

Together we can **Stop MS**

All you need to know
about our **biggest ever**
fundraising appeal



Inside
**Research
Matters
magazine**

The research
journey



Issue 133
Autumn/Winter 2019

I'm delighted to say we have now launched Stop MS, our biggest fundraising campaign to date. We're aiming to raise £100 million and find treatments for everyone with MS. It's an ambitious amount of money, but our goal to find treatments is more reachable than ever before. Together we can stop MS. Thank you to everyone who is helping us fundraise – we couldn't do it without you. You can read more about our appeal on page 24.

From the many people living with MS I've met, I've learned that MS is different for everyone. So for this issue, we asked you the question: what does MS mean to you? Read the responses on page 36. We also hear from Bella who was diagnosed at 15 (page 30) and Sophie who responded to her diagnosis by heading to Australia (page 35). If you're feeling inspired to travel yourself, we have holiday tips on page 22.

People find many different ways to manage their MS symptoms, include turning to creative pursuits. On page 18, we talk to three talented people who found relief through painting, writing and acting. And on page 52, we feature some beautiful poems that you've sent in.

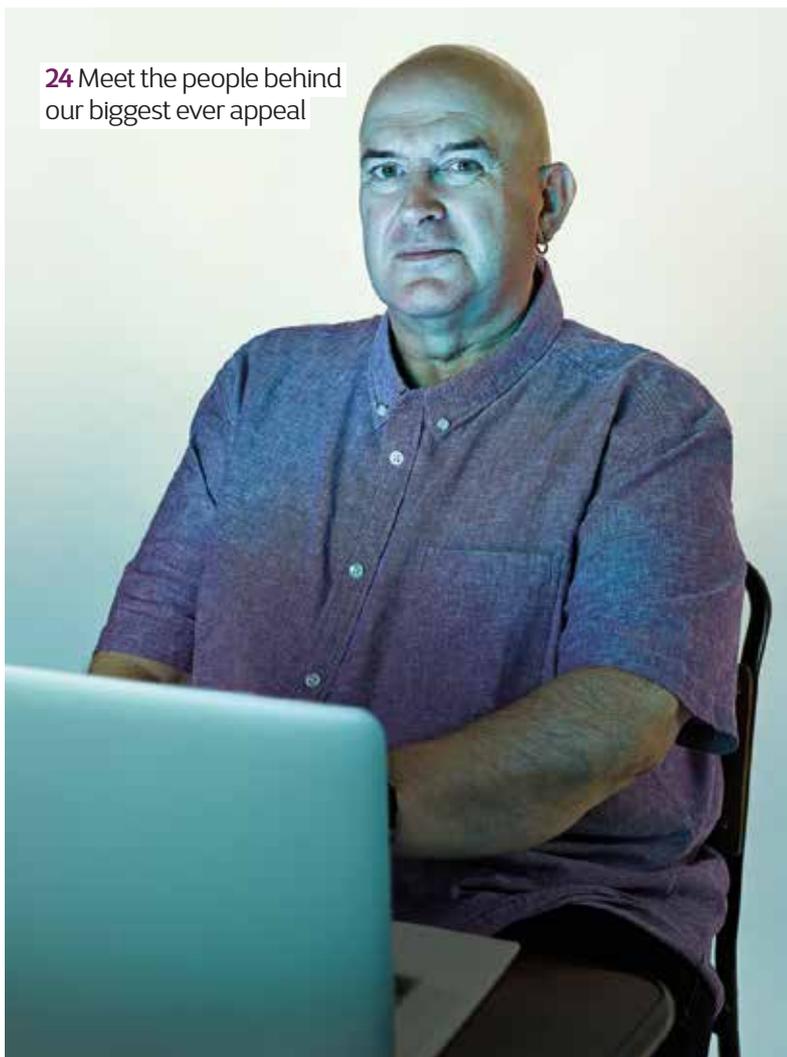
I am also excited to let you know that we have added some new features to this edition, including a letters page (page five), an update on treatments (page 28) and a behind-the-scenes look at the MS Society (page 45).

We're determined to make this magazine the best it can be, and to do that we need your feedback. So please take the time to fill out our Membership and MS Matters survey, which you'll find as an insert inside the magazine. We'd love to hear your views to help us shape the future of our membership as well as the magazine.

Wishing you all a wonderful Christmas and New Year.

Nick Moberly
Chief Executive

24 Meet the people behind our biggest ever appeal



NEWS

- 6** Cannabis: one year on from the change in law
- 9** PIP training in Northern Ireland
- 11** News from our ambassadors
- 13** Our new services and a symbol for #AnyDisability
- 14** We are Undefeatable campaign launches
- 16** Find out the results of our Friends and Family survey

INSIGHT

- 18** Three people tell us how being creative helps manage their MS symptoms
- 22** Tips for travelling with MS
- 24** **COVER STORY:** Our Stop MS Appeal launches
- 28** Spotlight on new treatments for MS
- 54** Pretty shoes for wonky feet

Did you know you can help stop MS through your mobile?

You can give a regular gift of £3 a month to help stop MS. Just text NOW to 70372 to give £3 each month. Together we can change the future of MS. For full terms and conditions visit mssoc.uk/mobile





6 An update on cannabis and MS



18 Gillian tells us how writing helps manage her MS



22 Our top tips for travelling with MS



40 How we celebrated Pride 2019

Research Matters



Turn to the centre of MS Matters to read Research Matters. Find out how new treatments for MS are developed, and hear from our experts on heat sensitivity, vaccines and the tiny tropical fish making a splash in MS research.

talk Need support or information? Call our MS Helpline on 0808 800 8000 or email helpline@mssociety.org.uk Want to talk to other people with MS? Our online forum is a welcoming space for you to share experiences. Get to know your MS community and join the conversation. Visit: community.mssociety.org.uk **Got a question about membership? Need MS Matters on CD? Call our Supporter Care team on 0300 500 8084.**

REAL LIFE

- 30 Real life stories: diagnosed at 15, life as a curator, and the accessibility of public spaces
- 33 Anthony Stone on his journey with MS
- 35 Sophia Monkman on a year in Oz

COMMUNITY VIEWS

- 5 Your letters
- 36 Community views: what does MS mean to you?
- 38 Blog spotlight: memory and MS
- 52 Creative corner: your beautiful poems

GET INVOLVED

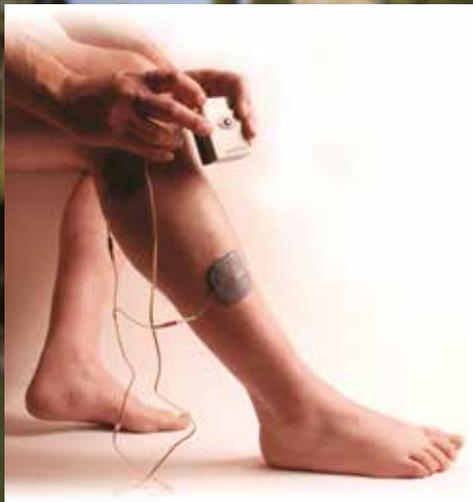
- 46 Our MS superstars and dates for your diary
- 51 Four ways to stop MS this Christmas; and how to make a Will

COMMUNITY NEWS

- 40 #MSTogether at Pride 2019
- 43 Living with MS in Northern Ireland
- 45 30 years of volunteering and a behind-the-scenes update on our new strategy

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Your Letters



"I think it's imperative that the MS Society's awareness raising gives a much higher priority to the present crisis regarding welfare and rights. It amounts to a sustained and deliberate attack on people with MS and other disabilities across the board, including on independent living, social care, various disability benefits, access to the law and more.

"Without public knowledge and understanding, there can be little public support for our cause and it will make little headway. The response from organisations, including opposition parties, who should support disabled people has been disappointing. It seems that resistance is being left to us."

- Robert

We agree that the welfare system doesn't make sense for people with MS and we've campaigned against changes that have left people with MS worse off. One of the reasons people are losing support is the PIP 20-metre rule. Last year, over 36,000 of us signed a petition calling on the UK Government to scrap it. We work with other charities to speak up on the importance of supporting disabled people to live independent and fulfilling lives. We know this issue is so important and won't stop campaigning until things change. You can read more about PIP on page 9.

Photo: Lucy Young

In response to 'Parking space vigilantes', Summer 2019

"We should always welcome a check on the use of the blue badge spaces, and should encourage the person who challenged them to keep up the good work.

"And it will get more fraught as the scheme extends at the end of August to those with (invisible) psychological problems. The number of permits will increase – but where is the increase in the number of places? We should be campaigning for more blue badge spaces."

- Allan

We welcome the UK Government's decision to widen eligibility for the blue badge scheme, which we called for in our response to a government consultation last year. Eligibility for blue badges is determined by the UK Government, but the responsibility for ensuring there are enough disabled parking spaces lies with local authorities. We work with local decision makers to fight for the services people with MS need and look for opportunities to campaign on issues like this.

In response to 'Notes from a small life', Summer 2019

"My thanks to the columnist who wrote so eloquently about caring for his wife. His words perfectly expressed my feelings and experiences of caring for my husband. The article moved me to tears, it is so true to our experiences.

"It is good to read of all the energetic activities many of your contributors get up to, but a world away from our daily struggles just to do the basics. So I don't feel quite so alone after reading this excellent article."

- Anonymous

Thank you. We're so pleased it was helpful and have passed on your thanks to the writer.

We love to hear your feedback on the magazine and the articles you've read. Share your thoughts by writing to us at msmatters@msociety.org.uk

News

We bring you the latest
MS updates

Speaking up on cannabis for MS

One year on from a change in the law, access to cannabis-based medicines remains extremely limited. We're determined to change that.

When the government changed the law in November 2018 to allow specialist doctors to prescribe cannabis-based medicines, this raised the hopes of many people with MS. However, one year on, many people with MS continue to be denied this treatment option.

Thousands could benefit

We know that dealing with painful symptoms like muscle spasms, often on a daily basis, can be relentless and exhausting for people with MS. Our medical experts say up to 10,000 people with MS could benefit from cannabis-based medicines to help manage these symptoms.

Yet so far, access on the NHS has been minimal, and we continue to hear from people who feel forced to buy illegal forms of cannabis to help manage their symptoms, and to get a good night's sleep. This is simply not right.

Access to Sativex

Sativex, a cannabis-based spray for muscle spasms in MS, is not routinely available on the NHS in England, Scotland or Northern Ireland. The National Institute for Health and Care Excellence (NICE) has recently consulted on guidelines for NHS doctors on how to prescribe cannabis-based medicines in England. We were bitterly disappointed by its draft recommen-

Your views

Over 300 of you wrote in with your experiences, which fed into the NICE consultation. Here are some of the voices from our community.

dations, including on Sativex.

NICE said Sativex was too expensive and should not be made available on the NHS in England. We want to see this decision changed because we know Sativex helps people with MS, including in Wales where the treatment can be routinely offered on the NHS.

To build our response, we heard from over 300 people with MS and spoke to several MS health professionals. The message was clear - nothing has changed for people with MS, and we urgently need to see access to cannabis-based medicines on the NHS for people who could benefit.

We are talking to the company that produces Sativex, along with stakeholders and decision-makers across the UK, to keep the pressure up for people with MS to routinely access the treatments they need.

What happens next?

NICE is expected to publish its final guidance in November 2019, and we must see changes that reflect the needs of people with MS. We are also continuing to engage directly with the government to argue that one year on from the change in the law, people with MS should be able to access cannabis-based medicines that could help.

If you would like to share your experience, please email campaigns@mssociety.org.uk

“Accessing cannabis is obviously illegal. I have constant worries about that. If I had a cannabis-based medicine on the NHS, it would mean I could have conversations about my treatment without feeling like they are used against me. On top of that, I’d have a £220-a-month surplus that I could be using. I haven’t been on holiday for years, I could get a car. I have to pay double – I pay national insurance contributions for an NHS that won’t treat me and then extra to get a treatment that does help me.”

James, 30, living with relapsing remitting MS

“The NHS constitution says that it’s there for those who need it, not those who can afford it. So why, when you have a doctor saying that it would work, can you not get it on the NHS? It blows my mind and is so unfair. I am 40, doing something that I never in a million years thought I’d do. And I feel bad about it. And I’ve had to sit my children down to tell them why I’m smoking cannabis – all because the NHS won’t make Sativex available. There aren’t many options out there for people with primary progressive MS.”

Anonymous, 40, living with primary progressive MS

“I was prescribed Sativex by a neurologist. I had been using it for seven months when the clinical commissioning group (CCG) stopped it, saying it wasn’t cost effective. The hospital then said it was only prescribed by the pain management department, which refused my prescription, saying I was a new patient. I’m still waiting for help from my MP, but I’m not feeling confident that the outcome will be good.”

Yvonne, 73, living with secondary progressive MS

“As I live on the Wirral, it seems totally unfair that the consultant working from the Countess of Chester Hospital tells me he can prescribe cannabis for his patients coming from North Wales but not England.”

Elaine, 58, living with secondary progressive MS

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Improving access to PIP in Northern Ireland

In Northern Ireland, we've been helping PIP assessors to understand MS

Driven by the negative experiences of people claiming Personal Independence Payment (PIP), we've been actively engaging and influencing the Department for Communities and the PIP assessment provider.

Alongside promoting our MS: Enough campaign, we've also taken a proactive approach to improving PIP assessments for people living with MS. Most recently, this resulted in people affected by MS providing training to over 70 disability assessors and PIP

decision-makers in Belfast.

The training sessions, designed by medical professionals and people living with MS, covered issues such as fatigue, pain, cognition, anxiety, depression, MS treatments and mobility. Ten people living with MS, an MS nurse and a neuro-physiotherapist facilitated a day of training sessions. They presented their experiences, offered solutions, answered questions and engaged with PIP assessors on how to improve the assessment process and the experience for people affected by MS. The training programme was

extremely well received by both the Department for Communities, the assessment provider and by our volunteer trainers.

Iain Crosbie was part of the training team and led sessions on fatigue. He said: "I thought offering practical training was both pragmatic and effective. The assessors appeared interested and engaged in what we had to say and listened to our personal experiences, criticism and suggestions on how to improve things. Time will tell but it was very positive.

"I could see the assessors trying to turn what they were hearing into practice. They were trying to find how what we were saying equated to the questions they needed to ask. As an example, there wasn't a clear guideline on fatigue, so we suggested asking the person at the start of the assessment to give a score out of 10 – then repeat this question at the end of the session to give some measure of how the assessment had affected the person. This was readily accepted."

Find out more about our MS: Enough campaign and what we're doing to help make welfare make more sense for people living with MS at mssociety.org.uk/ms-enough

Join the MS Society's professional network

Are you a health or care professional who supports people with MS? Then the MS Professional Network is the place for you – a community of hundreds of professionals working with people with MS.

By joining, you will:

- receive the latest and most

up-to-date information resources about all aspects of MS, including what's happening in MS education and research

- receive our quarterly e-newsletter
- engage with fellow professionals to share your experiences and ideas.

Sign up today at [mssociety.org.uk/professional network](https://mssociety.org.uk/professional-network). And if you have any questions, or want to find out more, email professionalnetwork@mssociety.org.uk





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CEO Nick Moberly with Trishna at the awards ceremony

Trishna receives prestigious award

MS Society volunteer Trishna Bharadia has been awarded an Outstanding Alumni Award by Manchester University.

Trishna was diagnosed with MS five years after receiving her degree in European Studies and Modern Languages from the university. She received the honour in recognition of her work as an advocate for those living with MS and other chronic health conditions.

Trishna, an MS Society Ambassador, said: “During the award ceremony, I had the opportunity to share my

experiences with this year's new graduates. I felt it was important to emphasise that life doesn't always go to plan. However, it doesn't mean you can't still achieve your ambitions – you might just have to adjust the way you get there.”

The presentation ceremony was attended by our CEO, Nick Moberly, who said: “Trishna has volunteered for the MS Society in many ways, from helping establish the Asian MS support group to speaking at events to raise awareness of the Stop MS Appeal. It's wonderful to see her achievements recognised in this way.”

Alun Armstrong becomes MS Society Ambassador



Actor Alun Armstrong, whose sister Elaine has lived with MS for over 40 years, has joined our nine-strong ambassador team. His ongoing support has included presenting at the MS Society Awards and campaigning to scrap the Personal Independence Payment (PIP) 20-metre rule.

Alun said: “I'm an ardent supporter of the MS Society, so being made an ambassador is a great honour.

“Over the years, I've met many extraordinary people affected by MS who are so brave and dignified despite the problems that the condition presents them. It's a really humbling experience. As an ambassador, I'll have my work cut out trying to emulate these remarkable people.”

Elaine, who is a member of the Lymington and New Forest MS Society Group, said: “I'm really thrilled about Alun's new role. When he comes to the local group, they think it's the most wonderful thing!”



Alun and his sister Elaine

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Mind My MS launches in Northern Ireland



We've received £155,973 from the Big Lottery's People and Community Fund to deliver the Mind My MS project in Mid and East Antrim. The project was co-designed with people living with MS, and partner organisations Aware NI and New Life Counselling. It will improve emotional wellbeing, social connections and people's ability to live well with MS.

Over the next two years, people with MS will be given regular opportunities to meet informally, get information about living well with MS, and take part in counselling and mindfulness activities. Mind My MS will also facilitate community cafes and provide one-to-one counselling sessions and four-week mindfulness programmes.

Caroline Millar lives with MS and helped design the project. She said: "I am a glass-half-full person and I think that really helps me live better with MS. I believe this project will make a real difference in people's lives, to their outlook and ultimately to their health."

For more information, contact the Mind My MS team in Belfast on 028 9080 2802

New service for newly diagnosed people in Tayside

On 3 June, we launched My MS, My Way, a service for people newly diagnosed with MS in Tayside. It was co-designed by members of the local MS community.

People diagnosed with MS in the last five years can now access information and emotional support from the service, which



will run for two years. This includes support at MS clinics, counselling, one-to-one peer support, an information line, local events and virtual Living Well with MS sessions.

For more information, contact 01382 938 082 or mymyway@mssociety.org.uk

Volunteer for us

Volunteers play a vital role in this service, from providing support at MS clinics to sharing their experiences as peer support volunteers. Could you volunteer with the project? Find out more about volunteering and the service at mssociety.org.uk/my-ms-my-way-tayside.



Campaign for #AnyDisability



We're proud to support the new inclusive #AnyDisability symbol. Inspired by a campaign by 14-year-old

Grace Warnock, who lives with Crohn's disease, it's been designed to represent people with all disabilities who use accessible facilities.

Many people with MS live with hidden symptoms. Our supporter Jessie Ace was refused entry to a disabled toilet because she "looked fine". Jessie told us: "We need to build a united front across all disability charities with invisible symptoms to educate people about this."

We're working with the MP for Grace's constituency, Martin Whitfield, to find ways to get the symbol adopted more widely.

Join the campaigns community at mssociety.org.uk/campaigns to get involved.

We Are Undefeatable

We are proud charity partners of the latest Sport England campaign, We Are Undefeatable. You might have seen the advert on TV, heard it on the radio or saw a poster at your local pharmacy.

Over one in four people in England live with a long-term health condition, including MS. And new research shows that over two thirds say they would like to be more active. Despite this, people with a long-term health condition are twice as likely to be inactive.

Fifteen leading charities, including us, have come together with support from Sport England and the National Lottery, to launch the inspirational We Are Undefeatable campaign. The aim is to inspire people living with health conditions to get active in a way that's right for them.

The campaign features real-life

"It's a common myth that people with MS will make their condition worse if they exercise. In reality, physical activity can help manage symptoms like fatigue, balance problems, or muscle spasms – as well as improve your mood and generally keep you as healthy as possible. MS is unpredictable and different for everyone. But whether your symptoms are minimal or severe, it is possible to be active with MS – you just need to find something that works for you. It could be cycling, gardening or simply stretching. This campaign is designed to challenge the misconceptions of life with a chronic condition like MS, and show that exercise can be for everyone."

Nick Moberly, MS Society Chief Executive



experiences of people with long-term health conditions getting active despite the ups, downs and unpredictability of their condition. The people featured in the campaign, and many more people with long-term conditions, were involved in its development, from the initial research right through to the design of the campaign films.

It launched on national TV, radio and social media in August.

Rebecca (pictured right) is one of the advert's stars. She was training as a physiotherapist when diagnosed with MS. As her condition progressed, she found it increasingly hard to be active – and impossible to do the job she'd trained for.

Taking up wheelchair dancing helped her manage the depression that came about after her diagnosis, and has become one of the activities she loves most.

For Rebecca, there's no better way to get moving than dancing. She's able to let loose and have fun, no matter the style of dance. She says it's completely changed her life, and she always comes away from her sessions feeling much better than when she started.

Swimming helps relieve Meena's arthritis



Visit weareundefeatable.com for inspiration and tips on how to be active.

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How can we better support family and friends?

Our MS Family and Friends survey taught us what we need to do better to support carers across the UK.



As many as 85% of people living with MS in the UK are supported by family or friends to live independent lives. This summer, alongside our My MS My Needs survey, we launched our first MS Family and Friends survey to understand how people providing unpaid care and support can be better supported themselves.

The survey asked a wide range of questions about the tasks family and friends help with, the impact this has on them and the support they need as individuals. Your feedback was incredible – we received 714 responses. Thank you to everyone who took part.

The full results will be shared later this year. They demonstrate the need for changes in government policy to improve care and support for people living with MS and those who support them. We will be using what you've told us to take action – so watch this space.

Here are some of the highlights of what we learned we can do better to support carers. We'll be using these findings to develop our services and support over the coming months.

You can get involved in our campaigns by joining the campaigns community at mssociety.org.uk/campaigns



Information is key

Nearly half of respondents (46%) hadn't received sufficient information about support services that could help them in the past 12 months. This means that unpaid carers are too often struggling on their own, unaware of what support is available.

It was great to hear how many respondents got information and advice from the MS Society. In the past year, 33% of participants had read our information booklets and leaflets, and 34% had found information on our website. Moving forward, we need to develop ways to increase awareness of these resources and find ways to make them more accessible to those who need them.

46%

Nearly half of respondents (46%) hadn't received sufficient information about support services that could help them in the past 12 months

34%

had found information on our website

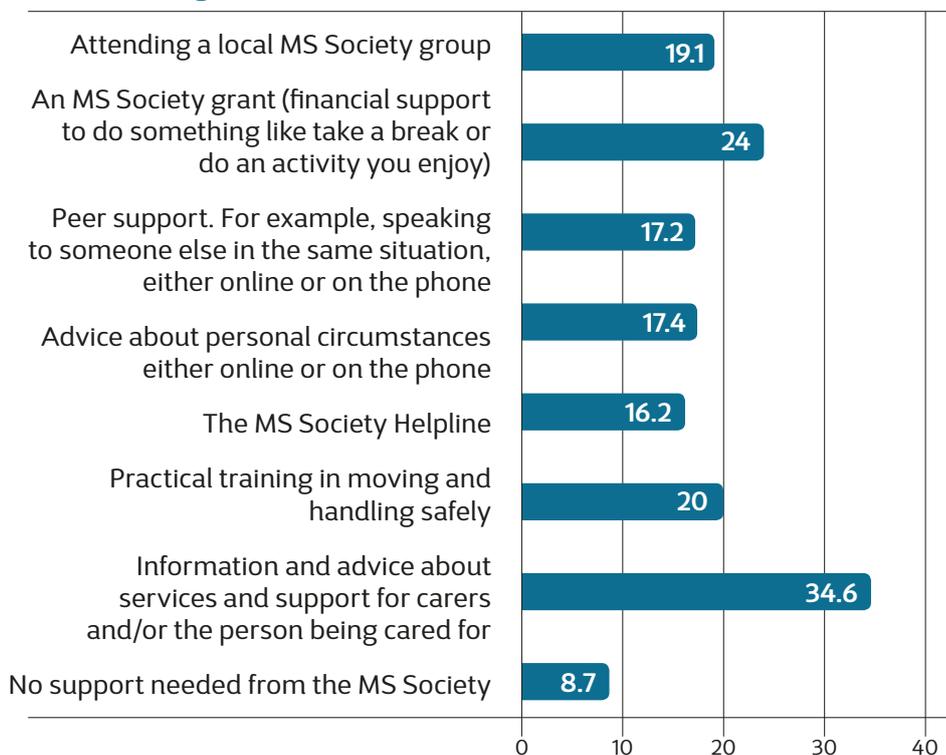
A wide range of support needs

We wanted to know how we can make our services better and whether there is anything carers feel is missing from what we offer.

People were asked to rank a selection of services as to how likely they would be to access them if they were available. Over a third of people (35%) said they would be very likely to access information and

advice about services and support for carers/people living with MS. Close second was MS Society grants (financial support for things like taking a break) – almost a quarter (24%) were very likely to access these. And coming in third was practical training in moving and handling safely, with a fifth (19%) very likely to access this training.

The percentage of people who said they'd be very likely to access the following services.



Help for carers

If you'd like more information about supporting someone with MS, or about local MS Society groups, visit mssociety.org.uk/carers. We have a wide range of booklets available with information for friends and family, and more detailed information for carers supporting those with advanced MS. Our MS Helpline can also offer advice, information and a listening ear on a wide range of issues – call **0808 800 8000** or email helpline@mssociety.org.uk



Creativity and MS

Three people tell us how being creative can help manage MS symptoms.

Steve Barnard-Long ▾

Painting took on a new significance for Steve when he realised it could stop his clonus attacks.



I've always enjoyed painting – and have exhibited my work around the world – but it never formed part of my career. Then, six years ago, I was diagnosed with secondary progressive MS. I was living in Thailand at the time, and because MS is virtually unknown there, my wife and I decided to return to the UK.

When we came back, I thought, I've got to do something with my time. I can't just sit here and do nothing. So, I came back to my art.

I suffer from very bad clonus, which causes involuntary movements in my arms and legs. These bouts can last anything from 10 minutes to five hours. After a while, I noticed that when I sat down to paint, the clonus would stop. What's more, I could do very fine, intricate work without my

hands going off in all directions.

I was astonished when I realised that there could be a connection between my art and the alleviation of my symptoms. It's as if by concentrating on something that's both creative and important to me, my brain doesn't let the MS take charge.

Now, when I have an attack, I'll sometimes do a sketch or even start a new painting. I've found it does help, but it's when I'm doing a work that I'm deeply involved in that the effect really kicks in, and I can be almost 100% symptom-free.

Now, I exhibit and sell my work at the local market. I'd like to say to everyone who has MS, that sometimes the MS can take a backseat. You can live your life and do the things you want to do.



I was astonished there could be a connection between my art and my symptoms.



◀ Gillian Shirreffs

Gillian discovered that when she was writing stories and poems, she no longer noticed her neuropathic pain.



I began writing around the time I was diagnosed with MS in March 2007. I have relapsing remitting MS and my first relapse was quite extensive. I couldn't feel anything from my toes to my chest and I also had a lot of pain, especially in my feet and hands.

I was banished to bed and it was then that I started writing. I was waking up in the wee small hours of the morning with words rattling around in my head. I would then spend hours and days trying to make sense of them. As I did, the words seemed to arrange themselves into long, thin shapes that might almost be mistaken for poetry.

After three months – and 12 poem-shaped slivers of memory – words stopped waking me up in the middle of the night. By this time though, I was hooked. I had realised that when I was typing on the keyboard, fighting with words, I wasn't aware of the invisible shards

“My brain was so engaged that I didn't notice the pain.”

of glass sticking into my skin. My brain was so engaged that I didn't notice the pain.

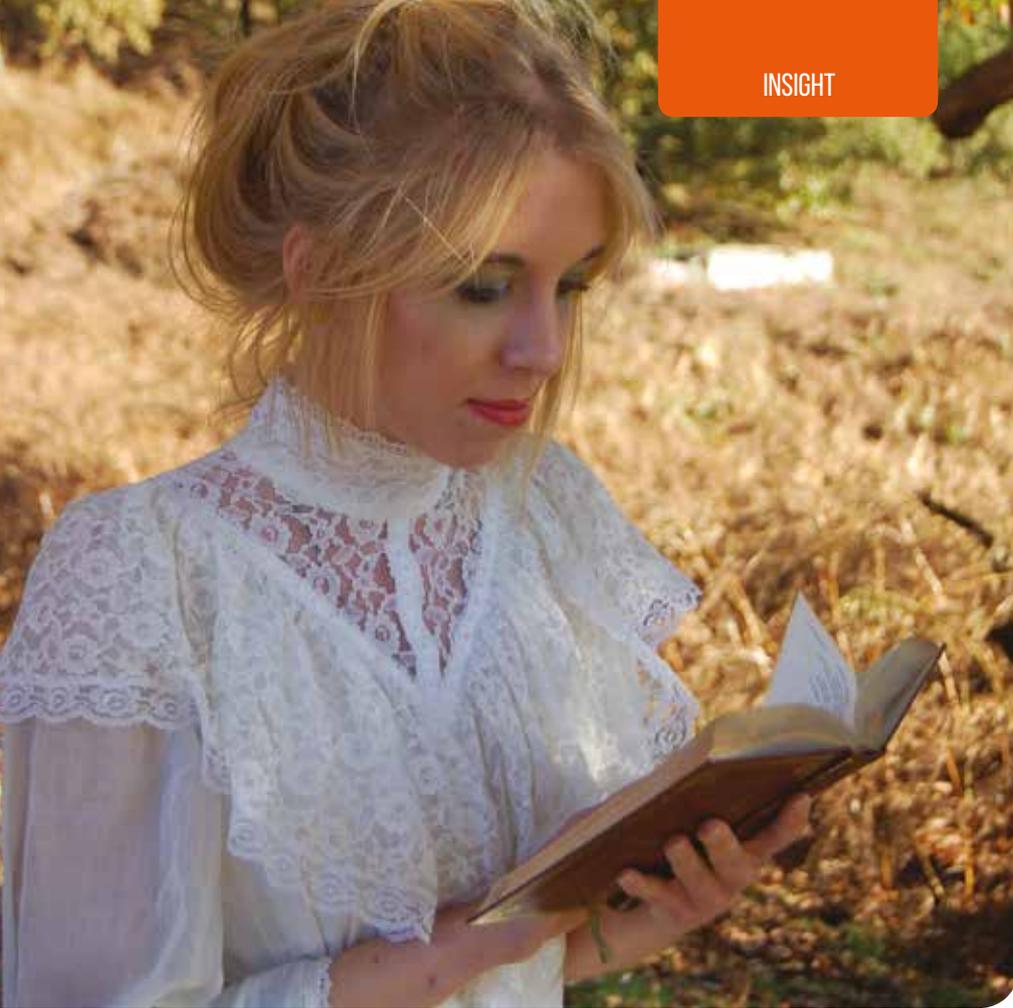
My writing soon moved away from poetry. I started to write fictional tales inspired by my interest in the people I would see in the waiting rooms of hospitals, clinics and GP surgeries. I found I enjoyed fiction more, because it wasn't about me. Most importantly, it kept my neuropathic pain at bay.

I now know that this way of coping with pain is called distraction technique. At the time, I didn't know there was a term for it – I just thought it was because I enjoyed writing so much.

If neuropathic pain is something you're struggling with, and you're looking for an additional tool to add to your arsenal of tools for managing it, it's worth trying out something that is very distracting. It could be knitting, painting, writing – anything you really enjoy that gives you a creative outlet.

Twelve years later, I'm doing a PhD in creative writing. I've written a novel, but it's not about the end result – my real pleasure comes from the act of writing.





It's a really nice chill-out break from MS.



You don't have to join a group to do drama though – you could get some friends together and read a play. You could even make a little film on your phone. It's a great way to get away from your stresses, give your mind time to relax and have fun.

Personally, the kind of stories I love are fantasy fiction like Harry Potter, where you can immerse yourself in a different world. And some of the lines from the books speak to me even more now I'm living with MS.

One of my favourites is: "What's comin' will come, an' we'll meet it when it does." I don't want to spend lots of time worrying about how my MS will affect me. I'd rather try and enjoy life and make the most of today.

▲ Heather Russell-Kay

Actor and drama teacher Heather found that focusing on acting took her mind off her symptoms, so she set up a drama group for people with MS.



I've always had a passion for theatre and drama, and I've been acting since I was 16. After my MS diagnosis five years ago, I found it helped me to deal with my condition. When I'm acting, I'm so focused that my mind doesn't register that I'm feeling tired, dizzy, or my feet are tingly. It's a really nice chill-out break from MS.

We can all be a bit self-conscious at times, but when you're acting, you can let that go, be really silly or explore another part of yourself. It helps you discover that the things that make you a bit different are also things that you can celebrate and use to your advantage. And if I'm having a rubbish day, it's great to play a grumpy character as a way of getting it out of my system.

There are lots of ways I've found acting beneficial, so I decided to set up a drama group for people with MS, which ran for about eight months. The aim of the group was to allow people to build confidence, have fun, meet other people and learn new skills. It was great seeing people's confidence develop. Some were a little shy when they joined, but by the end they were playing amazing, loud characters.

Turn to page 52 to read some poems about living with MS, including one by Gillian. And if you have a 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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www.theinberwicktrust.org.uk

Time to take a break

Taking a break is really important for everyone's wellbeing, and it can be even more important when you're living with MS. You may need a bit of extra support and planning to organise a break, but there are lots of useful services out there and we have plenty of tips to help.

We're here for you

Our Short Breaks Service is available through our MS Helpline. We can help you plan your holiday, including looking for respite care, discussing airport procedures for traveling with a wheelchair, and locating equipment hire and suitable holiday facilities in the UK and abroad. Call us on **0808 800 8000**.

We also have a useful booklet called *Short Breaks: a guide to holidays, short breaks and respite*. It's filled with bite-sized tips on how to arrange a short break, including examples and ideas, directories for accessible accommodation, and information on equipment hire, financial assistance and transport.

Download our short breaks booklet at mssociety.org.uk/short-breaks-guide-booklet

Top tips for planning a holiday

Here are some top tips to make your holiday planning a breeze.

1 Plan your budget

Make a budget before you begin to plan your break, remembering things like car hire, insurance and renting any equipment you need. This will help you get the best from your holiday. It may be possible to get financial help towards a short break. Our Short Breaks

Service can chat to you about options.

2 Think about access

MS can mean you need a bit more support when travelling. For example, accessible rooms, roll-in showers, equipment hire and in-airport assistance. Our short breaks booklet has plenty of

information on how to book this.

3 Get help with train travel

You can book travel assistance to help you at train stations and work out the best route to your destination. Call or book online with your train company, or call this central number, 0800 022 3720.

Wheels on the beach

Linda Hammond, who is living with primary progressive MS, tells us about her holiday to Australia.

I went to Australia in February. I prefer warmth with my MS, which I was diagnosed with in 1990.

I selected more leg room on the plane and requested assistance during the journey. And I took my walker with me, using it as a balance-aid and as a wheelchair.

One of the places we visited was Airlie Beach, including a boat trip to the Whitsunday Islands. Normally I miss out on going to the beach because it's difficult to manoeuvre the walker. But when the crew realised I would find walking on the beach a challenge, they suggested a beach wheelchair, which they had recently raised money for with donations.

The wheelchair was brilliant. It had big balloon tyres that made it easier to move along the sand. I was able to join in with feeding the fish on the water's edge, and dip my feet in the ocean while sitting on the chair with my family by my side.

We also went to the Great Barrier Reef. I went in a submersible, which enabled me to see the fish and the reef. And I also managed to get in a helicopter for a flight over the reef.

It's not impossible to try different things if you have the help!



The wheelchair was brilliant. It had big balloon tyres that made it easier to move along the sand

Image: iStock

4 Book airport assistance

Airports are responsible for help in the airport, and airlines for help on the plane. You book assistance with the airline, and then they share the request with the airport.

You can read about flying on the TryB4UFLy website – they provide information and advice for

adults and children with disabilities. There's an FAQ section and a video of what to expect, from arrival at the airport to boarding the aircraft.

5 Talk to hotels

There are many hotels, B&Bs and self-catering places that offer a good level of accessibility, providing things like wet rooms or

walk-in shower facilities – but they may not always advertise it on their websites or brochures. It's always worth asking.

6 Other places to seek help

AccessAble, Tourism For All, Visit Britain, Visit Scotland, Visit Wales and Disabled Access Holidays are just some of the

websites that can be used to find accessible accommodation in the UK.

Tourist information centres are helpful, offering information on disability access and things to do in the area. And Motability's Rough Guide to Accessible Britain and Visit Accessible England are also helpful tools.

Our biggest ever appeal

Our Stop MS Appeal has launched with a bang. Stop MS is our biggest ever fundraising appeal, aiming to raise £100 million to find treatments for everyone with MS. It launched publicly on 8 October with a huge advertising campaign.

Our 'Don't Stop' TV advert aired on national television, including on Channel 4, and in cinemas. And the stars of our campaign – Jacqueline, Donna, Glyn, Nikki, Alastair and Charlotte – could be seen all over the media.

The TV advert was shown at launch events in Edinburgh, Belfast, Cardiff and London, and it gained huge exposure thanks to our community who shared it far and wide on social media.

We've reached thousands more people through a special partnership with The Telegraph. They've guaranteed a million

views or shares of the TV advert and provided coverage on their website and in the paper itself.

We hit the headlines with the news that leading scientists agree that MS could be stopped, with treatments for everyone in late-stage trials by as early as 2025.

The appeal featured on the BBC News at Six, where journalist Caroline Wyatt interviewed leading MS researchers, as well as Karine, who lives with MS, and her wife Sarah. We got coverage in a host of national and regional newspapers, including the Financial Times, Daily Express, Mail Online, Metro and Belfast Telegraph.

At our launch event in Wales, Glyn (pictured on the cover) spoke about why he's so proud to be involved. He said: "I jumped at the chance to sing in a film. I'd been memorising the words, so there was just a tune to hold – repeatedly! The words sunk in and it strangely got harder to sing them because I was thinking about the meaning behind them, but this also took away the self-consciousness. I'm proud of being involved – it's a powerful advert."

Donna (pictured left) spoke at the launch event in London and told us what it meant to her: "When I arrived at the launch, it was overwhelming, especially the reaction I got when I spoke. The event was bigger than I envisioned! That's what we need – to get people talking about MS.

"When I heard the researchers speak at the launch event, it gave me goose bumps. When I was diagnosed, there wasn't anything available. Now I'm filled with hope. If we can get to a stage where we can give everybody treatment, that would be huge."

The advertising campaign

We wouldn't have been able to reach so many people without our partners Publicis and MediaCom who've generously given their time and resources to help.

We've been lucky enough to work with two award-winning artists: **James Lawes**, who directed the TV advert; and **Andy Lo Pò**, whose stunning photography helped create a series of digital and print adverts.

We caught up with James and Andy to find out what being part of Team Stop MS means to them.



Andy
Lo Pò

What made you want to get involved in the appeal?

ALP: Anything I can do to help raise money and awareness of MS, to improve the lives of people diagnosed with it, I'm always happy to be involved with. It's been very rewarding.

JL: I loved that the script's intention was to involve real people living with MS. It gave an opportunity to present people authentically. We set out to create a connection rather than the more typical 'us and them' advertising approach.

What was unique about this shoot? How was it different from others you have done?

ALP: Working with people who are living with MS at various stages made it feel very real. They were all great to work with



James
Lawes

and completely committed to creating a heartfelt campaign.

JL: There is always a fear when casting 'real people' that they will be self-conscious in front of the camera. In this case, they even had to sing. We spent a long time finding the right people who were both representative of all aspects of MS and who also felt comfortable to perform.

What was the best thing about this shoot?

ALP: The best thing was seeing some of the people involved being visibly moved by the imagery we created.

JL: The highlight was seeing the determination and dedication from our contributors. It takes a lot of courage to put yourself out there and sing for the world to see, surrounded by cameras and strangers.

Will you join Team Stop MS?

We're in the best place we've ever been to find life-changing treatments for everyone with MS. By 2025, we want to be in the final stages of testing treatments, but we can only do that together as Team Stop MS.

We've seen Cake Breaks and My MS Walks held across the UK and hundreds of people taking part in MS Walks in London and Belfast. Celebrity supporters, such as Tom Kerridge, Scott Mills and Laurence Llewelyn-Bowen (to name a few) have joined Team Stop MS too and shared the appeal.

There are lots of ways to get involved. Whether it's donating, fundraising, sharing, storytelling or inspiring each other to go the extra mile (sometimes literally).

Jessica, from Hampshire, joined Team Stop MS and organised a

My MS Walk (pictured below), raising a whopping £60,000.

She told us: "I was nervous about organising the walk. But when we reached our end point, it was the most exhilarating and empowering feeling.

"The best thing about it was the number of people who embraced it. Every single one of those supporters now understands more about MS. I am so grateful to all of them.

"I want our researchers to halt MS and find treatments for everyone."

Read more about My MS Walk on page 49.



Nick with Josh Krichefski, CEO of MediaCom who helped create the Stop MS campaign

"At the launch event in London, I was hugely moved and humbled to speak to Jacqueline and Glyn (stars of our campaign). I was so proud to see what had been created – a film that tells the truth of what living with MS is like for them. I left with hope that we can make a difference.

"When I speak to our researchers, the conviction that the appeal can make transformative progress towards stopping MS is inspiring.

This is our moment to get MS on the map. Make a noise on social media, share the appeal with friends and family, your local school or community group to reach more people and to raise more money. This is our time."

Nick Moberly
CEO of the MS Society

To get involved and find out more about the Stop MS Appeal, visit mssociety.org.uk/stop-ms or find some great fundraising ideas at mssociety.org.uk/fundraise



Team
STOP
MS

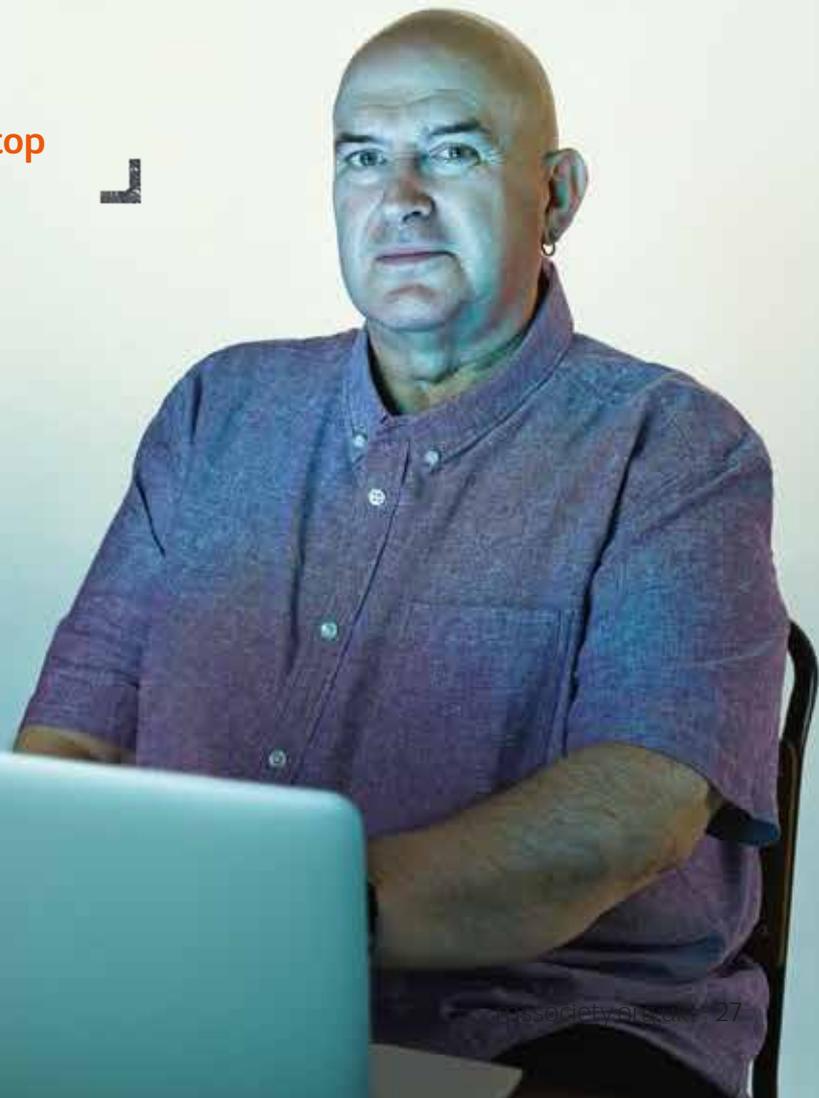
DAY 7349

The moment I was diagnosed, my world began to shrink. My job, my car, my ambitions – over 20 years, multiple sclerosis took them all away. And now those links are broken, I do all I can to stay connected.

My laptop is my lifeline. Through it, I can still help my local support group and see the progress research is making towards stopping MS. It's clear that one day soon, no one will have to go through what I have. And if I can do anything to help bring that day closer, I will.

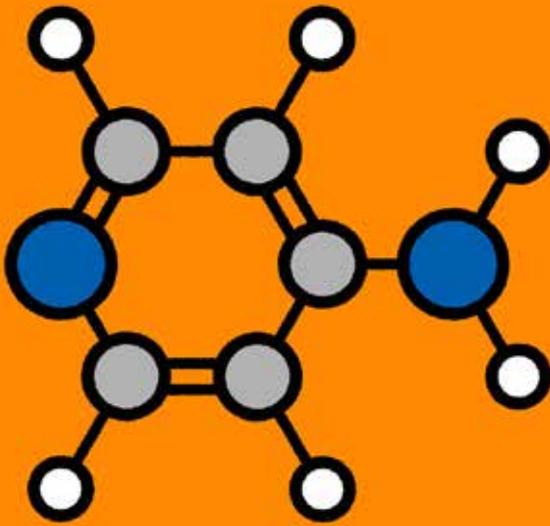
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Spotlight on treatments

Here we turn the spotlight on the latest developments in MS treatment and what we're doing to make sure your voices are being heard by decision makers. You can also read in depth about how treatments are developed on page four of Research Matters.



Fampridine (Fampyra): a treatment to improve mobility and walking

Fampridine, a treatment to improve mobility for people with MS, is going to be appraised by the agency that approves treatments for use on the NHS in Wales.

We've been calling for fampridine to be made available since it was rejected for routine use on the NHS in the UK in 2014. We will respond to the appraisal and are hoping that people in Wales will be able to access fampridine by the end of this year.

Fampridine doesn't

work for everyone, but it can have a big impact on quality of life.

Patrick, 64, lives with secondary progressive MS and has been using fampridine for the last two years. He was on the original clinical trial. He said: "Fampridine winds your MS back. Within three days I could feel my walking improve."

We will continue to encourage government and industry to make fampridine routinely available on the NHS across the UK.

Siponimod (Mayzent) for active secondary progressive MS

The body (NICE) that approves medicines for use on the NHS in England has confirmed its intention to assess the cost and clinical effectiveness of siponimod. This is a landmark step as there are currently very limited options when it comes to licensed treatments for people living with secondary progressive MS in the UK.

In the latest clinical trial, siponimod was found to reduce the risk of disability progression by 21% compared with a placebo. Eligibility is likely to be restricted to people living with active secondary progressive MS (this will be confirmed by MRI). Unfortunately, people requiring the use of a wheelchair will not be eligible.

A decision from NICE is expected in the spring of 2020.

Repurposed drugs

We want to improve the treatment options available for people living with MS who aren't responding to licensed DMTs. One option is repurposed or 'off-patent' treatments. These are treatments that were originally made, and are licensed, to treat another condition, but have now been found to help with other things, such as MS.

We want the government to take the potential of repurposed treatments seriously. So we're calling on them to plug the gap in research and fund clinical trials for off-patent treatments that could benefit people with MS.

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

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Real life stories: living with MS

Three people share their experiences of living with MS

Joanne Chapman is currently involved in helping York Hospital and English Heritage to make their sites more accessible for people with disabilities.

Public spaces make me feel disabled. I fear inaccessible places like cluttered, busy streets, especially when cars block pavements.

My local park's entrance is blocked by a bike gate. I can only access it with a walking stick. And the gate prevents many other wheelchair, scooter and pushchair users from getting through. When my mobility gets challenged, I can't visit the park, even though it's the closest to my home.

I need wider pavements, dropped curbs, step-free access, easier terrain, lifts and accessible toilets like Changing Places. I need opportunities to borrow mobility equipment, calm environments that don't trigger sensory overload, accessible accommodation, places to rest and space to move freely. My optic neuritis and failing eyesight mean I also need lift doors to stay

“Public spaces make me feel disabled”

open for longer.

When using public transport, I plan ahead, booking ramps, hidden disability Sunflower Lanyards for the airport (a godsend for this invisible condition), and I inform people like taxi or bus drivers. Getting mobility aids onto public transport is a huge struggle. And when driving, a Blue Badge doesn't mean closer toilets or resting places.

I wish for the day when all aspects of a journey are accessible, so I can be spontaneous and not have to plan ahead.

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



Joanne and her husband Dave took part in the York Marathon in October, with Dave pushing Joanne in a running wheelchair. Read more at justgiving.com/teams/JoanneDaveChapman

Lorne Campbell is a retired art historian who has worked with galleries including the National Gallery and the Prado.

I was diagnosed in 2000 with primary progressive MS. The neurologist told me I might manage for five years without a stick and ten without a wheelchair. Eighteen years later, I'm still not in a wheelchair and don't often use a stick. But it's affected me. I have to think before I go anywhere or even cross a road.

No-one's suggested that I take any drugs except a mild tranquilliser.

I take one every night to help me sleep. Before I took it, I'd wake up a lot thinking: 'What's going on

“Physio has been really helpful”

in my body and my brain?’ Then I wouldn't go back to sleep.

I do a lot of physio exercises and that's been helpful. When I say to the physio that I think I'm wasting her time, she says: “You're putting a lot of effort into this. Don't do yourself down.” It's nice to hear because they take an hour every night.

I also use a Functional Electro Stimulation (FES) device. It's fiddly and it makes me irritable when it doesn't work, but I wear it when I'm out and it speeds me up a bit.

I'm retired, but I'm still pretty busy. When I'm working, I tell

people about my MS so they know I'm not as agile as I could be. Sometimes, when you're looking at a big painting, you have

to climb on ladders and I can't risk falling onto a painting. People are very kind and hold my hands to keep me steady. I've also found balancing exercises really help.

Read more about Lorne at mssociety.org.uk/lorne



Lorne (far right) on a trip to France with colleagues

Photo: Griet Steyaert

Bella Parkhouse from Surrey has lived with relapsing MS from the age of 15. Two years on, she shares her experience.

I didn't tell everyone at first. When I did, people didn't really know what it was. One girl said 'you'll be like the character on Coronation Street,' while another said I'd end up in a wheelchair.

That year at school, I got rest breaks during exams as I had pain all over my body. I would come home and fall asleep straight away – Mum had to wake me up for dinner. I had to go to loads of hospital appointments and tried to give Mum every excuse to get out of them.

I've been on a disease modifying therapy (DMT), Gilenya, for over a year

and a half. It took 10 months after I was diagnosed to be given it, and I'm doing so much better. I go to college and have a part-time job

“It's made me grow up faster”

in the local leisure centre. I have an amazing boyfriend and I plan to go to university.

There are days when my MS plays up – my legs can go really weak and I collapse on the floor. Or my hour-walk to and from college can leave me so fatigued I find it hard to speak. Sometimes it feels like I've got weights on my arms and legs and no amount of caffeine can wake me up.

I'm still learning how to manage my MS, and what to say to people when they ask what's wrong. I know I don't look unwell, so I carry a card that says I have MS in my phone case. I won't let MS define me. If anything, it's made me grow up faster.”



Bella and her mum Sarah

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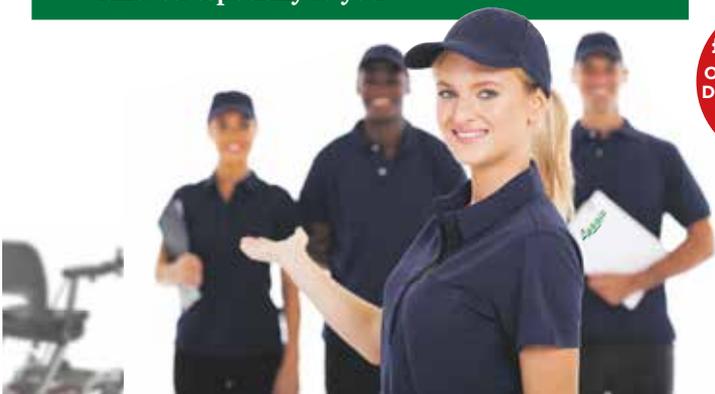
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The MS road is long. **Anthony Stone**, who's had MS for half his life, recalls how it's turned out both better and worse than he could have imagined.

A Journey without maps

Although MS is full of surprises, I soon realised most are not of the party popper variety. Even after having this disease for nearly 30 years, it still has the ability to sneak up and blow a raspberry in my face when I least expect it.

The first surprise was being diagnosed. There was no history of multiple sclerosis in my family and I had no idea what MS was. I couldn't even spell it. I thought I was being told I had multiple cirrhosis and expected the treatment to be alcohol abstinence.

But, like everyone, I recalibrated and carried on with life. I was married the year after diagnosis and now have two teenage children and a career in the civil service.

Over the years, the relapses and remittances began to bleed into one another, and I developed the progressive form of the disease. I began to use a walking stick, and then crutches. I started needing a wheelchair in my 40s.

I've tried various disease-modifying drug therapies over the years. None of them have worked for me. I'm now well on the way to quadriplegia. I find it surprising and heartening that people often say how well I look.

I'm still working four days a week. I can do this because my team has made reasonable adjustments (I control my computer using voice recognition software) and I have a supportive boss who really gets disability.

I'm not sure what's next. I can no longer use a knife and fork or hold a pen. My tongue is thickening and going numb, making speech more effortful. I now experience pain in a way that fortunately bypassed me for most of the first 20 years. It can be all-consuming and makes me a little irritable at times.



My thinking can be affected too, and this leads to confusion. My bowels and bladder have not been immune to problems. I get crushingly fatigued.

It doesn't sound too good when you put it all down in black and white. But despite the tremors and the day-to-day nuisances of disability, my glass, while not brimming over, remains half full. And that's the biggest and most unexpected surprise of all.

If you have a story to share, please contact us at msmatters@mssociety.org.uk



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Let's go to Australia

When Sophia Monkman was diagnosed with MS at the age of 29, one of the first things she did was go to live in Australia for a year.

Before the diagnosis, I was starting to have a meltdown. I was about to turn 30 and I was single, with no children, living with my parents and doing a job I wasn't enjoying. I felt I hadn't achieved anything during my twenties and was thinking: "My life has got to change." Well, it did, the MS came.

I had already started thinking about going to Australia to experience a new way of life and to embrace being 30. But being told I had MS was a massive push for me to go. I was worried if I didn't go, the opportunity might pass me by.

I left the UK with only a rucksack. I had left my job, sold my car and said goodbye to my family. Looking back, I can't believe I was brave enough to do it. I went to Australia with no job and not a clue where I was going to live, but it was exactly what I needed.

Having MS didn't stop me one bit while I was over there. I know I get tired, so I managed my time

correctly and made sure I got plenty of rest when I needed it. When I told people I had MS, they couldn't believe it. I was able to take part in all the activities, including surfing, sea kayaking and snorkelling. I was treated like an equal.

In Sydney, I was very fortunate to get a job at a racecourse. I explained to my manager that I had MS and she was very understanding. She made sure I got rest when I needed it and finished work at a suitable time on race days. I'm a passionate fan of horse racing and I had to pinch myself most days – it really was the dream!

I'm now home in the UK and trying to write the next chapter for my life. Having MS does mean you have to plan extra care and look after yourself, but I'm adamant that it isn't going to define me. The memories I made in Australia will last a lifetime and, whatever happens in the future, the MS can't take that away from me. I am Sophia Monkman full stop. Not Sophia Monkman who has MS.

Read tips for travelling with MS on page 22.



Living with MS is a different experience for everyone. As part of a new MS Matters feature, we'll be asking you a different question each month and sharing responses from the community.

To kick things off, we asked the question:

What does MS mean to you?



“The hardest part is coming to terms with the situation where the mind says do this and the body says no. Even after all these years, it is hard to accept.”

Stephen

“I was diagnosed nearly 13 years ago. Fatigue is my worst thing. It’s robbed me of so much. It absolutely sucks. However, I am so grateful for little things every day. I sometimes kind of forget when I have good days, then pay for it later! I’m not patient with myself at all.”

Tracey

“I have four children and my symptoms became too bad to ignore after my youngest son was born. I believed I had a trapped nerve and hoped it was nothing to worry about. But eventually my diagnosis came. It’s changed our lives massively and I know I have to adapt, but it is extremely hard for my husband watching me deteriorate slowly.”

Beccy

“I have found a strength and determination beyond my stubbornness. Most days I can just carry on with my normal life, but the days when it hits me, it hits me hard. My worst symptoms aren’t visible as they involve my bladder and bowels, and that makes it hard as they’re completely taboo subjects at the best of times. I hate the feeling of being a fraud most of the time.”

Emma

“MS gave me a life filled with more gratitude and compassion for others who are suffering from an illness that's long term.”

Alison

“I’m so scared of the damage that’s happening inside my body when I get muscle weakness, speech issues, fatigue, pains, brain fog, and so much numbness and tingling. I haven’t told many people about my condition as I don’t want to be treated any differently and I definitely don’t want pity. I won’t let this illness define me.”

Emma-Louise

“I have realised that you have to listen to your body and give in, which sometimes I find very hard. The menopause was awful. It definitely made things worse. I stay strong and do what I can when my body lets me.”

Fiona

“I was diagnosed with PPMS last November. I am tired most of the time and my left side gets very weak, but luckily I am right-handed. I try to explain to people what it’s like, but it always seems like nobody understands. Unfortunately, it has defined who I am as it has consumed my mental state.”

Garry

“I work part-time and believe this keeps me from letting MS take all of me. I feel as though my whole body is wired up wrong most days. It’s about learning to listen to your body and not feeling like a failure. We are strong even on our weakest days.”

Lisa

“Six years ago I lived in skyscraper heels, worked part-time as a high school teacher/uni lecturer and gigged with my band. Now I can just about walk across a room. But I still gig, from a stool and less often. And yes, you can do music festivals on a mobile scooter, and walk a dog and do a food shop for two. I have MS but it won’t be having me.”

Alison

“I find the uncertainty of what MS will throw at you next hard. The very unpredictability is a really difficult thing to deal with, as much as any of the symptoms you might get.”

Sarah

“MS to me is an opportunity to make the most of each day, to appreciate things I never did before and to meet incredible people I would have never had the pleasure of meeting. I feel like my eyes have been opened to the world around me for the first time. I was diagnosed at 22 years old.”

Jessie

For our next issue, we’re asking: what’s your top tip for people living with MS? Send in your answers to the MS Matters inbox at mismatters@mssociety.org.uk or keep an eye on our Facebook page, [facebook.com/mssociety](https://www.facebook.com/mssociety) where we’ll be posting the question later this year.



Community views

MS and memory problems



Caz Makin shared her thoughts on our blog about coping with memory

problems and MS.

She said: "I've been thinking about stuff lately, which is funny because I lose my train of thought, amongst other things, constantly! Joking aside, 'brain fog' is a massive issue for me

I get overwhelmed most days - it's like my mind shuts down. Here are some tips I use to manage my memory and thinking issues:

- List writing is essential. I make a list of things I absolutely need to do, then another one of the things I'd

like to get done but aren't urgent.

- I think reading (when I can focus for long enough) is great exercise for my brain. Word searches, crosswords, sudokus and so on are all good stimulation.

- Ask for patience and understanding when you become overwhelmed, confused or zone out. You're not a bad listener or not interested in others - it's a symptom of your condition.

- Be kind to yourself. On days when it just doesn't come together, I let it go and try again tomorrow. And look into things that might help your memory and thinking."

Get tips for memory and thinking problems at [mssociety.org.uk/memory-and-thinking](https://www.mssociety.org.uk/memory-and-thinking)

Caz's article struck a chord with many of you on Facebook. Here are some of the responses:

 **Anne**

"Yes me too, I feel stupid sometimes as I go into a glazed look. It's not that I'm not listening - it's just taking me longer to take it in."

 **Simon**

"Nice to read other people's tricks. Getting people to let me receive information and process it in my own way is something I haven't found a way around yet - people blast me with more information or confuse me with overload of the same info in different formats."

 **Rob**

"I am obsessed with keeping an electronic diary. I know what I have to do and what I have done. I feel so much better being able to look back and know what I have done."

 **Stuart**

"This is a really important issue when living with MS. We need to share these experiences and make sure people are aware of this."

 **Jacqueline**

"Things I need to remember, I write down. That's if I can remember what it was by the time I've found my pen..."

 share

Are you a budding blogger? If you'd like to write for our online community, get in touch with us at [✉ msmatters@mssociety.org.uk](mailto:msmatters@mssociety.org.uk)

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

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Proud

to be here for everyone with MS

This summer, we proudly marched as #MSTogether at Pride in London, Belfast and Cardiff. Staff and volunteers took part to celebrate the diversity of our MS community, in what were truly joyous occasions.

No matter how you identify or who you love, we're here for each other. Four people from our community tell us more about why it was so important to take part.



David

David Harland's mum had MS for 30 years before passing away just over a year ago. David has raised over £21,500 to help stop MS.

"I was honoured to join the MS Society in this year's London Pride celebrations. I'm passionate about celebrating Pride, not just because I'm gay myself, but because it's so important to celebrate individuality, love, inclusivity, how far we've come (but to remember how far we've still got to go) and to show solidarity against hate. This year at Pride, I could do all of the above and also stand with a group of amazing people who are passionate about raising awareness of MS - and I did it with my mum's spirit by my side."

Karine

Karine (pictured below left with her wife Sarah) was diagnosed with primary progressive MS in 2013. She and Sarah travelled from Edinburgh to take part in London Pride.

“Marching through the streets of London representing the MS Society was a true honour and an experience like no other.

“Not only did the march celebrate LGBTQ+ rights and hopes for equality, but it raised important awareness of the MS Society and the people the charity represents. We kept this in mind as we marched, or in my case rolled, through the streets feeling a little like a rock star.

“We finished the march as the sun was beginning to set, but it did not set on the feelings of pride and joy that I still feel when I think about that incredible day.”



Pauline

Pauline (pictured centre) was diagnosed with MS in 1988, aged 25. She was delighted to take part in Belfast Pride for the first time.

“Never having taken part in a parade of any type, the whole day was a revelation and an education for me. It was open, inclusive and diverse. And the Taoiseach (Prime Minister) of Ireland, Leo Varadkar, stopped for a quick chat with us when the parade was over!

“The joy was evident in every single person who was living the message: ‘No matter how you identify or who you love, we’re here for each other.’”

Sue

Sue, who lives with MS (pictured left with her daughter Amanda) attended #CymruPride.

“I came to Cardiff Pride partly because my daughter is gay and I’m very proud of her, but also because I believe we should all support each other. I’ve been before and the atmosphere is like a carnival. Everyone is friendly and non-judgemental. It’s a great day!”



Get involved

We’d love to take part in more Pride marches across the UK. If you’d like to get involved, or if you have other ideas for how we can do more to promote equality, diversity, and inclusion, please contact **phillip.anderson**
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Living with MS in Northern Ireland

Taking place every two years, the Living with MS event in Belfast brings together hundreds of people for the largest MS gathering in Northern Ireland. People living with MS, carers, family and friends, MS professionals, organisations and MS researchers come together to learn from and share with each other.

This year's event took place on 14 September. It included sessions covering the latest in MS research, advice and support on physical activity and mental wellbeing, and professionals on hand to give one-to-one advice.

Here's what some of the attendees living with MS had to say.



Mike Hardy

"Hearing some of the work going on in research, particularly on secondary progressive MS, was really interesting to me. I like to keep on top of any new developments and drugs."

Philippa Watson

"I was diagnosed two years ago. I found the event really informative. There was a session on mental health, including things we can do and ideas on how we can look after ourselves and each other. It was really helpful."



Helen White

"The sessions were fantastic. We got a lot of advice, guidance and new information. But for me, the big impact is the real connections you make with other people. I think the MS community coming together has been brilliant."

Catherine Doran

"When you have MS, I think it's really important that you see other people living with MS. Otherwise you can feel like you're by yourself. At an event like this, you get to see other people living with MS and quite well too. Generally, the more you understand what is out there, and the more you hear about research, it gives a real sense of hope."



Photos: Paul Moane / Aurora PA

Are you suffering from poor sleep?

The innovative Gx Suspension Pillow cradles your head and neck to give you an uninterrupted night

A NEAR tragedy has led to an amazing new development in sleep technology. When Georgia Miles was recovering from a serious accident, her father Alexander looked around everywhere for a pillow that would keep her comfortable throughout the night. After examining countless types, Alex, a furniture and domestic product designer, decided to engineer his own.

UNIQUE BREAKTHROUGH

He made a breakthrough when he realised that all pillows spread out and flatten down as the weight of the head rests on them.

This flattening progresses through the night, leaving the head and neck poorly supported – and sleep interrupted.

This is why many people find themselves half awake and 'pillow-punching' in the middle of the night, desperately trying to get comfortable.

EXTRA COMFORT AND SUPPORT

The innovative model that Alex designed has internal ties that hold the filling in place, and pull the pillow in and up to cradle the head and neck.

This provides extra comfort and support that lasts through the night and ensures that you get the most benefit from an undisturbed sleep.

“ I can honestly say that your pillow has made the world of difference... and fully endorse your pillow as being quite unique in its ability to maintain support throughout the night. ”

Dr Deane Halfpenny
Harley Street Consultant and Spinal Pain Specialist

LIFE CHANGING

Delighted customer Ann Morris says: "I've had pain-racked nights for years, but with this unbelievably



Harley Street Consultant, Dr Deane Halfpenny

effective pillow I can at last sleep through."

Made in Britain, the Gx pillow comes in a choice of two levels of support: Medium-Soft, which most people seem to prefer, or Medium-Firm for those who like a little more resistance.

The pillow has already transformed the lives of thousands of people. So if you have spent a lifetime looking for the perfect pillow, your search may well be over!

INFORMATION: gxpillows/0800 316 2689

Amazing new pillow helps thousands to sleep better

Gx Suspension Pillow™



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Many of us have bought pillows without finding the right one because most conventional pillows, whatever their filling, flatten throughout the night. This can lead to disturbed and broken sleep. There is now a solution to this problem so it's time to replace troublesome conventional pillows with the Gx Suspension Pillow. It keeps its shape and cradles the neck and head for an undisturbed night. The Gx Suspension Pillow will change the way you sleep so you wake refreshed, rejuvenated and ready for the day.

It's the intelligent choice...

The pillow has evolved

The design of the revolutionary new Gx Suspension Pillow is a leap forward in pillow technology. The unique 'double X' internal ties resist the flattening by pulling the pillow in and up to give the extra comfort and support that so many of us are looking for. Thousands already say the Gx Suspension Pillow is the best pillow ever.

Rediscover a great night's sleep

NEW - 2nd generation Gx Suspension Pillow

- 100% cotton shell
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- Vented end for cooling air circulation

How Gx Pillows helped actor, Rula Lenska

“ It is rare that something advertised as unique and life changing turns out to be true!! I have a chronic back and neck situation and I can honestly say these pillows make a huge difference!! Comfortable...supportive...and positively magical for my neck!! Congratulations! Many, many thanks **”**

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Volunteer spotlight: 30 years of dedication

Caroline Birch is co-founder of the Lymington and New Forest MS Society Group, which she started in 1989. She tells us how it's evolved over the decades.

“I used to work as an occupational therapist in Lymington Hospital. Thirty years ago, we identified a need for more support for local people living with MS. So, together with social worker Jean Pond, I set up a new MS Society group and started holding monthly social meetings for 25 people.

“Today, we have well over 100 members in our group. We offer many different activities, from exercise sessions, such as yoga and Pilates, to massages and information days. We're constantly evolving to meet people's needs, whatever they might be – whether it's

joining us for a pub lunch or simply having someone on the telephone to talk to.

“Over the years, I've met many amazing and inspiring people who live positively with MS. They've come to us, feeling shattered by their diagnosis, and often said: 'It's made me realise I don't have to give up.' I've also made some true friends I would never have met otherwise. It's been a joy and I love it.”

Caroline also runs a number of groups for young, working-age men in Hampshire to talk about caring for a partner with MS. For more information, contact Caroline on 07544 583679.



From left to right: Sue Niekirk, Lymington and New Forest Group Coordinator, Caroline Birch with her grandson Rowan, and long-standing MS Society member Oliver Nimenko

Behind the scenes

A strategic update

Nick Moberly, our Chief Executive, updates us on the new MS Society strategy.



We're really excited that you endorsed

our new strategy at the AGM in September. We can now get straight to work with putting it into practice.

We created the strategy in collaboration with you our members, our volunteers and staff, and people living with or affected by MS. This made sure we could really understand the existing challenges that are facing our community today, as well as the new challenges that have evolved since our last strategy was set.

We have three new goals to help us reach this vision. These will guide everything we do in the next five years and help us build on the progress we have made so far.

1. Effective treatments and preventing MS
2. People living well with MS
3. Connected communities, powerful voices

In our next issue, we'll take you through these goals and show you what we plan to do, as well as how our incredible community can help.



Celebrate our MS superstars

Bike the UK for MS

This year, 58 adventurers pedalled up and across Britain for the Bike the UK for MS challenge. Riders could choose to ride the length or breadth of Britain, or pick a segment of the route to take part in. Organised by James Whateley, the challenge raised over £29,000,

with more donations still coming in.

Among the riders this year was Al Redworth who is taking part in celebrity chef and MS Society supporter Tom Kerridge's transformational Fresh Start programme and TV show. Al lost

more than two stone, trained hard and joined in with the cycle from Hereford to Bath. His experience is due to be aired on BBC Two in January.

Find out more about Bike the UK for MS at biketheukforms.org



Al (right) with Tom Kerridge (centre) and Dan Bunce, Al's brother-in-law

Team MS Trooper



Team MS Trooper have raised an incredible £30,000 in memory of Anna Mitchell Martin who had MS and was our Fundraiser of the Year in 2014. The team do collections as Star Wars characters. And this year, Anna's husband Pete did his first 10k run with fellow fundraiser Aid Baker. May the force be with them!

1,000 one-liners



Comedian Richard Pulsford hosted a marathon five-hour stand-up show at this year's Edinburgh Festival Fringe to raise money for the MS Society. The show, 1,000 one-liners, saw a line-up of 20 top comics deliver 1,002 jokes (we counted!).

Minch rowers battle conditions



A team of five from a village in the Scottish highlands have completed an arduous 14.5-mile row from the Outer Hebrides to mainland Scotland, raising an amazing £24,000 to support people living with MS. The crew battled poor conditions and bailed out their boat on two occasions to beat their target time.

Find out more about their challenge on Twitter [@MinchRow](#) or [facebook.com/RowingTheMinchForMS](#)



Dates for your diary

Be a superstar and join one of our events to help stop MS. To find out more, visit [mssociety.org.uk/fundraise](#), email challenge@mssociety.org.uk or phone 0300 500 8084.

12-13 December

Northern Ireland Christmas Collections

Join us for our Christmas street collections in Belfast (12 December) and Derry/Londonderry (13 December).

29 March

London Landmarks Half Marathon

This stunning, closed-road route showcases the very best of London's sights.

19 April

Brighton Marathon

Run along the seafront and past the iconic Brighton Pier in this seaside marathon.

25 April

Zipside Zinger, Perthshire

Let gravity do the work while you soar through the trees, your fans cheering below.

23-24 May

Edinburgh Marathon Festival

Join our biggest Scottish event of the year.

23-24 May

London 2 Brighton Challenge

Walk, jog or run in this epic capital-to-coast route.

6 June

Zip It to Stop MS, Bethesda

Brave the world's fastest zipwire in Wales.

22 August

Ben Nevis Night Hike

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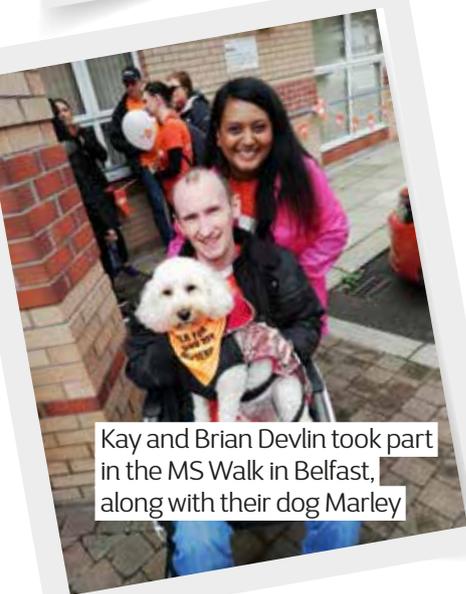
There were a whole range of emotions, inspirational stories and a fantastic atmosphere at MS Walk 2019



In London, it was another memorable day as we turned Battersea Park and the streets of London orange

What a day! MS Walk 2019

Thank you so much to everyone who helped make MS Walk 2019 the best yet. In London, over 600 superstars took on the four different routes and walked, rolled or strolled to stop MS. The event is on track to raise an incredible £150,000. And in Belfast, another 60 people took part, choosing from a one, three or ten-mile route along the Lagan Towpath and south Belfast.



Kay and Brian Devlin took part in the MS Walk in Belfast, along with their dog Marley

Missed out on this year's walk or can't wait to do it all over again? Visit mssociety.org.uk/ms-walk or email mswalk@mssociety.org.uk to sign up for 2020.



After being diagnosed with MS in February at 19 years old, Zach completed the 10km in London and has raised nearly £2,500

Emma's story: walking for Dad

This year, for the first time, hundreds of you organised your own My MS Walks. On 28 September, Emma Bennett arranged one in Tredegar, South Wales in memory of her dad, Carl, who died from MS complications in 2017.

Emma said: "Working with MS Society Cymru and volunteers from the South Wales Fundraising Group, we planned and organised the walk, and were delighted that over 70 people signed up and many more donated. Despite the horrendous weather, the turn-out

and atmosphere were wonderful. "We're hoping to have raised thousands for MS research. I hope that one day, no-one will have to go through the pain my dad and my family went through, because there will be treatments that stop the progression of MS for good."





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Four ways to give this Christmas

This Christmas, celebrate while also supporting vital MS research. With four excellent ways to give, there's something for everyone.

Pop a card in the post

Re-connect with old friends, family and neighbours by sending Christmas cards and spreading festive cheer. See our range of special MS Society cards and find out where to buy them at mssociety.org.uk/xmascards

Support our Christmas appeal

We're working on an exciting way to get new treatments faster. This could help speed up the process and deliver a new treatment into the final stages of testing as early as 2025.

With your help, we can make this possible. Support our Christmas appeal by donating at mssociety.org.uk/xmas2019

Choose an advent calendar with a difference

Count down to Christmas and support the MS Society. This festive season, we're collaborating with Advent of Change, who have chosen us as one of the charities that will benefit from their Charity Advent Calendar (pictured left).

Find out more at adventofchange.com

Win £10,000

Take part in our special Christmas raffle for a chance to win our biggest ever prize of £10,000. When you play, each £1 raffle ticket you buy will support people affected by MS. Enter online at

raffleentry.org.uk/mssociety.

The draw closes on 19 December.



Will-making made simple

Thinking of making a Will, but not sure where to start? Our Legacies Manager, Adam West, answers some common questions.



Why should I make a Will?

Having a Will is the only way to ensure your wishes are carried out after you pass away, and that the people and causes you care about are looked after. But if you don't have a Will yet, don't worry – we can help.

Is Will-making complicated and expensive?

Making a Will can be simple – and even free. The National Free Wills Network has solicitors throughout the UK who make free Wills for charity supporters. We can put you in contact with them. There's

no obligation to leave a gift in your Will to the charity, although many supporters do choose to.

We can also arrange for your Will instructions to be taken at home through The Goodwill Partnership. Both these services are trusted and reputable, and have helped thousands of people make or update their Wills.

Where can I go to find out more?

You can give me a ring on **020 8827 0374** or email me at legacies@mssociety.org.uk. We also have more information on our website at mssociety.org.uk/legacies

Poetry Corner

Art is a powerful way to explore our emotions. Here, three people affected by MS share their beautiful poems.

Julie Stevens publishes poetry under the name Jumping Jules. She writes honest, funny and moving poems about her experiences living with MS. Her poem, *If I can't*, won a #hiddenvoices poetry award in 2019. It's about how MS won't win and how there's always a different way of looking at things. Read more of Julie's work at jumpingjulespoetry.com

If I Can't

If I can't walk that fast
 Then I'll start a new race
 If I can't keep my balance
 Then I'll sing as I sway
 If I can't use my hand
 Then I'll learn a new trick
 If I get so very tired
 Then I'll run in my sleep
 If the heat is too much
 Then I'll wave at the sun
 If I forget the answer
 Then I'll find a new question
 If I can't sleep at night
 Then I'll say good morning to the stars



Graham Bedford's wife has had MS for 36 years. He sent us this note and beautiful poem.

“My wife is in the secondary progressive phase with significant disabilities and chronic severe pain. During one of our almost nightly ‘acute with pain’ sessions, we thought I might pen a poem about her coping with this cruel illness. The poem is frank and honest, and yet is spelling out that in the depths of despair, one can find a positive – and must do so. Try to live a life and not an existence.”

Did you sleep well?

MS is cruel.
So cruel.
It knows how to get to you
How to first beat you up,
And I'd only gone to the loo
At 1, 3 and 5 in the night.
That action had angered the demons
Who sent the spasms flooding in
'Caution demons at work'.

Rigid screaming muscles
Involuntary jumping, flexing.
My husband's hands work deftly
To defeat or even placate
The erupting skin and muscle.
Massage of thighs, then calves
Down to toes, and you know,
In a different context it
Might be termed 'pleasuring'.

With sessions of up to two hours
Often laced with tea, biscuits
And teleshopping viewing at 3am.
We focus and will and curse.
Beyond these spasms, the always theres
The legs basting in boiling hot oil
24/7, not time to time nor placation
To think the neurologist back in '83
Said "MS has no pain dear"



The more science explores
The less it seems to know
And even less it understands
About controlling real pain
Chronic, severe, not paracetamol pain. No. No
I am still trying so hard
After almost forty years of this
Relapsing and remitting to secondary progressive
Cruel MS.

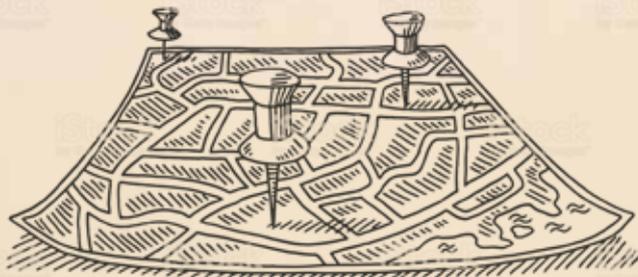
I contribute something to each day
We get by, or I pretend to do.
I'm not incontinent though
Even though I sleep well prepared
And I can still put socks on!
Life has a quality because of 'we'
Today we're off in my two leg powered chariot
To the garden centre and café
For a red geranium and fruited scone.

Oh, and as for your question
No we didn't. Again!

On page 18, **Gillian Shirreffs** told us about how writing helps ease her MS symptoms. Nowadays, she concentrates on fiction, but *Exacerbation* is one of her early poems.

Exacerbation

There is no guide
no map
or chart
to navigate
this maze
with its
blind corners
and barbed wire.



share

Do you have a
creative work
you'd like to
share? Email

mismatters@mssociety.org.uk
for a chance to see your work
in the magazine

Pretty shoes for wonky feet

When **Christine Hoyle** was invited to a summer wedding in a smart hotel, she knew finding shoes would be a challenge.

Over the years, living with MS, I have less feeling in my feet, so choosing shoes is important and has to be done with care. The shoes need to be easy to get into, and my foot has

to feel enclosed and secure, with no flapping, wobbling or sliding. Flat shoes are a must for me, but flat, pretty, comfortable, foot-secure shoes are not easy to find.

Searching on the internet at home saved me trawling the shops. I tried searching using the terms: shoes, flat, pretty, comfortable. Eventually, after multiple attempts, I found a pair of slightly wedge ballerinas with a high-cut design on the top of the foot (pictured inset). This crucial difference made them more secure on my foot. They were also made in colours other than black, brown, white and navy. I bought a pewter-coloured pair and was confident that they were okay. However, after wearing them, the leather stretched and the second time out they weren't so secure. At least they were good for the wedding, but next time I'll look for a different, less stretchy material and maybe customise them.

Christine's top tips



- 1** Flat shoes are the easiest to wear as there is less risk of wobbling and tripping.
- 2** A secure fit is essential. A lace-up shoe is the easiest for me as it can be fully opened and tightened.
- 3** The sole of the shoes should be comfortable but not too springy.
- 4** Removeable insoles allow the fitting of a functional electrical stimulation (FES) device, if used.

Activity corner

Dealing with fatigue



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

It might seem to go against common sense, but research shows that exercise can help with fatigue. Regular exercise can help you maintain muscle strength, improve your mood, and help with sleep – all of which can give you more energy.

And combining sensible exercise with a balanced diet can help you maintain a healthy weight and get the energy you need.

We worked with neurophysiotherapist Rachel to create exercises to help you manage your fatigue. You can do the exercises at home without any special clothes or equipment. Watch the video at mssociety.org.uk/exercises-for-ms-symptoms

For more information on fatigue, you can download our fatigue booklet at mssociety.org.uk/fatigue And our MS Helpline can provide information on staying active, and tell you where you can go for help. Call **0808 800 8000** or email helpline@mssociety.org.uk



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