

Making a connection

How loneliness affects people with MS and what we're doing to tackle it



Inside
Research Matters
magazine

Why the UK is a world leader in MS research

Launching the New SpeediCath® Flex Pocket Size

It's easy to open. You just twist the cap and you don't need to touch the catheter.

Twisted SpeediCath® Flex user

I think the biggest advantages of the SpeediCath® Flex is its flexible tip, its compact design and how practical it is.

Peer SpeediCath® Flex user

NEW
Pocket
Size



Fits in your pocket
Fits in your lifestyle

SpeediCath Flex Pocket Size for men is a soft catheter with a dry-sleeve and a flexible tip. From opening to disposal, it's designed to make every step of catheterisation easy.

NEW



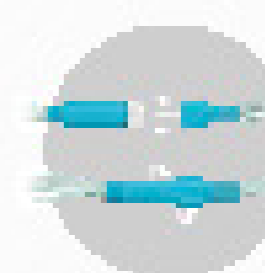
Hygienic

The soft-squeeze grip and dry-sleeve make insertion easy without having to touch the catheter itself. For hygienic and trouble-free catheterisation.



Flexible

The flexible tip and soft catheter ensure easy insertion and gentle passage through the bends and curves of your ureters. For smooth and comfortable guidance to the bladder.



Discreet

After use, the catheter can be re-closed and be returned to the packaging, which can also be re-closed for discreet disposal when and where it suits you.



Easy to open



Easy to close



Easier on the environment

For your **FREE SpeediCath® Flex Pocket Size Sample Pack**, fill out the form below, pop it in an envelope and post to **FREEPOST COLORPLAST** (that's all, no stamp required) or visit www.colorplast.co.uk/MS

Request your sample today and our product specialist will support you through your trial.

Title:

First name:

Surname:

Address:

Postcode:

Phone:

Email:

Signature:

I've been assessed and prescribed catheters by a Healthcare Professional
I would like to sample

SpeediCath® Flex Pocket Size (2x10)
 SpeediCath® Flex Pocket Size (2x12)
 SpeediCath® Flex Pocket Size (2x14)

OR

I'm unsure if a new catheter is right for me, can a product specialist call me?

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SpeediCath® Flex





Issue 131
Spring 2019

Not long after joining the MS Society, I was delighted to speak to campaigner Dee Dee Morgan for MS Matters about my first impressions and the challenges that lie ahead (see page 10). One of the things that has impressed me is the strong sense of purpose within the organisation. All the members, volunteers and staff I've met so far are passionately committed to doing the best they can for people with MS. I'm looking forward to meeting many more of you in the coming months.

In our cover feature (page 14), people with MS talk about the impact loneliness can have and what the MS Society is doing to tackle it. Many of us feel lonely at some time in our lives, but our research shows that people with MS are more likely to be affected. It's not surprising when MS symptoms including pain, fatigue and mobility problems can make it a difficult to get out.

Also in this issue, our regular columnists Joanne Chapman and Elaine Moore discuss what loneliness means to them, and staff and volunteers from the MS Helpline talk about the vital support this service offers (see pages 31-37).

On another note, I'm excited to share that plans for the public launch of our Stop MS Appeal are well underway. The campaign, which will launch later this year, will bring us closer to our ambition to raise £100 million for research to stop MS in its tracks. We're extremely fortunate to be working with two top media agencies, MediaCom and Publicis Health (UK), who have given us their support pro bono to create a memorable campaign. Find out more on page 18.

We are also in the process of developing a new strategy (see page 12), so please share your thoughts on how best the MS Society can support you.

Nick Moberly
Chief Executive



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talks about MS

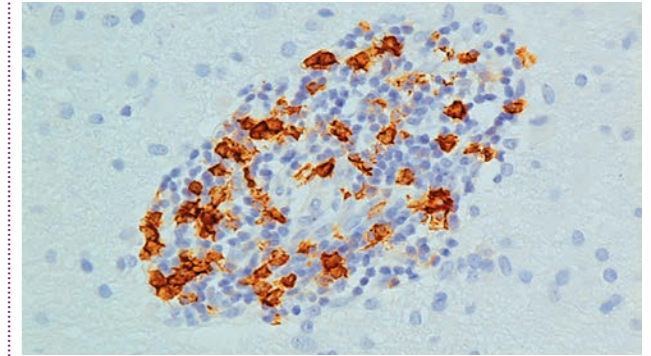


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non-judgemental support



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business helps me
work around MS

Research Matters



Turn to the centre of MS Matters to read Research Matters. Hear from our experts on pain, fatigue, diet and new treatments to stop disability, plus more on the causes of MS, the latest clinical trials and what the UK MS Register can do for you.

talk

Need support or information? Call our MS Helpline on 0808 800 8000 or email helpline@mssociety.org.uk

Want to talk to other people with MS? Our online forum is a welcoming space for you to share experiences. Get to know your MS community and join the conversation. Visit: community.mssociety.org.uk

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

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i newspaper raises more than £65k for MS Society grants

Rebecca Faith/MS Society

We were absolutely thrilled when the i newspaper selected us as its Christmas Appeal charity partner.

From the start of December until mid-January articles ran covering all areas of our work from the impact of our grants, which can help people with MS live more independently, to our campaigning around issues like disability benefits and social care, to the amazing research we fund. Some of our Ambassadors – including Paralympian Kadeena Cox and Felix White from the Maccabees – also shared their stories.

Quality of life

Katy Pitsi is 50 and was diagnosed with MS in 1994. She received a grant from us to help pay for a standing frame which she says is making an incredible difference to her quality of life. She told the i: 'Because I can't walk and stand any longer, more than anything, it's the sense of wellbeing.

'It takes you right up to a standing position. You feel stretches and muscles being used that haven't been used for ages.

'It's just a wonderful feeling. It's not going to magically help me walk again but when I'm stood up there, it's like wow.'

So far, we've received over £53,000 in generous donations from i readers, with money still coming in. All the money will go towards our grants, to help more people like Katy.

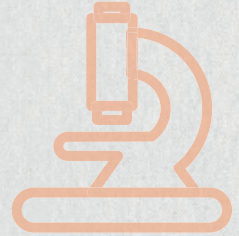
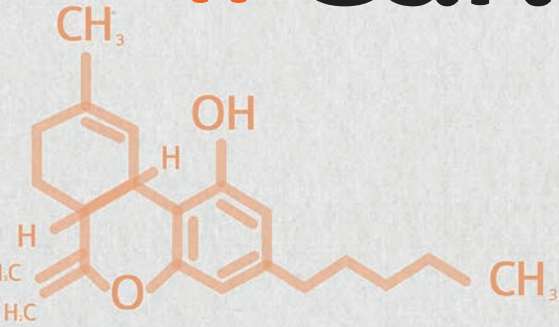
Independence

Ed Holloway, Executive Director of Services and Support, said: 'We are incredibly grateful to everyone who has donated to the appeal. The generosity of i readers means we can reach more people affected by this painful and exhausting condition. More than 100,000 people in the UK have MS, and every donation will help us to provide grants for things like vital equipment, home adaptations, activities and breaks – giving many people the freedom to live more independently.'

The appeal has done an enormous amount to raise awareness of MS and our work. We've been really moved to see so much support for the MS community and have received a huge amount of positive feedback in response to the appeal.



#CannabisForMS



In November 2018, the UK Government rescheduled cannabis for medicinal use, meaning specialist doctors are now legally able to prescribe cannabis-based medicinal products once all other treatment options have been explored.

The change in the law was a massive win for all of us who campaigned to make this happen. However, despite the legal change, access to medicinal cannabis in the UK remains very limited, including for the 10,000 people with MS who could benefit. Due to restrictive short-term guidance and a lack of available cannabis-based drugs, we're increasingly hearing from people with MS who are extremely frustrated at being denied cannabis for medicinal use. This needs to change.

'Constant pain'

Paul, who is 48 and has MS, said: 'I am really angry that despite a change in the law, I still can't get cannabis to help manage pain.'

'I've been through so much trial and error and I'm still in pain 24/7 with constant spasms. Cannabis

Cannabis for MS campaign goes to Westminster

might not work for me but unless I'm given the opportunity to try it then I'll never know.

'Why bother changing the law unless it is actually available? It doesn't make any sense to me.'

Speaking up for people with MS

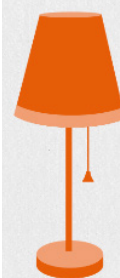
In March, we took our campaign to the UK Parliament and gave evidence to a committee of MPs who are analysing the new system. Genevieve Edwards, our Director of External Affairs, said: 'Government cannot afford to stand still, it must take this issue seriously. People with MS are experiencing symptoms of pain and spasticity every day and continue to be denied a treatment option that could help.'

We called for evidence that cannabis can help people with

MS to be recognised in guidance for clinicians due to come out in October. We also proposed a cross-government plan to increase access to medicinal cannabis over time, for people with MS who could benefit.

Our priority is to ensure that people with MS who could benefit are able to access cannabis for medicinal use, so they can get the relief they need when they need it.

Get involved in the campaign at mssociety.org.uk/campaigns



It shouldn't be illegal to

be able to sleep through the night.



‘A broken and unfair system’

Iain Crosbie, who has lived with MS since 2004, talks about his experience of the PIP assessment process, highlighting why things need to change



I'd received a lifetime Disability Living Allowance award in 2005 but, in November 2018, a letter dropped through my door telling me I had to reapply for Personal Independence Payment (PIP). I filled in the 54-page form and included letters describing how my condition affects my daily living from a neuro physiotherapist, an MS nurse, a counsellor and a GP. I also added 21 pages of my own.

Weeks passed but nothing happened, so the MS Society Resource Centre in Belfast contacted the PIP assessor in Northern Ireland on my behalf. They had received my form from the Department but none of my supporting evidence.

We resent the evidence, but the assessor maintained that I needed a physical assessment. This seemed ludicrous and was causing stress, so I booked a break to leave the day after the assessment: stress and my MS do not mix well.

On the day of the appointment, the assessor did not appear: no notice, no cancellation. My planned de-stress break was not going to happen, and I was forced

to rearrange my life around another assessment. Just before my next appointment, the assessor cancelled again, with no explanation. I was enraged and refused their alternative dates, explaining about rearranging my break and the costs of doing so. I was told this would impact my claim, even though they had cancelled twice!

After following up again, miraculously new appointments were made available. Now 10 weeks in, I was fed up, stressed out and angry. And there was to be a final twist.

At the start of the process, I had provided my consultant's details, who had given evidence on my behalf. Incredibly, this had never even been read. With a final push, this evidence was considered, and my assessment cancelled again – this time because I qualified for a paper-based assessment. In fact, I had qualified the entire time.

I am delighted that the MS Society is continuing to campaign against the worst of welfare reform. I will certainly be campaigning to change what is a faulty, broken and unfair system.

MS: Enough campaign

Last year we launched our campaign to scrap the PIP 20 metre rule, with 36,041 of you signing a petition we handed into the UK Government in October. This year we're keeping up the pressure on the Government to scrap the rule and calling for other changes to help the welfare system make sense for people with MS. For the latest updates go to mssociety.org.uk/msenough

People with MS speak up for reforms to social care

A group of people affected by MS in England are working alongside our Campaigns Team to shape our End the Care Crisis campaign.

Established at the start of 2018, the group are invaluable in drawing on their own experiences to advise on the direction and tone of our campaigning and how we can best involve the MS community. They've also contributed directly, writing emails to our Campaigns community.

Lynda, a member of the group, said: 'People often say "I don't want to make a fuss", but when social care has gone seriously

wrong, we need to speak up to make sure things change.'

Most recently, the group met to discuss how we can keep up the pressure on the UK Government to take action. In 2017, the Government promised a public consultation on proposals to improve social care in England (known as a Green Paper) but this has been delayed six times and we're still waiting. In February, Care Minister Caroline Dinenage said these delays are partly due to Brexit taking priority – but we know the social care crisis can't wait.

We've heard from members of the group just how stressful it is to keep waiting for changes which could majorly affect everyday life, and the impact this can have on their health. We're working with 80 other charities under the Care

and Support Alliance, calling for the consultation to happen and for urgent funding for social care to be provided.

We want to make sure the Government hears what the MS community needs – we'll let you know how you can get involved to share your experiences.

Social care in Wales

Our survey with the Wales Neurological Alliance (WNA) shows people with neurological conditions are missing out on vital social care:

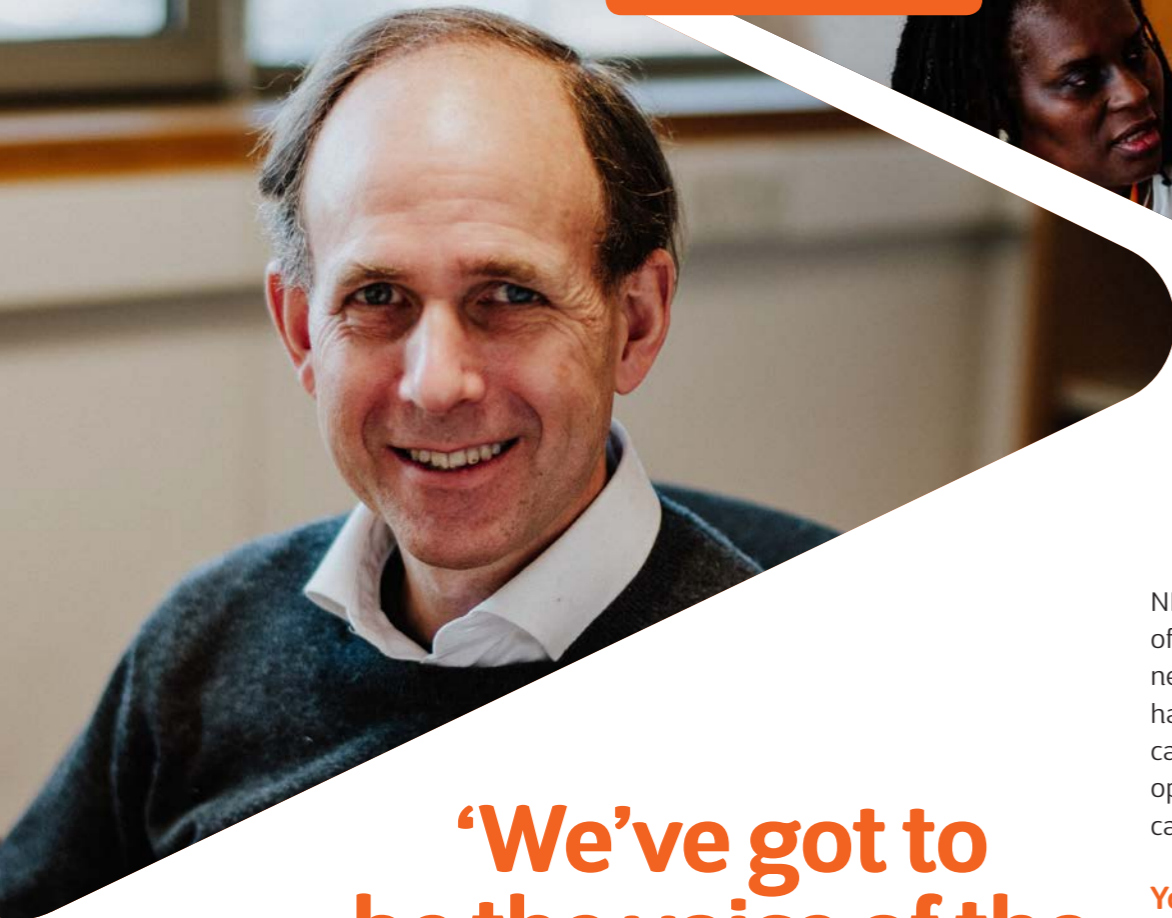
- 73% have not requested or been offered a formal assessment.
- 80% did not receive any services from a local council as a result of a care plan.
- 79% have not been referred to other organisations for support.

We've raised the survey findings with Welsh Assembly Members and will be working alongside the WNA to see that improvements are made.

Email mymscymru@mssociety.org.uk or call 0808 800 8000 for advice on social care in Wales.

Photo: Amit Lennon

Contact us at campaigns@mssociety.org.uk to share your story of social care. Join our Campaigns Community at mssociety.org.uk/campaigns



‘We’ve got to be the voice of the MS community’

New CEO Nick Moberly speaks to MS campaigner Dee Dee Morgan about why he’s joined the MS Society and the challenges that lie ahead

Firstly, please can you tell me a bit about yourself?

I have a lovely family, who I very much enjoy spending time with. I’m keen on kitesurfing, skiing and I do a bit of running – including running home to West London from the MS National Centre in Cricklewood. I also enjoy cultural things like theatre, music, film and reading.

What’s your motivation for joining the MS Society?

I enjoy working for organisations which have a strong, important purpose

and where I think I can make a difference. That’s what attracted me to being here at the MS Society.

I’ve been chief executive of teams who run hospitals – at King’s College Hospital in London, which is one of the major Neurosciences Centres, and the Royal Surrey County Hospital in Guildford.

While I was at King’s, I worked alongside some fantastic charities, who play an incredibly important part in supporting people with serious medical diagnoses, often alongside the

NHS. I also got a first-hand view of the impact that progressive neurological conditions can have. So those two things came together and, when the opportunity at the MS Society came up, I leapt at it.

You’ve been out and about meeting people in the MS Society. What are your impressions?

My overall impression is how passionate and committed people are. There’s this tremendous sense of connection with the MS community; a desire to go the extra mile.

I’ve visited four great groups so far: Hull, Huntingdon, Richmond and Croydon, and Gosport and Fareham. I met people who have been living with MS for a long time and have considerable support needs. There is a huge sense of hurt and frustration about the benefits system – especially PIP and the assessments associated with that. I also met some people with a relatively new diagnosis. On their minds were another broader set of issues around: ‘how I get to grips with what MS is for me’.

I’m also visiting Cardiff, Belfast and Edinburgh to meet our

councils and wonderful teams and volunteers in the nations.

What do you think the biggest challenges are for people with MS right now?

There are many challenges. For people who are newly diagnosed, it’s getting to grips with a life-changing condition, thinking through what the right treatment options are and trying to get the NHS to respond to those.

There are also real concerns about the perception of MS in the workplace, and how one can have a positive conversation with one’s employer about a very difficult subject.

And clearly the whole benefits system is working in a way that is absolutely not in the interests of people with MS and other progressive conditions. I think we have a lot of work to do in speaking truth to power and trying to get some positive change in that area.

How will you fight the corner of people with MS?

We can fight the corner by trying to capitalise on progress on effective treatments. There’s

a lot we can do to get new treatments through the clinical trials process and to advocate with central government to make sure they’re taken up by the NHS.

Working through our local groups, we can provide thoughtful support for people with MS who have significant day-to-day needs. And we’ve also got to be the voice of the MS community and maximise the pressure on the government and others on the issues that really matter.

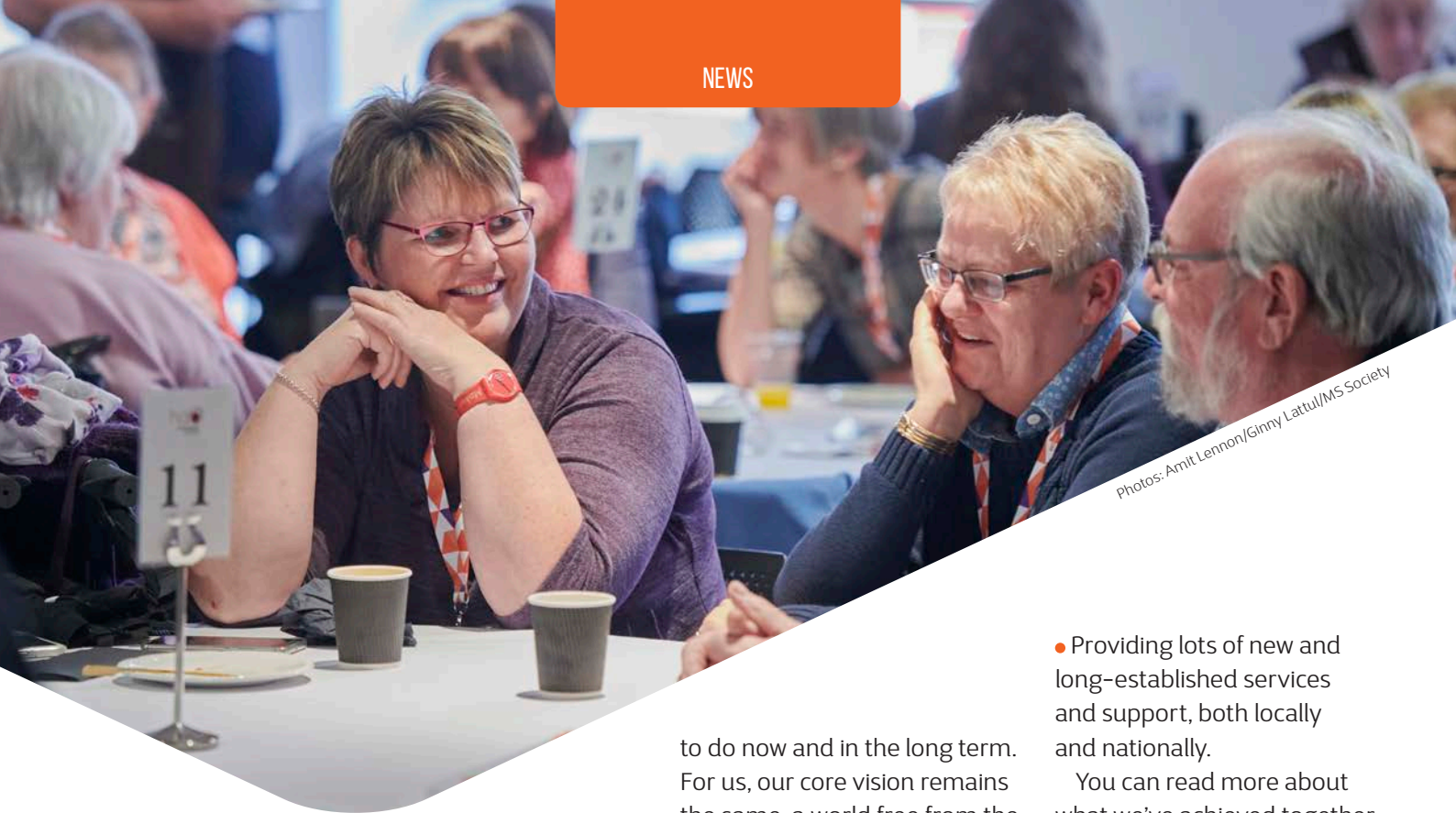
What do you think the future holds for the MS Society?

I’m a great optimist, so I think there is a huge amount we can do to make the lives of people with MS much, much better. We are currently developing our new strategy, which must be based on what’s important to people living with MS, so I’d like to encourage readers to get involved in that (see

page 12). I’ve no doubt that we can continue to develop our offering and raise our game, so we’re really supporting all parts of the MS community – whether you’ve been living with MS for a long time, you’re newly diagnosed or you’re just getting on top of managing the condition.

Dee Dee Morgan lives in Harlesden, West London. She has highly active relapsing MS, which has significantly affected her balance, and relies on a wheelchair to get around. Dee Dee is an active campaigner on behalf of people with MS and her portrait featured in our MS Connections photo exhibition.





Photos: Amit Lennon/Ginny Lattul/MS Society

Help us shape our strategy

What's important to people living with MS? What's most challenging and how do we make sure we're meeting people's needs? Our current organisational strategy comes to an end this year. As we develop our next strategy these are the types of issues we'll need to understand to make sure we're focusing on the right things. We want to know what matters most to you, so please tell us what you think by calling our Supporter Care team on 0300 500 8084 or visiting <http://tiny.cc/strategy2024>

Why we need a strategy

Our strategy sets out the difference we want to make and how. As a charity, it defines our goals and what we want



to do now and in the long term. For us, our core vision remains the same: a world free from the effects of MS.

Our 2014–2019 strategy was endorsed by you, our members. Our 2020–2024 strategy will go to the AGM this September. Like our current strategy, our new one will focus on the things that matter most to people living with MS.

Building on what we've done so far

We've done a lot to progress our seven 2014–2019 goals,

including:

- Speaking out and campaigning on access to treatments, the benefits system and social care.
- Focusing research on developing treatments for progression, including co-funding a clinical trial testing if simvastatin can slow progression in secondary progressive MS.

- Providing lots of new and long-established services and support, both locally and nationally.

You can read more about what we've achieved together at mssociety.org.uk/our-impact

Overcoming challenges

We know there's still a way to go. Particularly, there are still challenges for people accessing treatments, care and support. We're working to understand these issues to address them in our next strategy. You can tell us about your experiences through our My MS My Needs survey (see Research Matters, page 7).

Let us know your views

Please take a few minutes to tell us what you think we should be focusing on and how we can better support people living with MS now and in the future.

Your feedback will be considered with all the feedback we receive – from members, our wider community and staff to build an accurate picture of everyone's views.

Thank you for taking the time to share your thoughts. If you have any questions, please let us know at strategy2024@mssociety.org.uk

Northern Ireland neurology review underway

In December, the Department of Health in Northern Ireland began a full review of the delivery of neurology services. This is one of the steps being taken by the Department following the recall of more than 3,500 patients and relates to the work of Consultant Neurologist Dr Michael Watt.

The review will look at how the current service is planned, how well it is working and how it can be improved. It will also assess what resources will be required to provide a quality neurology service to everyone in Northern Ireland.

David Galloway, our Northern Ireland Director,

has been asked to sit on the steering panel for this review.

The Department of Health will be spending this year assessing the current services and seeking views from patients and medical professionals, before making proposals for improvements to the service. We would love to hear from you and for you to be involved. Throughout the review, we will be highlighting the experiences and views of people affected by MS and how the service should be shaped to best meet the needs of the MS community.

If you would like to share your views on the neurology service you currently receive, or improvements you would like to see, contact

nireception@mssociety.org.uk

Speaking out about MS

During MS Awareness Week (22-28 April) and on World MS Day (30 May) we'll be promoting our work and highlighting the challenges faced by people living with MS.

Scotland: parliamentary reception

George Adam MSP will host a reception at the Scottish Parliament on Tuesday 23 April. The event will focus on the positive impact of MS research happening in Scotland and our Stop MS campaign, which is launching later this year. If you'd like to attend, contact Katherine Paterson at scotlandcampaigns@mssociety.org.uk

Wales: raising funds and awareness

We'll be asking local groups to help us to raise awareness of MS and promote our projects in Wales through a series of articles in local newspapers. Meanwhile, a group of 10 courageous volunteers from South Wales will be aiming to raise over £5,000 by taking on a wing walk.

Northern Ireland: working with politicians

In Northern Ireland, we'll be working with elected officials in the lead up to MS Awareness Week on issues such as personal independence payment (PIP), waiting times and the current review of neurology services. Find out more by emailing stewart.finn@mssociety.org.uk



Making the MS Connection to fight loneliness

We're shining a spotlight on how isolated MS can make people feel and reaching out to those affected

We are living through an epidemic of loneliness. The UK's first ever Minister for Loneliness was appointed in 2018 and, according to a 2017 report published by the Jo Cox Commission, more than nine million of us often or always feel lonely. But while many people have felt lonely at some point, our recent research found the issue disproportionately affects people living with MS. We found a shocking three in five people with MS (60%) feel lonely because of their condition, 58% feel isolated because of MS, and more than four in 10 (42%) have worryingly felt both.

The MS Connection

To show the stories behind these statistics, we teamed up with Mumford and Sons bassist Ted Dwane and photographer Louis Browne from digital agency WMA to create The MS Connection. Our unique photography exhibition featured the stories of 19 people affected by MS from all over the UK, and highlighted how staying connected can be a lifeline for people who are isolated – something Ted Dwane can relate to.

The musician – whose mum Sarah lives with MS – says: 'Having the right support can change everything, and ultimately both my sister and I made a conscious decision to move back closer to home. A lot of people with MS simply don't have that network, and can end up feeling totally left out of society.'

Bitter depression

This issue's cover star Soo Lyon-Milne (53) from Stockport was diagnosed with secondary progressive MS aged 51. Together with her partner Dave and son Charlie, she shared her story for the campaign.

She says: 'Being diagnosed with a progressive condition is a lonely business. In early 2017

I found myself waxing lyrical about "being positive" and how I "wouldn't let MS define me" when in reality I was falling into an all-encompassing, soul-destroying, bitter depression. I was really good at hiding how I felt and on my darkest days, I'd plan how to take myself out of the equation. The main thing that stopped me was the unbearable thought of Charlie or Dave finding me.

Ready to start living again

'Then one day it just hit me. I haven't really changed. I'm still creative, I still like the same music, still laugh at the same jokes, still love meeting up with friends new and old. It's just how I approach things that has

to change. And just as quickly as it had descended on me, my depression turned and left. I'm not sure I'll ever get used to having MS, but I think I've finally reached a point where I'm ready to work with it. I'm ready to start living again.'

Charlie (18) says: 'It's an intense thing to deal with, figuring out how to support someone who's going through these sudden physical changes. But the physical side isn't what bothers me, even though there are things we can't do together anymore. What's harder is the emotional changes and unwanted feelings that nobody is prepared for.'

'I don't think Mum has changed, but she has ups and downs. There was a point last year when I was really worried, but her mood has really improved since she started going to the gym, getting out, and getting more active. There's no straightforward "fix",

but we're always growing, and trying to figure out strategies to make life with MS easier.'

MS took my identity

Mark Carey (46) was diagnosed with relapsing MS in 2003. Since then, he has played a key support role in the Pembrokeshire MS Society Group, and The MS Connection was just one of many campaigns he has been involved with.

He says: 'I'd been a mechanic for 17 years when I was diagnosed with MS in 2003. The news was devastating – I didn't know anything about MS and I felt like it had taken my whole identity away. My job meant a lot of manual labour and I'd been struggling but wouldn't admit it, so I didn't tell anyone what was going on. While I was trying to come to terms with the diagnosis I was told to give up work. I knew I had to talk, but instead, I shut myself off



Soo with her son Charlie and partner Dave

Mark was diagnosed with MS in 2003

What we're doing in Wales

MS Society Cymru recently shared the experiences of people living with MS with the Welsh Government, as part of a consultation on loneliness. We have passed on your major concerns, which include:

- a lack of timely and appropriate health and social care
- a lack of accessible housing, transport and public toilets
- a lack of opportunities to be involved in community and physical activities
- poverty and the impact of welfare reform
- digital exclusion.

We're working hard to tackle loneliness and isolation through our 16 groups in Wales, along with several other projects which bring the MS community together. For example, our Active Together project promotes fitness and friendship for 200 people living with MS in Merthyr, Rhondda Cynon Taf and Cardiff. And our Big Lottery/Masonic Charitable Foundation-funded My MS, My Rights, My Choices project arranges Living Well with MS and Newly Diagnosed Days, and provides one-to-one support to help people access benefits, grants, employment rights and social care services.

from everyone.

'Volunteering for the MS Society changed everything for me. I am naturally a shy man, so the idea of me going to the House of Commons to give evidence about employment or speaking to MPs about PIP isn't something I ever thought I would do. But getting involved in campaigns has given me a new self-confidence and belief that, as a community, working together and sharing our voices is vital.'

No one should face MS alone

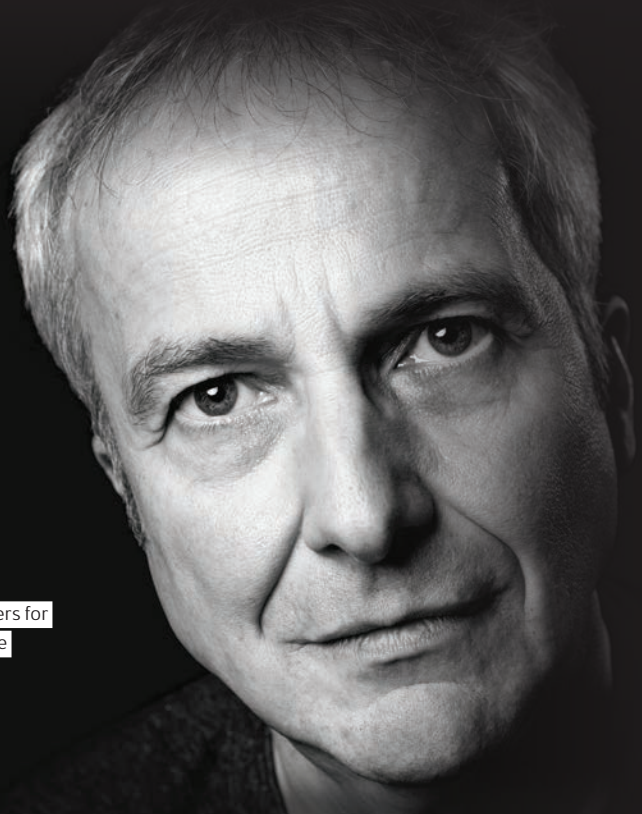
We offer a whole host of support to people affected by MS, including a free MS Helpline (see page 32), a grants programme, a network of over 270 groups across the country and an active online community. Our services really do make a difference – of the 60% of people with MS who said they've felt lonely, 78% said

being part of their local group reduced this.

Aleks de Gromoboy, (56), who featured in The MS Connection, was diagnosed with relapsing MS in 2010 and became an MS Helpline volunteer after using the service himself. He says: 'We get lots of calls from people struggling with relationships. It's hard, but it's very common to feel lonely or socially isolated, especially when you've just been diagnosed.'

'One of the things I try to tell people is that there are lots of people with MS – even in the public eye – who are still living their lives and you would never know anything different about them. They have brilliant jobs and relationships and are doing amazing things. You don't have to resign yourself to a life of disability, and certainly not a life of being alone.'

Call the MS Helpline on 0808 800 8000 or email helpline@mssociety.org.uk



Aleks volunteers for the MS Helpline

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Michelle
Healthcare Partner

Jenny
Pharmacist

Hajma
Healthcare Supervisor



How are you today?

Behind the scenes of the Stop MS Appeal

Supported by two of the world's best media agencies, our Stop MS Appeal launches to the public this year. We talk to agency heads Josh Krichefski and Alison Ferrucci about why they got involved.

Josh Krichefski, CEO, MediaCom UK Campaign strategy and planning



I'm a member of the MS Society Appeal Board which is trying to raise £100 million to fund research into how to stop progressive MS.

MS is close to my heart because my brother has it – that's why I got involved in the first place. So, from the very first day I joined the MS Society's Appeal Board, I said I would support the appeal in any way I could, including providing pro bono support from MediaCom.

Everyone from the MS Society to MediaCom and Publicis has put a huge amount of work into creating a campaign that is really special. So, to ensure that we help the MS Society punch above their fighting weight, we'll be working with some key media partners to achieve maximum exposure. We'll also ensure that we secure as many free advertising opportunities as possible through our

media networks.

It sounds obvious, but the big challenge is how we go about capturing the hearts and minds of potential donors when they're committed to other charities who are running their own public appeals. You need to find a way to cut through the clutter – like whispering in someone's ear when they're in a noisy room.

Our media campaign will help to raise awareness of what it's like to have MS. It will also highlight what is happening in the world of MS research and shine a light on what fundraising activities there are for people to take part in. The campaign will feature a video which will be available across a number of different platforms including social media, and we'd like everyone in the MS community to share it with as

many people as they can.

It's been hugely rewarding to work on this campaign. MS research is at a real tipping point; it's critical that we raise the funds to realise the potential that researchers believe we have. If we can raise this money, I believe we will get to a point where we will stop MS in its tracks. That's a tangible and hugely motivating goal, and something I'm personally very proud to be a part of.

MediaCom UK is the UK's largest media and communications agency.

As MS Matters went to print, we were close to deciding the exact timing of our launch. Follow us on social media to see how we progress and to share the appeal far and wide.

[Facebook](#)

www.fb.com/MSSociety

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'MS is close to my heart'

Alison Ferrucci, General Manager, Publicis Health UK Campaign strategy, creative and production



Publicis Health UK is a network of healthcare communications agencies. With health and wellness being at the heart of everything we do, there is no better way for us to drive our corporate social responsibility (CSR) strategy and make a difference that matters.

We began our partnership with the MS Society in May

2018, as everyone across our business is passionate and committed to supporting people affected by multiple sclerosis. The condition was the outright winner in a cross-company survey.

Many of the team have personal connections with MS which makes our relationship with the MS Society stronger. And we also have an in-depth

**'There's no better time
to launch this campaign'**

understanding of the condition itself and treatments available, having launched a number of new MS therapies over the last few years through our work with pharmaceutical companies. This all makes our connection to the MS Society a natural fit. As well as providing pro bono support for the Stop MS Appeal, our employees are also involved in fundraising, volunteering and sharing skills to support the public appeal.

We are so proud to be supporting the MS Society launch the Stop MS campaign. A campaign like this needs a big idea. An idea that pushes MS and people's understanding of the condition up the agenda. At the same time, we're trying to raise awareness of what the Stop MS Appeal is all about; raising a large

amount of money to support the largest-ever clinical trial platform in MS research.

It's a challenging brief but, from a creative perspective, it's been really exciting. The team has absolutely loved working on it. We're now at the stage where we've chosen the final creative route and we know it's going to be both engaging and memorable.

When launched, Stop MS will be a multi-channel campaign to connect with people in the right places, at the right times and in the right way. Its aim is to raise £19 million from the public – a sizeable contribution towards the £100 million appeal. Whilst

it's an ambitious target, there's a very clear agenda about why we're trying to do this and the difference we can all make.

There's no better time to launch a campaign of this nature. Together we can stop MS in its tracks. So we need everyone in the MS community to get involved. Everyone has a role to play in helping to stop MS.

Publicis Health (PH) is the largest healthcare communications network in the world.

Photo: Simon Rawles

'I was excited to be involved'

David Allen, who has MS, is a member of the England Council. David was involved in the consultation with Publicis on the creative concepts for the Stop MS Appeal. He says:

'I was humbled and

excited to be involved right from the start at the briefing stage with Publicis, as well as being able to speak to all the creative teams about what it is like living with primary progressive MS and how it

affects my life.

'When we returned to hear the pitches for the different concepts they had created, it was very reassuring to see that they had got it. "We were mindful of what David said"

was a phrase they used during their pitches.

'As a person living with primary progressive MS this is a truly exciting time for research and I hope this will take us one step closer to finally stopping MS.'

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Score a hole in one with a golf fundraiser

Golf is a big part of many people's lives, which makes it a great way to raise funds to help stop MS

If you're a keen golfer – or you know someone else who is – then there are different ways you can get involved. This could be as simple as running a sweepstake on the number of shots it will take you and a group of friends to get around your local course. Alternatively, you could hold your own charity golf day, ask your club to choose the MS Society as the Captain's Charity or support other MS Society events. Here are some fantastic golfing fixtures to inspire you.

MS Golf Day, Handsworth

Ivan Hutchings, an avid golfer who is living with MS, started the MS Golf Day in 2009 at his home club of Handsworth, Birmingham to raise money for the MS Society.

The golf day started after Ivan raised £10,000 the previous year to provide his sister, Annette,

who also had MS, with a wheelchair as she was told she would not walk again. Sadly, Annette passed away in 2010 from MS-related complications. Each year the teams play for the Annette Austin Memorial Trophy to celebrate her life. Since 2009 the event has gone from strength to strength, raising nearly £66,000.

Ivan says: 'The cost of entry is £250 for a team of four and we regularly have 25 teams. By keeping the entry fee reasonable, everybody enjoys themselves and wants to come back year after year – generating significant amounts for the MS Society.'

This year's event takes place on 17 June. Contact Ivan for more information at ivanjayne@talktalk.net

Porthcawl Annual Golf Tournament

Roger Evans has organised an annual golf tournament



Our new golf fundraising pack is full of resources and ideas. Contact your Area Fundraiser on 0300 500 8084, email SupporterCare@mssociety.org.uk or visit mssociety.org.uk/golf

at the Grove Golf Club in Porthcawl over the last 16 years, raising a total of £40,000.

When Roger retired last year, the event was handed over to our South Wales Fundraising Group.

Kathryn Foot, a founding member of the Group, says: 'Late last year the Cardiff and Swansea fundraising groups merged. Pooling our resources meant more creativity, more people and more scope for fundraising. So, when I was asked to step into Roger's shoes (a scary task!), it made sense for this to be our first collaborative project.'

'It is a privilege to take the reins and ensure this popular event continues. The sun usually shines, the course is in a beautiful location, it is great value and there is always a fantastic atmosphere. Plus, there are some awesome prizes up for grabs. We have room for a few more teams of four and

Inclusive golf

Golf is a sport that suits a wide range of abilities, with different equipment and formats to try. Find out more at:

• England Golf
englandgolf.org/play-golf/disability

• Scottish Disability Golf and Curling
scottishdgc.org.uk
• Welsh Disabled Golf
facebook.com/welshdisabledgolf
• Disability Sport Northern Ireland
dsni.co.uk

always welcome sponsorship.'

The event takes place on 30 May. Contact sian.dorward@mssociety.org.uk

Darren Clarke Golf Day

Named after the Northern Ireland native and 2011 Open Championship winner, the Darren Clarke Golf Day is an annual golf competition attracting clubs and players from right across Northern Ireland. In 2018, 15 clubs took part with many raising additional funds beyond their entry fee.

Once entered, clubs organise their own qualifying event where the winner progresses to the main event. The grand final is played at the current champion's home club with the 2019 event due to take place on 20 October 2019 at Clondeboy Golf Club, County Down. There are prizes for first and second place, winning team, nearest the pin and longest drive.

Clubs can enter by emailing nireception@mssociety.org.uk

Rigmar Group Annual Golf Outing

Staff at Rigmar Group were inspired to raise money to help stop MS when one of their colleagues, Peter Stevenson, was diagnosed in 2015. For the past two years, they've held their Annual Golf Outing at Peterculter Golf Club in Royal Deeside, which has raised funds through kind donations, sponsorship and raffles. In total, Rigmar has raised a brilliant £4,000 through the golf day and other events.

Keith Nelson, Rigmar Group's CEO, says: 'We hold our annual golf outing as a thank you to our clients, staff and friends of Rigmar, whilst also raising money for a great cause. Rigmar Group is proud to be associated with MS Society Scotland.'

If you're interested in holding a golf day in Scotland, contact Mark Colley-Davies on 0131 335 4050 or msfundraising@mssociety.org.uk

Tony Johnstone, Sky Sports golf commentator and MS Ambassador, says:

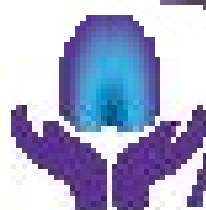
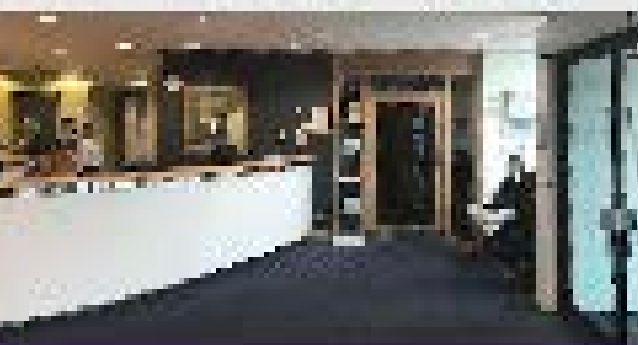
'Research funded by the MS Society helped find a treatment for my MS which extended my playing career and continues to help me travel the world as a commentator. By holding a golf event in 2019 you can help the MS Society transform the lives of people affected by MS.'

Tony will be hosting a season-ending finale golf day for the MS Society at Handsworth Golf Club in Birmingham on 3 September. Find out more at mssociety.org.uk/golf



Photo: Colette Hilson/F8 Photography

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Al-Araji Specialist MS Clinic

About us

Our highly specialised and unique service aims to deliver a comprehensive package of care for anyone living with multiple sclerosis (MS). With over 20 years' experience in delivering exceptional care to people with MS in the State-of-Texas and our award-winning team to make up of passionate health-care professionals, we put their patients at the very heart of all they do. We also welcome patients from across the UK.

Living with a complex condition means that you need a comprehensive approach to treatment.

Our team is ready to listen, understand and co-create a bespoke treatment plan for anyone living with MS. Contact us for more information on who might benefit from a visit to our clinic and how to book an appointment. We look forward to hearing from you!

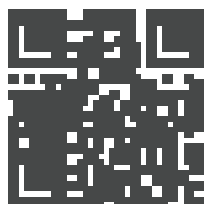
*"We know that your MS is unique to you
and that means your treatment should be personalised to you too."*

Dr Adnan Al-Araji, Consultant MS Neurologist

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More information

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Park St, Parklands Hospital,
Petersfield, Hampshire



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If you or your family or friends are interested in taking on a challenge, visit mssociety.org.uk/fundraise, email challenge@mssociety.org.uk or phone 0300 500 8084.

Why I took on the challenge

'I ran the Cardiff Half Marathon last year to support the MS Society. Not only did it help raise awareness, but it also helped the MS Society to do some incredible work via support and funding research projects. I am currently involved in a clinical drug trial and without this new medication there is no way that I would have been able to run.'

Jason Lawson, who was diagnosed with relapsing remitting MS in 2017



Edinburgh Marathon Festival 25-26 May

A brilliant 115 MS Superstars have signed up to the Edinburgh Marathon Festival in May. There are still some places left – could you join our team? Email msfundraising@mssociety.org.uk

Cykelnerven 12-16 June 2019

Fancy being one of the first to cycle this year's Tour de France? Then Cykelnerven could be for you! All the money you raise will go to MS International Federation to fund MS research. Visit cykelnerveninternational.org

London to Brighton Bike Ride 15 September 2019

Saddle up solo or as a group, and immerse yourself in this picturesque 55-mile route from Clapham Common to Brighton's vibrant seafront.

Great Manchester Run 10K and Half Marathon 19 May

Don't look back in anger if you miss out on this fantastic event. Take on Europe's biggest and best 10K race or go the extra mile on the half marathon route.

The Big Leap 2 June

We're thrilled to have our Big Leap event back for another year. Join over 100 daredevils as they take to the sky at our exclusive skydiving day across the UK.

South Coast Challenge 31 August-1 September

Join our MS Superstars to walk, jog or run through stunning English scenery. Choose from three distances and enjoy a fun, rewarding, once-in-a-lifetime experience.

Cardiff Half Marathon 6 October 2019

Entries are now open for this year's Cardiff Half, the UK's second largest half marathon event. Last year, our MS Superstars raised an amazing £27,000. Email sian.dorward@mssociety.org.uk



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Celebrate your special day with us



Are you planning a birthday party, wedding, anniversary or another celebration? If so, we'd love you to consider making us part of your special occasion – and raising money to stop MS along the way.

We've created a new range of celebration products, with something for every occasion. Wear an orange ribbon badge or pin badge to raise awareness of our cause, or fill goody bags with our wristbands, badges, pens and other items for guests to take away. We've designed place cards to complete your table setting, and let your guests know you've made a donation on their behalf. We also have collection boxes

to put out for collecting any leftover change.

We can provide all these items and more for a small suggested donation.

Alternatively, you could ask friends to make a donation instead of giving presents or to help celebrate your special occasion. You can set up a JustGiving page for the occasion – it's easy and effective. Every penny goes towards changing the lives of people affected by MS by funding research, running our MS Helpline and campaigning for the rights of people living with MS.

Together we can stop MS, so let's get partying!

To see the full range of items and find out more visit: mssociety.org.uk/celebration

Inger and Adam: helping a charity close to our hearts

Adam and I have been together nine years and we have two beautiful girls, Isla (seven) and Keira (five). Adam is a builder and I work part time along with looking after the girls and our dog Marley.

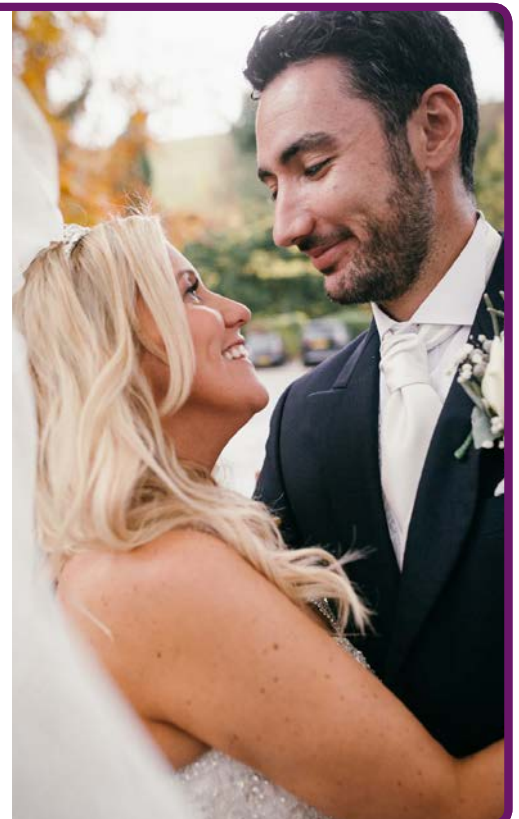
I was diagnosed with MS in December 2015 and Adam has been so supportive with helping me come to terms with my diagnosis. When I'm struggling he really does take care of me and the family.

Adam proposed on a break in Malta in April 2017 and we soon booked our wedding for November

2018. It was great to have something to look forward to and we also wanted it to be a day that hopefully our children will remember.

Instead of gifts, we decided to give a donation as our wedding favours, as something that means a lot to us, and also to raise awareness of MS. We wanted to help a charity close to our hearts.

Everyone at the wedding commented on what a lovely idea it was to give a donation to the MS Society and we hope this may also encourage others to donate too!



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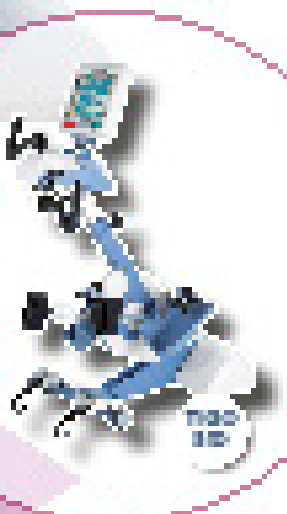
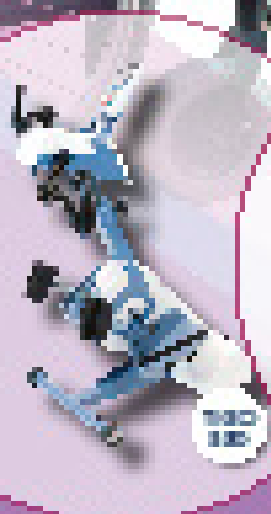
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Fight Song embodies battle with MS

US hip-hop legend Masta Ace talks to Lee Dainty, our Celebrity Supporter Manager, about why MS makes an appearance on his new album, *A Breukelen Story*

You were diagnosed with MS in 2000 but, at the time, you wanted to keep it private. How did you feel when you decided to make it publicly known, in around 2013?

It was a relief – like a weight was lifted off me. Once I started getting reactions from people, on social media, I realised that it might actually help some people out there. They were inspired by my openness and willingness to talk about what I was dealing with.

How would you say MS has changed your outlook on life?

It opened up my mind to things that I might have been closed to in the past. For one thing, I learned to ski. I think that's a big part of it, just getting out there, looking at your life and saying: 'I don't know what 10 years from now is going to be like. Here's an opportunity to do something that I still can physically do.'

You have a new album out, with Marco Polo, *A Breukelen Story*. There's a brilliant track on the album, about having MS, called 'The Fight Song'.

A friend of mine, Paul Barman, who's an MC, had this idea. He said: 'I think you should do a song where it's like a battle but instead of an MC, the MC is MS'. As Marco was making beats, and sending me music, there was this one beat where I said: 'This could actually work'.

I laid my verse down and then we had to figure out who's going to be the perfect MC to embody MS. Pharoahe Monch was the perfect guy for the job. He's an incredible lyricist and a really visual guy. He adds voice changes and inflections to morph into this being; this disease; this monster.

You've been very prolific since your diagnosis. Has MS influenced you creatively?

Yes. My best albums were written after the diagnosis – I just had this new-found determination. I don't know what the future holds. But I'm going to make sure that everything I do, I put my all into it and I make it as good as it can be.

Watch the full interview at mssociety.org.uk/masta-ace

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‘We need to nip loneliness in the bud’

Joanne Chapman tells us what juggling MS and looking after a little one has taught her about coping with loneliness

Despite living in a connected world, many people feel alone. I was warned about parental loneliness but not about how having MS puts you even more at risk. The research says it all: three out of five MSers experience this hope-sapping condition. We need to nip loneliness in the bud before it breeds.

‘Am I lonely?’

For me, loneliness is driven by my frustration of losing spontaneity, independence and femininity. I’m more house-bound and reliant on others.

That’s before you throw emotions, prejudice, future concerns and symptoms into the mix. So, when I’m feeling lonely, I ask myself: ‘What do I miss the most and how can I address this as an MSer?’

I can’t control my unexpected, awkward symptoms. I can control raising awareness through education, especially as MS is so individual. Stress brings out my symptoms, so to reduce this, and help me feel less lonely, I prepare for each day. I research

products, rest, plan low-energy activities, use reminders to aid brain fog and support Little Man’s development by building up his independence.

Be connected

Baby groups developed Little Man and reduced my parental loneliness as I left home and connected with people. But sometimes I still felt alone as these groups weren’t set up for my limited mobility, erratic bladder and fatigue symptoms. As the only disabled attendee, I had many concerns like: ‘Will there be disabled parking, a seat and a toilet?’

I’d reach out more if I could turn the clock back because learning to live in balance and establishing a network can help prevent loneliness creeping up. The right support, advice and

friendship makes you realise you are not alone. For MS, there are local groups, medical staff, counselling, and the MS Society online community and Helpline. There are also social media groups specifically for mums with MS, such as ‘muMS UK’ on Facebook.

I find my online support network helpful when dealing with MS and parenting issues. When you seek out others in the same boat, you don’t have to keep explaining. I may be an MS Mummy but I’m still me and preventing loneliness is key.

You can get in touch with Joanne through her blog: poorlyparents.wordpress.com





We're here to listen

Our award-winning MS Helpline has been answering your questions and giving non-judgmental support for the last 28 years



The MS Helpline offers free, confidential support and information and a safe space where people can talk and share their concerns. All volunteers and staff have undergone an intensive training programme, so they're well-equipped to answer a huge range of enquiries and signpost people to the most

useful sources of information. But many callers simply need someone to listen to them.

'We are here to support anyone affected by MS,' says Abigail Stidston, Helpline Services Manager. 'We're here to provide a listening ear and for enquirers to discuss what's on their minds.'

'Some people affected by MS can feel isolated due to where they live or symptoms

they are experiencing. We're here to provide support and answer questions people may have. Also, the nature of MS is that the symptoms can be hidden, and some people find that others may not understand what is going on for them. Being able to talk about your worries without being judged is really important.'

Flexible volunteering

The MS Helpline currently has 23 volunteers, who work from their own homes all around the UK. This means we can reach more people, as well as offering flexibility for the volunteers, some of whom are affected by MS.

MS Helpline volunteer Helen Cooke says: 'I have MS and I'm managing fatigue all the time, so the team allows me to split my shift across the day. This works a treat, otherwise I wouldn't be able to carry out my role.'

'Callers I tend to remember are those who wonder if they have MS or are newly diagnosed and in urgent need of information. It is a privilege to be alongside and supporting them at what can be a time of high emotions. I take pride in



reassuring callers they can trust our information; I feel part of something bigger than myself.'

Specialist services

As well as offering general information and emotional support, the MS Helpline provides specialist support and information on certain subjects.

Omar Tucker, Physical Activities Specialist (right), joined the MS Helpline team a

Moving More with MS

Omar Tucker, Physical Activities Specialist, runs 'Moving More with MS', a new phone-based programme to help people with MS in England get more active.

'I help people by talking with them about what activities they would like to do and the barriers that are getting in the way – for example lack of time or sensory problems. We talk about how they can overcome these barriers and put an action plan together. I follow up with regular calls to see how the person is getting on.'

'I can refer people to local MS Groups, help them find out about activities in their area and check that sports facilities have disabled access.'

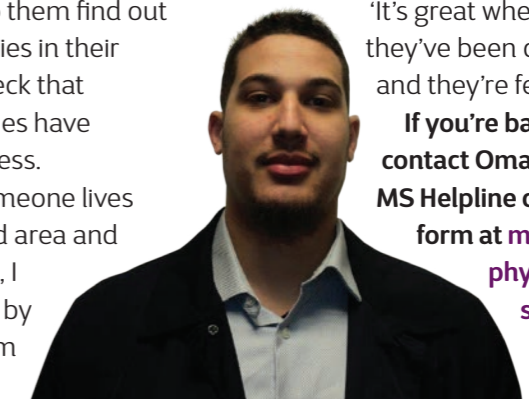
'Even if someone lives in an isolated area and can't get out, I can still help by sending them

our 'Moving More with MS' exercise videos. Instead of just leaving them to it, I'll follow up regularly to see if the exercises are working for them or if we need to change something.'

'Research strongly suggests that exercise helps alleviate some MS symptoms, such as balance issues, muscle stiffness and spasms. It releases endorphins, which can make you feel more positive. It can help people maintain their condition, to stop it getting worse, and reduce the risk of long-term health problems such as diabetes and obesity.'

'It's great when people tell me they've been doing the activities and they're feeling much better.'

If you're based in England, contact Omar by calling the MS Helpline or completing the form at mssociety.org.uk/physical-activities-specialist



Get in touch

In 2018, 23 volunteers and 14 staff answered:



16,799
calls



2,056
emails



372
private Facebook messages

You can call our MS Helpline for free on 0808 800 8000 or email helpline@mssociety.org.uk. To get in touch on Facebook, visit facebook.com/MSSociety. We're open Monday to Friday, 9am to 7pm, except bank holidays. If you are interested in volunteering, please get in touch.

Helpline Services Managers Julie Gaynor (left) and Abigail Stidston (centre) receive the award from Paula Ojok, Helpline Partnerships CEO



Advice on benefits

Alan Blackett, Benefits Adviser, can provide advice, information and support around benefits for people with MS.

'It's a nationwide service covering everywhere in the UK. If someone phones in and they have a question about welfare benefits I'll be able to answer it. For example, if someone is not well and is unable to carry on with their job, I can advise what benefits they could claim.

'I can also help people challenge decisions by the Department of Work and Pensions and give people tips for completing a Mandatory Reconsideration. Unfortunately, a lot of decisions on Personal Independence Payments (PIP) fail at this point, so then you have to appeal. I also offer advice for social security tribunals – I can advise through the whole process.

'The most rewarding thing about the role is getting people justice and the benefits they are entitled to. The system is very complex, so I can help people understand the knock-on effects that claiming one benefit may have on another. It's about empowering people by giving them the right information.'

Contact Alan through the MS Helpline or by emailing msbenefitsadvice@dls.org.uk


few months ago. Working with Sports England, Omar is helping people with MS to become more active. Also new to the team is Alan Blackett, Benefits Adviser. Working in partnership with the Disability Law Service, Alan can offer advice about what benefits are available to you (see left).

There are also two Information Officers, who can help with complex information enquiries, and a Short Breaks Specialist, who can give information on planning a short break or respite care. An MS Legal Officer provides advice for callers in England and Wales, answering over 1,800 calls last year and can support people with MS on enquiries related to employment, community care goods and services, and disability discrimination.

Winning awards

In 2018, the service won Helpline of the Year at the Helpline Partnerships Awards, which recognises the vital role helplines play in supporting people going through a crisis. We came second in the Innovation category and our volunteer Aleks de Gromoboy got third prize for Helpline Volunteer of the Year.

'We won Helpline of the Year for the work we've been doing to make sure we're accessible for people with MS,' says Abigail. 'What we've seen over the years is that people want to contact us in different ways. As well as answering phone calls, we respond to people via email and Facebook messenger, and people can write to us. Now we're developing web chat and British Sign Language to improve our accessibility even more. We're always looking for ways to expand and develop to support more people.'



"It was such a relief when I was able to manage my MS related bladder and bowel symptoms with the correct therapies so early on. Now I can leave the house, and live my life more actively again with my family."

Lee 30, Nexiva user

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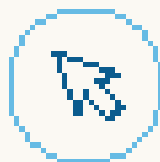


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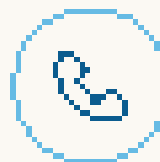


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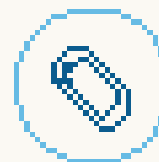
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It's good to talk

Elaine Moore shares how we can all do more to help people with MS feel less lonely

Only the Lonely was a monster hit for Roy Orbison back in 1961 and is still perhaps the ultimate anthem to loneliness (well, it is if you take out all the 'dum-dum-dummy doo-wahs'). He is saying that you can only understand how he's feeling if you've experienced it yourself. Well, I think a lot of us with MS understand – MS can be a lonely illness.

Health risk

Lonely in the sense that you are the only one who knows what you are going through. Lonely in the sense that the people around you don't understand the illness. Lonely in the sense that nobody can appreciate the sheer effort it can take to get through each day. But loneliness is not good for us. In fact, it's considered to be as

bad for our general health as smoking 15 cigarettes a day (although I've no idea how they proved that)!

Get in touch

There are over two million people in the UK who describe themselves as lonely and invisible. Some of them have MS. So how can we help them? Methods are in place to get in touch with someone who understands MS – the MS Helpline, the online chat service and the numerous community groups and drop-in centres spread across the country. But what if none of these is your 'thing'?

A friendly voice

Sometimes, just being able to

hear another voice is enough. It doesn't have to be a fellow-sufferer (comparing symptoms is hardly the best way to lift one's spirits) and, most important, it doesn't even have to be about MS. Sometimes all we need is a gossip and a good laugh. So here's a thought. All of us, if we still have the power of speech, could speak to someone with MS every week. Just to say 'hello', to check they're okay. And to break their loneliness, just for a little while.

Read more from Elaine on her blog: wheellife.co.uk

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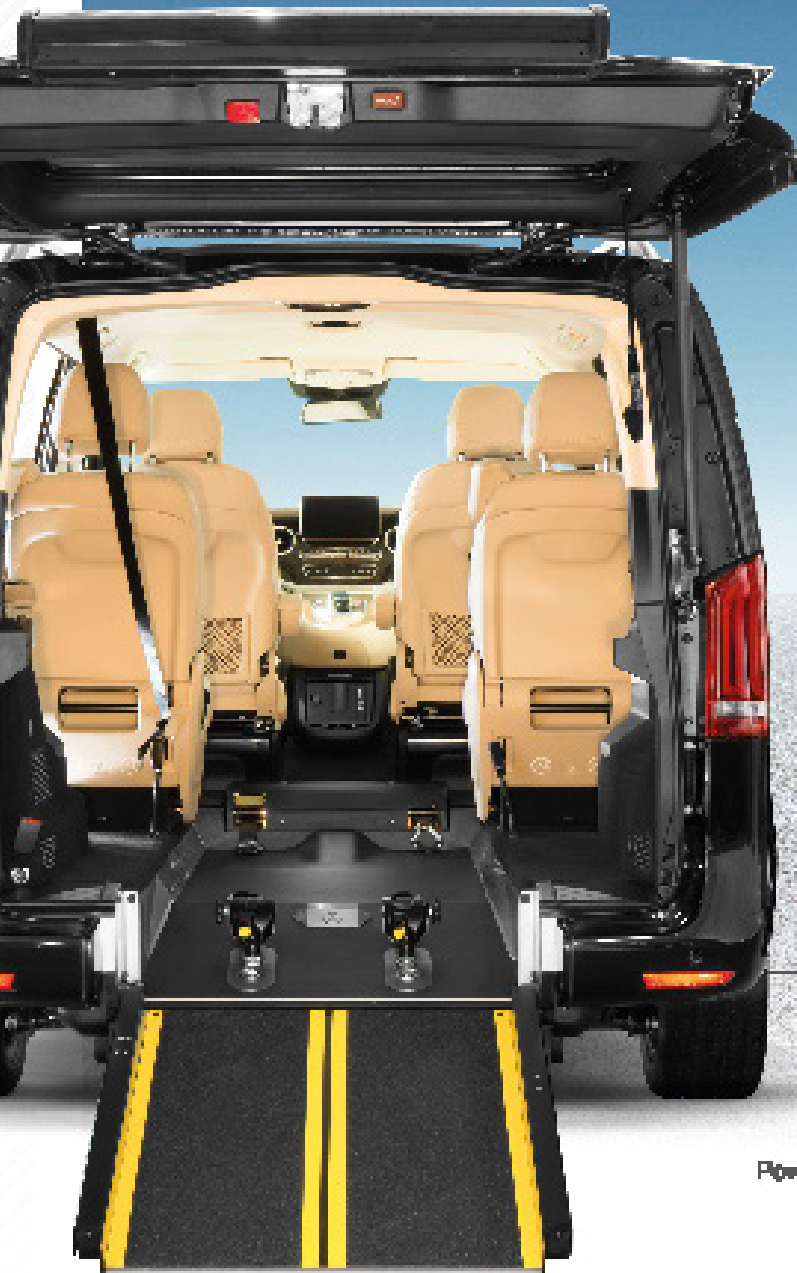
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‘Studying gave me something to focus on’

Paul Smith (45), who has secondary progressive MS, turned his life around with the help of a PhD

I stopped working not long after I got diagnosed with MS back in 2005. I was a successful business manager, and when I lost that, it was devastating for me. I needed something to keep my mind occupied – and that’s how I ended up going back to university.

I went as a part-time undergraduate to start with, studying politics and management at Robert Gordon University in Aberdeen. When I finished that, my course leader suggested a PhD. I never thought I was good enough academically to do that, but he gave me the confidence to give it a go. I ended up studying the impact of social media on the political process and, after four and a half years, I finally got my PhD last year.

Supportive university

The support from the university’s disability and dyslexia service was fantastic – they helped with my mobility issues, paying for a taxi from door-to-door, and providing

specialised equipment, like a dictaphone for when I couldn’t write very well.

Now I have a part-time teaching job at the university and I’m looking to get some articles published. I’m not sure I’ll ever get back to working full time, but I still haven’t given up hope of getting into a position where I can make a living out of it. In the future, I’d love to get some research funding.

Decision to change

In the years following my diagnosis, I was desperately unhappy. As well as my job, I lost my marriage and house. I was living a really unhealthy lifestyle – I was overweight, smoking and drinking too much.

So I decided to change all that, which helped both my physical and mental condition. And throughout it all, studying was a constant. It was something to focus on. It’s been an amazing journey and I never thought I would get to where I am now. I’m proud of myself, and I didn’t have much to be proud of for a long time.



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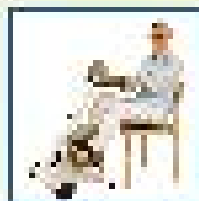
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‘Age means nothing, attitude means everything’

Glen Mills (85) has found a novel way to help with her MS by going indoor skydiving every week

It started with hang gliding in Canada in 2002. I saw some people doing it and before I knew it, I was up there too. I think that’s what set fire to my tail feathers. I’ve abseiled a couple of times since and my husband and I try to do a zip wire every year. I get a kick out of doing things outside my comfort zone.

The indoor skydiving was a gift from my daughter one Christmas – she knew I needed some mischief. While waiting to go in, the wind came out and hit me, and it was so soothing, energising and exciting that I

was hooked before I even started. It was the best thing I ever did.

Wonderful feeling

While in there, you’re totally suspended on the air. I realised if I could get better at it, I could get longer periods of that wonderful feeling of no pain – and that’s what happened.

The first time was in 2015, and now I go to iFly in Manchester every Tuesday for two sessions of two minutes each.

There are enormous amounts of things to learn, and although I’m slower than

most people, the instructors are fantastic at finding other ways for me to do things. My legs were practically useless when I started, but I used toning tables (exercise machines that increase strength and flexibility) to build up my strength. This meant I could try different types of flying. And now I have stronger shoulders than most 85-year-olds. I’m so determined to keep going as long as possible: age means nothing, attitude means everything.

I have a mantra that I made up many years ago:

I do not live with MS, MS lives with me. Since being diagnosed 40 years ago, I’ve always found ways around things, and I’ll keep skydiving as long as I can. When I’m in there, it’s almost a state of euphoria.

For a 15% discount at iFly’s centres in Manchester, Basingstoke and Milton Keynes, contact jsidgwick@ifly.co.uk and quote ‘Glen Mills MS Matters’. Valid before 1/8/19.

Inspired to skydive

Carole Hassall (61), who also has MS, was inspired to try indoor skydiving after seeing Glen doing it on the TV. ‘I thought if Glen could do it then I could too. I was worried beforehand, but on the day, as coincidence would have it, Glen was there, so I got to watch her first and that gave me the confidence I needed. It’s such great fun and I’d definitely go back.’

Being my own boss helps me work around MS

Three women tell us how they've met the challenge of working with MS by setting up their own businesses

Katie Silverthorne

'I wanted to bring liberty and purpose to people who otherwise feel they might not be able to do a job.'

When my daughter was one, I was feeling sentimental, so I made a keepsake bear for her, out of her old baby grows. I put a picture of it on Facebook and I soon got the question: 'Can you make me one?' And that's how my business started – it was accidental more than anything else.

I quickly realised that working from home and having my own business was a pretty good idea. There's no travelling involved, and I can do it in my own time. I look at my able-bodied friends, commuting and juggling childcare, feeling stressed and exhausted, and I can't imagine doing it. I created my

business to work in harmony with how my body functions. I choose when I work, and I make time to meditate and exercise, because if I don't do those things, I get sick really quickly.

I kept the business small until my daughter went to school, and now I employ five seamstresses. I created a flexible model where they can work as much or as little as they like – I wanted to bring liberty and purpose to people who otherwise feel they might not be able to do a job.

There are downsides to having your own business – there's no sick pay and it can be stressful when you're the only person doing everything, from finance and tax through to marketing. I think it's really important to find your tribe: people who understand what it is you're trying to achieve from a business point of view – it's those people who become your support network.

Katie's tips

'Never stop learning: listen to audio books, watch TED talks, read books and attend seminars. And there are lots of Facebook groups to join, which are great for finding your tribe.'



Rachel Shapey

'I'm still a music teacher, I'm just not in the classroom anymore.'

I was a secondary school music teacher for 12 years, and I got to the point where I was finding it a struggle. I was diagnosed in the year I started working, so I'm pleased I was able to do it for so long – but teaching is a notoriously stressful and tiring job, plus I have two young children.

I decided to leave teaching, but I knew I wanted to do something else. I read a book called 'Make your creativity pay' by Pete Moseley, which encourages you to think about what you're passionate about. For me, that's composing music and teaching. I came up with the idea of using my classroom resources and methods to

create online composition tutorials for school students.

I went to a local web designer and we created the I Can Compose website. There's nothing like it out there and I've had a really positive response. In 2018, I won a Stelios Award for Disabled Entrepreneurs, which meant I was given £10,000 to put into the business.

I'm not an experienced businesswoman, so I've learnt how to run things as I go along. I wasn't on Twitter or anything like it before I started, so I've had to learn to use social media. I joined lots of music education groups, which has been a really good way to do direct market

research and promote I Can Compose.

This job is great because I can work from home, take my kids to nursery, and do what I love. I'm still a music teacher, I'm just not in the classroom anymore.

Rachel's tips

'Don't quit your job straight away. If you can, work on your ideas at the weekends or evenings. Once the business has wings, go part-time in your other job and do it in stages.'

Tracey Ebbs

'It's so much better for my wellbeing. I really love what I do.'

When I was made redundant, I picked up cake decorating as a hobby and soon started getting requests from friends and family. I realised that instead of doing it for free, I could turn it into a business.

The financial rewards aren't as good as my old job (working in an insurance company), but in

Tracey's tips

'Don't overstretch yourself physically. Build in rest days and allow yourself plenty of extra time in your contingency plans.'

terms of job satisfaction, it's one hundred per cent better. I can work it around my MS, and I have more time socially to spend with my friends. It's so much better for my wellbeing. I really love what I do.

I limit the amount of orders that I take on based on what I can manage with my MS, and I do some things in advance so I don't have a massive rush at the end. I can sit down when I need to, and if I have a fatigue day, I can do a bit of work and then have a rest.

Most of my business is through word of mouth, but I've also put a couple of ads in local parish magazines. Plus I have a website, and Facebook and



Instagram pages. It's through recommendation more than anything else.

I think it's important to follow your aspirations but be aware that you don't go from zero to a massive success instantly. You have to build up your customer base and there's a lot of hard work involved. But if you're realistic about your expectations, there's no reason why you can't achieve your dreams.

Information and support

There are many things to consider when setting up a business and being self-employed. Our Work and MS booklet has some useful advice and considerations, including a list of organisations that may be able to provide support. Download the booklet at mssociety.org.uk/work-and-you



Could you help us be more effective?

With an annual income in 2018 of around £29 million, we're the largest UK charity for people living with MS. We have four national offices, close to 300 staff, and around 30,000 members, 270 local groups and 5,000 volunteer roles.

Join our Board of Trustees

We're looking for talented people to join our Board of Trustees. People who want to help us to become even more effective and who share our commitment to stop MS. Strategic thinkers with excellent communication skills, who can assimilate complex information and ask challenging and strategic questions.

The Board's governance responsibilities, and the way in which the world views charities,

are getting tougher. This makes it even more important to have good people in our governance structures.

The Board is responsible for setting our strategy and monitoring its implementation. It agrees annual business plans and performance targets, approves and monitors our budget, and monitors risk and compliance with regulatory and statutory requirements.

Make a difference in your nation

We also need new volunteers to join our National Councils in England, Northern Ireland, Scotland and Wales.

These are a vital link between our Board and our senior staff – and our local groups, members and the wider community of people living with MS. They are responsible to the Board and

help us make sure that voices from the UK's nations inform our UK-wide strategy. They are one of the ways we ensure that the day-to-day experience of people affected by MS is heard and understood.

Council members need to attend meetings around four times a year, as well as other activities which connect with the MS community.

Who are we looking for?

We're committed to equality of opportunity and are serious about broadening the diversity of the Board and National Councils.

We have introduced targets that work to ensure the Board and Councils are diverse and inclusive. These include a minimum number of people with and closely connected to people with MS, as well as from groups under-represented on similar bodies elsewhere.

For the Board we would particularly encourage applications from people with MS, people from a BAME background, people under 35, people who would broaden the geographical areas from which the Board are drawn, or who would increase the breadth of social and economic experiences on the Board. Applications from across the UK are encouraged.

For our National Councils we would particularly encourage applications from people living with MS, younger people and

people who would broaden the geographical areas from which council members are drawn.

For either role

We welcome applications from individuals from any background with the right skills and experience. Expenses are paid and we'll provide you with a full induction.

Board of Trustees

The deadline for applications is 5pm on Friday 10 May. Interviews will be held on 20 and 21 May, at MS National Centre, London.

We expect there will be three Trustee vacancies.

National Councils

The deadline for applications is Friday 10 May (5pm).

- Cymru Council – We anticipate there will be four vacancies (interviews – 3 June)
- England Council – We anticipate there will be nine vacancies in: Yorkshire & the Humber; North of England; Kent; East Anglia; South West; West & Wessex; Surrey & Sussex; Thames Valley; Cheshire & Merseyside (interviews – 3 and 6 June)
- Northern Ireland – We anticipate there will be four vacancies (interviews – 20 May)
- Scotland Council – We anticipate there will be four vacancies (interviews – 20 May)

Elections are during August and September, with results announced at our Annual General Meeting on Saturday 21 September.

'It's been the most rewarding time of my life'



'This is my fourth year on the council and my second year as chair. Being on a National Council is like being an ambassador for

the MS Society in the region you represent. I visit a lot of local groups to find out how the charity can support them; what we're doing well and what we could do better. The best thing is meeting all the amazing local volunteers, who go above and beyond to help people with MS.

'We want to attract people of all ages and from all backgrounds – the most important thing is that you understand the MS Community. From my point of view, it's been the most rewarding time of my life. I feel as if I'm making a real impact.'

Phillip Gamble
England Council Chair

Find out more

If you're interested in one of these roles, please contact Amber Esposito at governance@mssociety.org.uk or 0208 827 0470. Amber will provide you with all the information you need, including the specific additional skills and experience we're looking for this year.

For more information about our Board and Councils visit mssociety.org.uk/what-we-do/our-people



How our virtual sessions can help newly diagnosed people

By joining our online Living Well with MS sessions, people diagnosed with MS in the last five years can connect with others who've been newly diagnosed. The sessions, which are run in small groups over a few weeks, are a chance to explore the support that can help you live well with MS. Gillian (31), from Greenock, shares her experience of taking part.

'I was diagnosed with relapsing MS two years ago. Fatigue is my biggest challenge, as it is for a lot of people with MS. I get quite a lot of numbness, pins and needles, leg drop and chronic migraines.

'I was looking for support and saw a post about the Living Well with MS sessions on Facebook. There were face-to-face and virtual sessions. It made sense to do it online because of where I live.'

No silly questions

'Each session was relaxed and informal. You could ask anything you wanted – there were no silly questions. I went away with hints and tips on managing things, and got a different perspective.

'The most beneficial thing was feeling that I was able to manage things and prioritise better. The managing fatigue session helped me keep track of my symptoms and what triggers them. Now I'm not so hard on myself. There's always tomorrow – not everything needs to be done today.'

Being there for each other

'After taking part I signed up as a volunteer, helping to run the sessions alongside MS Society staff member Susi. I wanted to

do something that gave me a sense of purpose and would help other people with MS.

'It was quite nerve-wracking waiting on that first person logging on for my first session. But I enjoyed it so much, talking to people who'd been recently diagnosed and reassuring them. There are days you're going to feel horrible, and that's OK because not every day is like that. My experience is that it gets easier.'



Have you recently been diagnosed? Join a session and connect with others from the comfort of your own home. Visit mssociety.org.uk/living-well-with-ms-events

Access to exercise helps people with MS get more active

A new partnership in West Cheshire is helping people with neurological conditions, including MS, get access to exercise classes and facilities.

Supported by Sport England, Access to Exercise identifies people who want to increase their physical activity and helps them achieve this by linking them to clubs and exercise programmes. It also trains leisure centre staff in how best to support them.

Seven organisations are involved in the partnership, with Ruth Austin-Vincent from the MS Society chairing the steering group. She says: 'We know how it can be difficult to get motivated, and

even find information about what's on offer locally.'

Feeling included

'This new partnership will enable people living with MS and other neurological conditions, such as Parkinson's disease, to be more active and feel included in the community.'

Anyone in West Cheshire can sign up to the scheme and go through an assessment to determine what activities will be appropriate for their age and condition. They will then be given the choice of classes and activities that are available locally.

For more information about Access to Exercise, email jane@neurotherapycentre.org
To find out about the training, email lorrynicholson@wrightfoundation.com

Ruth adds: 'What's also great about the partnership is that it's making people who work in the fitness and leisure sectors more aware of people with neurological conditions.'

Training for fitness professionals

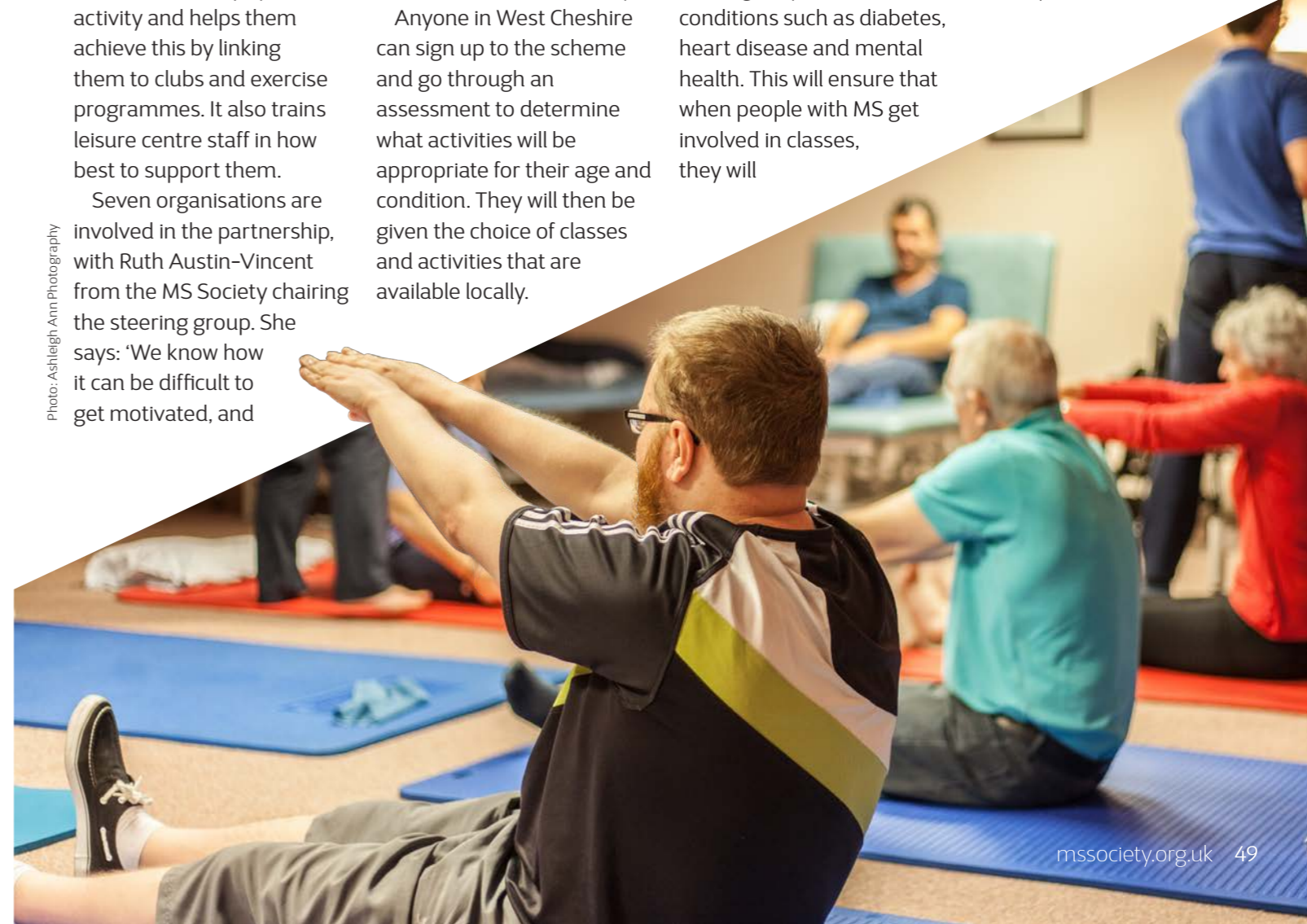
'The Exercise for Long Term Neurological Conditions training course, the first of its kind for fitness professionals, is the equivalent of the training they receive on conditions such as diabetes, heart disease and mental health. This will ensure that when people with MS get involved in classes, they will

receive support from staff who have an understanding of their condition.

'This is something people living with neurological conditions have said time and again is really important to them.'

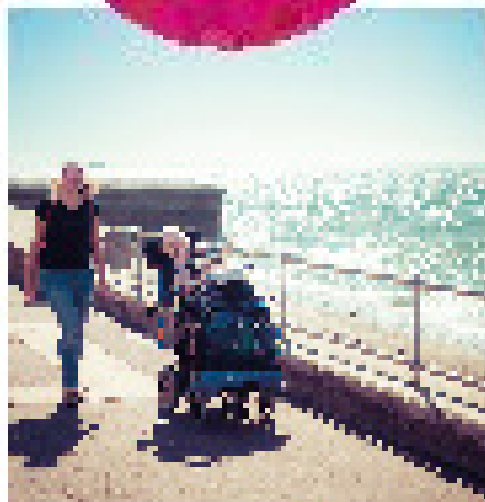
As well as West Cheshire, fitness professionals from Blackpool, Fylde and Wyre, Halton, St Helens, Crewe and Liverpool have also attended the training course. There are plans to roll it out across other parts of the UK.

Photo: Ashleigh Ann Photography

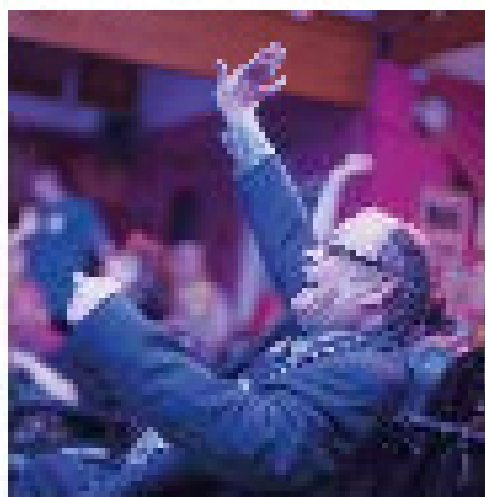


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Tayside service to support people newly diagnosed with MS

We're delighted that hundreds of people living with MS in Tayside are set to benefit from a new service – My MS, My Way: Tayside.

The service will provide support at MS clinics, counselling, self-management sessions and bespoke one-to-one peer support. Our research found there is a great need for these services, particularly among people newly diagnosed with MS.

In partnership with the MS Therapy Centre Tayside, we'll receive £132,773 from the National Lottery Community

Fund over two years to support people with MS in Dundee, Angus and Perth and Kinross.

The service is also receiving £18,454 from the NHS Tayside Community Innovation Fund.

We co-produced the service with MS Therapy Centre Tayside, which means the project was designed with input from a group of 35 local people with MS. It will be delivered as part of a community partnership between people living with MS, MS Society Scotland and MS Therapy Centre Tayside.

Yvette McAngus, Chair of the MS Therapy Centre Tayside, lives with MS and helped to shape the service.

I was diagnosed with MS in 1993. I was working and my daughter was very young. It was overwhelming being diagnosed with a condition that would be there for the rest of my life.



That was one of the main reasons I got involved with this project. The My MS, My Way: Tayside service will be there straight away when people are diagnosed, so they will have more support and information about what's available to them.

The service was designed in partnership with people affected by MS. It was important that people could share their experiences, say what wasn't there for them when they were diagnosed, and what could be improved.

The design of the service also included lots of discussions with the MS team at Ninewells Hospital, who do a super job. They're full of support for the service, which will make it easier for them to support their patients.

It's exciting to be part of a project that will hopefully make people's journey with MS easier, and that of their families. My hope for the future is that nobody gets a diagnosis and walks out of the hospital feeling alone, and will get access to suitable quality information and receive the support they need.

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ITV show transforms Nina's house and garden

Nina Parry, who has primary progressive MS, was overwhelmed when her family was chosen to appear on ITV's Love Your Home and Garden.

Nina and her husband Steve, who are both wheelchair users, struggled with a badly laid out living space and an inaccessible garden. Steve, who is paraplegic due to a spinal arteriovenous malformation (AVM), constantly uses a wheelchair and couldn't

even see the garden from inside. This made it difficult for Nina's children Oscar (10) and Lexi (six) to play there.

The programme, which aired on 15 January, saw presenter Alan Titchmarsh and his team of architects, builders and gardeners transform the space, both inside and out.

Nina says: 'A close friend of mine put our family forward for the show, but I didn't expect to be chosen. The whole process took nearly a year. So, when Alan Titchmarsh turned up at our door, we couldn't believe it! Then it all happened really quickly. We had two days to move out of the house before the filming started.'

'It's been life-changing. The garden is now somewhere safe that all of us can access at any time, so we can all be together.'

Nina and her team are raising funds for her local MS and Neurotherapy Centre through a rugby event. She raised funds for the MS Society at a similar event a few years ago and plans to do so again in the future.

Visit: letsgetourbootson.com



Nina (first row, left) and her family with the Love Your Home and Garden team

'Balls to MS' nets £8k

When Kev Shurmer, from Croston, retired due to his MS he hit upon a unique idea for raising funds for the MS Society.

Kev decided to collect signed balls and memorabilia from as many different sports as possible. Calling his initiative 'Balls to MS', he spent hours every week contacting sports clubs. With the help and generosity of clubs, friends and friends of friends, he collected 91 items.

In October 2018, Kev and his wife Samantha held a live auction at Bolton

Whites Hotel, as part of a black-tie gala dinner.

He also held online auctions to offer the items to a wider audience. Thanks to the couple's determination and creativity, the whole initiative went brilliantly and raised £8,329.

Kev and Samantha have decided to trial living in Spain to see if it helps his MS. They deserve a rest after such a big achievement, for which we're very grateful.





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Support us this spring

There are so many ways you can help improve the future for people with MS. Here are just three!

1

Enter our Spring Raffle

Don't be sheepish - enter our Spring Raffle now for the chance of winning £4,000! When you play, each £1 raffle ticket you buy will be supporting people affected by MS. There are also lots of smaller prizes to be won, including 25 M&S vouchers. The draw closes on 9 May, so what are you waiting for? Enter online at raffleentry.org.uk/mssociety

2

Play our Weekly Lottery

Be in with a chance of winning a fabulous £10,000! For just £1 a week, you can enter our weekly draw to win great prizes - over £25,000 has already been won. 2019 could be your lucky year if you enter at lottery.mssociety.org.uk today!

3

Celebrate with us to stop MS

Share your special day with us, and raise money to stop MS along the way. Got a wedding, birthday or big event coming up? Head to page 27 to find out more!



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communityviews

Living with an owner who has MS

In January we shared a post by a very special guest blogger – Felix the dog – on living with Al, who has primary progressive MS. Hundreds of you liked or loved Felix's blog on Facebook.

Al and I met when I was only eight weeks old. He drove for four hours to meet me and my siblings, and I made sure he chose me to take home.

I knew that Al was slowing down since I first met him in March 2015. He was officially diagnosed with primary progressive MS in July 2017.

We spend more time at home than we used to, especially in this cold weather. While Al is always happy, I do notice he is much slower in moving and his balance is an issue.



A word from Al, Felix's human

Felix is more than a pet, he is a friend with plenty of character, love in abundance and loads of companionship.

I took part in the blog as part of my campaigning to get ocrelizumab available to all people with primary progressive MS who can benefit. I wanted to show we are people who have a life and want to improve our futures, prospects and expectations. I've shared it with my MP, and she's replied praising its approach.

It's great that people have identified with the serious message in the blog, as well as the humour and love for our pets.

In summer we go on bike rides – he finds that his balance isn't such a big issue when he's cycling. And last week we went on a car trip to pick up a used folding electric wheelchair. This means I get long walks again!

Al's very determined. I know he has been campaigning with others within the MS Society to get NICE to approve ocrelizumab for primary progressive MS.

I just wish they'd hurry up and approve this. If he starts on this treatment, it would be so much better for him and it would make me so much happier knowing we would have a better future together.

share

Do you have a pet story you want to share? Are you a budding blogger? If you'd like to write for our online community, get in touch with us at:

✉ Email mismatters@mssociety.org.uk

Facebook www.fb.com/MSSociety

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

‘Art has been my salvation’

Avid artist **Jenny** on discovering a new passion in her seventies

I'm 77 years old and was diagnosed with primary progressive MS in 2009. I was relieved that it was something I could live with, but it was still frightening. I looked things up on the internet but then I thought: it's my life, I'm going to try and do something about it.

Art has been my salvation. I'd painted in my twenties and always loved art – years ago I visited all the art galleries in Paris. When I saw an MS art group advertised I decided to give it a go. And I've gone from strength to strength!

Going with the flow

When I'm painting I forget everything except what I'm doing. I just think about how to find colour, shadow, expressions – that kind of thing. I love reflections so I've done a lot of pictures with water.

The MS art group has finished and now I attend a class for people with acquired brain injury at Evesham college. It's fascinating seeing people paint in different ways. Mainly people have had strokes and have learned to paint with their left hand, or they have help to paint. I find the classes social and



inspiring. I also paint at home every week and have a special unit in the kitchen where I can stand with support.

We're all individuals

Last year I was delighted to get a certificate for outstanding achievement from the college. This hobby has given me back myself. When I was diagnosed with MS I felt I'd been given this new label, but now I deal with it as a positive thing. I have MS and I paint. It can be helpful to

do something so MS isn't the biggest thing in your life.

From an age perspective, it's also good to do something positive. As an older person you've got the experience of a lifetime to draw on. Everyone has different interests, we're as individual as our fingerprints. Some people paint, others write, others enjoy flowers – it could be anything.

I would like to think if you're reading this that it has made you smile.

share

Do you have creative work you'd like to share? Email msmatters@mssociety.org.uk for a chance to see your work in the magazine.

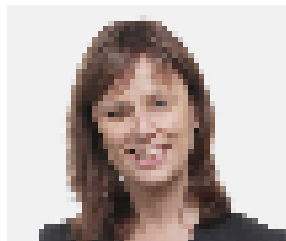
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