

Living well with MS

Summer 2018 • Issue 129

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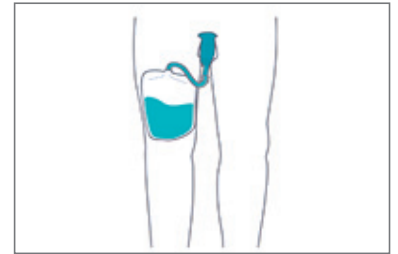
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1. Chartier-Kastler E Et al: Randomised, crossover, prospective, multicentre study comparing quality of life related to the use of urinary sheaths versus diapers in incontinent men, British Journal of Urology, accepted for online publication September 2010.

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Issue 129
Summer 2018

THIS ISSUE OF MS Matters is all about the incredible things we can achieve by sharing our stories.

Through our MS: Enough campaign, many of you have spoken out about why the current welfare system doesn't make sense. Together, we've tackled disability benefits assessments and support to stay in work. We've seen some improvements, but there's still a lot to do.

You've told us that one of the biggest obstacles for people with MS is the PIP 20 metre rule. Personal Independence Payment (PIP) is supposed to support people with disabilities. But this rule means those who can walk even one step over 20 metres don't qualify for the highest level of support.

Your stories were key to developing our #ScrapPIP20m campaign, which we launched in June. Our petition calls on the UK Government to scrap this senseless rule. With 20,000 signatures and counting, find out how you can get involved on page 6.

On World MS Day, we launched Our Treatment Stories, six interactive films from people with relapsing MS, explaining how they made decisions about treatments (see page 8). If you're thinking about treatments, we hope the films will give you confidence when discussing your options with a specialist.

In April, we celebrated our amazing community at our MS Society Awards. On page 12, Hannah, our Digital Media of the Year winner, explains why she's so passionate about raising awareness of the 'positives and the realities' of life with MS.

By sharing your stories, campaigning, volunteering and fundraising, you're helping us reach more people than ever before. But while our reach has been growing, our membership numbers have been falling. On page 40, you can read about our proposal to strengthen our community to better support people with MS. We want to know what you think, so please take the time to read the article and get in touch.

Michelle Mitchell
Chief Executive of the MS Society



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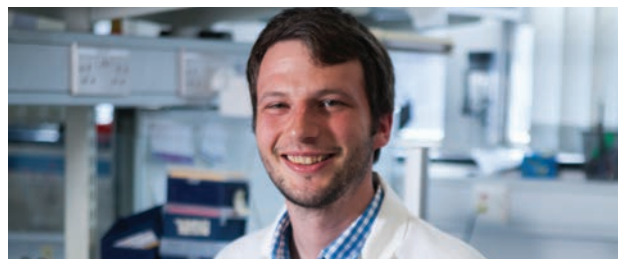


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Need support or information? Call our MS Helpline on 0808 800 8000 or email helpline@mssociety.org.uk

Want to talk to other people with MS? Our online forum is a welcoming space for you to share experiences and find support from like-minded members who are there for you. Get to know your MS community and join the conversation. Visit: community.mssociety.org.uk

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CAMPAIGN

WHY PIP MUST CHANGE

The 20 metre rule is failing people with MS

People with MS are losing access to the support they need to live independent lives. And it's because of the PIP 20 metre rule.

If you can walk just one step over 20 metres, which is roughly the length of two double-decker buses, the UK Government says you don't need higher level mobility support. Even if you're using aids like a walking stick.

The 20 metre rule makes no sense. And it's the main reason people with MS aren't getting the right support. That's why we're campaigning for change.

New evidence

On 19 June, we launched the next part of our MS: Enough campaign, calling on the UK Government to scrap the PIP 20 metre rule.

Our new report, PIP: A step too far, reveals just how much harm PIP is causing.

In a UK survey of people with MS, of those who had support taken from them in the transfer from Disability Living Allowance (DLA) to PIP:

- 65% said the transition had a negative effect on their MS
- 39% increased their use of GP services
- 39% had to reduce spending on food.

The evidence shows that the 20 metre rule is the main reason people with MS aren't getting the support they need.

To Westminster

We've launched a petition calling for the rule to be scrapped, and a video encouraging more people to take action.

At the launch of the campaign, we went to Westminster. Here, people from our community talked about their experiences of PIP, and we shared our latest research with MPs.



20 metres

Caryl's story

'It felt like taking our messages straight to politicians could really make a difference.'



So far, over 20,000 people have signed the petition. Add your voice, spread the word and help us tell the UK Government: enough is enough. PIP needs to change.

Support the campaign

1. Sign the petition: mssociety.org.uk/msmatters-pip20m
2. Share the campaign video to help spread the word - search **#ScrapPIP20m on Facebook or Twitter.**
3. Meet your MP. If you think you might be interested in meeting your MP to talk about PIP, email campaigns@mssociety.org.uk for more information.

What is PIP?

Personal Independence Payment (PIP) is designed to support the extra costs of living with a disability. It replaces Disability Living Allowance (DLA), and has two parts – often called components. These are:

- a daily living component – for help with everyday life
- a mobility component – for help with getting around

Caryl, 65, lives with her husband in Carmarthenshire. She has had MS for 20 years, and six months ago was told she now has secondary progressive MS.

Under DLA, Caryl received the higher rate for both care and mobility, and used her payment towards buying an automatic car, because the left side of her body is weak. When she was reassessed to PIP in 2016, she lost the higher rate for both care and mobility. Her mobility award was reduced because her assessor said Caryl can walk more than 20 metres.

Caryl came to the campaign launch in Westminster, and spoke about how the 20 metre rule has impacted her.

20 metres is nothing

'To move 20 metres is nothing. The bus stop is further than that



and I can't walk it. I have to drive everywhere which is an extra cost. [When I moved from DLA to PIP] I expected it to stay the same, this silly new rule has impacted quite significantly on us.

'It was great to be involved in the MS Society campaign launch in Parliament and have the chance to speak to politicians about my own experiences. I was there with a number of other people with MS. Unfortunately all of us have had negative experiences of PIP but the conversations we had with MPs felt positive.

Making an impact

'It meant a great deal to speak in Parliament, especially about something which I feel passionately about.

'I was a little awed and nervous. I had prepared my speech beforehand but didn't make half the points I wanted to. However, I felt that my speech made some small impact and was well received.

'We all watched the #ScrapPIP20m video together at the event, and a number of politicians commented on how powerful it was. It felt like taking our messages straight to politicians could really make a difference.'

CAMPAIGN

SHARING OUR TREATMENT STORIES ON WORLD MS DAY

Natalie explains why she wanted to share her experience of making treatment decisions

WEDNESDAY 30 MAY WAS World MS Day. This year, the international MS community came together to celebrate what we've achieved in MS research so far and share our hopes for the future.

One of the most significant achievements in MS research has been the development of disease modifying therapies (DMT) for relapsing MS, from none 20 years ago to around a dozen now.

The first DMT for early

launched Our Treatment Stories – a series of honest accounts from people with relapsing MS about how they made a treatment decision.

We hope that hearing from people who have made treatment decisions will help others feel more confident and informed to speak to an MS specialist about their options.

Natalie's story

Natalie, 36, was diagnosed with relapsing remitting MS in 1997.



Hannah, via Facebook

I'm at a crossroads regarding treatment right now (yay or nay) and the films are really helping me, thank you for publishing them.



primary progressive MS is also in the pipeline, and we're working hard to influence decision makers so it becomes available on the NHS (see page 11).

Complex choices

Many people with relapsing MS who have the choice of taking treatment say the decision is complicated – there are so many things to think about.

So on World MS Day, we

She explains why she shared her treatment story as part of our campaign.

'Being diagnosed with MS at age 17 (just over 20 years ago!), I've seen the changes in treatments available for MS. I've tried lots of different treatments over the years, adapting to what suited me and my MS at each stage of life, and taking breaks sometimes too.

'I often volunteer for MS-related projects. I feel it's



important to raise awareness for the community. When the MS Society approached me about sharing my treatment story, I was immediately interested in taking part because I think people need information and support to help them make treatment decisions.

'The interview and filming



Photo: Rebecca Cresta

couldn't have gone better. It was an early start, and typically raining – this is England after all! But within an hour, a bare room in my new apartment was transformed into a really cosy space for the interview. Through answering the questions, I was able to give an honest account of my experiences.

'I've met many people who

find it difficult to decide what treatment to take. Or even if they should go on treatment at all. People think about so many different factors like lifestyle, family commitments, worries of side effects, or telling others.

'Hopefully my story will help people decide what's right for them, or speak to a specialist about their options.'

Spreading the message



ON WORLD MS DAY in Scotland, we published our report into prescribing practices for DMTs: Right Treatment, Right Time. Overall, good progress has been made in Scotland in recent years, with an increase in prescribing and people having broadly positive experiences of decision making about DMTs. But there's still room for improvement. Our report includes recommendations for building on the progress so far. These have been shared with MSPs, and we'll engage with all Health Boards in Scotland to discuss how we can implement them at a local level.

In Northern Ireland, we held two events around World MS Day where people with MS could talk about the latest MS developments and treatments with consultants Dr Gavin McDonnell and Dr Orla Gray.

And in Wales, we shared the voices of people with MS, highlighting their urgent need for access to the right treatment, care and support.

We took these concerns to the Welsh Government and Local Health Boards. Plans are now afoot for a whole system review to ensure that people living with MS in Wales have access to the right care, at the right time, in the right place, with the right professional.



You can watch Our Treatment Stories – six interactive films – at mssociety.org.uk/treatmentstories

HEALTH CARE

NEUROLOGY PATIENTS RECALLED BY BELFAST TRUST

How we're working to support the MS community



At the beginning of May, the Belfast Health and Social Care Trust announced a recall of 2,500 neurology patients under the care of a specific neurologist. The recall was the result of internal and independent reviews. The Belfast Trust committed to reviewing each of the affected patients within 12 weeks.

We know this has been a worrying time for many people with MS in Northern Ireland, and we're working to make sure you have the support you need.

You may have seen us in the media, commenting on news about the recall. We've tried to do this in a measured and constructive way, helping raise awareness of the issue and highlighting the concerns of people affected.

Meeting decision makers

We've also been working behind the scenes. We regularly engage with trusts and health decision makers, and have held meetings specifically on the recall with both the Belfast Trust and Department of Health.

We're meeting with the Department of Health every two weeks for updates. Members of our Northern Ireland council attend these meetings to give feedback on the impact of the recall from people living with MS.

Support for all

We've been working to ensure counselling and support is available at clinics, that the patient advice line continues to work well for people needing help or information while awaiting their review and that the hardworking neurologists and nurses running the extra clinics are being supported.

Continued questions

We've also raised questions with the Belfast Trust and the Department of Health on the events and decisions which led to the recall, and will continue engaging with both organisations on these questions and the public inquiry process.



TREATMENTS NEWS IN BRIEF

Myelin repair switch

Our researchers have uncovered a switch called Acvr2a in the brain and spinal cord that can promote myelin repair. Studies in mice have shown that a protein called activin-A triggers this switch and increases the number of myelin-making cells, boosting myelin repair. Researchers will now look for drugs that can target Acvr2a to promote myelin repair. These could then be developed into treatments for people with MS.

Step forward for siponimod

Analyses of the EXPAND trial have confirmed siponimod can reduce the risk of disability progression in secondary progressive MS. In the trial, 26% of people taking siponimod experienced a worsening of disability, compared with 32% who took the placebo. The company developing siponimod hopes to submit the drug for licensing later in 2018. Find out more at mssociety.org.uk/siponimod

TREATMENTS

NICE SAYS INITIAL NO TO OCRELIZUMAB FOR PRIMARY PROGRESSIVE MS

Decision based on cost-effectiveness but NICE will consider further evidence

The National Institute for Health and Care Excellence (NICE) has provisionally decided not to recommend ocrelizumab for people with primary progressive MS on the NHS.

This is the first stage of their review process into this new MS treatment.

This provisional decision applies to England and Wales only. Northern Ireland usually follows NICE decisions.

Ocrelizumab (brand name Ocrevus) is an intravenous infusion taken every six months. It was licensed to treat both people with relapsing and early primary progressive MS by the European Medicines Agency (EMA) in January this year. NICE has approved it for use on the NHS for people with relapsing MS (for those unable or unwilling to take alemtuzumab).

Cost question

NICE have acknowledged the importance of ocrelizumab as the first licensed treatment for primary progressive MS, but still refused to approve it.

They say it's because the evidence submitted by pharmaceutical company Roche doesn't meet their cost effectiveness criteria.

What next?

This is not the final decision - NICE will consider further evidence. They're still in talks with Roche. We'll continue to speak up for people with primary progressive MS at every opportunity. And we'll use the feedback you gave us earlier this year to tell NICE why it's so important ocrelizumab is made available to everyone it could help.

Our Director of External Relations, Genevieve Edwards, said: 'We've been waiting a lifetime for an effective treatment for primary progressive MS. It's simply unacceptable to deny people a treatment they urgently need.

'Thankfully this isn't the end of the road. We urge both sides to come together and find a solution that allows everyone who could benefit to access ocrelizumab as soon as possible.'



Ocrelizumab in Scotland

The Scottish Medicines Consortium (SMC) decides whether a drug should be available on the NHS in Scotland. In July, it decided ocrelizumab won't be available for relapsing MS. The SMC felt its benefits weren't worth how much the drug cost.

After this decision, the drug's makers decided not to try to get the green light for it to be used for early primary progressive MS.

We're working to understand the full reasons for these decisions, and will continue working with the SMC and others to see new submissions in future.

learn

Stay up-to date with the latest developments on ocrelizumab at

mssociety.org.uk/news

YOUR SOCIETY

MEET THE STARS OF THE MS SOCIETY AWARDS

There was barely a dry eye in the house when we came together to celebrate the heroes of the MS community in April

'WE'RE ALL WINNERS FOR DOING WHAT WE DO FOR MS'

Digital Media of the Year winner Hannah Smith shares the excitement of the day



Photo: Rebecca Cresta

Let's go back to the middle of March 2018. I'd just gotten home from a food shop with mum when I received an email from the MS Society congratulating me on my nomination for Digital Media of the Year at their awards. The email continued by saying that I'd been shortlisted as a finalist!

My first thought was 'What!? It's a joke right?!' I sat down with my mum and read it properly. We were both overwhelmed with excitement.

I would travel to County Hall in London to attend the awards ceremony, celebrating the fantastic work people do in the MS community.

Ceremony highlights

We met the loveliest people. The atmosphere was electric – full of love and joy.

I'm so passionate about spreading awareness of MS. Through my blog and YouTube channel, I want to tell the truth about MS. I love being positive, but people need to be

aware of the realities of MS too. MS doesn't have me, but I need to be mindful and listen to my body – that way I can live the life I'd like to.

The awards themselves were magical. I've never seen so many inspiring, courageous, talented people in one room. All their stories moved me. I believe we're all winners for doing what we do for MS.

The awards included Inspiration of the Year, Young Carer, Campaigner, Employer and many more.

Celebrity spotting

I was beyond excited to meet the fab Scott Mills during the afternoon. He was hilarious and our selfie was definitely a highlight.

Presenting my award was Jane Felstead (from Made In Chelsea). I was dying to meet her all afternoon and when I realised she was handing out the award I was beside myself! We had such a good chat. She's a wonderful person – it was great to meet her.

Overall the MS Society Awards were THE best event I've ever attended.

It just goes to show there are positives in MS. It brings people together and that, for me, is the biggest positive out there.

Read more from Hannah on her blog hannaheliza.wordpress.com

AND THE WINNER IS...

Inspiration of the Year

Professor Susan Pavitt

Outstanding Partnership of the Year

The Disability Benefits Consortium

Young Fundraiser of the Year

Joint Winners - Lewis Gardner, Ciaran Hanks and Darcie Janes

Young Carer of the Year

Joint Winners - Zaynab Inam, Darby Mitchell and Sophie Tudor

Research of the Year

Regulatory T-Cells promote myelin regeneration in the central nervous system (Yvonne Dombrowski, Denise Fitzgerald and colleagues)

Employer of the Year

Oxygen House

Volunteer of the Year

Anna Holmes

Media of the Year

Jon Vale

Digital Media of the Year

Hannah Smith

Political Supporter of the Year

Simon Hoare MP

Carer of the Year

Marie Nixon

Professional of the Year

Dr Martin Duddy

Campaigner of the Year

Borders MS Society Group

Fundraiser of the Year

Noel Wilson

MS Society Group of the Year

Northamptonshire MS Society Group



FUNDRAISER OF THE YEAR

Photo: Rebecca Cresta



YOUNG CARERS OF THE YEAR

Photo: Jon Bradley



GROUP OF THE YEAR

Photo: Rebecca Cresta



VOLUNTEER OF THE YEAR

Photo: Rebecca Cresta



EMPLOYER OF THE YEAR

Photo: Jon Bradley

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GAME-CHANGING DISCOVERY WINS RESEARCH AWARD

Researchers showed that some immune cells can promote myelin repair in mice

We typically think of immune cells as the 'bad guys' of MS, attacking the protective myelin that coats nerve cells.

But last year, a piece of research changed our perspective. Dr Denise Fitzgerald and Dr Yvonne Dombrowski, from Queen's University in Belfast, showed that a certain type of immune cell can actually help repair myelin damage in mice.

This game-changing discovery was named Research of the Year at the awards – a prize given to the scientific achievement judged likely to have the biggest impact for people with MS.

'It's really overwhelming to have won,' says Yvonne. 'We were absolutely honoured to have just been nominated, so to go on to win – it's incredible.'

All together now

Denise and Yvonne led the international collaboration of some of the brightest minds in MS research, including scientists from our dedicated research centres in Cambridge and Edinburgh. Denise said: 'By bringing together these

experts from immunology, neuroscience and stem cell biology, we've been able to make this landmark discovery.'

It's hoped that this finding will open up new areas for treatment development, as our researchers continue to unpick how these immune cells interact with myelin-making cells.

Looking to the future

At the moment, the researchers are cautious about their findings. 'While we are very excited about the possibilities that this discovery brings, we need to remember that this was an early-stage study done entirely in mice,' says Denise.

Plans are already being made to move the work forward: 'We're working with people with MS, scientists and clinicians to try to find out whether our findings in mice also hold true in humans. It will definitely be an exciting finding if it does!'

Get all the latest research news at mssociety.org.uk/latest-research

share

Who's the star of your community? Email us at mismatters@mssociety.org.uk to let us know. And keep an eye on MS Matters to find out when nominations for the 2019 awards will open!



DR FITZGERALD (RIGHT) AND DR DOMBROWSKI (LEFT) WERE THRILLED WITH THEIR AWARD



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‘I resisted being called a carer. I was just looking after my wife’

From Carers Allowance to cross-stitch, Sarah Mather on what helps her as a carer



SARAH (LEFT) AND KARINE ON THEIR WEDDING DAY

Karine and I met on our first day at university. I got up the guts to ask her out two months later and we've been together ever since. We're lucky we met the right person early on. After she was diagnosed with MS five years ago, Karine wanted to push me away, so I didn't have to go through it with her. But no way. She's the person I fell in love with and I can't imagine not being with her through all this.

For a long time I resisted the label 'carer'. I was just looking after my wife. Now I've become less resistant to the term. This is mostly because I've heard other people who are doing the same thing as me using that

label. And I find it helpful when I'm communicating with people like doctors. I feel it gives me more validity.

Getting support

Because I was resistant to being called a carer, I didn't look for any help for myself. I'm still bad at asking for help and sometimes don't know what I need until someone provides it. For example, recently Karine and I were away and while Karine's mum was housesitting, she did all our laundry for us. It was wonderful to come back and find it all done!

One of the things that's helped is getting Carers Allowance. I've only just

starting claiming it after being wrongly told that I couldn't. I do part-time work and it doesn't bring in very much. Getting Carers Allowance each week means I can cover the shopping or put petrol in the car.

Help with benefits

Once I knew I could claim I put it off for a couple of months because I've been suffering from anxiety and depression. But it only took 20 minutes online. Having gone through forms for Personal Independence Payment (PIP) and Employment and Support Allowance (ESA) with Karine I was expecting it to be awful, but actually it's not as complex.



When it comes to applying for benefits, getting help can really take the pressure off. I'd recommend making an appointment with an organisation that gives advice about benefits – we found a local organisation in Edinburgh called the Community Ability Network (CAN) really helpful.

You could also see if you could get some assistance filling out the forms for benefits like PIP and ESA, as these forms can be intimidating. [Your nearest MS Society group has details of where you can get help from advice agencies locally. This might be from an organisation like CAN or Citizens Advice].

Breathing space

I got to the point last year when I felt that I was useless and I couldn't help Karine or myself. I'm now taking medication for my anxiety and depression, and I've recently discovered cross stitch. It's wonderful because it allows my brain to switch

off from everything else and concentrate on the pattern I'm doing.

Karine's also been volunteering for a few hours a week. That gives me a bit of space to myself, and she's found that having a purpose again is helping her mental health and giving her more confidence.

A love of Lego

Our relationship works because we complement each other really well. We find things we like to do together, like Lego – we're both obsessed!

Recently we became ambassadors for Euan's Guide, the disabled access review site. We've helped them map the Royal Mile in Edinburgh for accessibility and gone to see the Glasgow Rocks Basketball team play at their Commonwealth Games venue. Being involved with Euan's Guide and with the MS Society has given us some great experiences.

This spring I was shocked and honoured to be a finalist in the Carer of the Year category at the MS Society Awards. There were so many amazing people collected in one room, it was such an inspiring ceremony.

Caring for us carers

If you know someone who's a carer I'd say don't get annoyed if they can't tell you what will make their life easier. Personally, I find it easier if someone says: 'right, I'm popping round' or 'let's go out'. Simple things like being taken out for a coffee can make a big difference.



Photo: Simon Rawles

Help and support for carers

Visit mssociety.org.uk/carers for information on getting help and support or head to mssociety.org.uk/benefits for information about benefits. You can call our free MS Helpline. It's available for carers and families and anyone affected by MS. Call 0808 800 8000 or email helpline@mssociety.org.uk

About Carers Allowance

Carers Allowance is a benefit you might get if you look after someone at least 35 hours a week. Carers can only claim Carers Allowance if they meet certain criteria, and if the person they are looking after with MS is already receiving certain benefits. For more information on what these criteria are, visit www.gov.uk/carers-allowance. You can also find information on the Carers UK website – select 'Help and Advice' from the menu and then click 'Carers Allowance'.

Changes in Scotland

Carers Allowance is one of a range of benefits being devolved to Scotland. From late summer 2018, a Carers Allowance Supplement will be paid, which will increase the level of Carers Allowance to that of Jobseeker's Allowance. If you're already receiving Carers Allowance, you'll automatically receive the supplement.



SARAH AND KARINE AT OUR MS SOCIETY AWARDS 2018

‘Riding takes me back to before MS’

Pam rekindled her passion for horse riding thanks to our MS Active Together programme in Scotland



I have a passion for horse riding which began when I was seven years old. I love the beauty and personalities of horses.

I rode until I was 25, but then I stopped after gaining a lot of weight. My weight affected my confidence, and my MS affected my mobility. I stopped leaving my house.

But recently my confidence has been coming back. I lost six stone after going to Slimming World. Then I saw on Facebook that the MS Society was offering sessions in horse riding with the Riding

‘My legs usually feel numb and heavy, but on the horse they feel weightless.’

for the Disabled (RDA) group at Ravelrig. Straight away I wanted to give it a go.

I hadn't been on a horse for 18 years and I had some fears: what if I fall off? What about my bad back? I'm not as young as I was... But the volunteer helpers and the horses were fantastic and made me feel very comfortable.

Feels like home

The first time I felt a bit wobbly because of my balance and it was strange being up there again. I was a bit disappointed that my mind wanted to go faster than my body would let me. But riding my horse felt amazing – it felt like home. It felt like I was meant to be there.

The effect it's had on my state of mind is amazing. It takes me back to before MS and I can't wait for each session. My legs usually feel numb and heavy, but on the horse they feel weightless.

My body is slowly getting used to riding again, but at a slower pace. I've absolutely improved. I started off with someone leading me and now I'm let loose and riding my RDA horse Thumper on my own! And recently, I won a dressage test class at the RDA Dressage Qualifiers. I also won the best turned out trophy. It was fantastic being back in a competitive environment.

I will absolutely carry on horse riding. It's an incentive for me to stay slim as well.



join

Inspired to give horse riding a go? Find out more about Riding for the Disabled at www.rda.org.uk

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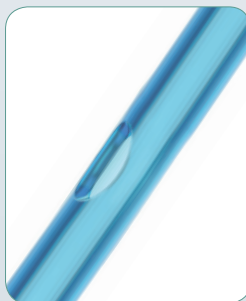
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iQ2104.18	372-5413

FREEPHONE:

0800 999 5596

Helpline email:

helpline@manfred-sauer.co.uk

Website:

www.manfred-sauer.co.uk

NOT ALL HEROES WEAR CAPES

Our MS Superstars have done some incredible things so far in 2018



A MAGICAL MEAL

On Saturday 14 April, our Cardiff Fundraising Group hosted its annual Black and Orange Ball, in aid of the MS Society and the Merthyr RCT Support Group. They raised almost £6,000 for the two causes!

Guests were treated to a three-course meal, live music from local band Helter Skelter, table magic by James Hawker and an exciting auction with a selection of generously donated lots.

Sian Dorward, our Fundraising Manager for

Wales said: 'Our sincerest congratulations and thanks to the Cardiff Fundraising Group for their efforts. A wonderful night was had by all and the amount raised is absolutely incredible – we are looking forward to next year's Ball already!'

The Group would like to thank all their supporters and donors, in particular: Church Village Funeral Services, Alex Lloyd Jenkins Photographer, Mooneerams, Willmott Dixon, MDJ Law, Gallery Loft Conversions & Construction, and Oprema.



Photo: June Nicol

join

Do you want to be a #MSSuperstar too? Head online to **mssociety.org.uk/fundraising** to find out about our fundraising challenges.



AN AERIAL ADVENTURE

THIS MAY, OUR #MSSUPERSTARS zipped through the trees at Crieff Hydro in Perthshire to help stop MS.

There were nerves, excitement and great anticipation as 35 brave souls got harnessed up to face their fears.

Here's what two of our superstars had to say about taking part.

Julie, who took on the challenge with two friends said: 'I've been living with MS for over 10 years. It affects every aspect of my life. Instead of dwelling on what I can't do, I chose to focus on what I can do.

'I took on the zipline to raise money for MS research, in the hope of finding more

treatments and ultimately a cure.'

Our receptionist Katrina (pictured) took on the challenge with her friend Hillary, who was celebrating her 50th birthday.

'It was just the best fun ever. Zooming through the trees was awesome and the support I received from our fundraising team was brilliant. Take the leap, you won't regret it!'

A huge well done to everyone who took part in the Zipslide Zinger challenge. You're all #MSSuperstars!

Feeling inspired? We'd love to welcome you to this amazing fully accessible event for its third year in May 2019. Contact msfundraising@mssociety.org.uk or 0131 335 4063 to find out more.



Superstar runners

► A massive well done to the 150 #MSSuperstars who took on the Edinburgh Marathon Festival this May. It was fantastic to meet so many of you at our charity tent and hear your inspiring stories! Entries for 2019 are now open and we would love to welcome you to the team.

► Thank you to everyone who's signed up to the Cardiff Half Marathon taking place on 7 October. Public places have sold out, but we do still have a few charity places available for this iconic race. Please contact Sian Dorward (email sian.dorward@mssociety.org.uk or call 029 2167 8920) if you or someone you know would like to reserve a place and be part of our team of #MSSuperstars. Don't worry if you can't take part, please come along and help us cheer on the day!

► Colin Goodman from Belfast recently took part in the Belfast Marathon, making every step count and raising £2,200. He is one of many heroes who abseil, zipslide, run, walk, sing, dance and bake cakes to raise funds so we can continue to provide support for people living with MS. They are truly amazing and we simply could not do what we do without their support!



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DM Orthotics have successfully provided a range of Dynamic Movement Orthoses to both children and adults for over 10 years, with our orthoses helping to manage the physical effects of a variety of neuromuscular conditions.

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www.dmorthotics.com



live your life.

MS WALK IS BACK

Walk, roll or stroll to help stop MS



Sign up to MS Walk and join over 600 MS Superstars on Sunday 23 September as we walk, roll or stroll to help stop MS.

We've got four fully accessible routes (1km, 6km, 10km and 20km) for you to choose from, all taking in some of London's finest views and iconic landmarks along the River Thames.

All four routes start and finish in Battersea Park, where we'll send you off with a musical warm-up and welcome you back for a celebration in the park. There'll be food, drinks and fun for all the family, so join us for a very special day out!

Beth's story

Beth Phipps was diagnosed with MS in the summer of 2017 and, just a few months later,

completed the six kilometre MS Walk with her friends and family. Together, they raised more than £2,000!

Beth was one of over 600 MS Superstars who took part, raising an incredible £85,000.

Beth told us her highlights: 'Being with such supportive family and friends on a beautiful sunny day, and seeing hundreds of other MS Society supporters who were so happy and motivated. The warm-up brought everyone together and made everyone feel so welcome.'

Would she recommend MS Walk 2018 to others? 'Definitely. It was my first event for the MS Society after my diagnosis. I was so nervous before arriving but really didn't need to be. Everyone was wonderful and in such great spirits. It was great for all ages and they were

even doing face painting. It was amazing to see such a sea of orange MS Society t-shirts.'

Sign up today

A place at MS Walk 2018 costs just £15 for adults and £7 for under 18s. Under 5s are free. We suggest a minimum sponsorship of £100.

When you take part, you'll receive:

- an MS Society T-shirt
- an event day pack with detailed maps and information
- an invitation to a fantastic post-event reception near Battersea Park
- lots of tips and advice from the MS Society team to help you raise as much as you can
- support on the day from MS Society staff and volunteers
- an exclusive MS Walk medal.

join

Get involved this September by signing up at mssociety.org.uk/ms-walk, by emailing challenge@mssociety.org.uk or calling 0300 500 8084.



Breaking news! MS Walk is coming to Belfast

Our first ever MS Walk in Northern Ireland will take place on Sunday 23 September in Belfast. The stunning route will start in the Titanic Quarter and finish in Lady Dixon Park, taking in the Lagan Towpath and Botanic Gardens along the way. Email eve.shearer@mssociety.org.uk or call 028 9080 2802 for more information.

This revolutionary new pillow could be the best investment you make this year...

The Gx Suspension Pillow™ has revolutionised pillow design and is helping thousands of people sleep better.

When Alexander Miles was looking to help his daughter Georgia recover from a horrendous accident it was impossible to find a pillow that supported her head and neck to keep her comfortable all through the night. Having purchased and dissected every pillow known to man, Alex, a highly regarded furniture and domestic product designer, decided to engineer his own solution and the Gx SuspensionPillow™ was born.



The breakthrough came when Alex realised that pillows, whether hollow fibre, foam, or feather, all 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 leading to the unfortunately familiar routine of 'pillow-punching', that irritating activity we all recognise, as, half-awake and fully disturbed, we try and rearrange our pillows in the middle of the night. Alex's innovative solution acts to counter the natural spread of a pillow; a system of internal ties hold the filling in place and pull it in and up to cradle the head and neck and provide extra comfort and support that lasts through the night. You might shift in your sleep but the pillow keeps its shape, ensuring that you get the maximum benefit from a long and undisturbed night's sleep.



This amazing new pillow is currently available for sleeping, the Gx Suspension Pillow™ (Medium/Soft) and for sitting, the Gx Support Pillow (Firm). We are also currently product testing a Medium/Firm version of the Gx Suspension Pillow for those who like slightly more support when sleeping—this new pillow will be available to buy in the next few weeks.

Actual customer reviews: -



"I've found my perfect pillow! I've been sleeping on it for 2 months now and it's wonderful!" - Doreen



"I've been sleeping on my suspension pillow for months. Gorgeous!" - Sheila

A wonderful unsolicited testimonial from a respected medical professional...

Testimonials from customers have poured in since the pillow was launched but a recent email took even Alex by surprise. Deane Halfpenny is a Consultant in musculoskeletal pain medicine, with a special interest in spinal pain and injury, at the London Orthopaedic Clinic. Having suffered a prolapsed C4/5 disc himself he decided on a conservative course of treatment including physio, exercise and pain relief; the one thing he struggled to find was a pillow that supported him through the night. His wife suggested the Gx Suspension Pillow™ and the effects were instantaneous, *"...from the first night I tried it, there was a noticeable improvement with less pain at night and less stiffness in the morning. I continue to improve week by week and can honestly say that your pillow has made the world of difference. I have subsequently shared my experience with patients who present with neck issues and fully endorse your pillow as being quite unique in its ability to maintain support throughout the night."*

Order your pillow online now, from
www.gxpillows.co.uk



RIDE TO THE SEASIDE

Could you or someone you know get pedalling to help us stop MS?



WHETHER YOU'RE A BIKE

beginner or a vélo veteran, the London to Brighton cycle could be the challenge for you.

On Sunday 16 September, our team of MS Superstars will join over 2,000 riders for a 54 mile cycle through the British countryside, finishing off at the beautiful Brighton beachfront.

Fuel up

The route is suitable for beginners as well as experienced riders. It's fully sign-posted, so there's no need

to scabble around with maps. And you'll be kept well-fuelled with a free buffet lunch at 29 miles in the idyllic village of Turners Hill.

Our fantastic cheerers will be on route to support you and keep those energy levels high!

So whether you're a cycling enthusiast or just love a new challenge, sign up to the London to Brighton cycle today.

join

The Do It for Charity London to Brighton Cycle takes place on Sunday 16 September 2018. Sign up at mssociety.org.uk/london-brighton-cycle. Questions about taking part? Email challenge@mssociety.org.uk or call 0300 500 8084.



Walking in the moonlight

Experience sunset from the mountainside as you trek Snowdon by Night

DO YOU LOVE the great outdoors? Are you looking for a challenge in 2019? Then we have the event for you! Join our Snowdon by Night challenge and climb one of the most scenic peaks in the UK by moonlight. Standing at the summit in the silvery glow will be an unforgettable experience.

Night and day

Trekking Snowdon by Night will

be like nothing else. You'll see sunset and sunrise from the mountainside as you trek to stop MS.

You'll descend in the early hours of the morning, taking in the incredible landscapes of the highest mountain in Wales as day replaces night.

Sign up today to secure your place for our bespoke event and get ready to enjoy trekking with our MS Superstars.



join

Sign up for Snowdon by Night at mssociety.org.uk/snowdon-by-night. The trek takes place on the weekend of 29-30 June 2019. Registration costs £30 and we ask you to raise at least £500 in sponsorship. Our friendly fundraising team will be on hand with tips to help you reach your target.

PROMOTIONAL FEATURE

Win a break for two at Leuchie House



Enter our competition for a chance to win a four night break for you and your carer, partner or a friend in the lovely surroundings of Leuchie House.

Located on Scotland's beautiful east coast near North Berwick, Leuchie House offers everything you need to have a relaxing, re-energising break with expert care 24 hours a day.

Leuchie's nurse-led team have years of experience of caring for people with

MS, so you can be confident you'll get all the specialist care you need. Physiotherapy is an integral part of every Leuchie break too.

But there's so much more to staying at Leuchie House than just great care and support!

From daily activities and entertainment, to a wide choice of outings around Edinburgh and East Lothian, the Leuchie team are focused on making sure your break is full of all the things that make a



holiday special. If you'd like to go to the theatre, or have a guided tour along the coastline, or even fly in a microlight, it's up to you! You can also enjoy the delicious home made food Leuchie is famous for, pamper yourself with a choice of therapies and beauty treatments, and relax in the tranquil grounds around the House.

HOW TO ENTER

Simply email your name, address and phone number to:
competition@leuchiehouse.org.uk

Closing date: 31 August 2018, 12am

For full terms and conditions, and for more information about breaks at Leuchie House, please visit
www.leuchiehouse.org.uk/msmatters

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FIVE REASONS TO GET RUNNING

Looking for motivation to dust off your trainers? Or know someone who is? Our running challenges could be the answer.



If you want to get active, but aren't sure where to start, here are five reasons to give running a go.

- 1. Get fit** – running is a fantastic way to boost your fitness levels. Start gradually and build up slowly – you'll be amazed what you achieve as the weeks go by!
- 2. Save money** – with no need to sign up for a gym, running is a cheaper way to stay active.
- 3. Make friends** – you can go for runs with friends or join a running club and meet new people.
- 4. Enjoy the great outdoors** – make the most of the last rays of summer by going to a nearby park, field or forest and enjoy your run there.
- 5. A sense of achievement** – signing up for a challenge is a great way to stay motivated. When you hit the wall, think how amazing it will feel to cross the finish line and get that medal around your neck!

Convinced? Join our MS Superstars team by taking on one of three fantastic events: the Bath Half Marathon, the Brighton Marathon or even the world renowned London Marathon. We'd love to have you on the team!



Bath Half Marathon

Run through this World Heritage city and enjoy the stunning views it has to offer. Get your charity place for the Bath Half and join the MS Superstars team. Use the discount code **BATHEARLY** to get **£10 off** your registration fee. The offer is valid for a limited time.

Brighton Marathon

The second largest marathon in the UK, Brighton Marathon with its unique seafront finish is a beautiful event to take part in. Get your charity place and join the MS Superstars team on this fantastic marathon along the seafront. Use the discount code **BMEARLY** to get **£10 off** your registration fee. The offer is valid for a limited time.

London Marathon

The iconic London Marathon sees 40,000 people run 26.2 miles through the capital's streets, lined with cheering supporters. This is the world's biggest one day fundraising event – simply unmissable! Will 2019 be the year you take your place on the start line?

join

For more information or to register for any of our runs visit www.mssociety.org.uk/running

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Photo: Brendan Foster

5 TOP TIPS FOR ASKING LOCAL BUSINESSES FOR SUPPORT

A handy how-to guide from area fundraiser Katie Bruce

Your local businesses want to keep a special place in your heart, so they're interested in the causes you care about. This means you're well placed to ask them to support the MS Society! Some businesses will have a formal process, like Charity of the Year partnerships, which you could ask them to nominate us for. But something as simple as a collection can at the till can raise awareness of MS in your area – and some money too.

Here's five simple tips for approaching your local businesses.

join

For more information, please contact your local Area Fundraiser. Our Supporter Care team can put you in touch. Contact 0300 500 8084 or supportercare@mssociety.org.uk

1. Make connections

It's who you know. Start by approaching your own employer, somewhere a friend or family member works, or a place you use regularly.

2. Identify the right person

Many larger businesses have a 'charity champion'. Find out who they are and see if they'd like to chat to you face-to-face or over the phone. Sometimes they will need you to introduce yourself first, which brings us to tip number 3...

3. Write them a letter

I'd recommend no longer than one side of A4, explaining why the MS Society is important to you, and giving some ideas of how their business could support us.

4. What will the company gain?

Aside from tax advantages, supporting a charity is brilliant for business and it's great for team building. Staff can take part in events like Cake Break, have a jargon jar in meetings or a dress down day.

5. Say thank you

Remember to thank the business and let them know how their support helped! We can provide certificates businesses can display, and give you all the facts and figures on how the money helps.

Parties, hikes and dragon boats

These are just a few of the ways that companies around the UK are showing their support.

- Facilities management company Mitie chose to fundraise for us through their annual ball. It raised a whopping £35,000, which was divided between us and a cancer charity.

- Cardiff-based technology company Oprema have chosen us as their Charity of the Year – it's going to be a busy one as they have lots of fundraising activities planned, including trekking Snowdon at night, Tough Mudder and a Halloween party.

- Our incredible supporter Laura, from Glasgow, nominated us to benefit from John Lewis' Community Matters donation.

- We recently received funding from NIE (Northern Ireland Electricity) to help fund our information programme.

- Staff at LexisNexis in Cardiff participated in the Cardiff Dragon Boat Festival and won, raising £1,725, which will be matched by the company.

WHEN 'LIFE' DOESN'T MEAN 'LIFE'

Elaine Moore on the frustrations of PIP assessments

was awarded Disability Living Allowance (DLA) for life. 20 years later I received a letter saying that my DLA was going to stop. There were new rules, the government was trying to save money, everyone needed to be reassessed. Hey ho, just make a claim for Personal Independence Payment (PIP)...

Not ok on paper

It took me three days to complete the 40 page claim form as I physically cannot write very much at one time. I sent in copious amounts of information but didn't qualify through my paper application. Why not? Did the assessor think my DLA claim had been fraudulent for the last 20 years?

medically trained. For them, it might be a box ticking exercise. For me, it's real life.

Even though I knew I qualified it was still stressful having to go through the process and wait for the decision. After all that, the assessment wasn't accurate – apparently I can prepare a meal if supervised.

Interview anxiety

I needed to be interviewed. Although the interview took place in my own home, I had to present my passport to prove who I am. Did they think John, my husband, might have rented a person in a wheelchair for the day?

The time for the appointment arrived and I was glad that John hadn't touched up the paintwork where I've collided with skirting boards in my wheelchair.

Should I wear make-up? I look unwell without it and never leave the house without my 'face' on. But would it be better if I looked pale and drawn? Vanity got the better of me!

Do I tick the box?

After the interview my assessor reported back to the Decision Maker who, by the way, is not

Counting the pennies

My claim was agreed. Enhanced rates all round. The amount I am to be paid is the same, to the penny, as I was receiving under the DLA system. So with all the costs of interviewers and assessors can someone please tell me where, exactly, did the government save money?

Read more from Elaine on her blog www.wheelife.co.uk



We're calling on the government to make PIP make sense for people with MS. With 20,000 signatures on our petition so far, turn to page 6 to find out more about the campaign and how you can get involved.

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STRENGTH IN NUMBERS

Find out how the man behind our Northern Ireland counselling service is helping more people than ever

We run a five-day-a-week, volunteer-led counselling service in Northern Ireland. It's a fantastic service, but how did it come about?

Tom Hunter was a broker working in London. He spent 26 years there, living a busy and stressful life until concerns about his health brought him back home to Northern Ireland. He returned for a quieter life, but with big reservations about leaving his London life behind, which at that point was a huge part of his identity.

An MS diagnosis quickly followed and Tom's life changed forever.

Meeting a need

Motivated by his own diagnosis experience and the absence of emotional support, Tom retrained as a counsellor and psychotherapist. He wanted to provide the support for others which he did not receive.

'In my experience, MS has one of the highest rates of anxiety and depression of any medical condition,' Tom says. 'This is because people are living with

a condition that can dominate their life. But we can address anxiety and depression and that's what I set out to do.'

Newly qualified in 2011, Tom contacted the MS Society to volunteer 'for a few hours a week'. Demand started to creep up and has been growing ever since. There are now four volunteer counsellors covering a five-day-a-week service. MS professionals, particularly consultants, are the biggest source of referrals. The service has already helped close to 500 people living with MS.

Share and care

Motivated to manage a small but consistent waiting list and to try a new form of counselling, Tom has recently been trialling group counselling sessions for people living with MS with positive results.

While group counselling is not suitable for everyone, it

has great benefits for some. It means clients realise they are not alone and face challenges similar to other people. It also provides a peer group that can provide support long beyond the end of the group sessions.

'Compared to my expectations I have been blown away,' says Tom. 'It was set up as a trial but I'm now planning more. The openness of clients has been impressive and how they empathise with each other has been exceptional.'

'Group counselling met the needs of the clients, exactly where they were on their journey with MS. The success is a credit to the participants and, as a counsellor, I got almost as much out of it as they did.'

'The MS Society and in particular Northern Ireland Director Patricia Gordon have been incredibly supportive in developing such a valuable service.'





About the service

Everything about the counselling service is carefully planned to have MS and people with MS at its heart.

The counselling room at the MS Society Resource Centre in Belfast is a safe haven for many. Its contents are carefully selected by the counselling team. Even the

clock communicates more than just the time. While slightly worn, with its damage often imperceptible to people, it still holds incredible value and, in keeping time, it carries out its role perfectly. A message Tom views as extremely important to many of his clients.

talk

To find a counselling service near you, head online to

mssociety.org.uk/near-me

Our MS Helpline is also on hand to provide emotional support and can point you towards other services that can help. You can call them on 0808 800 8000.

Group counselling – the difference it makes



Tammy

It was such a safe environment and no one was judging – it was brilliant. We've learned new coping mechanisms together, we made friends and have set up a WhatsApp group for contact and support. We're going to continue meeting and want to go to MS Society events and meet more and more people going through similar things.



Brenda

The group initiative was such a great source of support. It was an opportunity to talk to people dealing with similar issues. I now better understand myself, my MS and other people. The counselling has also helped our partners and families too. Because I understand more, I'm able to talk about MS more, be open and explain it. What this did was take the scariness out of MS for me. I know it is always going to be part of my life. But it isn't all of my life.



Leah

It's been great. I got so much out of it, I think we all did. I don't feel as alone anymore. It has been informal and strangely fun – I really didn't expect it to be fun. The bonus is I now have way more tools to deal with situations. It's been an empowering experience as individuals, but we also feel part of a community now, a family. There is a real strength in getting and giving support.



Brain fog: top tips for managing 'mind mush' from an MS mummy

Joanne Chapman on what juggling MS and looking after a little one has taught her about the importance of keeping her mind active



Brain fog turns my mind to mush. Every task becomes harder. I can't concentrate. I can't remember or find the right word. This can last from minutes to days.

As a mum living with secondary progressive MS, my focus is always on being the best I can for my little man. Keeping my mind active was on the backburner until I began to realise that, just like our bodies, our brains need regular exercise.

There are a few different things I do to help with my brain

fog. If you're worrying about your mind too, here are some things that might help.

Managing stress

For me, one thing that helps avoid stress is to leave emotional drainers behind (people or things that zap energy). I know it's easier said than done, but stress can bring on my brain fog and make my thinking worse. If I need to think, I avoid drainers.

Super smartphones

You're not a superhero, you don't wear your pants outside your clothes! And even superheroes had help (Batman had Robin). Your mobile phone can be a useful sidekick.

I use phone reminders for important things like appointments, medication and birthdays. I also use my phone to make memos for my blog or write lists.

My kitchen blackboard is a more traditional way to make notes, and can be used by the whole family. I still forget things, but it helps.

Living a busy life, even without MS to contend with, I try to get as much help as possible.

Mindfulness for MS

Mindfulness might seem like mumbo jumbo – I was very sceptical at first! But it was suggested as a way to keep my mind active and I gave it a go.

It involves focusing my attention on the present moment, the here and now. It centres my thoughts and helps deal with my brain fog. It isn't a cure, but it does help. It takes practice though – even just a few minutes a day.

Baby steps

My past columns have been about the importance of pacing yourself. Remember you are living with MS, you don't need any more pressure. This also applies to mind management.

My writing is my therapy, but it's not the only one. Try different things to keep your brain active until you find something you enjoy.

I hope this helps. I'd love to know your how you keep your mind active?

share

What are your tips for keeping your mind active? Email them to us at msmatters@mssociety.org.uk. You can read more from Joanne on her blog poorlyparents.wordpress.com

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TEENAGERS AND MS

MS isn't common in children. But if you know a young person with MS, you know it presents unique challenges. Here are some tips for helping teenagers with MS.

At this age, your teenager may need to know more about their condition, and in more detail. Knowledge is power, and it's important for your teenager to feel they have some control over their condition.

After a diagnosis of MS, teenagers can withdraw from their parents and not talk much about what's going on.

Although it's difficult to separate teenager behaviour from a reaction to having MS, it is possible. Listen carefully to what your teenager says and look out for signs of depression or problems with memory and thinking (cognitive issues).

Acceptance

It's not unusual if your teenager feels guilty or wonders what they've done to deserve MS. Or they may feel relief if they've had unexplained symptoms for a while – now they have an answer.

They may take some time to settle down and accept things. They may be in denial, especially if they haven't had a relapse for

a while, but these feelings may return if they get new symptoms or if their MS gets worse.

Help your teenager talk about what's bothering them. A favourite teacher, or someone your child trusts and respects, can also be people for your child to turn to.

Bullying

Unfortunately, teenagers can be cruel. If your child is missing a lot of school, or is perceived as different, then they may be subject to bullying. They're no different from other teenagers in this regard. Bullies Out (www.bullying.co.uk) is an organisation that offers support to young people (and parents) affected by bullying.

learn

This is an extract from our new booklet, *My child has MS*. It's full of information and tips on coping with childhood MS, including effects on the family. You can download a copy from mssociety.org.uk/children-and-ms



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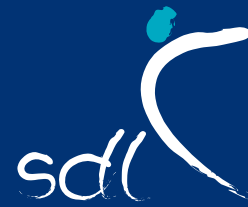


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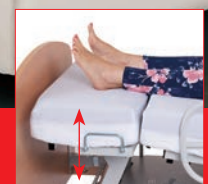
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EVENTS

FIVE HIGHLIGHTS OF OUR LIVING WITH MS EVENTS

Not sure if our events are for you?
Find out why you should give them a go

We're excited to let you know about the Living with MS information events happening this autumn.

Who are these events for?

- People who are newly diagnosed
- People who have lived with MS for some time
- Friends and family



Photos: Amit Lennon

Five reasons to come along

1. Meet people who 'get it'

Our events are a great place to meet people who understand the highs and lows of life with MS and share tips for coping.

2. Take part in interactive workshops

Choose from a great range of options such as exercise, symptom management, mindfulness and benefits.

3. Learn about the latest MS research

Find out about the research we're funding and get updates on a wide range of topics such as stem cell therapy, fatigue management and clinical trial news.

4. Speak to professionals and MS Society staff

We're a friendly bunch so if you have questions, please do ask! We'll do our best to help.

5. Visit relevant exhibitors

There'll be lots of time to speak to exhibitors from local and national organisations who can help you live well with MS.

If that wasn't enough, the events are free and include lunch and refreshments.

You don't have to commit to the whole day. We'd love to have you for however long suits you!

Dates for your diary

- Living with MS Dumfries – 14 September
- Living with MS Newport – 20 October
- Living with MS Coventry – 17 November

How to book

- Online: visit www.mssociety.org.uk/near-me and enter the name of the event in the 'Find support near me' box.

- By phone: 020 8438 0891.

If you'd like to know more, please give us a ring or email

conferenceadmin@mssociety.org.uk

We also run awareness talks. These shorter events focus on research or benefits. Find your nearest event at

www.mssociety.org.uk/near-me

HAVE YOUR SAY

GROWING OUR COMMUNITY

We're looking at how we can build the strongest MS community in a changing world and provide better support to everyone living with MS

Much has changed in the past 65 years. Perhaps the biggest change has been in the way we connect with each other. In the 1950s, if you wanted to find like-minded individuals, you might look in the local paper to find groups or activities nearby, go along, and return each week. Now, we can still connect locally, but the internet has expanded our horizons so much further – we can talk to people all around the country, and the world, online at the click of a button.

This means the way we connect with organisations has changed, too. 65 years ago, becoming a member of an organisation like ours was **the** way of belonging to a community.

Now, there are lots of ways to belong. Membership is one important way, but it's not the only way. And that presents challenges – and opportunities – for an organisation like ours.

The story so far

You're reading this because you're a member. Your support is important to so many areas of our work – thank you.

Over the years, membership has been seen as the most

important way to connect with us. But sometimes this has led to the suggestion that members are more important than other people in the MS community, whether those people support us in other ways or have no relationship with us. We know that, sometimes, non-members feel excluded or, worse, are actually excluded.

We also know that asking people to pay a membership fee is a barrier that stops some people joining us – whether it's the cost or simply the process.

Through our website, services and events, we're reaching more people than ever before. But, as the number of different ways to connect with us has grown, our membership numbers have fallen.

As membership decreases, there's a risk that governments and other decision makers will see us as a declining force and listen to us less – at a time when our voice has never been needed more. But, more than that, as long as our membership model is leaving some people living with MS feeling as though they're on the outside, different from us, we're not able to build the strongest MS community. And so we're not able to provide the best

possible support to everyone with MS.

This isn't good for anyone, member or non-member. Something needs to change.

We want to start on a journey that we think will take us to a place where everyone whose life is touched by MS – including those who are currently members and those who aren't – feels like they belong. It's only by getting there that we can truly support everyone through the highs and lows of life with MS.

It's by getting there that, together – as one, whole MS community – we'll be strong enough to stop MS.

Our thoughts for the future

After looking at the challenges and opportunities that we face, we're considering a new approach that doesn't attach being part of our community to being a 'member' or making an annual payment.

We've started to explore a free model, with online sign-up. We believe it may help us better connect to people who are newly diagnosed as well improving what we offer our existing members and supporters.

Photo: Ginny Lattul





Photo: Ginny Lattul



Photo: Paul Moane, Aurora PA

When we were founded in 1953, membership was a powerful and inclusive idea. We wouldn't be rejecting our heritage or leaving it behind. We're looking for a way to build on our history and values and the beliefs and attitudes of our founders to ensure we stay relevant, powerful, and united in a changing world.

We need you

As we explore this option, we want to know what you – our existing members – think.

We want your views on how best to grow our community. Importantly, we also want you to tell us how – no matter what changes are made – we can ensure that people with MS guide and actively take part in our work. How can we build the strongest MS community possible?

Share your views

You can send your comments and questions about this possible approach to

supportercare
@mssociety.org.uk

A resolution about these ideas will be discussed at our AGM on Saturday 22 September. If you're eligible to vote at the AGM, you'll have received an AGM booklet in the same envelope as MS Matters. Please take a look – you can find out more about these ideas in the 'Resolutions' section of the booklet. If you want to come to the AGM you're very welcome to do so. The AGM booklet also explains how to vote on this resolution if you can't attend.

This new model would help us provide a more personalised range of services, support and products to everyone in our community. And it would give our, hopefully wider, community opportunities to get involved in our work, have a voice and support us financially.

Our local groups will continue to be a vital source of support to people in their local areas. But there'll be a new way to connect, too. We know that membership fees are an important source of income for our local groups and any new model would protect that income for them in the medium term.

VOLUNTEERING

WE'RE INVESTING IN OUR VOLUNTEERS

Last year, over 5,000 volunteers gave over 700,000 hours of their time to help stop MS. We're making sure they have the support they need

Without our volunteers, it would be impossible to do what we do. Volunteers provide support and services to people living with MS, offer a listening ear through our MS Helpline, influence our research programme through our Research Network, campaign for change, raise funds – and much more besides.

While you're sure to see volunteers at a social meet-up or cheering on our MS Superstars, many of our volunteer roles are behind the scenes.

Never alone

Across the UK, our 270 volunteer-run groups offer a wide range of services to 13,000 people. From coffee mornings and yoga to horse riding and exercise classes, these activities help people living with MS to become more physically active, emotionally supported and, equally importantly, have fun.

Our volunteers also provide support and information on financial security with more than 30 advice partnerships.

Our MS Helpline volunteers help us answer a whopping 18,000 enquires a year!

All these volunteering activities ensure no one has to face MS alone.

Making change happen

Along with their fantastic work supporting individuals, our volunteers campaign for change. From benefits to access to medicines, our volunteers have made change happen.

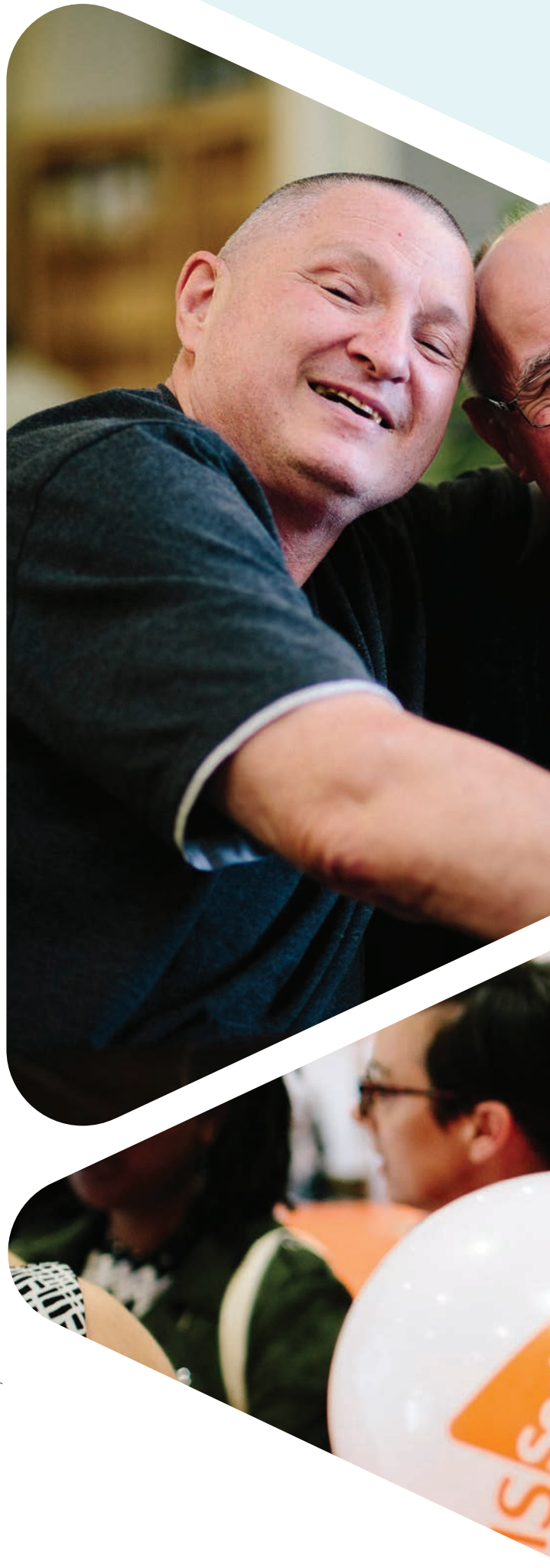
These campaigners help us have a positive impact on people living with MS everywhere, not just those who are directly in touch with us.

Better support

We take pride in ensuring all our volunteers have the best possible experience with us. So we're always looking for ways to improve our support for them.

In our 2017 volunteer survey, recruiting volunteers was highlighted as a priority. So we're introducing online recruitment - Coordinating Team roles with local groups are included in this. We're also developing new print resources to help groups recruit locally.

Photos: Ginny Latul







Investing in Volunteers

We're excited to be working towards achieving Investing in Volunteers. This is the UK quality standard for good practice in volunteer management. Achieving it will ensure our current volunteers are having the best possible experience and hopefully encourage even more to get involved.

Applying for this award has allowed us to assess how well we support our volunteers. We were delighted to find that we were already doing really well, with almost half of the criteria fully met, and many more partly met.

This year we're focusing on the things we can do better. When volunteers leave us, they now receive a thank you email or letter and a survey on their experience with us. We've also provided additional tools and

resources to help both staff and volunteers who support volunteers.

To keep us on our toes, volunteers will be heavily involved in assessing how we're doing. A random cross-section will be invited to give their opinions on volunteering for us, which will help decide whether or not we receive the award. We hope to be certified Investing in Volunteers by the end of this year. Watch this space!



Could you volunteer for us? Head online

to mssociety.org.uk/volunteering to find out the kinds of roles you could do. Already a volunteer? Thank you! Find out more about how we can support you at volunteers.mssociety.org.uk

Support Coordinator Trevor enjoys training with other volunteers

'I was diagnosed with MS in December 2015, about 18 months after my first attack. I've volunteered for 18 months as a support volunteer for the Croydon Group. Recently I've taken over as Support Coordinator for Croydon and District.

I feel well prepared for my role as I have regular contact with my Local Network Officer who keeps me updated on local and national issues. I'm also supported in my role by the Support and Wellbeing Facilitator. I've attended three Support Forums and found my training, support and networking with other volunteers invaluable.'



Photo: Ginny Lattul



Forum volunteer Val knows where to go for support

'I've been the MS Society's online message-board moderator volunteer for about 12 years. Although it is very much a 'behind the scenes' role, I feel I get the support and guidance I need.

'I know who to contact if there's a problem and I have a monthly call with a staff member who supports me and keeps me up to date with what's going on in the society.'

LIVING WITH MS

MY RIGHTS, MY CHOICES: ONE YEAR ON

Our information and support project has made a big impact in Wales so far, and there's more to come

MY MS, MY RIGHTS, My Choices – our project funded by the Big Lottery and Masonic Charitable Trust – has passed its first year. And what a year it's been!

Our project team of Adele, Tim, Naomi and Sophie have been working alongside our Local Network Officers to provide information and support.

Along with providing one-to-one support to people living with MS, during the past 12 months, the team has organised several events including sessions on grants, Personal Independence Payment (PIP) and Employment and Support Allowance (ESA), MS research, living well with MS, getting active, and employment.

So far 640 people have attended these events, 80% of whom are new to us.

Wide reach

Given that there are around 5,000 people living with MS in Wales, this is a tremendous achievement in such a short time.

It's also an indication of the potential that My MS, My Rights,

My Choices has to reach and support more people living with and affected by MS in Wales.

The team are now training volunteers who'll support the project and the MS community across Wales.

Coming soon

Over the next few months, there'll be a range of activities including newly diagnosed days, information days and conferences on progressive MS in south west and north west Wales.

In south east Wales, there'll be sessions on fatigue management, mindfulness, creative writing, self-defence and potentially a pottery class before the autumn.

In north east Wales, a mindfulness course in Wrexham will run weekly from 19 September to 31 October every Wednesday evening.

join

To find out more about these events and how to sign up, email mymscymru@mssociety.org.uk



Photo: Ginny Lattul



Photo: Amit Lennon



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FUNDRAISING

MERE MORTAL

Harper and MSer Jane Stokes on releasing her first album

I'VE BEEN PLAYING the harp for over 30 years and have been living with MS since 1998. The MS became secondary progressive in 2011. Lately, I've been thinking about what happens if my MS gets to the stage where I'm unable to play. I wanted to record what I'd achieved, as memories for myself and my children.

An album is born

Family and friends were very encouraging and so the idea of making an album was formed. It seemed natural to

raise money for the MS Society through its sales.

To keep costs down, I learnt to use a new computer program to design the cover myself. That's typical of my approach - it's about what you can do, not what you can't do. On days when fatigue makes it impossible to lift up my arms to play, I'll have a 'listening day', or develop new skills like arranging and composing.

Since the album's release in February, there have been exciting moments like having customers as far away as



Beijing and airtime in the USA.

So far I've raised over £750 for the MS Society. I'm pleased my hobby has become something that's making money for a good cause.

[Listen to Jane's music and buy the album at janestokes.bandcamp.com](https://janestokes.bandcamp.com)

YOUR SOCIETY

AGM 2018

IF YOU WERE a paid-up member of the MS Society on 23 June 2018, you're entitled to vote at this year's AGM. Your AGM booklet and voting papers are enclosed with this copy of MS Matters. Please take the time to read the booklet and vote.

The AGM booklet contains information about the resolutions which are being proposed including endorsement of the Stop

MS Appeal, Growing the MS Society's Community, receipt of the Annual Report and Accounts 2017 and the Appointment of Auditors. It also includes information about the candidates standing for election as Trustees and National Council members.

If you're entitled to attend the AGM or vote, then you have the right to appoint a proxy - someone to do that on your behalf. All the information on attending the meeting and on voting is included within the AGM booklet.

To book a place at the AGM or appoint a proxy, please complete the form at mssociety.org.uk/agm-2018 where you can also find the

AGM booklet itself, or call 0300 500 8084 (option 4). The AGM will be available live via our website.

Notice of AGM

The Multiple Sclerosis Society's 8th Annual General Meeting will be held at MS National Centre, 372 Edgware Road, London, NW2 6ND at 11am on Saturday 22 September. The agenda will include:

- Review of 2017
- Stop MS Appeal
- Growing the MS Society's Community
- The Annual Report and Accounts 2017
- Appointment of Auditors
- Elections of Trustees and National Council members.

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YOUR COMMENTS

Dealing with 'Dr Google'

In June, blogger Noor shared her top tips for dealing with 'Dr Google'

LET'S ADMIT IT, WE'VE all done it - an itch or tingle appears and we jump straight to the keyboard to check if others have felt this. What does it mean? Am I normal?

The internet is a vast space where anyone can put anything. Opinions can pose as fact. There are miraculous tales of recovery and the worst of horror stories.

I've realised it's about picking and choosing where you get your information, and deciding what you want to invest your time, faith and hopes in.

My top three tips for understanding your condition online are:

- What is the source you are looking at? Is it reliable information shared by professionals or an established MS organisation like the MS Society or MS Trust, or is it people sharing their personal experience? Ask yourself if that makes it fact or personal opinion and consider it carefully.
- Remember not everything you read will apply to you or will happen to you. Everyone is different.
- You will often see the extremes online. It's an easy medium to boast on, as well as to vent negative feelings on. Try not to get caught up in everything you read.



Noor's blog struck a chord on Facebook.

Ashley I was diagnosed a few days ago and of course straight onto 'Dr Google' and the panic and fear from that doesn't help. I'm still dealing with the fact I have been diagnosed... I will use this article to help guide me.

Sarah I was diagnosed in January this year and I've kept as far away from Dr Google... as I can. There's just too much out there. I've read what the neurologist has told me to read. That's been enough for me.

Clive It can be dangerous using Dr Google and you need to make sure that the information you get is both factual and up to date. Would recommend that people look for MS charity websites... Or if you have access to an MS nurse they can also give you material on MS that is factual and up to date.

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

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

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VOLUNTEERING

Why IT Matters

A new project is helping volunteers in Northern Ireland improve their IT skills

JOE WITH FORMER MS SOCIETY
CHAIRMAN HILARY SEARS



In Northern Ireland, we've been running a programme called 'IT Matters' to help our volunteers and local groups improve their IT skills.

Sessions cover things like social media, email and keeping safe online.

The programme is also supporting volunteers in their roles to communicate more effectively, promote our work and recruit new volunteers – all to support local people with MS. It's proving a huge success.

Prepare and promote

Joe Doran, Coordinator for our Omagh Group, told us what he thought of the programme.

'The programme is really worthwhile as it is supporting volunteers in their work and enabling them to achieve their aim of providing the best possible support to local people

with MS.'

'Our group in Omagh works tirelessly providing services and raising funds to support local people affected by MS. We have guest speakers, social outings as well as providing fitness and reflexology sessions for the MS community.

'But all of that needs to be administered and promoted so increasing our IT skills has been a great initiative.

'The programme was delivered in an interesting way, we had different experts coming in on topics helping out. It was really practical and really useful.'

learn

Are you part of a local group? Find out how you could use social media to reach more people and get information on tools including our volunteer portal at volunteers.mssociety.org.uk

About IT Matters

IT Matters is funded by the Big Lottery 'Awards for All'. The six-week programme has already taken place in Omagh and Belfast with sessions in Craigavon and Ballymena due to take place in the autumn.

The IT Matters programme covers:

1. How to share the work of the MS Society in a more engaging way on social media
2. How to better promote the great work we already do
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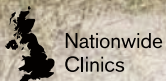
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VOLUNTEERING

‘Fundraising has given me confidence’

Susan’s coordinating one of our new local fundraising groups

DID YOU KNOW that we have local fundraising groups around the UK? These fantastic volunteer groups raise money to support our work, supported by their Area Fundraiser.

Susan Shand is coordinator for the Keepsmyelin Group in Keith. She said: ‘I got involved in fundraising as it’s nice to be able to put back. It gets me out to meet people too. Our group



has a good dynamic. We have a laugh.’

Fun at the fair

The group has decided to focus on raising money for myelin repair research. Their first event is an autumn fair this September. Susan said: ‘One of our members has done a beautiful painting which we’re raffling, we’ve a singer coming and a magician. We’ve started selling tickets and the fundraising buzz has kicked in.’

Susan says fundraising has helped her confidence. ‘I used to be shy. Fundraising has given me more confidence in

my own abilities. Now I don’t think twice about contacting local businesses to ask for their support. When you see the money you’ve raised it gives you a boost.’

Find out more about Keepsmyelin at www.facebook.com/keepsmyelinMS



join

Interested in starting a fundraising group in your

area? Get in touch with supportercare@mssociety.org.uk or call 0300 500 8084 to find out more.

The MS Society Christmas Concert

Tuesday 11 December,
St. Botolph-without-Bishopsgate

Join us for a memorable evening of carols, choral music and readings. On Tuesday 11 December, this celebration of Christmas will take place in the beautiful and historic setting of St. Botolph-without-Bishopsgate, London.

This special evening will help raise vital funds for the Stop MS Appeal.

For more information contact hettie.tetteh@mssociety.org.uk



CREATIVE CORNER

‘By the end we all had big grins on our faces’

Dundee group volunteer Lillian found joy at a singing class

OVER THE PAST FEW years our group has offered people living with MS the chance to take part in art courses, run through local organisation the Tayside Healthcare Arts Trust. This year, we decided to offer an eight week singing course. When it was first suggested I thought: I can't sing, I'm hopeless! But I'd also been very apprehensive about joining the art classes and I soon got into it. Although I can't sign my own name, I managed to produce pictures.

I've even got one hanging on my wall.

Nothing ventured

So, my attitude to the singing class was nothing ventured, nothing gained. I was a bit nervous before the first session but by the end we all had big grins on our faces. It didn't matter if I was singing flat, it was just good fun.

The coach, Alice Marra, was excellent. She was very positive and gave us lots of

encouragement. We'd start with warm up exercises and then sing songs in harmony like 'Swing low, sweet chariot' and Bob Marley's 'Three little birds'. We got to know the songs over time, and we'd sing them in different orders so it trained our memories as well. I also felt it was a good way to improve my breathing. At the end we always sung an Islamic song to calm our voices down.

Joy of taking part

It was really nice to get out and meet other people with a common purpose. We got on really well and it was very social. We've got MS, but so what? We're people, we enjoy doing the same things as everybody else. With the art classes and the singing class it doesn't matter about being really good at it, it's about taking part, joining in and getting a sense of achievement.

When we were singing you could see the joy on people's faces. People got a lot out of it and some went on to join choirs. Together I think we sounded good! For our last session we invited family and friends to come along and they were thrilled as well. We're now planning our next creative course, and I'm looking forward to whatever we choose to do.



share

Do you have a creative side? Whether it's poetry, art or something else, we'd love to hear from you. Send your work to msmatters@mssociety.org.uk – we'll feature our favourites in the magazine.

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