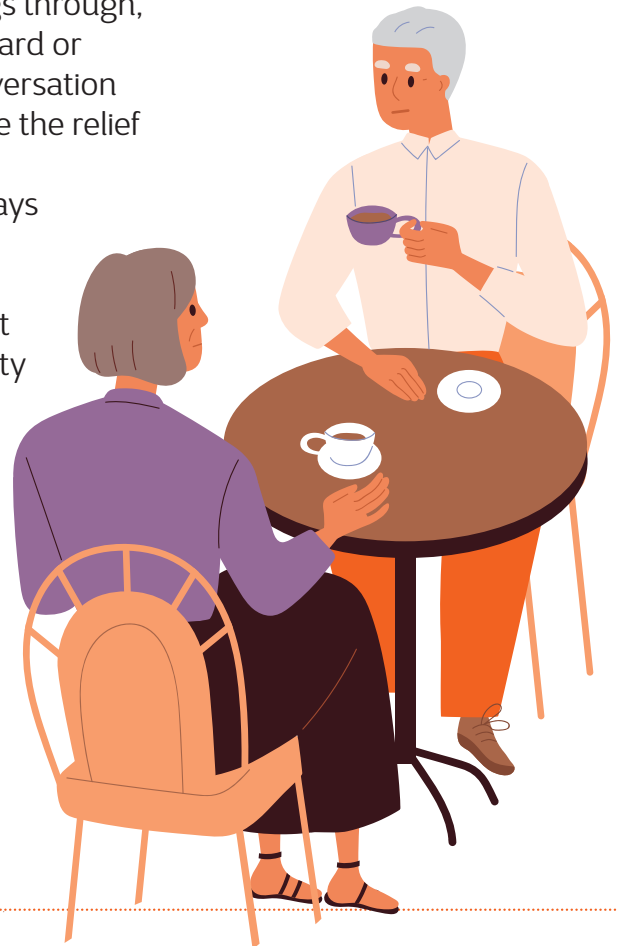
To meet their physical needs and be the 'encourager' and 'stimulator' too – providing positivity and affirmation wherever we can.

But perhaps our most important role of all is 'listener'. Talking things out is always good and never a waste of time or energy. Helping to talk things through, however bad, awkward or depressing the conversation is, might just provide the relief that's needed.

We all have bad days where we'd prefer not to emerge from under the duvet. But a caring responsibility means that carers often have to put their own needs second, or last. That pressure, which never

lets up, can be exhausting.

This means, as carers, we have to be good to ourselves, as well as 'being good' to the people we care for.



Find out more about support for carers at [mssociety.co.uk/carer-support](https://mssociety.co.uk/carer-support). Whether you're a carer or you've got MS, you can also call our MS Helpline for free on **0808 800 8000**.



## Ask the experts

# MS and mental health

Our MS nurses **Razia Khan**, **Jennifer McNeil** and **Liz Cooke** answer your questions.

### Q Can MS affect mental health?

It can be common to experience depression, stress and anxiety when you have MS. This could be caused by changes in brain chemistry or hormonal imbalance. Or by the effects of living with MS and its impact on daily life. And other life events may also play a part.

For some people, MS lesions can happen in parts of the brain associated with feelings and emotions. Medications such as steroids and some disease modifying therapies (DMTs) may also cause side effects that can contribute to low mood.

### Q Are there treatments that can help?

Treatments available to help manage mental health symptoms include medications, talking therapies, self-help and complementary therapies.

Some people find anti-depressants or anti-anxiety medication helpful. The most commonly prescribed are selective serotonin reuptake inhibitors (SSRIs).

Talking therapies, including

psychotherapy and cognitive behavioural therapy (CBT), can help. CBT looks for practical ways to improve your state of mind and can help you develop coping skills.

Other therapies some people may benefit from include mindfulness,

exercise and peer support.

To get advice and support on managing mental health symptoms, it's important to speak to your GP or MS team. They'll be able to advise on the most suitable treatments.





**Q Some people with MS find they laugh or cry when they don't feel that way. Why?**

Living with MS can affect your feelings, so it's not unusual to experience a range of powerful emotions. You may easily burst into tears or suddenly get very angry. These emotions may build up quickly and you may have no control over them. This is often called 'emotional lability' or 'emotionalism'. You might hear it called pseudobulbar affect.

Sometimes, these emotions are related to what you're feeling. Other times, they may

not reflect how you feel inside. You may react to bad news by laughing or start crying when you're feeling happy.

Research hasn't yet discovered why this happens. Emotionalism could be caused by MS-related nerve damage in the areas of your brain controlling your emotions. But a number of different factors may be involved.

**Q Can I get help with my mental health at work?**

If an employee has a mental health issue, it's important their employer takes it seriously. Employers have a 'duty of care'. This means they must do all they reasonably can to support their employees' health, safety and wellbeing.

Your workplace may be able to offer you an assessment with an occupational health professional. Together, you can look at your workplace and see

what you can do to minimise any issues you're experiencing.

**Q I find it hard to talk about mental health. Do you have advice?**

The first step is acknowledging that you find it hard. Think about the best person to speak to. For some, it might be a family member or friend. Others might find it easier to speak with a person who doesn't know their situation such as a helpline or counselling service.

It's normal to have times when you feel a little low. But it's important to recognise when you need to ask for help. Signs of low mood can include feeling sad, anxious or panicky, more tired or unable to sleep, angry or frustrated and having low self-esteem.

Talking and using self-help strategies may be enough. But if low mood lasts for two weeks or more it could be a sign of depression. Other signs of depression might include not getting enjoyment out of life, feeling hopeless, an inability to concentrate or having thoughts of self-harm or suicide. If you think you might have depression, you should contact your GP.



**learn**

You can find out more about mental health and MS on our website at [mssociety.org.uk/mental-health](https://mssociety.org.uk/mental-health) Or by calling our MS Helpline on **0808 800 8000**.





## “Yoga is my favourite way to start the day”

Having MS for over 30 years, I know the importance of a positive outlook. It can be hard at times and there are daily challenges. This is why I fell in love with yoga. It's a wonderful practice that can have many mental, physical, and emotional benefits. And I'm dedicating time to self-care, reducing my muscle stiffness, increasing mental clarity and releasing some of those happy hormones.

I saw how the pandemic had a negative impact on people's mental health and wellbeing. And I wanted to share yoga. So I started a free yoga channel on YouTube in March 2021.

- Tracy

## “Finding a therapist I could connect with really helped”

Counselling can be a great way to process life events and feelings. It's helped me understand difficult situations, how others may have experienced the same event and helpful ways of coping.

It can be hard to open up at first. But being open-minded and finding a therapist I could connect with really helped. Counselling isn't for everyone and it won't necessarily give you solutions. But I've found it helpful to speak to someone who was there to listen to me and not give me advice. - Noor



## “I lie on the board but I'm still surfing”

I've surfed since I was 13. But after my primary progressive MS diagnosis my mobility slowly dropped. I couldn't stand up on a surfboard, so I stopped surfing for 10 years. It was like I was in a state of mourning for who I was.

Then a few years ago a friend got me into adapted surfing. I went out one choppy January day and had a fantastic time. It gave me a boost and made me think about how I could do it differently. I can't stand up - I lie on the board. But I'm still surfing.

What helps me is to not fight against MS but to work out what I can still do and adapt to that.

- Mark



share

Do you have a story to share about how you support your mental health? Please tell us about it at [mssociety.org.uk/share-your-story](https://mssociety.org.uk/share-your-story)

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## How do you support your mental wellbeing while living with MS?

Our community on Facebook and Twitter offers some tips.

I run when I can and go to yoga at least once a week. I also make sure I get outside every day – even if it's just a short walk to a shop or café.

**Amy Thompson**

Pilates and using a mindfulness app help. I'm still waiting for NHS psychological help though. Needing a mobility scooter to get round Legoland with my grandkids was hard to come to terms with. I keep having to remind myself how lucky I am.

**David Bond**

Yoga and running help me a lot!  
**Swearer Menendez**

Dance!  
**Trishna Bharadia**

Doing some form of exercise helps my head – no matter how little my body lets me complete. Be it a walk, barbell training or body combat!  
**@micjandrew1976**



For our next issue, we're asking: **What low-cost or free things have brought you joy during the cost of living crisis?** Send your answers to the MS Matters inbox at [msmatters@mssociety.org.uk](mailto:msmatters@mssociety.org.uk). Or keep an eye on our social media ([facebook.com/mssocietyuk](https://www.facebook.com/mssocietyuk) and [instagram.com/mssociety](https://www.instagram.com/mssociety)) where we'll be posting the question later this year.

Mindfulness is a fantastic way of dealing with anxiety and stress. There are some fantastic videos on YouTube, which are free to use. It's a case of finding what's best for you.  
**Clive Whiteside**

# How we're supporting your wellbeing



Wherever you live in the UK, we offer lots of ways to help you look after your wellbeing – from local groups to webinars and our MS Helpline.

## Join your local group

We have 240 active local groups across the UK, which bring people together, reduce isolation and give peer support. They provide a wide range of services and activities, including social activities, counselling and mindfulness sessions, exercise and physical activity sessions.

Many of our groups also offer MS Support, a UK-wide service provided by around 500 volunteers attached to our local groups. They're trained to help you with:

- emotional support
- signposting to national and local services
- giving information
- helping people apply for grants where their group offers them.
- Visit [mssociety.org.uk/local-support](https://mssociety.org.uk/local-support) to find out about local group activities and your local MS Support volunteer. Our MS Helpline can also help.



## Check out ROC MS in Northern Ireland

We recently launched our new wellbeing programme ROC MS (Reach Out Connect MS) in Northern Ireland. ROC MS offers online support for mental health and wellbeing. The programme includes counselling, positive

mental health support programmes and socially active events. It's funded by the Mental Health Fund NI through the Department of Health and the National Lottery.

- Visit [mssociety.org.uk/wellbeing-hub-ni](https://mssociety.org.uk/wellbeing-hub-ni)

## Get support at our Scotland Wellbeing Hub

Scotland's Wellbeing Hub provides free virtual support to help you manage your mental and physical health and wellbeing.

One-to-one person-centred counselling is available for people with MS and their families. And through the peer support service, volunteers use their experience of living with MS to help others reach personal goals. Physical activity sessions like yoga and chair-based exercise classes might also benefit mental health.

- Visit [mssociety.org.uk/wellbeing-hub](https://mssociety.org.uk/wellbeing-hub)

## Start your own group

Are you looking to start or grow your own independent group? We've created a new hub of information and resources to help people make their own connections. These could be local, national, international, online or in-person.

You can find tips on getting started, practical advice on running a group and support on promoting your group online. You can also meet people through our forum.

- Visit [mssociety.org.uk/start-a-group](https://mssociety.org.uk/start-a-group)

## Call our MS Helpline

Do you want to speak to someone for emotional support or information? Or find out about MS Society services that can support you?

The MS Helpline has specialists in physical activity and welfare benefits, and MS nurses. In England, Wales and Scotland it has legal specialists who can offer support with employment, disability discrimination and community care. It can also refer you to our befriending scheme.

- Call **0808 800 8000** or visit [mssociety.org.uk/ms-helpline](https://mssociety.org.uk/ms-helpline)



## Boost your wellbeing in Wales

Our MS Cymru team and groups offer free services and activities for anyone living with MS and their families to help improve wellbeing. We offer one-to-one counselling sessions and acceptance and commitment therapy group sessions.

Physical activities include seated exercise to music, yoga, physio-led exercise, tai chi and boccia. Social and creative activities include bingo, knit and natter, creative writing, and our Men's Shed and Hens' Shed.

- Find out more from [mscymru@mssociety.org.uk](mailto:mscymru@mssociety.org.uk)

## Learn online with Living Well

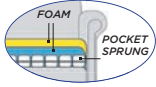
Our Living Well programme offers a variety of virtual sessions designed to help you gain support. They also help you learn about your own or your loved one's wellbeing, gain new skills and connect with people affected by MS.

Sessions include information webinars, where you can be an anonymous attendee, and small interactive group sessions. Why not join our Mental Health and MS webinar on 18 May (see page 13)?

- Find out about upcoming sessions at [mssociety.org.uk/virtual-support-events](https://mssociety.org.uk/virtual-support-events)

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# Counselling offers a safe, non-judgmental space

**Wendy Ferguson**, from our volunteer-led counselling service in Northern Ireland, talks about what to expect from counselling.

## What can I expect from counselling?

As counsellors, we understand that the thought of starting counselling can be intimidating. This can be even truer for people living with a long-term, progressive health condition like MS.

The people we help can expect a safe, non-judgmental space where they can talk about their experiences and feelings. Together, we explore their goals for therapy and develop a treatment plan tailored to their specific needs. Each session lasts around an hour.

## What happens at the first session?

During the first session, we discuss their symptoms and how they impact their daily life. We also talk about their coping strategies. This helps us understand the person's strengths and areas where they may need extra support.

We also explore any concerns about how their condition affects their relationships with others. This could include issues related to:



- self-esteem
- feelings of isolation
- difficulty communicating with friends, family or healthcare providers

## What benefits does counselling provide?

Counselling is not about 'fixing' a person or their condition. Instead, it's about helping them manage the challenges that come with MS and improving their overall wellbeing. Through

therapy, people can learn new coping strategies, develop better communication skills, and gain a deeper understanding of their emotions and how to manage them.

## How long does it take?

Therapy's a process. It may take some time to start feeling better. But with consistent effort and a positive attitude, counselling could help many people live with their condition in a more fulfilling way.

## How can people get referred?

For our counselling service in Northern Ireland, people can self-refer or be referred by a consultant or other healthcare professional. There's an optional donation of £5 a session. Email [nireception@mssociety.org.uk](mailto:nireception@mssociety.org.uk) to find out more.

read

Find out more about how to get help in other parts of the UK at [mssociety.org.uk/getting-help](https://mssociety.org.uk/getting-help)

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# A sceptic's guide to wellness

Journalist **Richard Sprenger**, who has MS, made a video series on the wellness industry for the Guardian. He tried a range of treatments including goat yoga.

## When were you diagnosed with MS?

I was diagnosed with relapsing remitting MS seven years ago. My main symptom is in my walking.

## What does 'wellness' mean to you?

'Wellness' covers a huge spectrum of different people doing different things. But for me, it's about taking health outside of a clinical NHS setting.

## How did you decide which treatments to try?

I wanted to try a range of things, some of which might work for me, while also telling a story. As it was a video series, I wanted to find some

with a visual element. Like goat yoga.

## Did you experience any benefits to your mental wellbeing?

Definitely. There's this whole thing about relaxation. The lovely thing about these treatments is spending an hour with someone talking to you in a calm voice about your problems. And being in a pleasant environment.

## Do you think some wellness practitioners put too much responsibility on the individual?

I think that's totally the case. There's a fine line between feeling empowered and feeling



**“With a diagnosis like MS, I think if you've got good mental health, it's easier to work on the physical stuff.”**

overwhelmed. Or if it's not helping you, feeling like it's your fault. I was very wary of that.

## What would you like people with MS to take away from the series?

It's about trying to do something positive for you. It might be wellness-tinged or something you just like doing. With a diagnosis like MS, I think if you've got good mental health, it's easier to work on the physical stuff. Or you can accept the physical stuff more easily.

view

You can watch the series at [mssociety.org.uk/wellness-series](https://mssociety.org.uk/wellness-series), which also features athlete Lina Nielsen (see page 14).

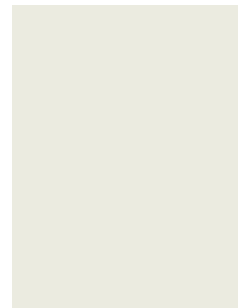


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Read more about Octopus at [mssociety.org.uk/octopus](https://mssociety.org.uk/octopus)

# How are treatments chosen for Octopus?

Our new trial will be able to slot in new drugs as they're discovered. **Professor Denise Fitzgerald** and Research Network member **Lyndsey Shellard** are helping identify treatments that could be tested in Octopus.



Professor Denise Fitzgerald

**D**enise and Lyndsey were part of a team who spent months creating a vast list of drugs that might show promise for treating progressive MS.

Lyndsey said "I went along to my first meeting and there were over 20 leading scientists. I remember thinking it was going to be something very special for MS research."

## Identifying existing drugs

They focused on drugs already used for other conditions. Denise said "If some existing drugs could be helpful in MS, it'd be a real shame to not take advantage of that. You can get existing drugs into later-stage trials more quickly than brand new drugs too."

They wanted candidates that might protect nerves. We all lose nerves as we age, but this can happen faster in MS.

## Ranking the options

The options were ranked and shortlisted to those with the most potential. Denise said "This process was a balancing act, weighing up the different factors."

The drugs on the shortlist had evidence they worked in the lab. They might've been successful in early MS trials. Or be effective in another neurodegenerative condition.

And clinical trials can't succeed if no one's willing to take the drugs. Lyndsey said "As someone with MS, I was asked to score each drug on things like:

- How is it taken - tablet, injection or infusion?
- How often would it need to be taken?
- What side effects would I be willing to tolerate to slow progression?"



Lyndsey Shellard

## Making recommendations

Denise and Lyndsey are now on a committee making recommendations for future treatments to the team running Octopus.

The first two drugs being tested are just the start. Denise said "There are other drugs we're excited about, but haven't crossed the threshold for recommendation yet." They'll keep an eye on the evidence.

Lyndsey said "We really feel like we're part of the team delivering Octopus. I feel very privileged to be involved."



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## “Connecting with other Black men with MS is important to me”

Nikoma explains why he created an online support hub for Black men with MS in a recent blog post for us.

I attend a weekly MS support group, which I find really helpful. I'm around other MS warriors and we can share stories and experiences. However, one thing that's clear week-on-week, is that I'm:

- A)** one of a very small number of men in the room, and
- B)** the only Black person in the room.


This almost mirrors how I've felt since my diagnosis – that I'm the only Black man living with MS. While I know this isn't the case, it's been rare for me to meet other Black men who are on this journey.


Connecting with other Black men with MS is really important to me. So I've recently started an online support hub


specifically for Black men with MS to come together and talk.

I believe traditional masculinity roles and stereotypes have caused many Black men to struggle with sharing emotions. And this has often made us reluctant to seek help for our mental health. But I'd encourage Black men to break that cycle and seek support.

Nikoma's blog struck a chord with our community on Instagram.

 **mcfall8124**  
Brave to speak out.

 **hugowhitenoise**  
Beautiful words Nikoma.

 **tinooas80**  
I feel his frustration and he should be really proud for sharing his story. I was diagnosed over 10 years ago and know how he's feeling!

Read Nikoma's blog in full at [mssociety.org.uk/nikoma](https://mssociety.org.uk/nikoma) and visit his support hub at [brothersupporthub.co.uk](https://brothersupporthub.co.uk)



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

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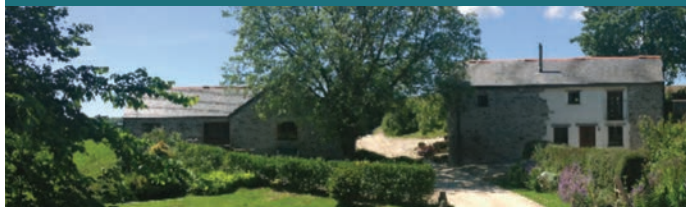
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Cherelle Gardiner

## Hope Reborn: a different perception of MS

A new single has been released to increase awareness of MS and raise funds for us and another charity, **Overcoming MS**.

Hope Reborn was created by classical music composer Fabio D'Andrea and was released in February. The accompanying music video stars our supporter, actress Rose Leslie. And it shows her character being diagnosed with MS and finding support from the MS community.

We'd love it if you could download the single. Some of the profits from the sales are being split between us and Overcoming MS.

Several people with MS appear in the film, including Cherelle Gardiner. She said "The Hope Reborn project is close to my heart, really and truly, because it's a different perception of MS. We're seeing it and we're living it. Now people who don't have MS can see it's amazing that we can do things people think we can't."

Watch the film and find out how to download the single at [mssociety.org.uk/hope-reborn-single](https://mssociety.org.uk/hope-reborn-single)

## Volunteer spotlight Zach Jewkes

Zach was diagnosed with MS in 2019 and volunteered at MS Walk London in 2022.

My aspiration to volunteer came from when I was diagnosed. After all the help I was given, I wanted to give something back to the MS Society.

I love volunteering for the MS Society because it helps a charity that's supported me and others so much. It feels great to meet so many like-minded people being so supportive and welcoming, all joining together to win the fight against MS.

Getting involved in MS Walk as a participant and a volunteer has definitely helped with my mental wellbeing. Seeing everyone singing and dancing at the start, being so supportive of each other is so uplifting, and there's such a strong sense of community.



Our fundraising events can only happen with the support of amazing volunteers like Zach. Find out how to get involved at an MS Walk at [mssociety.org.uk/ms-walk](https://mssociety.org.uk/ms-walk) or email [mwalk@mssociety.org.uk](mailto:mwalk@mssociety.org.uk)

# Getting to know you...



**Chris Murray and David Silver** are our newest MS Society trustees.

Chris has had a 45-year career in the energy sector. David has spent 23 years in investment banking.

## What's your day job?

**Chris:** I hold several non-executive roles in the energy, water and charity sectors.

**David:** I'm a non-executive director of a couple of private equity-backed companies. I'm also a trustee of the UK Kidney Association.

## Why did you become a trustee for the MS Society?

**Chris:** My family is directly affected by MS. I wanted to do anything I could to support them. By joining the Board of Trustees I can, hopefully, make a bigger difference.

**David:** I was diagnosed with MS in 2011. I wasn't open about my diagnosis

until very recently. I'm keen to contribute, so I initially joined the Stop MS Appeal Board and then applied to become a trustee.

## What do you hope to achieve in this role?

**Chris:** I want to support the MS Society in every way I can. In particular, I'd like to see how we can encourage everyone impacted by MS to help us achieve our goals.

**David:** I hope to help the organisation raise funds and communicate its clear reason for being, and how it can help the community.

## What's your greatest achievement?

**Chris:** The obvious and true answer is the two children

that my wife and I are blessed with. But, on the professional front, heading the company that built the natural gas industry in Northern Ireland was an amazing opportunity.

**David:** I've been married to Gaby for 26 years and have two boys, aged 15 and 13. I am very proud of, and lucky to have, all three.

## What is the most important lesson life has taught you?

**Chris:** That, no matter how busy you are, if there's a family event that will only happen once, you have to be there.

**David:** Social connections can really help, whether that's family or friends, old or new.

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