



Pregnancy and MS

Two new mums talk about treatment decisions, relapses and life after birth

Inside
Research Matters
magazine

Our researchers address some of your biggest questions

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“It’s discreet. I can just be myself.”



My name is Liselotte, I’m 53 and I’m an office assistant and living in Hillerød with my fiancée. Between us I have a son and he has a daughter.

Ten years ago I was told that I had multiple sclerosis (MS). One of the complications associated with MS is urinary incontinence. For me the issues started very early. I always had to carry incontinence pads around with me, even though pads didn’t work when the bladder suddenly emptied. This meant that I needed to take a big suitcase with me wherever I went, for the security of having a change of clothes with me. It was very humiliating when suddenly I would have an accident and because of that I just stopped going out.

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Using SpeediCath Compact Eve has given me a freedom that grows every day. I’m more myself once again.



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Issue 130
Autumn 2018

IT'S A TIME of change for the MS Society, as Michelle Mitchell moves on after five years as Chief Executive. It's been a privilege to work with Michelle and I wish her the best of luck in her new role as CEO at Cancer Research UK. You can read about her highlights at the MS Society on page 12.

At the same time as saying fond farewell to Michelle, I'd like to welcome our new CEO, Nick Moberly, who brings with him many years of experience in the NHS, most recently as CEO of King's College Hospital Foundation NHS Trust (see page 6). As Nick joins us in January, I will be Acting CEO in the interim, to help ensure a smooth transition.

In this issue, our cover story looks at the experiences of two new mums with MS during pregnancy and after the birth of their babies. We also offer insights into home adaptations, provide some tips on staying active in your daily life, and advice on looking after yourself if you're a carer.

At the start of November, following a long campaign by people in the MS community, the UK Government legalised cannabis for medicinal use. Although this is welcome news, much more needs to be done to ensure people with MS can benefit. Find out more on page 11.

We had some extremely disappointing news, too. The National Institute for Health and Care Excellence (NICE) has rejected ocrelizumab for early primary progressive MS for cost reasons. We've launched a campaign to reverse this decision – find out how you can add your voice on page 10.

And in October, we handed in a petition at Westminster calling on the government to scrap the Personal Independence Payment (PIP) 20 metre rule (see page 7). More than 36,000 people signed the petition, making it our biggest ever. We'll keep you updated on any changes in policy.

Patricia Gordon
Acting Chief Executive



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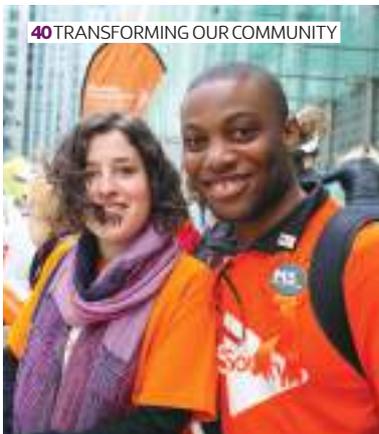
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Research Matters



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- whether vitamin D can help slow MS progression
- what the gut microbiome is and the role it plays in MS
- how exercise is helping people manage their MS symptoms

talk

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

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

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

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Meet our new CEO

Nick Moberly, who has exceptional experience and a strong background working in the NHS, will take the helm at the MS Society in January. His last two roles have been as CEO – most recently at King’s College Hospital NHS Foundation Trust.

While in charge at King’s, Nick oversaw staff who played a critical role in major incidents in London,

including the London Bridge terror attack and the Grenfell Tower fire. King’s is renowned for being at the forefront of research and innovation and is one of the biggest Neurosciences centres nationally.

Nick Winser, Chair of the MS Society, said: ‘I’m delighted to have Nick Moberly on board as our new CEO as we move closer to reaching our ultimate goal of stopping MS. He brings with him a wealth of

experience in health, and the strength of leadership to further increase our impact and improve the lives of people with and affected by MS throughout the UK.’

Nick Moberly said: ‘During my career in the NHS, I’ve seen the impact that progressive neurological conditions like MS can have, so the MS Society strikes a strong chord with me. I’ve also worked alongside many charities, and have been hugely impressed with the work they do day in, day out to provide help and support to improve people’s lives.

‘I’m keen to contribute my energies to making sure everyone affected by MS gets the best deal possible, through research, support, fundraising and campaigning across the UK.’

Turn to page 12 to read an interview with Michelle Mitchell, our outgoing CEO.

New Director for Northern Ireland

DAVID GALLOWAY TOOK up the post of Director for Northern Ireland in September, replacing Patricia Gordon.

Patricia joined in 2008 transforming the fortunes, services and reputation of the MS Society in Northern Ireland. She will continue to play a role as Acting CEO and help with the transition when new CEO Nick Moberly joins in January. When Patricia leaves, she

will be greatly missed as a passionate champion and advocate for people affected by MS.

David joins the MS Society from the Royal National Institute of Blind People where he was Northern Ireland Director for five years and, most recently, held a UK-wide role. Before that he worked at the Department of Health in Belfast, where he was involved in decision-making

about investment in disease modifying therapies (DMT) and MS services.

With a family experience of MS, David was impressed with our passion for helping people affected by MS and improving care and treatment. He said: ‘The energy and commitment of everyone involved in the work of the MS Society stands out and I am really looking forward to being part of that.’





Lucy Young/MS Society

PIPville built in Westminster

36,000 people call for an end to the 20 metre rule

On 17 October, people with MS went to Westminster to hand in a petition calling on the UK Government to scrap the Personal Independence Payment (PIP) 20 metre rule.

The petition was signed by over 36,000 people, making it the biggest MS Society petition ever. Thank you to all of you

who supported the campaign.

But that's not all. We went to Westminster and built PIPville – population 9,400 – representing the people with MS who've lost out largely due to the 20 metre rule.

High profile supporter and actor Alun Armstrong joined people from the MS community. Together, holding placards, they demonstrated the impact the rule is having on people with MS; taking away their independence and leaving many trapped in their homes.

join

For more information on the campaign visit
mssociety.org.uk/ms-enough

'20 metre rule is a travesty'

SIMON, 38, FROM BANGOR

in Northern Ireland, lost his independence as a result of the 20 metre rule. He had his mobility car taken away and had to fight to have the decision overturned months later.

'I walk in pain using a crutch and get fatigued easily yet my original PIP assessment deemed me able to walk 20 metres and my mobility car was taken away. Along with the car I also lost my independence and became increasingly isolated. I became depressed, had my medication increased and was anxious about becoming a virtual prisoner in my own home. All of this worsened my MS.

'The 20 metre rule is a travesty. People with genuine conditions, both constant and fluctuating, have found themselves in my position, stripped of their independence and left isolated and dependent.

'In many ways, I was lucky. My MP got involved and helped eventually overturn the decision. Those months without mobility support were dark and difficult. We need to scrap the 20 metre rule; it is damaging people.'



Photo: Paul Moane

MS-STAT2 trial offers new hope

Biggest ever trial for secondary progressive MS in the UK begins recruitment



The MS-STAT2 trial will involve 1,180 people with secondary progressive MS at around 30 sites across England, Scotland, Wales, Northern Ireland and Ireland. Participants are being recruited until the end of 2019.

The Phase 3 study will confirm whether simvastatin – which is currently used to treat high cholesterol – could become one of the first drugs to slow or stop disability progression in secondary progressive MS.

Positive results from a smaller trial showed simvastatin could improve levels of disability and slow disease progression. It also reduced the rate of brain atrophy (shrinkage), suggesting the treatment could protect

nerves from damage in secondary progressive MS.

Promising treatment

Professor Jeremy Chataway, from the UCL Institute of Neurology, is leading the trial. He told us: 'Simvastatin is one of the most promising treatment prospects for secondary progressive MS in our lifetime. People with this form of the condition have been waiting decades for a drug that works. While it's still early days, we believe simvastatin could change lives.'

Steve Hornett, 56, from Southend (pictured above), is taking part in the trial. He was diagnosed with secondary progressive MS two years ago, after living with the relapsing form of MS for nearly 20 years. Steve says: 'I've had MS for a third of my life, but it never

impacted me that much until it became progressive. I had to buy a wheelchair two years ago, and although I'm not in it all the time I do rely on it. I can see myself slowly getting worse, but this trial might change that. If it leads to a new treatment for secondary progressive MS, the next 10 years could look completely different.'

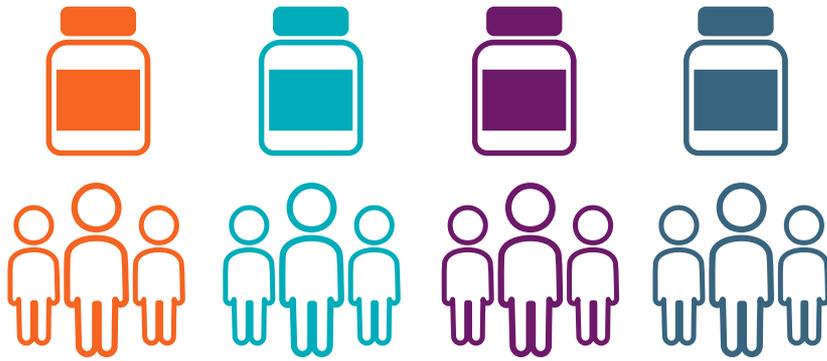
We are proud to be funding this multi-million pound trial in collaboration with the National Institute for Health Research, the National MS Society (US), the NHS and UK universities.

register

If you have secondary progressive MS and would like to be considered to participate in MS-STAT2, register your interest at <http://ms-stat2.info>



DR JEREMY CHATAWAY (RIGHT) IS LEADING THE MS-STAT2 TRIAL



MS-SMART trial results announced

First multi-drug clinical trial in MS successfully completed

The results of the MS-SMART trial, announced in October at a major European MS conference, have ruled out three repurposed drugs for the treatment of progressive MS.

This is the first time a clinical trial in MS has tested multiple drugs at the same time, delivering answers up to 10 years earlier than a standard clinical trial.

What was the MS-SMART trial?

The Phase 2 trial tested three drugs – riluzole, amiloride and fluoxetine – in 445 people with secondary progressive MS. These three drugs are already used to treat other conditions, and were chosen based on promising results in experimental and early

human studies. Unfortunately, the results have shown that none of the three drugs tested have the potential to benefit people with progressive MS.

What does this mean for people with MS?

Dr Susan Kohlhaas, our Director of Research, says: ‘We know this is extremely disappointing for people with progressive MS and everyone involved with the trial.

‘However, we’ve learned a huge amount from this study, which will increase our chances of future success. We’re now better placed to identify and rule out treatments that won’t work, and have demonstrated how to run faster, cheaper trials successfully – meaning we can test more potential drugs, quicker.

‘There are over 100,000 people living with MS in the UK and the community remains dedicated to finding effective treatments to fight this condition. We believe that, with the right investment, we can stop MS.’

learn

Read more about our work to find treatments that can stop progression in MS at mssociety.org.uk/progressive-ms-research

NEWS IN BRIEF

Social care survey in Wales

We’ve been working with the Wales Neurological Alliance to ask people living with neurological conditions about their experience of social care. Thanks to everyone who has completed the survey so far. We’ll be producing regular reports to Assembly Members. If you’d like to share your experience, contact Fiona McDonald on 029 2167 8924 or fiona.mcdonald@mssociety.org.uk

Scotland plan: have your say

The Scottish Government has recently launched its draft National Action Plan for Neurological Conditions. This is the first-ever plan of its type in Scotland and gives us a chance to transform neurological services and care for people with MS in Scotland. The MS Society will be responding to the draft plan and we would welcome your input. Get in touch at scotlandcampaigns@mssociety.org.uk

Thousands call for ocrelizumab for primary progressive MS

More than 21,000 people have called for a new treatment for primary progressive MS to be made available

What happened?

In September, the National Institute for Health and Care Excellence (NICE), who approve treatments for the NHS, rejected ocrelizumab being made available for early primary progressive MS. This was because the cost of the drug is deemed too high for the benefits it can provide.

This decision is incredibly disappointing. Around 600 people in the UK are diagnosed with primary progressive MS each year. People like Holly from Milton Keynes (pictured above). Holly says: 'I had my hopes pinned on ocrelizumab. But



NICE has decided I can't have it.'

For many like Holly this decision is about more than pennies and pounds. She says: 'Ocrelizumab could help slow down my MS and give me back control of my life and my future.'

As a result, we launched a petition calling for the manufacturer Roche,

NICE and NHS England to put patients first and agree a deal to make ocrelizumab available at a price the NHS can afford.

It didn't take long for thousands of people to join the call. Within a few weeks the petition had over 21,000 signatures.

What happens next?

This isn't the end. The significance of this treatment, as the first licensed disease modifying therapy (DMT) for primary progressive MS, cannot be understated.

We will be doing everything we can to ensure the drug is available to everyone who could benefit. We want to reverse the decision, or find alternative routes to access the treatment.



join

Add your voice to our Campaigns Community at mssociety.org.uk/campaigns

Cannabis for MS campaign continues

UK Government approves cannabis for medicinal use but access is restricted

Since we started calling for cannabis for medicinal use in July 2017, a lot has changed. Following reviews and listening to people who could benefit, like people living with MS, the government has now rescheduled medicinal cannabis.

This means specialist doctors are now able to prescribe cannabis-based treatments once all other treatment options have been considered. However, we're concerned that the guidance for prescribing is too restrictive and people with MS may not benefit in the short term.

Our priority now is to ensure that people with MS who could benefit are able to access cannabis for medicinal use. This is why we're calling for NHS England to urgently revisit their guidance for specialist doctors, which discourages prescribing in all but a few cases. We will be engaging with decision-makers to ensure that cannabis for medicinal use can be prescribed in fair and timely way on the NHS for everyone who could benefit.



CAMPAIGNERS SUE COX (LEFT) AND GLYN FURNIVAL-JONES WITH LEANNE WOOD, ASSEMBLY MEMBER FOR RHONDDA, AT THE SENEDD

Digital campaigners

Sue Cox, from Cwmbran in South Wales, was shortlisted for the MS Society's Digital Champion award in 2018, along with fellow cannabis campaigner Glyn Furnival-Jones. The pair were nominated for their efforts in setting up and monitoring the Cannabis4MSinWales Facebook page.

Sue says: 'I was diagnosed with primary progressive MS in 2014 and I experience pain and spasms daily. My drug regime includes morphine, codeine, paracetamol, pregabalin and diazepam.

'I've tried cannabis over the years. I'm 64 and as a retired police officer I know it's illegal

and I'm risking prosecution, but it's helped me manage my symptoms.

'Like so many others, knowing where to get it has been a problem. We don't want to be going to a dodgy drug dealer at the street corner; we don't know where it has come from and or know what's in it either.'

Important milestone

'It has been a long road for many in the MS community who have spoken out and campaigned for years for the benefits of cannabis to be fully recognised and made legal.

'The decision by the UK Government to reschedule cannabis is an important milestone. But while welcoming the change in the law, the guidance published for specialist doctors is overly restrictive. Our campaign must continue to ensure that everyone who needs cannabis is prescribed it.'

learn

You can find out more about cannabis for medicinal use at mssociety.org.uk/cannabis

‘It’s been a privilege to work with this special community’

Michelle Mitchell stepped down as CEO of the MS Society in October. She spoke to Catherine Doran, Northern Ireland Council Chair, about how it’s felt to lead the charity since 2013

Speaking to Michelle Mitchell has always felt like you’re talking to a friend, despite her CEO status. That’s because the Wirral-born Chief Executive has always felt that her position is about people. People with, and affected by, MS.

It’s this focus on the person that remains at the heart of the charity’s goals and Michelle reflects that ‘it has felt like working with a family of people working to Stop MS’. Yet, despite the close-knit atmosphere, there has also been a wealth of important work happening too – during a time of huge changes across the MS landscape.

‘The job may be London-based but one of the great things about the role is you get to meet people all over the UK, and around the

world, because of our global collaborations, such as the MS International Federation.’

Changing attitudes

‘We are a UK-wide organisation but we work with the four nations, and at a regional level, to make sure we get the best solutions for people with MS, wherever they live in the UK. The most enjoyable part is working closely with people with, and affected by, MS and working to improve their lives together, whether that be through providing services, friendship and support, or changing public attitudes, policies and laws.

‘Five years ago, many of the issues which have affected people with MS, in the health service or through welfare benefit changes,

were just starting. We didn’t understand the scale and scope of the change and it has been absolutely massive.

‘Politics really do matter, whether that be UK-wide or specifically in Scotland, Wales, England or Northern Ireland. Having a strong presence and understanding about policy; and the services in each nation and region, is so important because we want to get local solutions to a local problem.

‘I’ll always remember the sheer determination and courage of the MS community and their strength in coming together in the face of really unfair changes to policy and laws, especially around changes to the benefit welfare system, like the PIP 20 metre rule.’

Investing in research

Despite the challenges, there have been many highlights during Michelle’s time as CEO. Since 2013 the MS Society’s income has grown by 12.5% and the percentage of people with MS who could benefit from a disease modifying treatment and are taking one has increased from 40% to 56%. The charity has also launched its biggest fundraising campaign to date. The Stop MS Appeal has raised over £35 million in the early stages already – and this is reflected in the in-roads being made through research.

‘Since we started, we’ve invested £218 million in research, we’ve fought for treatments to be available on the NHS when and where people need them, and secured improvements to services locally. Over the last five years we’ve seen access to treatments, as well as our ability to diagnosis MS early, significantly improve. There are now 14 licensed drugs available on the NHS, and a strong



MICHELLE (FAR RIGHT) CHATS WITH MS SUPERSTARS DURING THE MS WALK 2017

Photo: Colin Baldwin

pipeline of new treatments, especially for progressive MS.’

Marathon challenge

Michelle also took on a personal fundraising challenge in 2016, when she ran the London Marathon, raising more than £18,000.

‘It was just amazing because I would spot people with orange vests and they would tell you their story, of how their lives had been touched by MS. It felt like we were a family of people running to Stop MS. It was wonderful.’

Michelle has moved on to her new role as CEO of Cancer Research UK. While she is looking forward to this new challenge, she will be staying in touch with the MS Society.

‘It has been a real honour and privilege to work at the MS Society and I’m very humbled by my experience here. It’s a wonderful and very special community of people with a wacky sense of fun sometimes too. I’m not going to miss wearing orange wigs(!) but I’ll certainly miss the people – and will be keeping in touch.’

‘I have every confidence that the MS Society will go from strength to strength as we look to the future.’

read

Turn to page 6 to find out about our new CEO Nick Moberly, who joins the MS Society in January.

Photo: Jon Bradley



New grant for fitness and friendship in Wales

How the Big Lottery is supporting people with MS in South Wales

While many people living with MS can and do remain active with their condition, they often face challenges in doing so. Thanks to the Big Lottery Fund, this is about to change in Cardiff, Merthyr and Rhondda Cynon Taf.

MS Society Cymru has received a grant of £149,400 to run 'Active Together', a two-year pilot project to promote fitness and friendship among people living with MS.

Ann Jones from Rhondda

Cynon Taf was diagnosed with MS in 2001 and has been part of the project steering group.

She says: '95% of people living with MS who responded to our survey in Cardiff, Merthyr and Rhondda Cynon Taf told us that they would like to be more physically active but are deterred from doing so.'

'We need exercise classes which adapt with a person's MS and are tailored and bespoke, so that we are encouraged to move more when we are feeling well and to take it easier when we are having an off-day.'

Belfast neurology recall leads to public inquiries

We're seeking answers for people affected

In May, the Belfast Health and Social Care Trust began a recall of 2,500 neurology patients after investigations into the treatment and care provided by a specific neurologist. The Trust committed to reviewing each patient within a 12-week period.

Throughout this time, we have been talking to the Belfast Trust and the Department of Health, representing both the people affected and the wider patient group within the recall.

Unfortunately, we've been told that some people have received life-changing news, up to misdiagnosis. We're working to make sure everyone receives the care and support they need during this very difficult time. There are many questions that still need answers on the circumstances surrounding the recall and decisions made before, during and afterwards. We will continue to seek answers for those affected.

Due to the recall, several public inquiries have been announced. The first of these seeks input from people who have experience of neurology services.

The Department of Health has also announced a wider review of neurology, which will determine the future of services across Northern Ireland.

To submit your views on neurology provision in Northern Ireland, visit

www.neurologyinquiry.org.uk

Find out more about our work in this area or share your own experience by emailing

nireception@mssociety.org.uk

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JENNIE WITH HER DAUGHTER IVY

Photo: David Anderson

Pregnancy and MS: two new mums share their stories

There's lots to think about before trying for a baby and MS can bring extra challenges – as new mums Nicola and Jennie explain

Nicola lives in Newtownabbey, near Belfast, and gave birth to Alexander on 11 August. She was diagnosed with MS in 2014. 'I'd always wanted kids,' she says. 'Being diagnosed with MS made me think more about it. But I was worried about passing MS on to my children, and that pregnancy would exacerbate my symptoms.'

Nicola's worries were eased after she went to one of our information days in Belfast. 'One of the speakers, Catherine Doran, talked about being worried about having children when she was diagnosed, but she went on to have two girls.'

Jennie lives in Edinburgh. She was diagnosed with MS when she was 19 and is mum to seven-month-old Ivy. She says: 'I always knew I wanted

children and my concern always was – and still is – that I'll pass it on to them.'

Research has shown that MS is not passed directly from parents to their children because it isn't caused by a single gene. In the UK the chance of someone developing MS in their lifetime is about 1 in 330. If they have a parent who has MS, the chance of developing MS is still only about 1 in 67. So while MS can occur more than once in a family, it's likely that this won't happen.

And although genes do play a role in MS, they're only part of the story. MS is likely to be due to a mix of genes, something in your environment and some lifestyle factors. Researchers are working hard to understand how these factors interact to cause MS.

Treatment decisions

Both Nicola and Jennie have relapsing MS and had to make decisions about their medication before trying for a baby. Both stopped disease modifying therapies (DMT) before getting pregnant. 'I was concerned about coming off treatment, and how long I would give myself to stay off

I had questions like: am I going to be able to look after my baby after my husband goes back to work?

it while we tried,' Nicola says. 'Luckily, I fell pregnant quickly.'

Jennie says: 'After speaking to my MS nurse and consultant I stopped taking my DMT three months before we started trying for a baby.'

At the moment, Copaxone is the only DMT that is licensed for use during pregnancy, but several others don't appear to pose a risk. When making decisions about your treatment, consult your neurologist or MS nurse to decide what will work for you.

Both Nicola and Jennie also had concerns about being unwell after the birth. 'I read there's a higher risk of relapse after you give birth,' Nicola says. 'I had questions like: am I going to be able to look after my baby after my husband goes back to work? How am I going to

cope with normal exhaustion, plus fatigue?'

Pregnancy and relapses

Research has shown that if you have relapsing MS, you are less likely to have a relapse during pregnancy but the risk of a relapse does increase following birth. It's thought this is due to hormonal changes that occur during and after pregnancy – but we know women's experiences of pregnancy and MS can be variable. And many symptoms of MS, like fatigue and heat sensitivity, are also seen in pregnancy.

So it can be difficult to determine the cause.

Research has shown that pregnancy has no overall impact on the progression of MS, and post-pregnancy relapses do not increase long-term levels of disability. This means that on average having a baby won't make your MS any worse.

Nicola was relapse free during her pregnancy. 'The first few weeks I was really sick and in hospital with vomiting. I was worried I would relapse, but I didn't. My pregnancy symptoms subsided and, eight weeks after giving birth, touch wood, I haven't relapsed yet.'

NICOLA WITH BABY ALEXANDER





I feel like I've won the lottery each morning when I wake up and see my baby

However Jennie relapsed around the time she fell pregnant, and during her pregnancy. 'After stopping my medication to try for a baby I had a relapse out of the blue. A few weeks later I had another more extreme relapse. But I also found out I was four weeks pregnant!'

Jennie started to feel better but then relapsed again and was signed off work for seven weeks. She struggled to find other women who'd had a similar experience. 'I was looking online but I was faced with lots of positive stories, which made me feel worse and more alone than ever. That's why I want to share my story, so others can have the comfort that you will get through it and it will get better.'

second trimester.

She was very concerned about having another relapse after Ivy was born but luckily she didn't. She says: 'It's been a year now since my relapses. My hands are still partially numb, and this might never get better, but I still feel like I've won the lottery each morning when I wake up and see my baby.'

Nicola's advice to other women worried about having children is to talk to new mums and an MS nurse, and read information from the MS Society. 'Just don't Google everything,' she says. 'It's easy to overthink it but then you get stressed. You can't worry about the future, you just have to live your life as best you can.'

Life as a new mum

Jennie's relapse lasted for her first trimester, then she started to feel better at the beginning of her

More information

Visit mssociety.org.uk/pregnancy for information about pregnancy and birth and to download our Women's Health booklet.

For more information about genetics and MS visit mssociety.org.uk/genetics

Call our MS Helpline on 0808 800 8000 or email helpline@mssociety.org.uk The Helpline team are not medically trained but can provide information, support and a listening ear to anyone affected by MS. This includes new parents with MS or those who are thinking about starting a family.



JENNIE WITH HER HUSBAND JOE AND BABY IVY

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MAR

Bath Half Marathon 17 March

Run this flat and fast course through the beautiful World Heritage city of Bath.

Great Wall of China Trek 29 March–7 April (other dates available)

Stretching 8,500km across China, the Great Wall was built over two millennia. This demanding trek offers fabulous scenery and an insight into a fascinating culture.



London Landmarks Half Marathon 24 March

Coming back for its second year, the London Landmarks Half Marathon celebrates the capital's grand, hidden and quirky history. The stunning, closed-road route showcases the very best of London's landmarks including Big Ben, St Paul's Cathedral and the Tower of London.



Photos: Brendan Foster

APR

Brighton Marathon 14 April

Join us for this seaside challenge along Brighton's characterful beachfront promenade.

Zipslide Zinger, Crieff 27 April

Our award-nominated, fully accessible, Zipslide Zinger challenge is back. We can't wait to see our MS Superstars zip through the trees!



MAY

Kiltwalk Glasgow (28 April), Aberdeen (2 June), Dundee (18 August), Edinburgh (15 September)

Lace up your trainers, dig out your orange top, throw on a bit of tartan – and make every step count.



Belfast Castle Abseil 31 March

Go 'over the top' and enjoy spectacular views across Belfast before descending 100ft down the side of the Belfast Castle tower. This event is open to anyone aged 12 years and over. No previous experience is required.





**Arctic Trek
January 2020**
Our Scottish fundraising team are thrilled to launch their first overseas trek. Intrepid MS Superstars will spend three days trekking into

the Arctic. This trek isn't for the faint-hearted – you'll be pulling equipment in a sled and battling the elements in sub-zero temperatures. But you'll make friends for life and forever impress folk with the line: 'When I was in the Arctic...'

join

If you, a family member or friend want to find out more about any of these challenges visit mssociety.org.uk/fundraise, email challenge@mssociety.org.uk or phone 0300 500 8084.

Photo: Colin Baldwin

**Belfast City Marathon
5 May**

Join Team MS and run through North, South, East and West Belfast, starting at Stormont and finishing at Ormeau Park.

**Great Manchester Run
19 May**

Take in Manchester's iconic sights including Old Trafford and Salford Quays on this 10k run or half marathon. Roaring crowds and booming anthems will help you across the finish line.

**London 2 Brighton Challenge
25–26 May**

Walk, jog, or run from capital to coast. Whether you choose to take on the full 100km, or the half or quarter option, the challenge is sure to be rewarding, fun and achievable.

**Isle of Wight Challenge
4–5 May**

Join 2,000 people of all ages to walk, jog or run the island's stunning coastal path. The Full Island Challenge is 106km, with half and quarter options available.

**Edinburgh Marathon Festival
25–26 May**

Places for this famous race are officially open and we are thrilled to be a Premier Affiliate Charity again this year. Come and join our team.

Other

**Skydiving
Various dates**

Experience the thrill of freefalling from 13,000ft at 120mph. Join one of our bespoke days or choose a location and date that suits you.



**Velocity 2, Snowdonia
8 June 2019**

Conquer Velocity 2, the world's fastest zipwire, and experience the freedom of flight. You'll travel at speeds of up to 100mph on this accessible event*, while enjoying Snowdonia National Park's breath-taking scenery.

*Unsuitable for anyone with neck or spinal injuries. Weight restrictions apply.



**Three Peaks Challenge
Various dates**

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Thank you so much to all our MS Superstars who took part in an event in 2018

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this year

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of you have taken part in over

28 challenge events



You've **walked, jogged** and **run** more than

46,940
miles

You've raised over



£2.5M

and counting!



10in10 hits £400k

The 10in10 Challenge has raised £400,000 for MS medical research since 2011. The annual 10in10 and 5in5 events see walkers scale 10 of Cumbria's peaks in 10 hours, or five in five hours. This year, organisers Duncan and Yvonne Booth added the Family 5in5, a new challenge attracting walkers aged eight to 92. A huge thank you to Duncan, Yvonne and all those who have supported and taken part in these events over the last eight years.



Scott Mills, BBC Radio 1 DJ and MS Society Ambassador

I took on the Cardiff Half Marathon for the MS Society because I wanted to help people like my mum Sandra and my friend Beccy, both of whom have MS. I know the money I raise will make a real difference to the lives of people affected by MS - and that's been a great motivation.



Jenny, MS Superstar

The Great North Run was a great experience; with such a fantastic atmosphere on the day, running under the Red Arrows with so many others raising money for brilliant causes.



Making a splash for MS research

This year Louise Newman held her seventh swim fundraiser at Gourock's outdoor pool. Louise, who lives with MS, loves swimming at the pool and once a year she invites people to join her for a sponsored swim, raffle and food. Combined with her other fundraising, such as bake sales, Louise has raised over £24,000 for MS research.

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Three ways to support us this Christmas



It's the most wonderful time of the year – a time for connecting and thinking of others. Together, the MS community is there for everyone who needs support, no matter what. And this Christmas there are several ways you can connect, all while helping the community!

1

Donate to our Christmas Connections Appeal

Christmas can be a really difficult time of year for some people, particularly those affected by MS. Help us be there for people who need us most, not just this Christmas but all year round, by donating at mssociety.org.uk/paperchain

2

Enter our Christmas raffle

Be in with the chance of winning £5,000 and feel full of festive cheer by entering the Christmas raffle! When you play, each £1 raffle ticket you buy will support people affected by MS. The draw closes on 20 December – so what are you waiting for? Enter online today at raffleentry.org.uk/mssociety

3

Send our Christmas cards

Connect with old friends, family and neighbours this year by sending them an MS Society Christmas card. You can buy them online and in Cards for Good Causes pop-up shops all over the UK. Look out for the trademark red triangular Santa! To find out more visit mssociety.org.uk/xmascards



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Freedom through technology

Jane Tomlin explains how technology helps her deal with her MS

I'm now in my 60s with progressive MS. At the time I was diagnosed, 30 years ago, technology to really help with MS simply didn't exist.

As my legs finally gave up and stopped working, I at least knew that there would be a solution to my mobility problems – a wheelchair. But when my hands started to weaken I began to panic about losing my independence. It wasn't about getting myself a meal or a drink, or even personal care (I'm lucky enough to have good carers for that). It was the idea of not being able to answer the phone, to write letters, or read, or choose a birthday present for my husband on my own.

Wireless magic

I'm eternally grateful for two bits of technological wizardry which now give me a large measure of control over these aspects of my life. The first is a Possum – a small screen and button on my arm, which allows me to wirelessly:

- answer and make phone calls
- switch on the television and

radio, or watch a previously recorded programme

- turn the lights off and on
- page my husband Richard (unfortunately for him!)

So what does this mean for me? For one thing, I don't have to suffer TV programmes just because there isn't anybody around to switch channels. More importantly I can phone for help if I need it – and my husband can go out safe in the knowledge I'm not marooned and helpless in the house.

Staying connected

The second piece of wizardry is voice-controlled software that allows me to use my computer and mobile phone totally hands-free.

It means I can answer and write emails, send photographs from our family WhatsApp group, take part in group chats with my friends and Skype my grandchildren. I can also

log onto the internet, read the newspaper or a novel, and do my shopping. I can do all this just with my voice. I'm writing this with my voice right now. And this freedom is a privilege denied to many people with MS.

Technology empowers us

We wouldn't deny somebody a wheelchair because they couldn't walk, so we should use this new technology to empower us all. Social independence is no less important than physical independence. Everyone deserves the same freedoms I have.

learn

Read our new report 'Improving care for people with MS: the potential of data and technology' at mssociety.org.uk/technology



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'I wanted to do something meaningful for my family'

Why 12-year-old Chloe ran and cycled her way to raising more than £1,000 for the MS Society

When Karen Silverman was diagnosed with relapsing remitting MS in April 2017, she was initially unsure about how to share the news with her children, Chloe and Theo, then aged 11 and 10.

'I wanted to be open and honest with my kids about my diagnosis,' she recalls, 'but it took me quite a long time to come to terms with it.'

'I called the MS Helpline two or three times and they told me of some online resources, about the language to use and how to communicate, which is quite important. Having the MS Helpline really helped support me, so I was strong enough to support my children.'

Batmitzvah training

Earlier in the year, Chloe had signed up for the Hever Castle Triathlon and at the same time she was training for her Batmitzvah (the Jewish coming-of-age ritual for girls). One day, on her way to school, she spotted an MS Society charity shop and connected it to her mum's condition.

Chloe says: 'I realised that there's a charity that helps

people with MS and decided I wanted to do something meaningful for my family. Now I know that the MS Society provides a support line for people when they're diagnosed and researches into symptoms and cures.'

Tough terrain

The event took place on 23 September at Hever Castle in Kent. 'It was very cold and had been raining all day,' says Chloe. 'It was extremely muddy – people were slipping over and losing their shoes.'

Unfortunately, the cold temperatures meant the planned 200m open water swim – Chloe's favourite event – couldn't take place. Undeterred, she ran 1.8km, cycled 4km and then ran another 1.8km in 51 minutes and 29 seconds – raising a total of £1,045.

'I'm very proud of Chloe,' says Karen. 'It was quite tough terrain and it was cold. I'm very impressed with her and the fact she also connected the event with her Batmitzvah learnings, where she was encouraged to engage and demonstrate a set of values, and hence she was doing this and raising money to help people with MS.'



Have wheels will travel

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

As a mum living with secondary progressive MS, I've recently been on an emotional rollercoaster dealing with a new diagnosis, falls (balance shorts help; if only I had a wedding to go to as they suck you in!) and most noticeably my deteriorating mobility. Little man is a whirlwind like most youngsters. I literally can't keep up with him.

Fire up the scooter

Stubborn pride got in the way of wanting help. As a headstrong individual, I wanted independence. My stick meant

constant pain, wasted energy and not getting very far. I knew I needed another option. Getting a mobility scooter gave me back my freedom. I kick myself for taking so long. Little man's Daddy missed my involvement, which I didn't realise.

Great outdoors

Before MS really hit my mobility, I was no rambler but I always enjoyed walking for its sense of achievement and views. With any disability, you adapt and plan ahead. For my recent Cumbria holiday, I looked at accessibility. The Lake District is renowned for its scenery

so no wonder Beatrix Potter based her books there. I also wanted to recharge to help my fatigue. I knew I couldn't access the countryside on my usual scooter, but discovering off-road scooters are available at some National Trust properties helped me fall back in love with being outdoors and save energy. I might not be sprightly anymore but having wheels meant I could travel. And travel I did!

Whole new world

When you use a mobility aid for the first time, you enter a new world. Going from A to B is quicker but I found we live in a non-accessible world. It's getting better, but you desire ease and not ramming kerbs in the hope of getting around. Hopefully, things will change. At the moment, I'm probably the only non-elderly person using a mobility scooter locally so getting out there with my scooter is my way of breaking down barriers and normalising the sight of mobility aids for all.

I'd love to hear your views on mobility.

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

Visit nationaltrust.org.uk and read the 'facilities and access' information for properties to find out if scooters are available.

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Photos: Kasla Alexiou



There's no place like home

Gus Alexiou on what to consider when making MS-related adaptations to your home

Whether or not you subscribe to the adage that 'an Englishman's home is his castle', home can mean a lot more than that for people with MS. It is also a sanctuary, a safe place and familiar environment.

Shortly after my wife and I had our first child in August 2015, and seeing as we already had my wife's teenage daughter living with us, it became clear that our family and my MS had outgrown our cramped two-bedroom first floor flat in west London. Fortunately, we found a larger property in Ashford, on the border between London and Surrey, which ticked all our house-hunting boxes.

Thinking ahead

There are so many great things about having more space, but I knew that the one downside for me was that it would mean greater distances to cover and more walking.

Last summer, around the time of the big move, I was finding it tricky to work out what impact this might have on my MS, and what I would be able to do about it. I had been diagnosed for 13 years at this

point and was using a cane outside and a mobility scooter to negotiate long distances.

Had my MS been a little milder, I probably wouldn't have given home adaptations a second thought. If it were more severe, I would already have been well versed in the day-to-day high-level adjustments and interventions I would need to rely on to get by.

Applying for grants

I telephoned Surrey County Council and discovered that for this area of the country, there is readily available advice and financial assistance to fund home adaptations for disabled people, up to a value of £1,000.

For anything over £1,000, I would have to apply for a Disabled Facilities Grant, which is a rather lengthy process and is means tested. Even small adaptations would require prior assessment by a qualified occupational therapist (OT) during a home visit.

I began separating out my needs into different categories based on their importance, affordability and the ease of making a case for an adaptation, if I needed to get the go-ahead from an outside agency.



Do-it-yourself

It was hugely important to me that the house was relatively accessible from day one, so I opted to self-fund some inexpensive, but equally indispensable adaptations, as soon as we moved in.

The first of these was a second stair rail to be attached to the wall opposite the existing one. This would enable me to feel properly balanced when going up and down the stairs.

I also purchased grab rails to dot about the house, especially in places where there is a long stretch of flooring or a sharp

turn. These are an absolute godsend and, at around £8 for a pack of two, also a relatively inexpensive solution. There are now over a dozen located around the home, so they are very much part of the furniture.

For me, tactically placed grab rails are a lot more convenient than using a stick inside the house and with no need for wall-walking, the paintwork stays clean too!

Access all areas

After my first meeting with the OT, I requested several off-the-shelf products to help me out with daily tasks including: two trolleys to transport heavier items (one for the house and one for the garden), a shower seat and an over-bed table.

Where my local council and the OT really came into their own was in helping to manage the more complex adaptations, requiring specialist materials and labour.

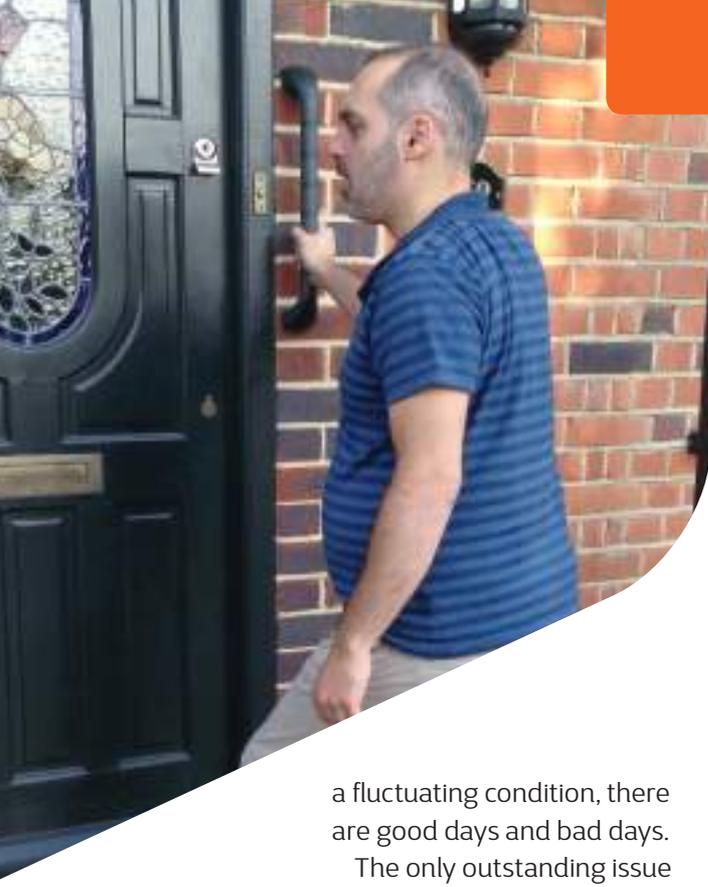
Accessing the garden was problematic for me. The step down from the kitchen was very high and had no support. The patio was wide and long, meaning that I would always need my stick to negotiate it, and there was another small step between the patio and the lawn.

We applied for funding for a couple of new steps by the kitchen door with a galvanized steel handrail. A second long handrail runs the length of the conservatory wall across the patio and a third, smaller rail, was installed to help manage the step down to the lawn.

Expert advice

What was fantastic about these adaptations is that my OT had a really good understanding of MS. It wasn't that I couldn't access the garden at all, just that it wasn't easy. She understood that with MS being





a fluctuating condition, there are good days and bad days.

The only outstanding issue is the access to the front of the house, where there is a small step up. We installed a couple of grab rails on either side of the front door, so this is fine when on foot, but accessing the property with my scooter still causes problems.

The ultimate solution will be to build a full access ramp to the front door, with a remote door locking mechanism that

will enable me to drive right in. Building this will take us well over the £1,000 threshold, so I'm applying for a Disabled Facilities Grant from the council. Assessors and engineers have already visited me at home to spec out the job.

Luckily, because I own a small folding mobility scooter, I can lift it over the step. It's a bit of an inconvenience for now but it will do until the proper solution can be put in place.

Timely support

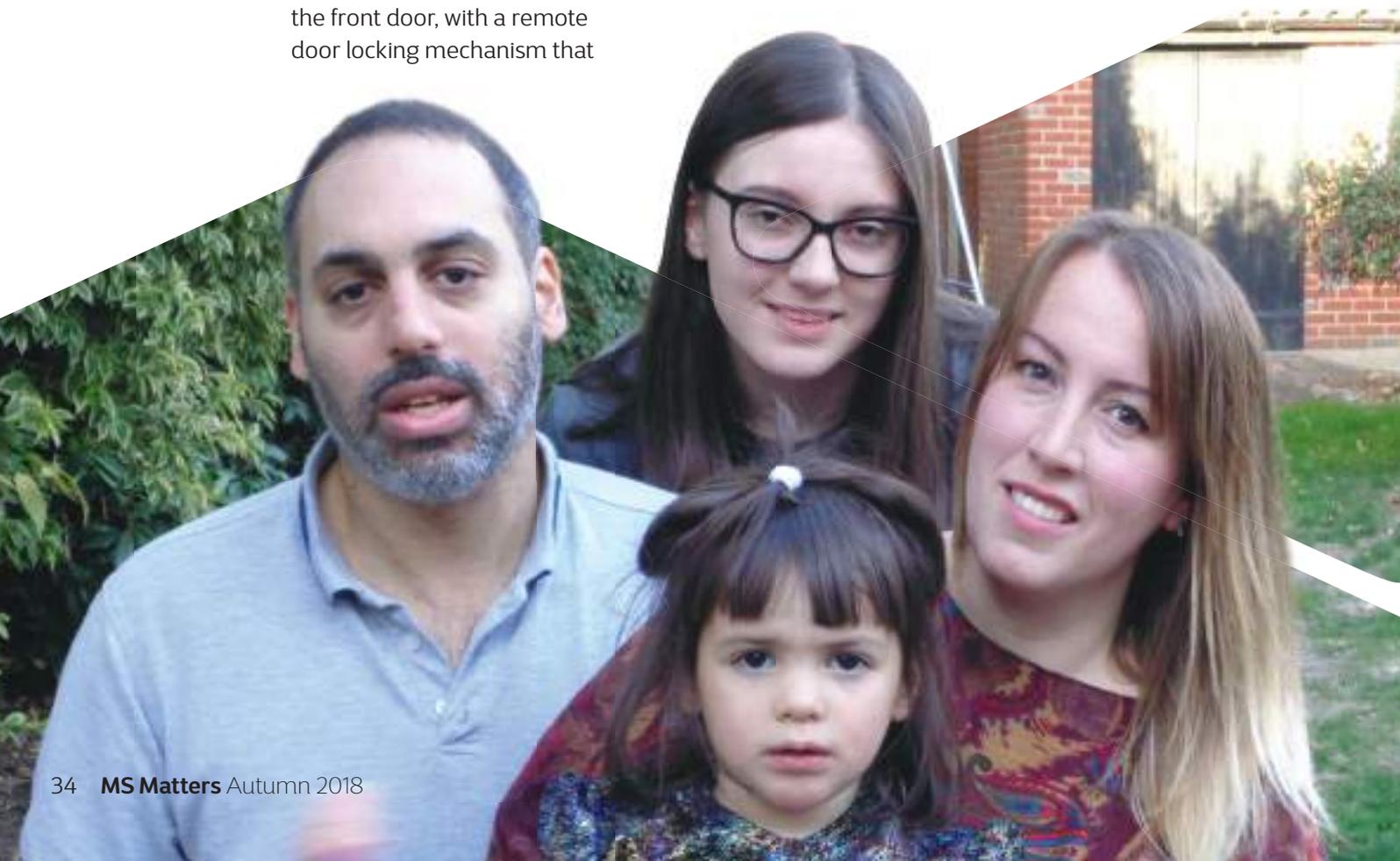
My advice to anyone considering adaptations to their property that are paid for by their local council is to always telephone them to check what the rules are for your area. In Northern Ireland, it's not your council that you go to but your Health and Social Care Trust or the Northern Ireland Housing Executive.

There is variation between different authorities – so it is unwise to assume anything – but a quick call to the Adult Social Care department will put you straight in the know.

The key is also to request help in a timely manner. There's no point in waiting until your MS makes your home completely inaccessible. Even the less costly adaptations need to be approved, funded and scheduled and that all takes time.

The good news is that sources of help do exist. Even if your mobility issues are quite severe, relatively simple, inexpensive measures can make a world of difference and help you feel like King (or Queen) of your castle once more.

Visit [mssociety.org.uk/home-adaptations-for-more-information](https://www.mssociety.org.uk/home-adaptations-for-more-information)



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The undervalued role of caring

Elaine Moore on why the social care system must do better for carers

Fact one: I have MS. Fact two: over the years my care needs have increased. Fact three: my husband John didn't marry me 36 years ago to become my carer. I'm sure it never occurred to him that after my diagnosis in 1991 he would take on all the household tasks, become my transport service and deal with elements of my personal care. He certainly couldn't and didn't plan for it but he does it because he loves me.

Hitting a brick wall

In the early years John struggled to cope as he tried to balance his own career with a few unnecessarily dramatic relapses on my part and my fast-increasing need for care. In the end he hit a metaphorical brick wall and slid down it in a heap. John's story is not uncommon – Carers UK report that 75% of carers suffer from mental health issues at some time. Lifestyle changes were necessary and, sadly, he gave up working to become my full-time carer.

Inadequate benefits

John was now in a position where he could claim Carer's Allowance. Wow! Carers

are really valued by the government, aren't they? The princely sum of £64.60 per week, reduced if you have other income, not guaranteed to increase each year, taxable and stopped as soon as you start receiving state pension. (What, did you expect to be able to claim more than one state benefit?) And don't get me started on how much unpaid care saves the government each year.

More support

Carers of people with MS have a difficult and constantly changing role. Many need

more support. And they need it now. John has never received any support but we're fine. We work as a team, facing each new MS-filled day with humour, albeit rather black at times. John's now receiving his state pension so as he's no longer considered a carer by the system, he says I'm on notice that his care could be withdrawn at any time!

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



We're holding the government to account on their promise to improve social care, so people with MS and their carers get the support they need. Visit mssociety.org.uk/end-care-crisis to find out how you can join our campaign.



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‘We want to turn a negative into a positive’

Tam Firth (36) and her three younger sisters found that fundraising has provided an outlet for their grief

Our mum Pip was 62 when she died earlier this year. She had progressive MS, which was diagnosed a couple of years after having my twin sisters, Rose and Jane, who are now 25.

Mum’s care was a huge part of our lives for the last six years. She went from being an extremely active lady – who loved gardening and aerobics

– to losing the use of her legs, her ability to drive and her independence.

She struggled to make phone calls for appointments, open letters, retain information, remember things like birthdays and to take her medication. We ended up having to run her life and think for her in every aspect of it.

Mum was a very proud lady, and it was heart-breaking to watch her deteriorate. When she passed away on 27 March, we were all there to say goodbye.

The last few months have been a blur of grief but now we’re trying to be positive and move forward. We’ve done a lot of fundraising together as a family over the last few years.

Three Peaks Challenge

My sister Sam (34) ran the London Marathon and the Bath Half Marathon for the MS Society a few years ago. In October, she completed her biggest event yet – the Three Peaks Challenge – climbing Ben Nevis, Snowden and

Scafell Pike in 24 hours with five friends to raise more than £5,000. We’ve all dealt with our grief differently and, for

Sam, pushing herself to become stronger through exercise has helped.

While Mum was alive, we did several comedy nights and a 1950s-themed night. She was very

sociable back in the day;

Dad used to be a DJ and she was a go-go dancer. When she was well enough, she came to some of the events we organised. Whenever we came up with fundraising ideas, we’d run them past her and she’d say: ‘that’s fantastic, thank you very much’. Altogether, we’ve raised nearly £9,500 for the MS Society, with more events planned.

Mum was a lovely, fun, kind, beautiful lady. Hopefully, by fundraising, we can help people with MS – and other families going through this – realise that they’re not alone. If something positive can come out of losing Mum, then pouring all our energy into it is such a good thing to do.



Pip with Tam's daughter Grace (left); Pip and Tam at a fundraising event (inset)



SAM (SECOND LEFT) TOOK PART IN THE THREE PEAKS CHALLENGE WITH HER FRIENDS, RAISING £5,000

Photo: Paul Moane

A new approach to growing our community

Following the AGM in September, we're moving forward with new ways of growing a strong and inclusive MS community by transforming the way we connect with people

In the summer edition of MS Matters, we talked about how the ways people connect with us have changed, and the challenges and opportunities this presents. We also said how important it was to remove barriers that might be excluding people from our community, to make sure we're reaching everyone living with MS who needs our support.

Building on our heritage, we want to make it as easy as possible for people to engage with us, to reach thousands more people who would benefit from the help and support we

offer. One way of doing this is through the introduction of a free 'friendship offer'.

We believe this new offer will provide thousands more people in the MS community with an attractive opportunity to access more personalised information and connect with like-minded people. It will also help people to get involved in more activities, campaigns and events, both national and local.

Support at AGM

Because this new approach means changing our current membership model, we wanted to know that you were happy

with the idea in principle.

We proposed a resolution to the membership at the AGM on 22 September 2018 that sought approval to explore this new approach further. Of the 4,000 members who voted, 97% gave approval to proceed. We are delighted with this support so far, but we know we have a long way to go.

What happens next?

In October, we began a nine-month programme to discuss and develop these ideas with a wide range of people including members, volunteers, supporters of the MS Society



Photo: Brendan Foster



Photo: Colin Baldwin



Photo: Ginny Lattul



Photo: Amit Lennon



Genevieve Edwards
Director of External Affairs

We're keen to build the strongest MS community in a changing world and provide better support to everyone living with MS.



and others affected by MS, not connected to us yet. We are kicking off our engagement exercise by talking to volunteers at the volunteer forums throughout the autumn. We will be creating a timetable of future events and opportunities for you to get involved and give your feedback.

Tell us what you think

Now we want to hear from you. We want to know what you, and others, would like to see from a

free 'friendship offer', and what is important to you in terms of being involved in running the MS Society.

Genevieve Edwards, Director of External Affairs, says: 'We're keen to build the strongest MS community in a changing world and provide better support to everyone living with MS. I'm delighted to see such a strong vote in support of us exploring what this potential free "friendship offer" might look like. We want to hear

members' views on this.'

We are excited about the journey we're embarking on with you. We believe we'll develop a compelling offer that will connect us to even more people living with or affected by MS. In doing so, we'll enable people to get the support they want, in the way they want it, and be involved in what interests them. So please do get in touch and get involved to help create the strongest MS community possible.

Email us at supportercare@mssociety.org.uk or call us on 0300 500 8084 to let us know if you'd like to be involved.

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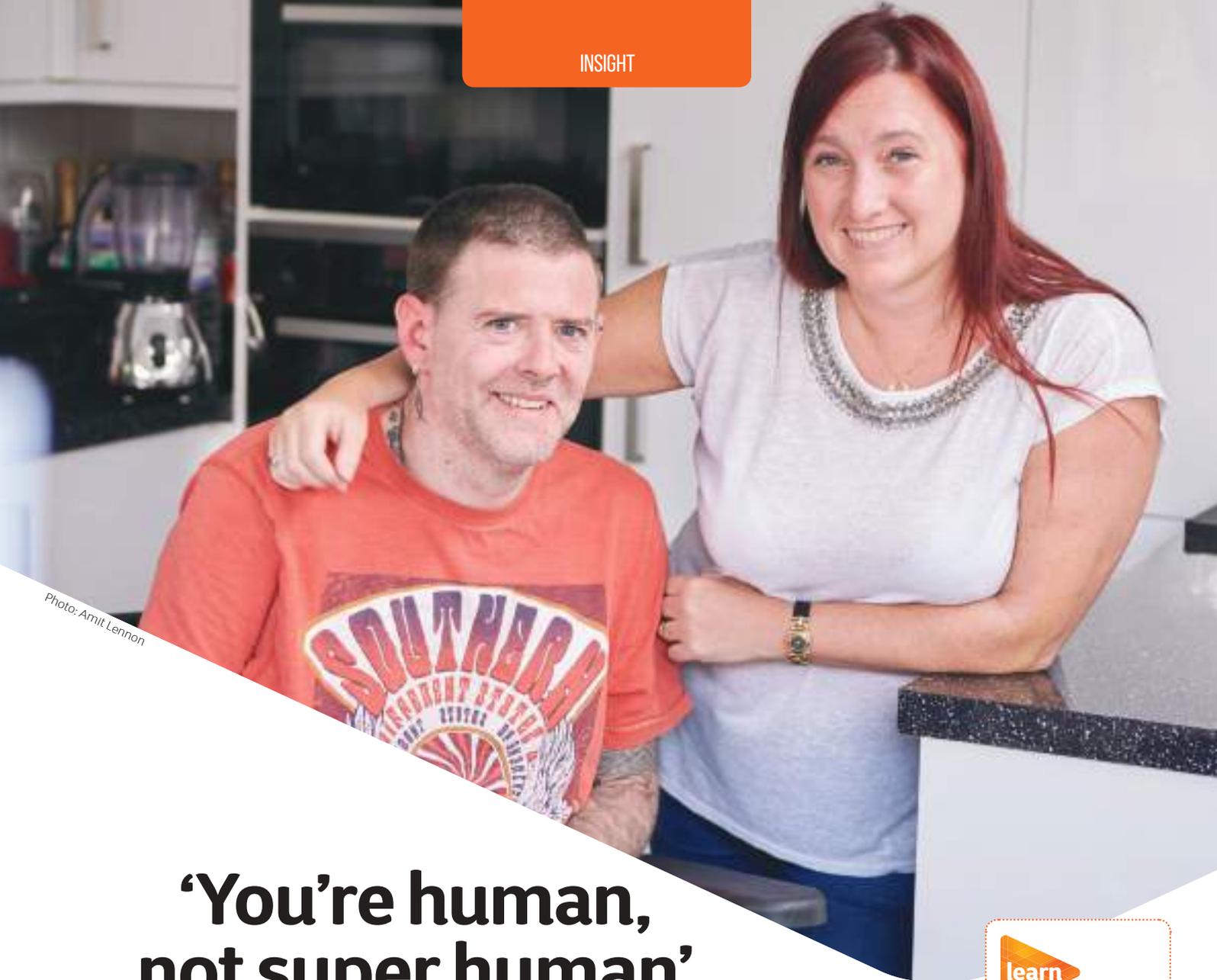


Photo: Amit Lennon

‘You’re human, not super human’

Liz Abrahams, whose husband Neil has advanced MS, offers some tips on looking after yourself as a carer

One of the biggest challenges is when to help Neil retain his independence. He wants to do everything for himself, but I have to be realistic about when to step in and take over. He doesn't always agree. It's resulted in difficult conversations to reach a compromise.

Another challenge is juggling everything. I'm Mum, wife, the main worker, cook, cleaner, DIY and car maintenance specialist, finance officer and homework

club. Now add 'carer' and those responsibilities!

I know many carers face similar challenges. And with all this going on, it's vital to realise that we are just as important as the person we're caring for. My advice is:

- Don't feel bad if you have bad days. You're human, not super human! It gets to us all sometimes. Don't bottle it in. And never feel guilty.
- Make time for yourself. It's easier said than done, but important. Walk the dog, meet

a friend for coffee, go to the gym, have a long bath...

- Prioritise what's important. Who cares if your house isn't tidy today? It can wait.
- Nothing comes to you. You have to do things for yourself. Research into help you can get and don't be embarrassed to ask for it.
- Most importantly, talk to people. Join MS and carers groups, including ones on social media. It was the best thing we did. A problem shared is a problem halved.

learn

Liz and Neil helped us produce our new booklet, **Advanced MS: a carer's handbook**. It's full of practical advice for carers – from looking after your back when lifting someone to accessing financial support. You can order it from the online shop or view it at mssociety.org.uk/advanced-ms

Top tips for getting more active

Leanne Atkins, Senior Neurological Physiotherapist at University Hospitals of Derby and Burton NHS Foundation Trust, offers advice on fitting physical activity into your everyday life

Starting to become more active can be a challenge, especially if you haven't done much exercise before and you live with MS. But gentle or moderate exercise can help with many MS symptoms and, most importantly, make you feel better. Everyone's MS is different so there isn't a one size that fits all rule; listen to your body and pace yourself with activities.

1 Try to fit activity in little and often during the day. For example, when you're watching TV, you could complete 10 bicep curls with a small weight or water bottle. To challenge yourself, try to complete a different exercise every time

there is an advert break. Or when waiting for the kettle to boil, you could complete 10 heel raises holding onto the kitchen worktop for support.

2 Keep all your joints moving and muscles active. If you sit down for most of the day, whether you are at work or because you use a wheelchair, small movements like bending and straightening your knees or marching your legs up and down can be vital to keep your joints in good working condition and help to prevent pain.

3 Try to 'sit up tall' and 'stand upright'. Think of your posture like a building. If it's not stacked upright with good

foundations, it might start to fall over like the leaning tower of Pisa.

4 Going to the gym isn't for everyone but consider doing some light exercise to help build up your stamina. Yoga, Pilates, Tai Chi and swimming are all low impact activities. Remember you can adapt exercises to suit you in the class environment. If you use a wheelchair, research activities such as chair-based yoga or locate swimming or hydrotherapy pools that have graduated steps or hoist access.

5 MS is unpredictable which means there will sometimes be good days and bad days. Listen to your body and don't over strain yourself. Try to balance your daily jobs with enough rest during the day – doing things all at once will increase fatigue.

learn

Go to mssociety.org.uk/staying-active for some simple workouts for MS or visit csp.org.uk/loveactivity

for advice from the Chartered Society of Physiotherapists on becoming more active.

Spitfire flight proves the sky's the limit

After David Staples was diagnosed with MS, he was determined to fulfil his ambition to fly in a 1940s Spitfire

I've spent the last 44 years flying around the world for my work, which involves helping people plan, design and build theatre buildings. I've worked in 67 countries and spent 22 months in the air, travelling on virtually every type of commercial aircraft. I've always had a hankering after flying in a Spitfire, which I think is the most beautiful aircraft ever designed.

Three years ago, I was diagnosed with primary progressive MS. For the first couple of months afterwards I was shell-shocked and had a lot of reactions: grief, anger, 'why me?', despair. But with the help of family,

friends and wonderful medical professionals, I recovered my equilibrium. I thought if ever there's a time to fly in a Spitfire, now's the time.

On 15 September 2018, Battle of Britain Day, just before noon, I took off from the Imperial War Museum Duxford in a Spitfire Mark 9. The peaceful purpose of my flight was to raise money for the MS Society. Thanks to the extraordinary generosity of friends and family, I raised over £4,000.

When I knew the date of my flight, I did a bit of research about what happened on that day. Exactly 78 years earlier on 15 September

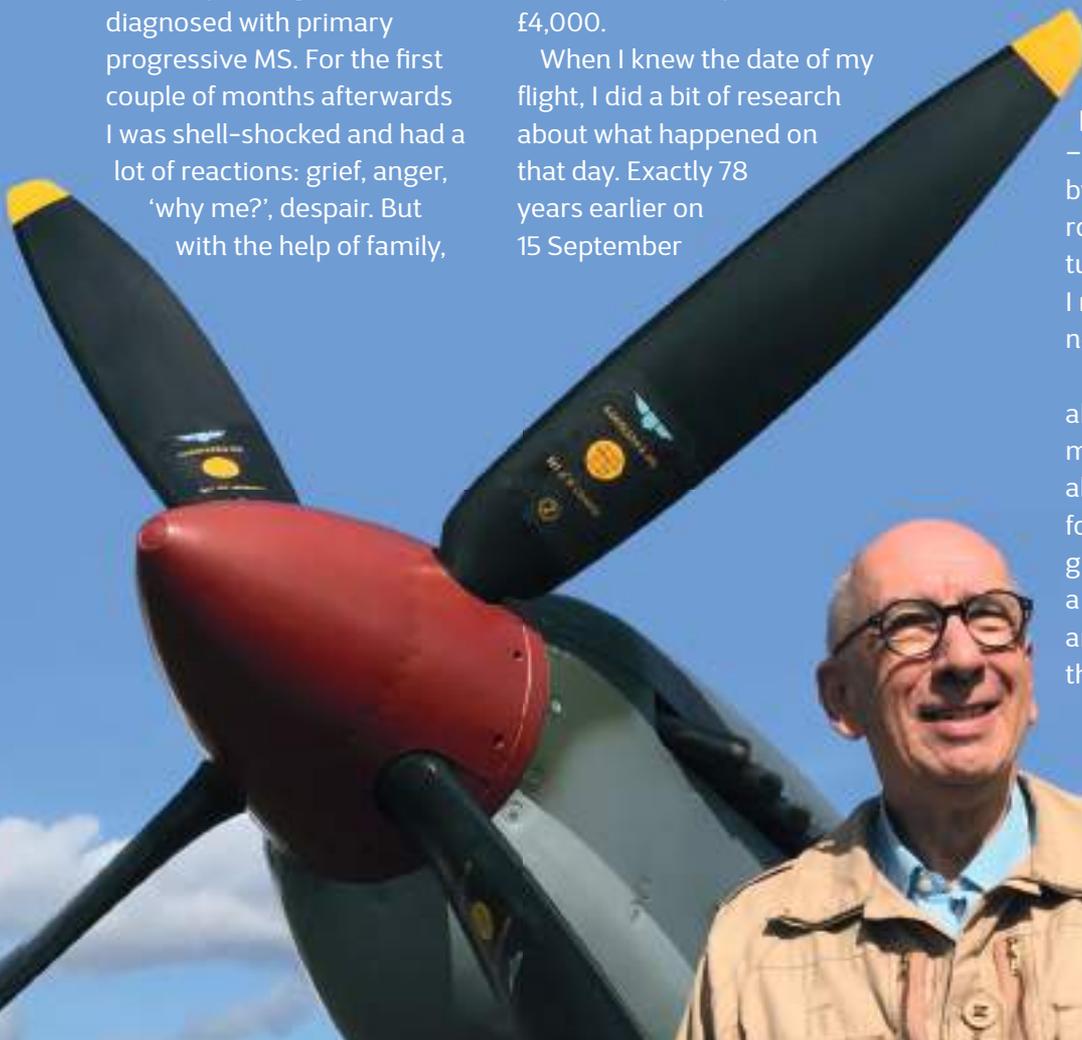
1940, just before 12 noon, Squadron Leader Douglas Bader led an attack from Duxford. I liked the symmetry of this, as Bader was disabled himself and remains an inspiration to everyone, especially to disabled people.

The flight itself was a wonderful experience. The pilot did some aerobatics – a very tight turn, followed by a barrel roll and a victory roll, during which the plane turned through 360 degrees. I must admit I felt a little nervous about my breakfast!

For me, the best thing about it was that 16 family members and friends came along to watch – including four members of my local MS group from Haringey. They're a wonderful group of people and it was very moving that they came to support me.



LEFT TO RIGHT: TARA, DAVID, LUCY, ELAINE AND JULIA FROM HARINGEY MS SUPPORT GROUP



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Ballet for MS

Scottish Ballet is starting an exciting new project – dance classes for people living with MS

These classes will be a gentle and fun introduction to dance, appropriate for all abilities.

Dance Health Officer Tiffany Stott says: 'The class is designed to develop movement skills with focus on fluidity of movement, balance, coordination, expression, posture and rhythm. It features elements of many dance disciplines including ballet and contemporary dance.'

To kick things off, Tiffany ran a taster session at our recent Living with MS information day in Dumfries. 'The taster sessions will help us tailor our classes for people with MS, based on feedback from those who take part,' says Tiffany.

Paul Kellas, who lives with MS, gave it a whirl.

'In the past I enjoyed dancing – clubbing wise,' he says. 'This was

different. I signed up as it was something I wouldn't normally get the chance to do.

'It wasn't actual ballet as such. Part of it was like salsa, part like an exercise class. It was a fantastic way to exercise. I try and exercise at home but a lot of it is by doing day-to-day stuff. I don't often have the energy to do extra exercise. During the ballet class I forgot I only have a limited amount of energy, I was so caught up in it.'

Inclusive and sociable

Paul says: 'We had a warm up and then gradually went into the dancing. It was very inclusive – whether seated or standing, everyone was taking part.

'The salsa was enjoyable and social – we were all in good spirits and there was a nice vibe. The only thing I found hard was

the speed, and I'll feed that back.

'The thing I enjoyed the most was the social aspect. It was a good way to come together as a group. I think it made everyone happy! There were lots of smiles, lots of warmth and a bit of laughter. I left on a high, feeling quite elated and energised. I'd definitely sign up for a class.'

Scottish Ballet hopes to start running regular classes in spring 2019. One class will be in Glasgow at Scottish Ballet headquarters. A second location is yet to be confirmed. Look out for more information coming soon.

share

To help devise the classes, Scottish Ballet would like to find out more about people's needs. If you'd like to chat Tiffany about your needs, email tiffanystott@scottishballet.co.uk

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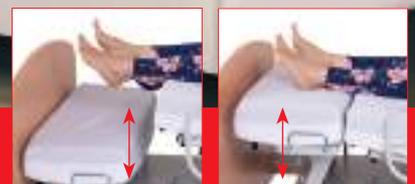
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‘Grants have given me my life back’

How My Ms, My Rights, My Choices is making a difference in Wales

My MS, My Rights, My Choices is supporting the MS community in Wales in a variety of ways, including through making grant applications.

‘So far, we have secured around £34,000 in grant funding for people living with MS in Wales who are in financial need,’ says Sophie Dymont, North East Wales Project Officer. ‘Over £13,000 of this has come directly from MS Society grants.’

‘The kind of things people apply for include scooters, wheelchairs, home adaptations and accessible bikes. We know only too well that people have got less money than ever before; the grants we are able to support people with are helping to fill the gap.’

Wheelchair struggles

Hayley Driscoll from Pontypridd (pictured), who was diagnosed with MS in 2009, received

an MS Society grant six months ago.

Hayley says: ‘I had been struggling with my wheelchair for a long time – it was so big and awkward, and I couldn’t move it. I was very, very down. I really wanted to get out and be more active but I felt like a prisoner in my own home.’

‘I saw some information about MS Society grants in MS Matters a few years ago but I didn’t do anything as I thought they were just for people who were really destitute.’

Joining the gym

Hayley adds: ‘Then I heard through my local group that support was available and

talk

If you live in Wales and need support to make a grant or a benefits application, call 0808 800 8000 or email mymscymru@mssociety.org.uk



decided to apply for a grant. Not only did I get £1,450 for a new scooter from the MS Society, but Tim from the My MS, My Rights, My Choices project also helped me apply for a Turn2Us grant to join a gym with accessible equipment.

‘Since having the grants, I have gone from 0 to 100. Being able to join and attend the gym has opened my outlook in life. I’m like a social butterfly now – I’ve made so many new friends and I’m now spending quality time with people. The grants have given me my life back.’



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A road trip to remember

Why a Newcastle couple drove 2,000 miles in a vintage Land Rover

KELLY THOMAS (25) and her boyfriend Thomas Hartley (26) spent two weeks driving their restored 52-year-old Land Rover 2,000 miles around the UK in September to raise £988 for the MS Society. Their journey took in John O'Groats, Land's End and many places in between.

Kelly, whose mum has MS, wanted to do something to raise money and awareness for the MS Society. When the couple rescued the beat-up Land Rover from Tanfield Railway they saw an opportunity to do just that. It took mechanic Thomas 18 months to restore the Landie, which the couple named

'Phoenix Overland'.

Kelly says: 'By travelling the UK in what was once a clapped-out and forgotten old banger, we wanted to represent the strength and fighting spirit seen in so many people with MS every day. Phoenix Overland is all about restoration, mobility, and especially togetherness, as we believe no one should face MS alone.'



In memory of William Pope

We recently received the sad news that William (Bill) Pope died on 4 June 2018, aged 94.

Bill was diagnosed with MS in his early 30s and was well known to the MS Society in the East Dorset area,

where he and his wife June made their home from 1987.

Bill's life was a testament to living well with the MS. He was a promising drummer in his youth, winning a Melody Maker award in 1945 with the Ron Goodwin Band. Following that, he worked with the GPO until 1994 when MS forced his early retirement.

Bill attended and supported physiotherapy sessions

run by his local MS Society group, and kindly arranged for the MS Society to receive a donation from his Will and for donations to be made to us at his funeral. We are very grateful to Bill and his family for these generous gifts.



To find out more about funeral donations or leaving a gift in your Will, please speak to Adam on 020 8827 0374 or adam.west@mssociety.org.uk



communityviews

It's good to talk

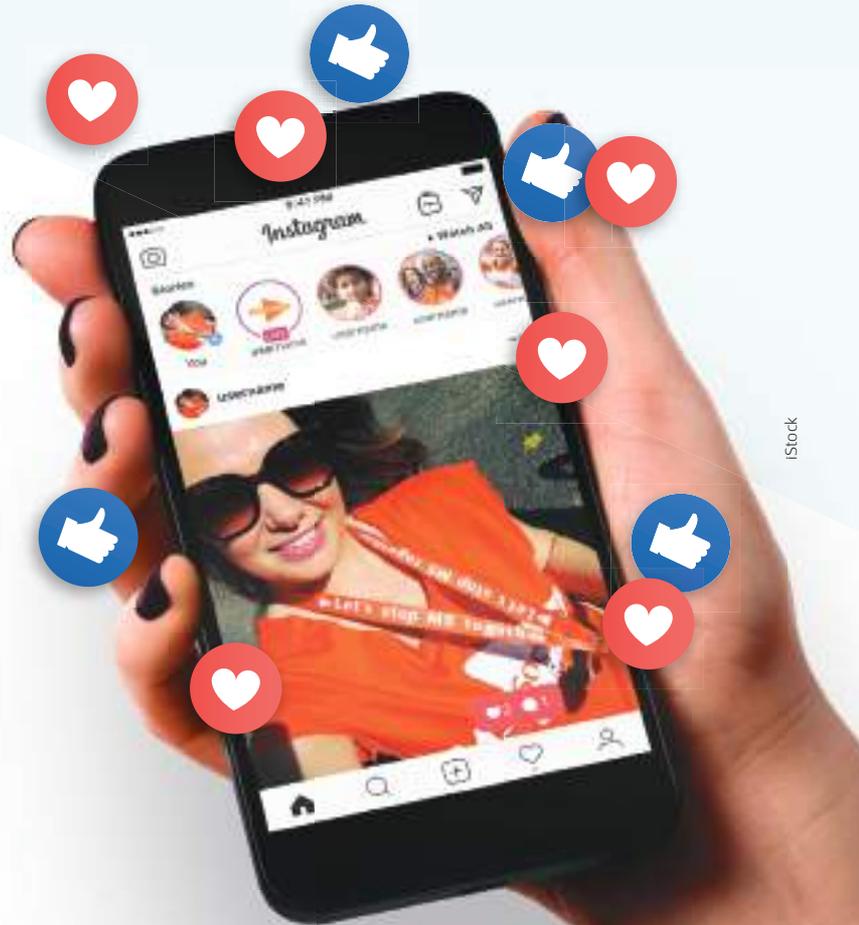
Lucie shares some thoughts on her diagnosis on our Instagram feed

WHEN I WAS DIAGNOSED, I took it fairly well as it had been mentioned to me as soon as I'd been diagnosed with optic neuritis...What I would say to someone newly diagnosed is to talk about it as much as possible; talk to friends, family, colleagues...I'm still surprised by how little knowledge there is of this condition, and the preconceived ideas people have of this. So, talking can only help people to understand and help you to cope with everything this disability can throw at you!

Lucie's post prompted others to comment on their diagnosis.

Rob Not being shy, not being ashamed but being open and talking about it was the best thing I did to help me come to terms with my diagnosis...Any questions you have contact your MS nurse support team...If in doubt check the @mssocietyuk forums.

Andy I started with the diagnosis of optic neuritis and was warned from the start it could be MS...it still came as a shock when I was diagnosed, however talking helped me massively. I am due to start treatment shortly due to volume of relapses but have no plan to let the MS monster win!

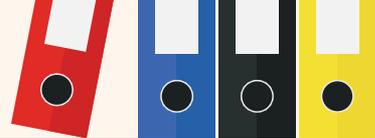


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‘I’m determined to achieve my goal’

CAITRIONA WROTE TO MS

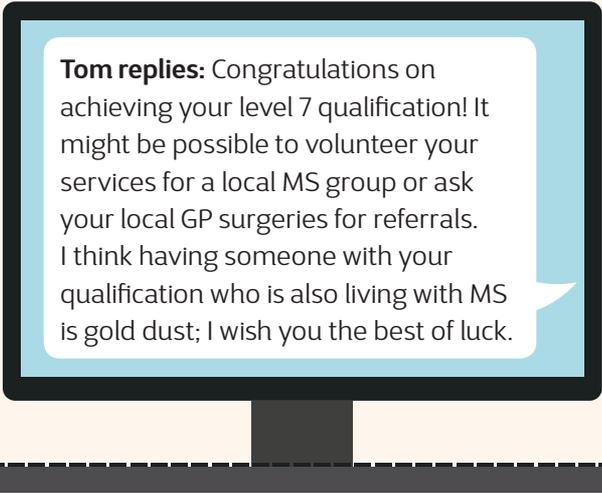
Matters after reading about the counselling service in Northern Ireland led by Tom Hunter (summer issue, page 32).

‘I have just completed a level 7, four-year psychotherapy course. Unlike most of my cohort, I’ve been unable to secure sufficient counsellor volunteering placements.

‘Because of my MS, the radius within which I feel I can confidently drive reduces the number of potential agencies with whom I can work. Within that radius, several agencies

only have counselling rooms upstairs. Others have required supervision well outside the radius; others require that you have accrued 100 hours of experience before you can volunteer.

‘Reading Tom’s article has boosted me. As I have primary progressive MS, I was questioning whether by the time I can get official validation as a therapist, my neurodegeneration will prevent me from achieving my goal – but I’m even more determined to achieve it now.’



Tom replies: Congratulations on achieving your level 7 qualification! It might be possible to volunteer your services for a local MS group or ask your local GP surgeries for referrals. I think having someone with your qualification who is also living with MS is gold dust; I wish you the best of luck.

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Photo: Julie Howden



Photo: Helen MacDonald/Wardrobe Conversations

‘I make MS visible through my designs’

Designer **Kirsty Stevens** is the first Design Champion for the new V&A design museum in Dundee – and her work is inspired by her MS

I WAS DIAGNOSED with MS in 2007 while studying for a degree in Jewellery and Metal Design at Duncan of Jordanstone Art School in Dundee. I decided it would be best for me to take a year out to come to terms with this. In that year I realised that living with this new chronically ill ‘label’ was manageable and not half as daunting as I’d first thought. But I also learned that MS was so unknown and misunderstood by people.

After my return to university I spotted a design trend which was heavily focused on science. And then it just hit me: I could use myself as a science project and design from my magnetic resonance imaging (MRI) scans. I based my degree show on my experiences of living with MS and it had a great response. It allowed people, including myself, to talk about MS freely without awkwardness. I knew I had to continue using this as my main creative focus.

Inspiring my career

It was a few years after uni when I managed to get back into designing and using my MS as the source for my design work. I went back to my

MRI scans and thought they were so intricate and delicate.

I also got thinking about how MS is an ‘invisible’ illness and how the damage caused by MS can only really be seen on scans of the brain and spinal cord. I decided I had to make MS visible by designing from these lesion shapes.

My designs are made into jewellery, scarves, stationery and prints. With these, I raise awareness of MS and give people a better understanding of what MS does to the body.

A beautiful transformation

It gives me a sense of taking control of my MS. As I design and transform these shapes into something beautiful, so far from the original scan, it becomes a relaxing but also exciting process. It makes me forget all about my MS!

I’m currently working on a colouring book full of patterns designed from my lesions. It’s been in the pipeline for a while but, you know, life and MS can get in the way. I’m putting a twist on it so it’s accessible to everyone, so keep a look out for it...

See Kirsty’s work at charcot.co.uk

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