Open Door
Quarterly newsletter of the MS Trust
May 2016

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How can occupational therapists help people with MS?
Open Door meets MS specialist OT, Gilly Burdon, to find out

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Taking control: what should you be considering for the future?
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Mags Lewis: putting MS on the political agenda
Play the MS Trust’s weekly lottery and try your luck to win up to £25,000, while contributing vital funds to help people with multiple sclerosis. 50p of every £1 you spend will be donated to the MS Trust.

You could be our next lucky winner! Visit mstrust.org.uk/lottery or call Unity on 0870 050 9240 to play the MS Trust’s weekly lottery.

“A big thank you, I received the cheque today! I have progressive MS which was diagnosed two years ago. The win will definitely come in handy right now.”
Paul from Norfolk won £1,000!

The promoter of this Unity lottery is Joanne Sopala, Multiple Sclerosis Trust, Spirella Building, Bridge Road, Letchworth Garden City, SG6 4ET. Registered with North Hertfordshire District Council under the Gambling Act 2005. Licence no. LICSL/01006/16
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Welcome to the May issue of Open Door!

How was MS Awareness Week for you this year? Here at the MS Trust we’ve been very busy spreading the word about our Let’s make MS care fair campaign, and helping lots of you raise funds and have fun with your Be Bold In Blue events.

We are always blown away by your efforts and this year looks set to be the busiest and most successful yet. Your support is vital to our work, and allows us to raise awareness and make a real difference to the quality of specialist services that people with MS rely on. On behalf of everyone at the MS Trust I’d like to say a huge thank you.

For some of you, who first came into contact with the MS Trust as results of this year’s awareness week, this may be your first issue of Open Door. I hope you find it interesting and useful, and I look forward to hearing your comments.

In this issue we take a close look at the value of occupational therapy and speak to Gilly Burdon, an MS specialist occupational therapist based in Hereford. We’re very interested in the way that Gilly works in partnership with her MS specialist nurse, and it’s an example we’re going to incorporate into our MS Forward View project, exploring innovative ways of making sure everyone with MS can access good quality care.

Also in this issue we hear from Mags Lewis, the Green Party disability spokesperson, who has been living with MS since 1994. Disability issues have been making a lot of headlines recently, and regardless of whether you agree with her politics, it’s great to see someone with MS making their voice heard on the national stage. Before I go I should also thank all the generous artists and art enthusiasts who have supported this year’s Secret Art Show. We received over 470 artworks the size of a CD case from more than 250 different artists, which we have been selling anonymously via our website over the past few weeks. Our shop at mstrust.org.uk/secret-art-show will be open until 18 May, so there’s still time to browse the remaining art to see if there is anything you like. The identity of the artist remains a secret until you receive your artwork in the post, so if you have a keen eye you could snap up a valuable piece for a great price!

Best wishes

Pam Macfarlane
Chief Executive, MS Trust

Articles marked by an asterisk have been produced in accordance with the Information Standard
In February the Public Accounts Committee published its report into services for people with neurological conditions.

The report by the influential parliamentary committee recognises the ongoing challenges facing neurology services, finding that, despite a similar review in 2012, there is still wide variation across the country in access, outcomes and patient experience.

The report warns that neurological conditions are not a priority for the Department of Health and NHS England, and raises a number of specific concerns about neurology services including that:

- diagnosing neurological conditions takes too long
- services in hospitals and the community are variable, leading to unsettling disparities in outcomes for people living with neurological conditions
- there is scope to give patients better access to neurologists by using existing resources more effectively
- the confusion over commissioning responsibilities is leading to ineffective commissioning of neurological services.

The committee describes its report as a wake-up call to the Department of Health and NHS England. Its message to the NHS chiefs is clear: progress on neurology services has been nowhere near good enough for far too long, and people with neurological conditions are suffering as a result.

**Turning recommendations into actions**

The report states unequivocally that neurological conditions are not a priority for the Department of Health and NHS England and that services for neurological conditions are consistently not good enough, with wide variation across the country in access, outcomes and how people experience services.

The reiteration that neurology services within the NHS require urgent attention is very welcome and extremely timely given NHS England’s proposal to cut the role of neurology services within the NHS.

“Progress on neurology services has been nowhere near good enough for far too long, and people are suffering as a result.”
of National Clinical Director for Neurology (a post that the report strongly recommends keeping). But how do we make sure that this vital analysis does not become just another tome on the bookcase of similar reports finding that neurology services are all too often the poor relation?

The Public Accounts Committee previously reported on neurology services in March 2012, making six recommendations aimed at improving services and achieving better outcomes. But in July 2015, the National Audit Office found that the Department of Health and NHS England had made good progress against only one of those recommendations, with progress against a further three assessed as poor, and the remaining two as moderate.

A 2015 report by the Neurological Alliance found that neurology has largely been ignored by local commissioners, with only 20 per cent of Clinical Commissioning Groups able to even identify the number of people using neurological services in their local area, let alone develop a thorough understanding of their needs.

As a result, neurology services continue to lag behind other conditions in service quality, availability and access, as seen in recent news that over half of people with MS in the Southern Trust area of Northern Ireland are waiting more than 18 weeks for a first appointment with a neurologist.

Working with the NHS to improve services for people with MS

The kind of rigorous scrutiny brought to bear on neurology services by a body as influential and well respected as the Public Accounts Committee can only be a good thing. However history would suggest that this report, on its own, is not enough to bring about changes in leadership, accountability, planning, funding and delivery of services that are necessary to see real improvements. That is why, earlier this year, the MS Trust launched MS Forward View: an ambitious programme bringing together everyone with a stake in the future of MS services to find ways to look at how MS services currently work, find ways to make best use of resources and skills to make sure specialist services work for everyone, and explore how we might measure what equitable care looks like in practice. Our ambition is that this work will help NHS England deal with the challenges highlighted by the Public Accounts Committee.

We launched our MS Forward View project because we believe that the MS Trust has a duty to use our skills and resources to work with the NHS to help improve services for people living with MS.

The Public Accounts Committee expects NHS England to report back to them by April 2017 on what it has done to make best use of the available neurologists and reduce variations in access, including through redesigning services and making more use of other clinical staff, particularly specialist nurses.

By mapping the MS workforce, looking at the skills needed to deliver what people with MS need, and identifying how commissioning systems can support service improvement, MS Forward View will directly tackle this challenge and provide a potentially valuable resource for NHS England.

Recommendations for minimising the risk of PML with Tysabri

The European Medicines Agency has carried out a review of the known risk of progressive multifocal leukoencephalopathy (PML) for people taking Tysabri and recommends that, for those at higher risk of PML, MRI scans should be carried out every three to six months.

PML is a rare but serious brain infection that can result in severe disability or death and is a recognised, but rare, risk for people taking Tysabri. Currently everyone on this medication should undergo full MRI scans at least once a year. The new recommendations suggest that people at high risk should have MRI scans every three to six months.

People are considered at higher risk of PML if they have:
• tested positive for JC virus and,
• been treated with Tysabri for more than two years, and
• have used an immunosuppressant (for example, azathioprine, cyclophosphamide, mitoxantrone or methotrexate) before starting Tysabri or, have not been treated with immunosuppressants but have a high JC virus antibody index.

These EMA recommendations will now be sent to the European Commission for a legally-binding decision.

To estimate your risk of developing PML visit clinicspeak.com/understanding-pml-risk-on-tysabri

For more about MS Forward View visit mstrust.org.uk/forwardview
New research in brief

**Drinking coffee may reduce risk of developing MS** Researchers have reported that people drinking more than 900 ml of coffee each day, roughly equivalent to three average-size mugs, are up to 30 per cent less likely to develop multiple sclerosis than people who drink no coffee. The researchers recognise the limitations of this kind of study which depends on how accurately people remember what they did in the past. They also point out that no firm conclusions can be drawn about cause and effect. To read more visit [mstrust.org.uk/coffee](http://mstrust.org.uk/coffee)

**Encouraging results from ozanimod drug trial** Ozanimod is a drug that works in a similar way to Gilenya (fingolimod) but with fewer side effects according to recently published research. Researchers in America and Europe compared two different doses of ozanimod with placebo in people with relapsing remitting MS. The main outcome measure of the trial was a reduction in the number of new lesions visible on MRI scans. The groups taking ozanimod had an average of 1.5 new lesions compared to 11.1 in the placebo group. To read more visit [mstrust.org.uk/ozanimod](http://mstrust.org.uk/ozanimod)

**Phase II study of epilepsy drug shows promise in optic neuritis** Results of a small study suggest that the epilepsy drug phenytoin may have a neuroprotective effect and could potentially be beneficial in people with MS. To read more visit [mstrust.org.uk/phenytoin](http://mstrust.org.uk/phenytoin)

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**Participants needed for MS-SMART secondary progressive MS trial**

The MS-SMART trial is looking at drugs that may limit the progression of MS. Researchers have been recruiting people with secondary progressive MS from across the UK, but are still in need of more people to volunteer to take part.

The trial will involve three drugs that are currently licensed for other conditions:
- fluoxetine for treating depression
- riluzole for motor neurone disease
- amiloride for high blood pressure and heart disease

Studying drugs where the safety profile is already known potentially saves years off the time usually needed to test newly-developed treatments. Previous studies have suggested that these drugs might be neuroprotective, protecting nerves from further damage from MS.

Participants will take one of the drugs or placebo for two years, but no one will know which treatment they are taking while the trial is on-going.

To take part in the trial you must:
- have a diagnosis of SPMS
- be aged 25 to 65 (inclusive)
- have had a steady progression of clinical disability in the preceding two years
- be still able to walk at least 20 metres (with the support of 2 crutches) or up to 500 metres without help
- be able to have an MRI scan

You can’t take part in the trial if you are taking certain medications including MS disease modifying drugs, fluoxetine, citalopram, escitalopram, and sertraline.

There are study centres across the UK, but the researchers are in particular need for more participants in the London area.

The MS Trust is not involved in the recruitment for this study. For further details about the study, visit the MS-SMART website at [ms-smart.org](http://ms-smart.org) which lists the hospitals involved in the study, more details on taking part and the opportunity to express an interest in participating.
In February this year, four friends who met at the University of Birmingham completed a 3,000 mile row across the Atlantic Ocean to raise funds to help people with MS. With over £70,000 raised so far, Jo Sopala, Director of Fundraising and Marketing at the MS Trust, writes about the Atlantic Lions’ journey taking on the ocean and taking on MS

At 1:21am UK time on Wednesday 10 February, after 51 days at sea, the Atlantic Lions rowed into Nelson’s Dockyard in English Harbour, Antigua for an emotional reunion with family and girlfriends.

The fact that they had spent 51 days at sea was particularly poignant for the team, especially David Middleton. This adventure was inspired by David’s uncle Gary, who sadly passed away aged 51, having battled MS for many years. Their boat, Tiny Dancer, bore the race number 51 in memory of Gary. Whilst the Lions admitted it would have been nicer to spend fewer days combatting wind, waves and sores, somehow it was meant to be.

The Atlantic Lions are four very special young men. David, Charlie, Matt and Joe met at Birmingham University and became best friends. David’s family have been big supporters of the MS Trust since 2008. In fact, David ran the London Marathon for us in 2011, so you might think he’d already contributed significantly. But knowing David, I wasn’t at all surprised when he rang to say he wanted to do something else to raise funds and awareness for the MS Trust.

I have to admit, I was taken aback when he told me the plan to row the Atlantic. Was that even possible? I think my first words were, “are you crazy?”, but I knew once he’d made his mind up, he was going to do it. What surprised me even more though, was that his three friends were willing to take on the challenge for the benefit of people with MS too. The strength of their friendship is humbling and their commitment to the cause has been magnificent.

Over the past eighteen months we’ve got to know the Lions very well and we’ve been amazed by their determination and drive. So far they have raised over £70,000 for the MS Trust, but before that they had to raise a significant sum to even participate in the challenge. There were race fees, the cost of a specialist boat, 60 days’ worth of food for four people and lots and lots of Sudocrem – all of which needed to be paid for before the race. The four of them worked tirelessly, as well as holding down full time jobs, to raise the funds needed.

There were rowathons, gala dinners, Caribbean events, swimming galas: you name it, they tried it! But they didn’t do it alone. The Pride is made up of family and friends who were unflinching in their efforts to raise the funds needed to get the Lions to the starting line, plan the logistics of getting the Lions and Tiny Dancer to where they needed to be, and promote the Lions’ magnificent efforts to raise funds for the MS Trust.

The Pride has provided phenomenal support and we at the MS Trust can’t thank them enough. I know the Lions will admit they couldn’t have done it without them. Special thanks must go to Geordie Hayward, Steve Middleton, Jackie Middleton, Ollie Hayward, Rose Reynolds and Kitty Soos who have enabled us all to share the Lions’ adventure through social media and regular updates.

At the MS Trust we received wonderful messages to pass on to the Lions from the MS community, which helped to keep them going through their toughest days at sea. People affected by MS have been amazed that anyone was willing to put themselves through this to support them.

We’ve all laughed and cried at their blogs, we’ve been moved and inspired by the Lions and now we are truly grateful they are safe and well. So from all of us at the MS Trust and on behalf of people with MS across the UK: THANK YOU LIONS!

Read the full story of the Lions’ achievement at mstrust.org.uk/lions
**Research update**

**MS AND TASTE**

**Can MS affect your sense of taste?**

Problems with taste are thought to be an extremely rare symptom in MS. This study looked at if the ability to taste was changed in people with MS.

**Authors** Doty RL, et al  
**Title** Taste dysfunction in multiple sclerosis  
**Journal** Journal of Neurology 2016; 263 (4): 677-688  
>> Read the abstract: tinyurl.com/ms-taste

**The study**

73 people with MS and 73 control participants matched for age, gender, ethnicity and education level took part in the study. Each participant took part in a taste test where the researchers placed a small amount of liquid containing a sweet, salty or sour ingredient onto part of their tongue. The participant then had to identify what type of taste it was and also how intense they perceived the taste to be. Usually on the same day as the taste testing, participants with MS also underwent MRI brain scanning using gadolinium enhancement.

**The results**

The study found that participants with MS had more problem identifying tastes than the control participants. Participants with MS rated the intensity of the bitter taste lower than control participants, but were still able to rate the intensity of the other tastes appropriately. Those participants who had more trouble identifying tastes also had a larger volume of lesions as seen on MRI brain scans. Overall, in both the MS and control groups, women were better at identifying the tastes and also rated them as more intense than men. This is probably because women have more taste buds.

**What does it mean?**

This study demonstrates that more people with MS could have problems with taste than previously thought. The results also suggest that MS has a stronger effect on the ability to taste and identify the type of taste, rather than how strong the taste is.

**Taste in MS**

Our sense of taste is important. It protects us from eating things that are dangerous or unsafe. Our tongues are covered in thousands of taste buds, that recognise five main tastes: sweet, sour, bitter, salty and umami (which can be described as a savoury taste). Women tend to have more taste buds than men. Taste is closely related to smell, as these combine together so you can experience complex flavours.

As this study shows, problems with taste could also be a symptom of MS. So eating a variety of nutritious food may be difficult, as certain foods may not taste as they should and may not be enjoyable or pleasant to eat.

If you are concerned about changes in your taste or are struggling to eat a balanced diet due to other symptoms, you could speak to your MS specialist team or GP. They may be able to help directly or may refer you to specialist support, such as from a dietitian or speech and language therapist.
Which leisure activities can help memory in MS?

About half of all people with MS have problems at some time with aspects of thinking such as memory. This study examined which leisure activities were related to better memory in people with MS.

Authors Sumowski JF, et al

Title Reading, writing, and reserve: Literacy activities are linked to hippocampal volume and memory in multiple sclerosis

Journal Multiple Sclerosis Journal 2016 Feb 26. [Epub ahead of print]

>> Read the abstract: tinyurl.com/ms-activities-memory

The study
242 people with MS in Italy and the United States took part in the study, all were aged over 25. Participants were asked about the leisure activities they had participated in since their early twenties. These activities fell into six different categories: reading, non-fiction writing, art, playing a musical instrument, games and hobbies. They also completed several tests that assessed their memory and had their brains scanned to look at the size of the region that is involved in memory (the hippocampus).

The results
The researchers found that doing more reading and writing activities was linked to having better memory. The area of the brain involved in memory was also larger in the participants who took part in these activities.

What does it mean?
The study shows that engaging in literacy activities, such as reading books or writing a diary, from early adulthood, could help memory in people with MS. This could be because as adults most of our new knowledge comes from reading about things and this could help protect the brain areas involved in learning and memory from MS-related cognitive problems. Although the study did not find a benefit to memory from activities involving art, music, games or hobbies, the researchers suggest this may be because these activities may involve learning and remembering in a different way, and may use a different area of the brain to the one looked at in this study.

The researchers suggest this research could lead to programmes of activities that could be used as brain training to help to keep the brain and mind healthy and protect against memory problems in people with MS.

Managing memory and other cognitive symptoms
Cognitive difficulties is the term used to describe a range of problems with slowed thinking, such as poor memory, attention span or concentration and difficulty following complicated instructions or problem solving. Cognitive symptoms are common in MS but may not be recognised. Management of these symptoms involves finding strategies that minimise the difficult. For example, if you have trouble remembering where you’ve put your car keys, always putting them in the same place will help.

You can find more information, tips and strategies for getting around cognitive symptoms, including memory problems, on the StayingSmart website. StayingSmart was developed by the MS Trust in partnership with Professor Dawn Langdon, a neuropsychologist at Royal Holloway University of London. The Tips and Tricks section includes ideas shared by people living with cognitive symptoms, while the Gadgets and Gizmos section features readily available equipment that may be helpful.

For more information, tips and strategies for getting around cognitive symptoms visit stayingsmart.org.uk
Supporting the children when a parent is diagnosed

This study looked at the needs of families where one parent had been diagnosed with MS, to identify any issues that could be addressed to make it easier for a child to cope with their parent’s MS.

The study
23 people from ten families in Sweden took part in the study. They shared their experiences in focus group interviews. Parents with MS, parents without MS and the children were interviewed separately. The interviews consisted of open questions related to the course of MS, from first symptoms until the time of the interview, as well as any needs they had or experienced.

The results
In the families interviewed, some had open communication about MS, while others felt they should keep it from their children. Many parents said they found talking about MS complicated as there was so much uncertainty around the condition and the conversations were emotional and difficult. However the children interviewed wanted to know more about it.

Some of the children already knew of someone with MS and assumed their parent would have the same experience, which in many cases worried them.

Others said seeing symptoms without any explanation to describe what they were was scary and made them anxious.

When there was little family communication about MS, the children tried to keep their feelings and worries to themselves, some asking their school or teachers for support or searching the internet for information on their own.

Many reported they became more protective of the parent with MS.

Some children reported they felt more secure after their parent had been diagnosed, as they got to see and spend more time with them.

The main theme that emerged from the interviews was parents’ desire to communicate better with their children and their partners, and to support their children through their MS journey.

What does it mean?
This study shows that MS affects the whole family and understanding and communication within the family shapes how well children can cope with the situation. Some parents may want to be brave about it or keep it secret but this can create barriers which makes the children anxious and worried. Health professionals could help support and empower the person with MS, by recognising that the family as a whole needs support.

Talking to children about MS
As well as being a person with MS, you may be a partner, parent, brother or sister, friend and work colleague, among other roles. After diagnosis, choosing whether to tell other people and if so, when to tell them, and how much to tell them, can be a complex decision as well as a very personal one. Telling children and discussing the changes that MS brings can be particularly challenging for some people. Likewise, the children of a person with MS can sometimes find it difficult to explore their feelings about MS and how it affects them.

The MS Trust has developed several resources to help families talk about MS and help children understand MS and also realise that they are not alone in the feelings that they may be experiencing:

• Talking with your kids about MS (for parents),
• Kids’ guide to MS (for 6-10 year olds) and
• Young person’s guide to MS (for 10-16 year olds).

To find out more order the books on p23 or visit mstrust.org.uk/family.
Gilly, can you tell us briefly what occupational therapy actually is?
Occupational therapy is about trying to enable people to remain as independent as possible. It’s a patient-centred approach where we work with people to identify the issues they’re having and what areas of their life they’d like to be able to engage in more. We look at ways to address their problems and hopefully enable them to become more independent or remain doing what they enjoy for as long as possible. This could be anything from enabling someone to be able to prepare a meal themselves, to joining their family to take their dog for a walk, to being able to use their computer more easily.

How did you become an MS specialist OT?
After I qualified as an OT, I moved to London where I had a role at the National Hospital for Neurology and Neurosurgery which is where I first worked with people with MS. When I left London I knew that I wanted to be working in a neurological setting, but ideally with people with MS. However, this didn’t seem likely, because I was moving to a rural area where there’s less scope for specialists. But when I moved back to Herefordshire I met up with Del Thomas, the clinical specialist MS nurse here. She was negotiating a new MS OT role and luckily I got the job.

How did Del demonstrate the need for a specialist OT?
Del is responsible for over 550 people with MS. The Care Quality Commission identified her service as needing support, so there was scope to change how the service was configured. A lot of the people she saw were struggling with fatigue. She was also having to provide increasing support in order to help to remain in work. She felt an MS specialist OT would be ideally placed to address these issues.

How do you help people manage fatigue?
Over 80 per cent of people with MS experience fatigue. It’s very common but it can be hard for people who don’t have MS to understand its impact. My role is to offer support to the person. I help them to understand what fatigue is and identify what type of fatigue they have. Together we identify strategies, which can help them to reduce their fatigue and manage their energy levels more effectively throughout the day.

What kind of strategies do you suggest?
It’s a good idea to try to incorporate rests into the day. There’s been lots of research carried out into the benefits of rest. The evidence suggests that having 20 minute rests, staggered throughout the day, can help people get through their day without having that afternoon crisis period when they feel they can’t carry on.

Other strategies include looking at someone’s lifestyle and the activities they’re doing in the day. Can we reduce some of the jobs they have to do? Can we delegate some of them? And then can we prioritise what’s really important to them?

It’s not about taking away roles or routines, it’s about looking at how we can get people to be as productive as possible through being really efficient at managing energy. A lot of it is about forward planning. For example, rather than being really busy on a Monday and Tuesday and then spending the rest of the week recovering, looking at ways to spread activities out, so people don’t experience the peaks and troughs.

How do you help people with issues around work?
My role is to ensure that people are aware of their rights, what help is available to
them, including what services are out there and how to access them.

I help people to draw up possible reasonable adjustments which they can make at work. Often I visit people in their work environment to list the different roles they carry out and what difficulties these pose. I’d then write a report of my findings and send it to the employer with a list of reasonable adjustments. Following that we’d meet with the employer so both parties can negotiate the proposed adjustments.

People can be supported to remain in work in many ways, for example, by introducing flexible working hours or reducing the amount of work somebody is given to do. I would also assess how somebody is able to access their work environment. For example, if somebody has got bladder difficulties, can we make sure it’s easy for them to get to the loo?

**Do you think your work with the MS nurse is a good model?**

Del and I share the same office so communication is fantastic. Although we’re busy, we’ve still got time to discuss patients, and we can update each other about any issues that are happening, which can only be a positive thing in terms of providing an efficient and ongoing service for people with MS.

Del has identified that more people with relapsing MS are starting on disease modifying drugs. This is great because it means people are being proactive about treating their MS. But monitoring the drugs takes up an increasing amount of nurse time. From my perspective, I think OTs are perfectly placed to help, by working with people with MS on the issues that are affecting their everyday lives.

It’s quite dynamic for Hereford to have an MS-specific OT, I think. There are not many of us in the UK, so it’s an incredible opportunity for me. My in-depth knowledge of MS helps me to really understand people’s symptoms and the problems that impact on their everyday lives.

**How does the MS Trust support you?**

The MS Trust are so supportive. I attend their fantastic annual conference which is partly subsidised by the Trust. I also went on the week long foundation course they offer to new MS specialists, from which I learned a lot and was able to consolidate my knowledge of MS.

The outcome from the course was a piece of research. The aim of which was to develop an area of my OT service. One of the areas in which I was lacking was my handwriting assessment. Although I could assess people, I didn’t have access to any adaptive equipment to trial with them. So although I could highlight the fact they were having difficulty, I wasn’t able to explore what might make things easier.

By doing my research I was able to produce a business case and secure the funding required to purchase the equipment. So I am now able to offer an holistic approach to handwriting, because I can enable people to trial different pieces of equipment to see what works and what doesn’t. It’s amazing how a small thing like helping people to write can make a big difference to their confidence. For someone to be able to write a birthday card to a loved one and be satisfied with the style and quality of their handwriting is hugely important.

I displayed my research as a poster at the MS Trust conference last year, and was amazed to win first prize. It was fantastic to win and for my work to be acknowledged. I didn’t even know there would be a prize! It was £500 to put towards training. I can now put that towards a course later this year.

**New ways of delivering MS specialist services**

At the MS Trust we believe that Gilly’s partnership work with Del, the MS specialist nurse, is a really interesting model for supporting people living with MS. It’s one of the examples we’ve been looking at in our MS Forward View project, exploring how we can best ensure that MS services work for everybody – whether they have relapsing remitting or progressive MS.

We’re going to be publishing the findings of MS Forward View this autumn. To find out more visit mstrust.org.uk/forwardview

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**Why I’m cycling London to Paris for the MS Trust**

I have always been a sporty person. And so, after all the MS Trust has provided for me, I just wanted to give something back! They provide such a great service to MS health professionals but also obviously to people with MS too. I’m on their website all the time, looking up information for people I work with and learning things myself. I’m mentoring an occupational therapy student at the moment and she’s using the MS Trust website a lot too for her studies during her placement.

I’ve decided to learn how to ride a road bike, because I’ve never done that before, so I’m very excited, if not a little nervous. I have begun training. I’m up to about 25 miles a session but I need to start upping it a little and getting on with it really. 100 miles a day for 4 days! It’s going to be hard, but it will be worth it.

I would be delighted if anyone would like to sponsor me through my website: virginmoneygiving.com/gillyburdon

To hear more from Gilly, Steph and Katie visit mstrust.org.uk/MS-OT

Find out more about MS Trust challenges and events at mstrust.org.uk/events
How Gilly helped me

Steph is a music and performing arts manager at an FE college. She was diagnosed with MS in 2008.

Steph: I had a baby 18 months ago. I’d had a really tough pregnancy. I had a back problem which stems from an MS-related foot issue, so I was in a lot of pain. Then after I had my son, I had an MS exacerbation. Del my MS nurse could see I was struggling and that’s when she referred me to Gilly. Gilly had just returned from maternity leave herself and that was really reassuring: speaking to someone who had a baby and also understood MS. Gilly made loads of recommendations about how I could manage better day to day around the house.

Katie was diagnosed with MS in 2008.

Katie: I first met Gilly through work. I was working as a dietician and I was having a few problems so I contacted Del the MS nurse. Gilly: Del referred Katie to me because she was struggling with high levels of fatigue. We did an initial assessment where I got lots of info about Katie’s MS. We made a list of what the issues were. Fatigue was one of them, but there were also work-related issues. We worked out that some of Katie’s main problems were due to cognitive changes.

Katie: I would talk to friends and they’d say, “Do you remember what we were talking about last night?” And I’d be like, “I know we were talking about something... But no I don’t.”

Gilly: I referred Katie to the neuropsychological team, and they carried out an assessment.

Katie: It was nerve-wracking, to begin with. They test your memory and ask you lots of questions.

Gilly: It looks at all of your cognitive abilities, not just memory. The results showed that Katie’s cognitive problems were a result of her MS. Once that was established, we could look at strategies for managing these issues and it was clear that memory was the biggest issue for her.

Katie: Initially I struggled with going to bed. I’d lie down and think: have I locked the door, have I done this, have I done that, is everything ready for tomorrow? All night, back and forth. So Gilly helped me make a little checklist. If I got to the bottom I’d know everything’s done and I can go and count sheep.

Gilly: When I first met Katie she used to have so many lists: lists of lists of lists. It was all quite overwhelming. So we looked at trying to eliminate all the masses of paper and just use one strategy – which is now Katie’s diary.

Katie: I put in there what I’ve eaten, who I’ve seen, where I’ve been, my appointments and how they went.

Gilly: We’ve also worked on making plans realistic and achievable. Instead of trying to do five things, Katie now focuses on doing one or two things really well.

Katie: I really wanted to get involved in the local carnival last summer. But instead of trying to enter all the baking and craft competitions, I decided to just focus on the fancy dress competition. And I won first prize!

Gilly: With regard to the carnival, by scaling down her aspirations she won it, which was fantastic! Katie had a reassessment of her cognition about 18 months after the first assessment. That was really positive. It highlighted that Katie’s made some great improvements as a result of our work together.
MY STORY

Making our voices heard

Mags Lewis was diagnosed with MS in 1994. After a career as a manager in the NHS, she’s now the Green Party disability spokesperson, and hopes to stand as the party’s candidate for Leicester at the next general election. She tells Open Door why she thinks it’s important for people with MS to get involved and make a difference.

First signs
Looking back on it, I had my first attack when I was 15. I was coming up to my GCSEs and I used to play the violin quite well. Around that time my fingertips went numb, and my playing standard and writing speed both suffered. They put it down to a virus and nothing more was said. When I was 24 I noticed a kind of numbness in my face and I was feeling really, really tired. I realise now that could have been MS fatigue, you know: when even blinking feels like too much of an effort.

Then in 1994 I was visiting my boyfriend in Newcastle and I woke up and I was feeling numb, and I knew I wasn’t safe to drive home. And I went to the doctor there, and he was the first to mention having tests to rule out MS. From then on I knew it was a possibility. I had an MRI scan about a month later and it was confirmed.

In fact it was my GP who told me I had MS, which is quite unusual. When I eventually saw a neurologist he told me if it had been up to him, he probably wouldn’t have even told me that I had MS. “I want you to go away and forget about it,” he said. “Go and live your life.”

Reassessing what’s important
I suppose I did try to forget about it, but it just plays on your mind. On the one hand you feel incredibly guilty because you think – I’m so lucky, I look fine, my symptoms are pretty mild. On the other hand you’re 24, 25, you feel your whole life crashing down. For a while you think I’m going to wake up and not be able to move. So it takes time. It’s hard to be told go away and forget about it. Because you can’t.

In some ways it wasn’t all a bad thing, though, because it made me reassess what was important to me. I’d been a very high achiever, working really hard, for really long hours, going to the gym before work. It made me reassess what was important to me. It did change my outlook from thinking my career would be the be-all and end-all for 10 years. It gave me a different perspective.

A dual perspective
I was halfway through an NHS management scheme when I was diagnosed. I was very interested in working in healthcare before I was diagnosed, but then it became even more important. Having that dual perspective of manager and a patient was quite useful to me, especially when I came to manage neurology services when the Risk-sharing Scheme came along, with the introduction of the first MS drugs, and this whole influx of cash into MS services.

I was involved in appointing the MS nurses here in Leicester and I thought to myself I might need to use you one day. And of course I do. The MS nurses here are great. There was nothing like that before. I know that if I was diagnosed today I would get really good care, right from the start.

New opportunities
I didn’t have to tell anyone apart from those closest to me and occupational health until 2004. Before my daughters were born I had another mild attack, but up until then I was OK. I noticed my foot was getting weaker, but I didn’t have that many concerns apart from the fatigue. Work were fantastic when I told them. I had to reduce my hours and that meant a financial hit. But work helped me do that. I know from experience that not everywhere is so understanding.

I was a very professionally driven person, so it was really hard deciding to stop working. I felt it was so much a part of how I saw myself. But I’d got to the point where even three days a week felt too much. I was unable to take my children to school or do anything else outside of work. So it felt like it was time to rebalance.

So we thought there was an opportunity for me to get more involved with the Green Party politics and do some good for people with disabilities in other ways. So I’m very busy now but I feel like I have more control over my work/life balance.
Becoming politically active
I’d always been fairly leftwing in that my family had always supported the Labour Party. But when we had our kids I started thinking much more seriously about environmental and social justice issues and what we were leaving for them. And that’s when I got involved in green politics and in 2007 I joined the Green Party. When I joined it was quite small, but we had a surge in support last year.

Being active in politics can sometimes feel even busier than having a conventional job. But I try and limit myself to one evening meeting a week. It was really tough in the run-up to the election, because I was standing for council. I was absolutely shattered for about a month. It was a reminder that I can’t do a lot of late evenings. It’s really annoying, but it’s a reality.

I’m mobile, but I do find walking long distances an issue as I have foot drop and wear an FES device. Obviously a lot of politics happens in London. When you go down there you might find that a tube station says that it is wheelchair accessible, and it is. But they don’t tell you that it’s a 15 minute walk from the station entrance to the platform. Which is a big issue for me. Disability isn’t all about being in a wheelchair.

I’m really pleased to also have a national role as disability spokesperson for the Green Party. I’ve got to meet some really interesting people. It gives you more of an overview of the challenges disabled people face. Not just people with MS, but across the spectrum. I feel passionately about disability rights, but also the green issues. For me it was a dream position really.

The Green Party subscribes to the social model of disability. If someone uses a wheelchair, for example, and they can’t access the local shop, it’s not that person’s fault, it’s society disabling that person. Vast swathes of the population have some kind of disability. If the way society is structured means that they can’t take a full part, they’re missing out, but also society is missing out. Because there are so many incredibly valuable people with so much to give who happen to have a disability.

New challenges
At the moment I’m really concerned with the hidden cuts affecting people with disabilities. Everyone talks about ATOS and PIP. But for me, trying to maintain the support packages disabled people have is equally important. I notice that the Red Cross Centre round the corner from my home has shut. They’ve got rid of the disability equipment aid budget. The hidden story for this is that for some people these were lifelines, and they’re gone.

The NHS is facing huge challenges of course. It’s scary from where I’m sitting. One of my real horrors is the homecare delivery market. Lots of people with MS have their drugs delivered to their home addresses. I know I experienced huge problems with private delivery services. I ran out of medication several times and spent several days, waiting and on the phone, in tears, trying to get my medication. And when I looked it up online it was happening to thousands of people. I was wondering - why aren’t they taking the contract away from them?

And then I realised it was because there was no one to take the contract back. The way it’s been set up, private companies can claim VAT back on drugs that are delivered to someone’s home, while the NHS would have to pay 20 per cent VAT. The market has been set up in a dysfunctional way. As an ex-NHS manager I thought, if I have an attack because I didn’t take my medication, the people who are going to pick up the pieces are the NHS. I’ll probably be admitted to a neurology ward. I’m sure there are good examples of private companies working in the NHS, but there are some terrible examples too.

The future
I hope to stand as an MP in the next general election. I think it’s important that disabled people see disabled people in public positions, or at least going for positions. Sometimes people tell me they appreciate my work, even the local campaigns. Some day when I’m tired I might walk with a stick, and people say I’m so pleased that you’re doing this. Sometimes you see other people with disabilities and you share that moment when you look at each other and share a common understanding.

I’d recommend that young people with MS who want to be politically active just go for it. It’s really important that our voices are heard. There are so many ways they can get involved online – it doesn’t necessarily mean that they have to go to meetings or go round knocking on doors on election day. Politics can get very frustrating, but every now and then you think - I made a difference! You can really feel energised.

To find out more about Mags and her work follow her on twitter: @magslewisgreen
PRACTICAL TIPS

How to manage common bladder problems

Bladder problems are very common in people with MS. However, with a little practice and some help from an MS nurse or continence advisor, they are often manageable. In this extract from our book, Managing your bladder, we introduce simple tips that can make a real difference.

**Food and drink**

Drinking too much can make bladder symptoms worse because it means you have to go to the toilet more often, and you feel a greater urgency to urinate. On the other hand, drinking too little can lead to concentrated urine that irritates the bladder and makes it prone to infection. The general advice is to drink around one to two litres, or six to eight glasses, of liquid per day (more if the weather is hot or if exercising).

Food and drink that can irritate the bladder and are best avoided include:

- drinks that contain caffeine, such as coffee, tea, green tea and hot chocolate, which can cause irritation to the bladder lining
- alcohol – particularly white wine
- fizzy drinks - carbonated and highly coloured drinks have been shown to worsen some bladder symptoms
- acidic fruit and juices – citrus fruits including grapefruit, orange, lime, lemons and tomatoes
- spicy foods - studies suggest that people who avoid spicy foods, like curry, chilli pepper and cayenne pepper, may reduce their bladder symptoms.

Keep a record when you eat or drink any of these and see if they affect you.

**Keeping a bladder diary**

This can give you an overview of how your bladder problems affect you over time. You can share it with your health professionals to demonstrate accurately what your bladder patterns are.

Write down what you had to drink, eat, any medication you take, when you go to the loo, and any problems with stopping or starting.

If you make any changes, for example the amount of caffeine you drink or starting a new medication, the diary can help you to see how this affects your bladder symptoms.

**Other lifestyle issues**

Being overweight can increase pressure on the pelvic floor muscles and this can result in stress incontinence. Nicotine in cigarettes can irritate the bladder.

**How to train your bladder**

The aim of bladder training is to increase the amount of time between going to the toilet. You gradually increase the time between urinating (this can be just by five minutes). It may take weeks or months to be effective but your continence advisor or MS specialist nurse can put together a timetable to support you to achieve this.

“Changing little things can make a big difference.”

“My MS specialist nurse told me to cut down on caffeine and I just couldn’t believe the difference it made.”
Pelvic floor exercises

The pelvic floor is a sheet of muscles that extend from the tail bone (coccyx) at the bottom of the spine to the pubic bone (at the front). They form the floor to the pelvis and support the bladder and bowel.

Pelvic floor muscles give you control when you urinate. They relax at the same time as the bladder contracts (tightens) in order to let the urine out. In MS neurological damage can result in weakness to the pelvic floor as a result of poor transmission of messages to the muscles by damaged nerves, mainly within the spinal cord. However, this can also be made worse by other factors such as having children, getting older or having surgery in this region of the body. Where bladder symptoms are mild pelvic floor exercises can be helpful. Men and women can do pelvic floor exercises.

Things to try

• You can feel your pelvic floor muscles if you try to stop the flow of urine when you go to the toilet.
• Sit comfortably and squeeze the muscles 10-15 times in a row.
• When you get used to doing this, you can try holding each squeeze for a few seconds.
• Every week, you can add more, but be careful not to overdo it and always have a rest in between sets of squeezes.
• It will take several weeks of regular exercise to regain strength in your pelvic floor muscles.

Working with your health professionals

Ideally before starting any treatment for bladder problems you should have the opportunity to consider all the different treatment options, ask all the questions you need to and discuss any concerns you may have. It is also valuable to have realistic expectations of what the treatment can offer and what the drawbacks may be. Knowing clearly what you would like the treatment to achieve can be helpful in ensuring that you and your health professionals are working together towards the same goal.

It can be useful to think of questions in advance and take them to your appointment for example:
• How long will it take to see any response?
• When will we review how things are going?
• What if the treatment doesn’t work?
• How can I get in touch if I have any problems? Is there a direct number or email?

If you don’t understand what was said do ask for an explanation. You can also ask for copies of any letters sent between your GP and other health professionals including hospital consultants. This keeps you informed and helps you to remember what was said. You should be able to discuss or review your treatment and management at regular intervals or when circumstances change. This can include changing your mind about treatment.

Don’t be afraid to ask your MS specialist nurse or GP to change your medication if you feel it’s not working. It is important to continue with treatment but if it’s not working ask what’s next. It can take some time to find the approach that works best for you.

Health professionals who can help

• MS specialist nurse – MS specialist nurses provide specialist clinical advice and support to people with multiple sclerosis. They often act to coordinate services for people with MS, referring someone on to a doctor, therapist, or other appropriate services. To find your MS specialist nurse see the map of MS services on the MS Trust website. www.mstrust.org.uk/map
• Continence advisor – continence advisors are experienced, qualified nurses who have undertaken specialist training to help people with continence problems. Many services accept self referral or ask your GP or MS specialist nurse to refer you.
• Specialist physiotherapist – physiotherapists experienced in the assessment and treatment of neurological conditions. They can devise and support you with exercise, pelvic floor and bladder training programmes. Your GP or MS specialist nurse can refer you.
• Urologist – doctors who specialise in treating disorders of the urinary tract such as bladder and continence problems. Urology also covers disorders of the male reproductive system such as erectile dysfunction.

To order Managing your bladder, see the form on p23 or visit mstrust.org.uk/bladder
PLANNING AHEAD

Taking control

Life can be unpredictable, and having a long-term health condition brings with it even more uncertainties. As an ex-palliative nurse, and as someone living with a neurological condition herself, Diane Shenton knows this more than most. Here she explains how she found reassurance in taking control and proactively planning for her future.

None of us know for sure what the future holds for us. Some of us may be fortunate and experience few health problems, while others may have more difficulties.

Regardless of this, in my view we all have two things in common. Each of us is born and, regardless of our health status, none of us will live for ever!

Most people plan for parenthood and yet few of us plan for end of life. Perhaps this is because it is an emotive subject and one that we do not like to dwell on. Or maybe we do not think too much about exiting life simply because there is not enough information around and what there is can be difficult to understand.

Whatever our reasons, in my experience planning ahead can be very reassuring. I take great satisfaction in making my own choices rather than allowing others or my condition to control me.

Planning ahead

For example, making my Will has given me a sense of satisfaction, knowing that my possessions will be dispersed according to my wishes.

I have also chosen to complete a Lifebook. In this, I have documented important contact details such as personal wishes and preferences like suggestions for my own funeral. Organisations such as Age UK supply this type of booklet free of charge, but some people prefer to develop their own.

This is also sometimes referred to as a statement of preferences and wishes. It is not legally binding, but if there are people looking after me, they would be required to take my stated views into account as part of any best interest decision.

I have also organised a Lasting Power of Attorney (LPA). Prior to 2007 this was called an Enduring Power of Attorney in England, Scotland and Wales and is still called this in Northern Ireland.

This is a legal document used to choose who I want to manage my affairs and allows me to name a person or people who I trust. Having an LPA is a safe way of maintaining control over decisions made for me.

Information, documentation and registration forms are provided by the Office of Public Guardian for people living in England, Wales and Scotland and the Office of Care and Protection for people living in Northern Ireland.

I completed my registration online. If you don’t have a computer or printer the documentation can be posted out to you. It costs around £110 per LPA. People on means tested benefits may get a reduction or complete exemption of this fee, which is explained on their website. If you prefer, you can ask a solicitor to help with this, but this will add to the cost.

I thought it was important to organise an LPA while I have mental capacity. This is the ability to understand, weigh up, retain and communicate decisions. If not, and I lose mental capacity, other people may need to apply to the Court of Protection to be able to make decisions on my behalf. This can be more costly than the LPA fee, and can be stressful for relatives, friends and carers.

There are two types of Lasting Power of Attorney. An LPA for financial affairs and property enables my attorney (I chose my husband) to make decisions for me both when I have mental capacity and when I lack mental capacity. For example, my attorney can make decisions about paying bills, dealing with the bank, collecting benefits and so on. If I do not want my attorney to have this control while I have mental capacity I can put a restriction on this within the registration documents.

The second type of LPA allows my attorney to make decisions on my behalf regarding health and welfare, for example, decisions on treatment, care and medication. There is a section where I can state what I want, or do not want to authorise my attorney to do, such as giving or refusing consent to life-sustaining treatment.

Talking to health professionals can help you fully understand decisions made and it is important to communicate wishes to those involved so they are aware of my preferences and understand where important documents can be found. And if I revisit my options and change my mind I can do, providing I inform those involved and alter the appropriate documentation.

Organ and tissue donation is a subject which I have also considered. This can be arranged via the NHS organ donation register or with a chosen organisation. This, like leaving a legacy to a chosen charity can be of great benefit to others, as well as giving some purpose to life.
How can palliative care help?

People with MS aren’t always aware that palliative care might be available for them. Research by Marie Curie last year concluded that people with MS are missing out on care that can make a real difference to their quality of life because there is limited understanding from both health professionals and the public of what palliative care can offer, who can benefit and when the time is right to access it. Below Diane shares the story of one woman who benefited.

When I worked as a specialist palliative care nurse at a hospice, a 44-year-old lady called Linda with primary progressive MS was referred to us. She had limited mobility, used a wheelchair and complained of severe neuropathic pain in her legs and feet, which was disturbing her sleep and making her feel anxious.

Following a holistic assessment and planning mutually agreed goals, Linda agreed to attend our day therapy unit at the hospice to participate in relaxation and complementary therapy sessions where she learnt skills to help her to relax and learn new coping strategies.

We also changed Linda’s medication and she responded well to amitriptyline, which helped her to sleep, reduced her anxiety and stabbing pain in her legs. We then added pregablin, which Linda felt controlled the burning pain in her feet. These drugs had previously been prescribed independently and initially at higher doses, which Linda could not tolerate. This regime is not a panacea for all, however, drawing from experience, knowledge and palliative guidelines, we were able to control Linda’s pain.

The hospice physiotherapist and occupational therapist reassessed Linda in her home and were able to make recommendations to improve mobility and independence.

We also discussed the notion of future planning, which prompted Linda to set up a Lasting Power of Attorney with our support.

Six weeks later Linda told us she felt relaxed, comfortable, more independent and pain free. She agreed to be discharged from the service and was happy to contact us again if required.

I recall Linda saying to us, “If only I had known that the hospice could have helped me earlier.” Her pain had been problematic for many years. Before hospice input she was beginning to think that she had no option but consider transfer to a nursing home – a decision which Linda felt at her age was inappropriate.

Planning my future care
As a retired palliative care nurse specialist myself, I am comforted knowing that these services are available to me if required. Palliative care can offer physical, emotional, social and spiritual dimensions to care. It can focus on my quality of life, and help me control my symptoms.

Health care workers such as GPs, nurses, occupational therapists, social workers, physiotherapists and support workers offer palliative care on a day to day basis.

People with more complex needs may require specialist palliative care provided by health care workers who are highly trained and specialise in palliative care. These teams are located within the community, hospitals and hospices.

Although facing some of the topics in this article can feel at the time a little uncomfortable, taking a proactive approach, making decisions and putting things in order has certainly helped me to feel in control and given me some reassurance and peace of mind.

Useful links
Age UK Lifebook: ageuk.org.uk/lifebook
Make, register or end a lasting power of attorney: gov.uk/power-of-attorney
Office of Public Guardian: gov.uk/opg

Have you made plans for your future? We’d like to hear about your experiences for an article in a future issue of Open Door. To share your thoughts email opendoor@mstrust.org.uk
A small idea that grew

For the past six years, MS Trust supporters have been opening their gardens and holding outdoor events to raise funds as part of our summer My Garden Party campaign. 12-year-old Megan Cass tells us about the garden party she held to support families like hers that are affected by MS, and why she’ll be doing the same again this summer.

I first learnt about the MS Trust when my dad was diagnosed with MS and we got some of their publications about understanding MS. Through reading the books and using the MS Trust website, my knowledge of MS and the MS Trust grew. My mum and dad have raised money through sponsored events but I wanted to do something to raise money for the Trust myself.

When I saw the My Garden Party campaign on their website I wanted to organise one. It started off as a small idea but quickly grew. I invited family and friends and asked them all to wear something blue. We decorated the garden with blue and white bunting and my dad even painted the decking blue and white. We organised a raffle and got lots of lovely prizes donated, from a night away in a hotel to hair straighteners and a cuddly toy. My brother did a great job selling raffle tickets to everyone who came. My neighbour also donated a big bottle of champagne for a game where people had to guess the number he had sealed in an envelope.

To keep the younger children entertained, we had soft play and a giant Operation game donated for the afternoon. My uncle set up a little photo booth with some props that we’d bought so that people could have a reminder of the day. Dad was in charge of the barbecue for the afternoon and cooked sausages and beef burgers.

I also held a bake off and over 20 people entered. My brother and I were the judges. Some people had never baked cakes before but wanted to support us. All the bakers won a wooden spoon trimmed with blue and white ribbon and trophies were awarded for best looking cake and overall best cake. We all enjoyed the cakes, although some were better than others!

Everybody who came said they enjoyed it and many people asked if I would be holding another party this year. It was lovely to see everyone joining in, wearing blue and helping me raise money. It was a great afternoon and although it was very busy, I really enjoyed it.

When my mum counted the money I couldn’t believe that my garden party had raised £1,000 for the MS Trust! I was really happy. To put the cherry on the cake, I wrote to Blue Peter and got awarded a Blue Peter badge for raising the money to help people with MS.

I am starting to make plans for another My Garden Party this year, but I am not sure what theme to go for yet.

Could you host a garden party for the MS Trust?

If an afternoon of tea, coffee, champagne, cakes and spending time with friends and family sounds up your street, why not join Megan and host your own My Garden Party in 2016? You can easily raise funds for the MS Trust alongside your celebrations and we will provide all the materials you need to make your party a success.

Your garden party can be as big or small as you wish and you can still take part even if you don’t have a garden – you could have a house party or organise something at a local park. The money you raise will make a real difference for people with MS, helping to provide vital information and support. For more information and to order your My Garden Party fundraising pack, visit mstrust.org.uk/mygarden or call our fundraising team on 01462 476707.
Our new fundraising challenge for 2017 takes place in a sacred land hidden deep within the Grand Canyon in Arizona. We’re looking for MS Trust supporters to join a 45 mile trek and explore one of the most fascinating natural wonders of the world.

The trek is designed to be challenging, with many steep uphill and downhill sections, some overgrown trails, creek crossings, heights and enclosed spaces. It can also be very hot walking within the canyon walls or at night. The local guides were fantastic too. A must for any trekker!

“it is a hidden paradise!” says Kenny Smith, who took part last year. “The scenery is breathtaking and the waterfalls are amazing. You wouldn’t believe what wonders there are one mile down in the ground. Amazing wildlife during the day and blankets of stars at night. The local guides were fantastic too. A must for any trekker!”

It costs £399 to register and you will be required to raise a minimum of £3,250 in sponsorship for the MS Trust. We will provide you with lots of advice and support in the run up to the challenge to help you reach your sponsorship target.

If you or a friend or family member are interested in taking part, please visit mstrust.org.uk/grand-canyon or contact Laura in our fundraising team. We would also be very grateful if you could display the enclosed poster somewhere to help us spread the word.
Amy Mackelden writes plays, poetry and pop criticism. Her most recent book is *Adele: the other side*, published by Eyewear Press. She was diagnosed with MS in 2014 and this year volunteered to join the advisory group of our MS Forward View project. Here she explains why she got involved and what inspires her.

When did you start writing? What inspired you?
I remember trying to write a novel in high school, and writing lots of sketches for my drama group. Creative writing classes at Uni helped me get serious about writing and start submitting my work. I’ve always been more inspired by movies, TV and music than by books. I know a lot of advice to writers is to read as much as possible, but that’s not what inspires me, and I think it’s fine to find inspiration elsewhere.

When were you diagnosed with MS? How did you deal with this news?
I had a major relapse in Oct 2013, but didn’t get my official diagnosis until March 2014. Finding out I had MS was a shock but it also explained a lot of the problems I’d been having – immense fatigue, brain fog, trouble walking far or at speed, tingling and numbness. It wasn’t a fun thing to find out by any means, but it was a relief to know that there was a reason I felt the way I did, and that I wasn’t imagining it. It took a long time to really process the news and understand what it meant for my life.

Did you find anything or anyone in particular that helped you get your head round diagnosis?
My family are very supportive and always let me know there was a place for me at home whenever I needed it. I found that my circle of friends tightened – some people didn’t know what to say, or gave unhelpful advice. I’m sure they didn’t mean to, but having MS has made me reevaluate my friendships. I realised how much of a people pleaser I was before diagnosis, and knowing that I needed to manage my health led me to focusing on the friends who supported me no matter what, never judged me, and looked out for my best interests. One friend spoke to me for hours at a time on the phone and would talk about absolutely anything, and that really helped. Going to the cinema, and binge-watching TV shows helped too, escaping from stress for a while into other people’s stories. I exercised whenever I could, and also had some counselling and CBT. Cheryl Strayed’s writing helped me find confidence in myself again.

Why did you think it was important to get involved with MS Forward View?
I’m so grateful for the care and treatment I’ve received from the NHS and I was keen to be involved in a project that looked more closely at how the system works. Having received treatment in Newcastle, and then in Southampton, I’ve had experience of MS services in the UK and know that the system varies from place to place. I’m very outspoken about having MS, and think it’s important to discuss all the things that could make day to day life better for MS patients.

You’re working on a new show called MS is my boyfriend. Can you tell us more?
I’ve written several articles about different aspects of having MS, and I always try to be as honest as possible. I think life with MS would translate well into a theatre show, and would help give a voice to people living with the disease who feel like there’s not enough information out there, or struggle to be understood by their friends and family. I’d really like the show to deal with many of the subjects that don’t get talked about nearly enough, like the ways in which MS can affect a person’s sex life, or the crazy side-effects some of the prescribed treatments can give. There were so many things I googled when I got diagnosed and couldn’t find satisfying answers to. I want to help rectify that, and demystify MS in any way that I can.

Which 2016 Girls revival are you more excited about: Gilmore or Powerpuff?
Gilmore Girls, definitely. Netflix is the gift that keeps on giving and I’m excited to see what’s happened to all of the characters. Lauren Graham, who plays Lorelai Gilmore, retweeted an article I wrote recently about her, and I’ll definitely be writing many more pieces about the show before the new episodes air.

What would be your first piece of advice to a teenager who’s just been diagnosed?
The best piece of advice I received was to not make any rash decisions. Finding out you have MS is life changing, and it impacts almost every aspect of your life, so put yourself first and give yourself as much time as you need to process it. Only you know what is right for you.
Information from the MS Trust

For a full list of resources or to read online visit mstrust.org.uk/pubs
If you order online you help us cut admin costs and focus on making a difference for people affected by MS!

Making Sense of MS
Little blue book (introduction to MS) MS-444
Living well with MS info sheet MS-443
Core pack MS-448 includes information sheets:
• About MS • What happens after diagnosis?
• Making the most of appointments • Living well with MS
• Sources of information and support
• Publications for people with MS from the MS Trust

Books
MS and me: a self-management guide MS-318
Living with fatigue MS-204
Managing your Bladder MS-429
Primary progressive MS MS-332
Secondary progressive MS MS-458
Talking with your kids MS MS-316
Young person's guide to MS MS-137
Kids' guide to MS MS-286

Factsheets
Clinically isolated syndrome (CIS) MS-321
Diet MS-92
Functional electrical stimulation (FES) MS-211
Vitamin D MS-314
Pregnancy & parenthood MS-134
Cognition MS-144
Spasticity and spasms MS-282
Pain MS-96

DVD
Move it for MS – a DVD of exercises for people with MS MS-246

Delivery details
Title
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Job title (if health professional)
Address
Postcode
Email
Please tick this box if you would like to receive information about the work of the MS Trust by email.
The MS Trust and our trading company value your support and promise to protect your privacy. To read our policy please go to mstrust.org.uk/privacy or contact us for a copy.

All items are free but we are only able to offer free, practical, reliable information thanks to the donations of people like you. With your help we can ensure no one has to deal with MS alone.

I'd like to make a donation of
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I want to Gift Aid this donation and any donations I make in the future or have made in the past 4 years to the Multiple Sclerosis Trust.
This means that for every £1 you donate, we will receive an extra 25p from HMRC at no extra cost to you!

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I am a UK taxpayer and understand that if I pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year it is my responsibility to pay any difference. Please notify the charity if you want to cancel this declaration; change your name or home address or no longer pay sufficient tax on your income and/or capital gains. If you pay Income Tax at the higher or additional rate and want to receive the additional tax relief due to you, you must include all your Gift Aid donations on your Self-Assessment tax return or ask HM Revenue and Customs to adjust your tax code.

Return to MS Trust, Spirella Building, Bridge Road, Letchworth Garden City, Herts SG6 4ET
Registered charity no. 1088353
The right information, in the right place, at the right time for you

Finding accurate, accessible information about MS can be hard. There’s so much out there, and so much of it seems contradictory, hard to understand or just scary.

Fortunately the MS Trust enquiry service is here to help. Our team can help you find the answers you need, whether you want to know more about MS symptoms, drugs, research or ways to live well with MS.

For MS info you know you can trust visit mstrust.org.uk email infoteam@mstrust.org.uk or call freephone 0800 032 38 39