

May 2020

# Open Door

Quarterly magazine of the MS Trust

Multiple  
Sclerosis  
Trust

MS

**"We will keep  
going together,  
united to live our  
best lives"**

The Bunby's (Natasha, Marc,  
London and Deon) on living  
with MS in the family





# Welcome to the May issue of Open Door



As I write this, Boris Johnson has just announced a nationwide lockdown, as the country battles to contain the spread of coronavirus. With things changing daily, it's unclear what

life will be like when Open Door comes out in May, but what I can promise you is that the MS Trust will be here to support you through these scary and uncertain times, every step of the way. Although the MS Trust's office is now closed for the foreseeable future, we are working at home and doing everything we possibly can to ensure the MS community is well informed through this crisis, not only about the coronavirus, but on all

aspects of life with MS, so you can make the right decisions for you.

This issue of Open Door is, as always, jam-packed with informative articles, practical tips and inspiring stories from the MS community. From coping with MS as a family (page 12) to a Q&A on pregnancy and MS (page 18). We really hope you enjoy reading it and that it provides you with some sense of normality in what is such a challenging time for everybody. Take care and stay safe.

**David Martin,**  
Chief Executive, MS Trust



**If you'd like to donate £3 to cover the costs of Open Door, please text OPEN25 to 70331**

Texts will be charged at your standard network rate. For terms & conditions, see [www.easydonate.org](http://www.easydonate.org)

## How we've been working hard for people with MS since our last issue

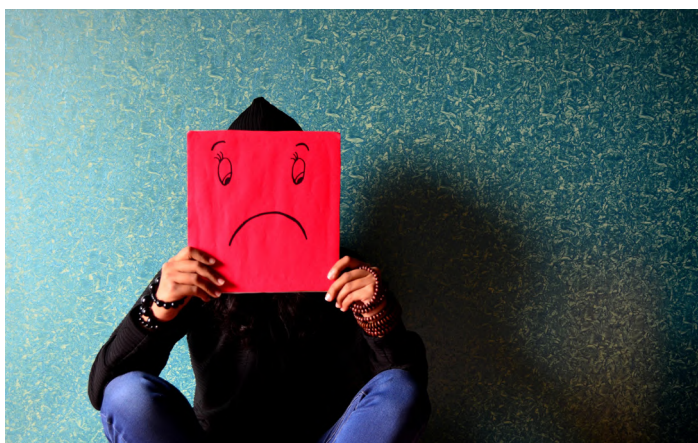


### Supporting paediatric MS nurses

MS is not a condition that just affects adults; although rare, children and teenagers can be diagnosed with MS too. The MS Trust is dedicated to ensuring nobody affected by MS, no matter their age, has to manage their condition alone. We've been working with the new network of paediatric MS nurses to ensure this promise is met. Recently that meant bringing the nurses together for a special study day where they could share best practice, talk about their experiences, and update their knowledge. Check out the MSTV YouTube channel for all our latest films for young people affected by MS. You can subscribe at [youtube.com/mstvuk](https://youtube.com/mstvuk).

### Providing information on mental health and MS

MS doesn't just affect your physical health, it can impact on your mental health too. With around half of all people with MS experiencing depression at some time in their life, as well as other symptoms like anxiety and stress. For our 2020 MS Awareness Week (20-26 April) campaign, we decided to shine a spotlight on these issues, with the aim of normalising the conversation around mental health and encouraging people with MS to speak up and seek support. We launched a number of new information resources as part of this campaign; find them at [mstrust.org.uk/wellbeing](https://mstrust.org.uk/wellbeing). Remember, it's okay not to be okay.



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## Busting MS myths

As many of you will already know, MS is a condition that is often misunderstood. Most people have heard of it, but many don't realise how it can affect you and what it's like to live with day to day. We're determined to change that, so back in February we launched our MS Uncovered campaign to sort the facts from the myths, challenge misconceptions and raise understanding, now and in the future. Thank you so much to everybody who got involved in this campaign and helped us raise awareness! If you'd like to continue to spread the word, check out our website for posters and social media graphics to share, at [mstrust.org.uk/spreadtheword](https://mstrust.org.uk/spreadtheword).

## Training MS health professionals

We train every new MS nurse in the country to ensure they can provide you, as well as your friends and family, with the vital support and care you need to live a life with MS, not a life defined by MS. Twice a year, we welcome new MS specialist nurses, therapists and health professionals to our week-long training course, which covers everything from fatigue management to palliative care. Find out more about our work with MS health professionals and how you can support it, at [mstrust.org.uk/what-we-do](https://mstrust.org.uk/what-we-do).



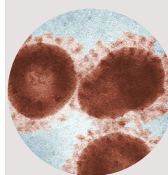
## Helping people with decisions about MS treatments

Back in March, we were delighted to be invited to an event at the Houses of Parliament hosted by pharma company AbbVie. The event showcased work being done by charities and NHS services to involve people in decisions about their care. Janice and Claire from our Information team went along to talk about some of the issues involved in choosing between disease modifying drugs and how our independent decision-aid MS Decisions can help people find a treatment that's right for them, in partnership with their MS team. You can find MS Decisions at [mstrust.org.uk/msdecisions](https://mstrust.org.uk/msdecisions).



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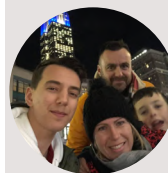
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Affected by any of these news stories? Call our Enquiry Service: **0800 032 38 39**



Keep up to date with the latest MS news by signing up for our regular email round-up  
[mstrust.org.uk/keepintouch](https://mstrust.org.uk/keepintouch)

# News

## 20% rise in the estimated number of people living with MS in the UK

New data\* from Public Health England (PHE) and the MS Society has revealed that the number of people living with multiple sclerosis in the UK has risen to over 130,000 – that's around 1 in every 500 people.

The new UK MS prevalence figure is over 20% more than previously thought, rising from 109,000 people. The latest research also shows an increase in the incidence of MS, which is the number of people newly diagnosed with MS each year. The number of diagnoses has risen from an estimated 5,000 in 2017 to 6,700.

The number of people living with MS in all four of the UK nations has also increased; there are an estimated 15,750 people living with MS in Scotland, 5,600 in Wales, 105,450 in England and 4,830 in Northern Ireland.

### What's causing the increase?

The new figures do not mean the risk of developing MS has increased. One reason for the increase could be improved survival in people with MS, as well as the general population, over the past 30 years. Another reason could be changes in the diagnostic criteria which means that people are being diagnosed with MS earlier in life.

### What challenges does this bring?

The increase in the prevalence and incidence of MS in the UK brings with it huge challenges. MS Trust research on service provision shows that MS services across the UK are already overstretched, with up to 80% of people with MS living in areas where MS nurses have caseloads in excess of the sustainable caseload figure of 315. If the number of people being diagnosed with MS continues to rise, this will put huge pressure on the NHS and the MS teams who are already at breaking point.

In 2019, the MS Trust also saw a 20% increase in the number of people calling its helpline, again highlighting the urgent need for more clinical and emotional support for people with MS and their families.

David Martin, MS Trust CEO, commented: "Having somebody tell you that you have MS is an incredibly challenging thing to hear, and we now know more people than ever before – around 130 every week – are having to face the reality of an MS diagnosis.

"Right now, too many of these people are being left to manage this condition on

their own. Our research shows that around four in every five people with MS in the UK live in areas where there are not enough MS nurses to look after everyone. We calculate that around 115 new nurses are needed to ensure everyone living with MS can access the specialist support and care they need and deserve.

"The new figures from Public Health England and the MS Society confirm that the need for better funded and better resourced MS specialist services across the whole of the UK is as pressing now as it ever was."

"The MS Trust is here for every single one of the 130,000; we're committed to supporting them on every step of their MS journey, funding more MS nurses and providing vital information so they can live their lives to the fullest. But we're urging the government and the NHS to sit up and take notice too. It's vital that nobody is left to manage MS alone."

**\* The new figure was generated using 2018 patient information taken from a GP database.**

Find out more at:  
[mstrust.org.uk/news](https://mstrust.org.uk/news)

Over  
**130,000 people**  
living with MS in  
the UK

**6,700**  
people newly  
diagnosed with MS  
every year

**130 people**  
diagnosed with  
MS each week

**1 in every**  
**500 people in the**  
**UK lives with MS**





# MS Trust funds new MS health professionals



*Tania Burge, the new Advanced MS Champion for Bristol*

The MS Trust is delighted to announce that we'll be funding three more MS health professionals in locations across the UK.

We're recruiting an Advanced MS Champion in Bristol, plus MS specialist nurses in Enfield and North Wales, ensuring that even more people with MS can access the care and support they need and deserve.

Paru Naik, Director of Health Professional Programmes at the MS Trust, commented: "We know that many people with MS are missing out on vital support because there's just not enough specialist MS health professionals to provide care for everybody. This is simply not fair. Through our Specialist Nurse and Advanced MS Champion Programmes we're doing all we can to change this narrative, ensuring everybody with MS can access the support they need when they need it.

"We're delighted to be able to fund MS health professionals in Bristol, Enfield and North Wales, but we know there's still much more work that needs to be done to ensure nobody has to manage MS alone. With the help of our amazing supporters, we promise to continue doing all we can to ensure this promise is met."

We have already funded and

supported MS specialist nurses across seven NHS Trusts, who in turn have provided care and support to 3,612 people with MS. The Specialist Nurse Programme enables the MS Trust to provide each NHS site with 80% of 15 months' funding towards the cost of a new nurse, along with training and mentorship from our expert team.

The Advanced MS Champion Programme funds specialist 'Champions' across the UK to provide guidance, support and coordinated care for those people living with the multiple, ongoing and complex symptoms that characterise advanced MS, as well as support for family members and carers. The Bristol Champion will be our sixth in the UK, with the other Champions operating in Salford, North Cumbria, Swansea, Poole and Norwich.

To find out more, or support our work with MS health professionals, please visit [mstrust.org.uk/health-professionals](https://mstrust.org.uk/health-professionals)



## Introducing our new Director of Information and Engagement

We're delighted to introduce you to our new Director of Information and Engagement, Lucy Harmer, who joined the team at the beginning of March.

Lucy has worked in the charity sector for over 13 years, leading national information and advice services. Most recently she was Director of Services at Independent Age leading their helpline, public information and friendship services for older people. Previously she was Head of Services at Age UK.



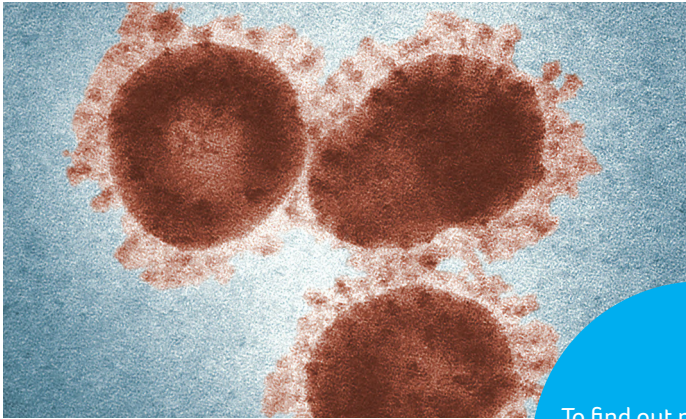
Lucy joins the Information and Engagement Team at a time when our services are more in demand than ever, with record numbers of people calling the Enquiry Service, visiting our website and reading our publications for information they know they can trust.

"I'm delighted to be joining this brilliant charity, which makes such a difference for people living with MS across the UK," Lucy says. "Over the past couple of months, I've witnessed first-hand how much people value the MS Trust's clear, practical and evidence-based information, and I've also seen the passion and expertise every member of Team MS Trust puts into ensuring this information is the best it can possibly be.

"I'm very much looking forward to meeting and working with many of you in the MS community and helping to ensure you have the support and information you need to live a life with MS, not a life defined by MS."

# News

## The coronavirus and the MS Trust



We know that this will be a worrying time for many of our readers and you're bound to have lots of question about the coronavirus (COVID-19) and MS. The MS Trust is here for you as we all try to navigate the uncertainty. Things are changing fast and it's likely to have changed again as this issue of Open Door goes to press, but we'd like to direct you to the COVID-19 page on our website, which we hope will provide you with answers to common questions and help ease some of your worries.

This page gives the latest guidance for people affected by MS, covering topics like disease modifying drugs, the risk of catching the virus, what you can do to reduce the spread of the virus, employment, taking care of your mental wellbeing and lots more. You can find the page at [mstrust.org.uk/coronavirus](https://mstrust.org.uk/coronavirus).

We will update this page as new information becomes available or advice changes, so please do keep checking the MS Trust

To find out more about the coronavirus (COVID-19), see [mstrust.org.uk/coronavirus](https://mstrust.org.uk/coronavirus)



news pages and social media channels for updates. You can find us on Facebook ([facebook.com/MSTrustUK](https://facebook.com/MSTrustUK)), Twitter ([@MSTrust](https://twitter.com/MSTrust)), Instagram ([@mstrust](https://instagram.com/mstrust)) and YouTube ([youtube.com/mstrust](https://youtube.com/mstrust)).

If you have any questions about your MS and coronavirus COVID-19, please do email [ask@mstrust.org.uk](mailto:ask@mstrust.org.uk) and someone from our Enquiry Team will do all they can to help you find the answer.

### The impact of COVID-19 on the MS Trust

The MS Trust relies greatly on the generosity of our supporters to continue to provide our services – around 90% of our income comes from fundraising and we receive no government funding. As has been the case across the charity sector, our fundraising efforts have been considerably effected by COVID-19 (for example, the postponement of this year's London Marathon – our single biggest fundraising event of the year.)

Of course, we're deeply aware of the loss of life and hardship the virus has caused and we fully understand and support the need for social distancing measures. So, at a time when our services are more in demand than ever, we have been looking for 'coronavirus compliant' ways that you can support us. Be it through virtual events (such as MS Play and Virtual Cuppa), digital fundraisers (eg celebratory giving on Facebook and Instagram), effortless giving (eg via Amazon Smile) or an increased focus on regular giving and legacy giving. Please don't hesitate to contact us on [fundraising@mstrust.org.uk](mailto:fundraising@mstrust.org.uk) if you'd like more information on any of the above – or if you have a brilliant fundraising idea you'd like to share!

## Introducing our new virtual events!

In light of the coronavirus social-distancing measures, we have two new and exciting virtual events for our supporters to get involved with.

Staying connected is more important now than ever, so we'd like to introduce the Virtual Cuppa! The premise is simple, make yourself a cup of tea, a coffee, or something with bubbles (!), cut a slice of cake and invite your friends and family for a chat online. Have a brew, talk it through we like to call it! Encourage everyone to donate the cost of their drink to the MS

Trust so we can continue to support people with MS during these uncertain times. See [mstrust.org.uk/virtual-cuppa](https://mstrust.org.uk/virtual-cuppa) to find out more and to set up your fundraising page.

Our second fundraiser is a Virtual Quiz. You might not be able to go to the pub, but that doesn't mean you can't bring a pub quiz to your home! We'll be holding a number of virtual quizzes over the coming months for you to test your knowledge, have fun, and help make a difference for people with MS. Entry is just £3 and there will be cash prizes to be won. Find out more

at: [mstrust.org.uk/virtual-quizzes](https://mstrust.org.uk/virtual-quizzes).

Kelly Boston, Senior Community Fundraiser at the MS Trust, commented: "It's a strange and scary time for people at the moment, with day to day life affected in so many different ways. But we hope our two new virtual events will help bring communities and families together, spreading some joy in these uncertain times, all while helping to ensure we can be there for everyone affected by MS."



Keep up to date with the latest MS research by signing up for our email  
[mstrust.org.uk/keepintouch](https://mstrust.org.uk/keepintouch)

# Research update

## Testing iStep-MS, a programme to encourage physical activity

Getting started and then continuing with regular physical activity can be a struggle. Researchers have developed a programme (iStep-MS) which encourages people with MS to be more active. Before testing it in a large-scale clinical study, the researchers wanted to be sure that the course was safe and acceptable for participants and suitable for physiotherapists to provide.

### The study

Participants who were able to walk in the home with or without a walking aid were recruited for the study which was carried out at the Berkshire MS Therapy Centre. 30 people were randomly assigned to take part in the programme and 30 received routine support (treatment was given as needed, this could range from intensive physiotherapy to no treatment). All participants were given a pedometer.

Participants taking part in the programme received four face-to-face sessions, each lasting 30–45 minutes, with a physiotherapist at the centre over three months, backed up by a printed handbook. The physiotherapist discussed benefits of increased exercise and encouraged and supported the participant to reduce time spent sitting down and increase time spent in physical activity. Participants set and recorded their own goals for physical activity, sedentary behaviour, and step-counts, and monitored and recorded these using diaries incorporated in the handbook.

Assessments were carried out at the beginning, and at three and nine months.

### The results

Fatigue and pain levels did not increase in the iStep-MS group. Physiotherapists reported that the programme was feasible

to deliver and they were able to cover the content of each session. All but one of the participants attended at least three out of the four sessions. Participants found the programme acceptable but suggested improvements to usability of the handbook and alternative formats for recording activity.

The number of people in the study was not enough to give an accurate indication of the effectiveness of this approach to encourage physical activity, but several measures, such as levels of pain and fatigue, improved in the programme group at three and nine month assessments.

One limitation of the study was the fact that all the participants were already regular attendees of a therapy centre and may not be representative of the wider population of people with MS in the UK.

### What does it mean?

Fatigue and pain did not increase in the iStep-MS group, indicating that encouraging people to improve their levels of physical activity did not lead to more severe symptoms. Improvements at the 9 month assessment point suggest that the course does lead to long-term changes to levels of physical activity, which last beyond the end of the face-to-face sessions.

The researchers concluded that the

course was safe, well-attended and well-received by both participants and physiotherapists. Feedback on materials and recording of physical activity will allow them to fine tune the course materials before testing the effectiveness of iStep-MS in a larger study.



Read the full summary of this study at  
[mstrust.org.uk/istep-MS](https://mstrust.org.uk/istep-MS)



### Find out more about staying active with MS

Regular, moderate exercise is recognised to be an important part of maintaining good health and wellbeing. There is evidence that it can help with many MS symptoms, and also with general quality of life. But getting started and sticking with regular physical activity can be a struggle. If you are looking for ways to be more physically active, have a look at our web pages on exercise at [mstrust.org.uk/exercise](https://mstrust.org.uk/exercise).





# Testing a cognitive rehabilitation programme

About half of all people with MS have difficulties at times with aspects of thinking such as memory, concentration or problem solving, known as cognitive problems. These can have a big impact on work, social and family life, and consequently quality of life. Cognitive rehabilitation aims to retrain cognitive skills and help people learn ways to cope with cognitive problems. In this study, a programme developed to improve cognitive skills was tested in a large clinical trial. Read the full summary of this study at [mstrust.org.uk/braintraining](https://mstrust.org.uk/braintraining).

### The study

Participants who reported having day to day cognitive difficulties which were confirmed by cognitive tests were recruited from five MS centres in England. Out of a total of 449 people, 245 were assigned to the cognitive rehabilitation programme (CR group) and 204 received standard advice on how to manage cognitive difficulties from an MS nurse or occupational therapist (SA group).

A trainee psychologist presented the cognitive rehabilitation programme to groups of four to six participants who met weekly for 10 sessions. The content of sessions was set out in two manuals, one for presenters and one for participants (you can read manuals for trainer and participant online <https://bit.ly/2UyCcpd>). The sessions covered techniques and exercises to retrain cognitive skills and taught a variety of practical ways to cope with memory issues in daily life.

Participants and a partner or friend were asked to complete a number of questionnaires at the beginning of the study, and at six and 12 months. The main measure for the effectiveness of the programme was the result at 12 months of a questionnaire which assessed the psychological impact of MS on quality

of life. To get a standardised measure of concentration, planning and memory, participants also completed a set of cognitive tests at the beginning of the study, and at 6 and 12 months.

### The results

There was no difference in psychological impact of MS between the two groups at 12 months. However, there was a small improvement in psychological impact of MS for the cognitive rehabilitation group at six months.

Other measures showed some improvements; at six and 12 months, those in the cognitive rehabilitation group reported fewer memory problems in day to day life (from the point of view of participants as well as relatives) and better mood. Participants in the cognitive rehab programme gave positive feedback; they reported that they found the programme helpful in reducing cognitive problems and had more confidence in daily life.

There were no differences between the two groups for cognitive tests, levels of fatigue, employment status or measures of carer stress at both 6 and 12 months.

Delivering the cognitive rehabilitation programme cost slightly less than giving

standard advice.

### What does it mean?

The study failed to show a long-term effect of the cognitive rehabilitation programme on quality of life, but there was an improvement in the short term. There was also evidence that cognitive rehabilitation improved both memory problems in daily life and mood.

The researchers questioned whether quality of life was appropriate as the main measure of effectiveness. It is a complex measure, influenced by many factors. While improving quality of life is an important overall aim, it may be unrealistic to expect to achieve this from a treatment which focuses on a single aspect of MS. They recommend that future studies of cognitive rehabilitation consider more direct measures of cognitive ability in daily life.

Overall, the researchers conclude that the results support providing cognitive rehabilitation, given the short-term improvements and the lack of alternative, more effective treatments. They also suggest that future studies should consider how improvements can be maintained and whether or not some people benefit more than others.



# Learning a second language improves brain structures in MS

Research in people who do not have MS has shown that learning a second language is linked to changes in brain connections, known as neuroplasticity, in parts of the brain which are related to language learning. Learning a second language also leads to improvements in general cognitive skills, not just those associated with language. This has not been studied in MS, so researchers designed a pilot study to see whether people with MS gained similar benefits from learning a new language.



Read the full summary of this study at [mstrust.org.uk/language-research](https://mstrust.org.uk/language-research)

## The study

Researchers in Austria recruited 11 people with early stage relapsing remitting MS and 12 people who did not have MS for comparison. Participants attended an eight-week English language course which consisted of three hours each week in a classroom setting, and completed extra tasks, such as learning vocabulary, at home between classes.

MRI scans were used to measure the volume of grey matter in the brain. Scans were carried out before and after the language course. Participants also completed questionnaires to assess quality of life relating to physical and mental health and completed tests to measure their improvement in speaking and understanding English.

## The results

Before the course, the level of English proficiency was the same for the two groups, those with MS and those who did not have MS. After completing the course, both groups had increased English proficiency with significant improvements in listening comprehension, speaking fluency and vocabulary knowledge in all participants.

Before the course, quality of life for

physical health was similar in both groups, but mental health quality of life was significantly lower in the MS group. After the course, physical health was unchanged for both groups, but scores for mental health were significantly improved in the MS group.

MRI scans taken before the course showed a significantly lower grey matter volume in several regions of the brain in people with MS when compared to those who did not have MS. However, after completing the course, the scans showed an increase in grey matter volume in areas of the brain responsible for short-term memory, learning and environment recognition.

Further analyses also showed that, in the MS group, increases in grey matter volume in specific areas of the brain were associated with a gain in vocabulary knowledge.

## What does it mean?

The increase in grey matter volume seen in this study provides some evidence of neuroplasticity, the brain's ability to make new connections and rewire itself. The researchers suggested that improved mental health for MS participants showed that taking part in the language course

was a positive experience and enhanced their confidence in dealing with challenges.

The small number of people in this study means that the results should be interpreted with caution; a larger study will be needed to confirm the findings. It would also be interesting to see whether the increase in grey matter volume is maintained beyond the end of the language course and whether similar improvements are seen in people who have had MS for a longer time. Further studies could also investigate whether learning a second language or another skill might protect or improve broader cognitive skills in MS, such as memory and concentration.

## Fancy trying it yourself?

You can learn new languages using free online resources such as Duolingo or Memrise. Both offer a wide range of languages, you could really challenge yourself by tackling Klingon or High Valyrian!

# "I am jumping for joy with all the happiness it has brought"

**Julie Stevens** - AKA Jumping Jules - turned to poetry to help her make sense of MS and, over 100 poems later, she says it has brought her incredible happiness. Here she tells us about her MS journey and her dream to publish her own book of poems.



My MS started when I was 19. I was at Homerton College in Cambridge training to be a teacher. I specialised in music and found I couldn't play the piano with my left hand. I couldn't coordinate my fingers, nor press the keys. This recovered after a course of steroids and rest. Being told you couldn't go to your first end of year ball was hard!

Two years later, my legs became very weak and I had to stop all sport. Again, I recovered. I could now play hockey, sprinting down the wing, and went swimming every week. I later developed optic neuritis and this led to being diagnosed with MS in 1995, three years into my teaching career. It was a shock, but was good to have an answer to all these problems.

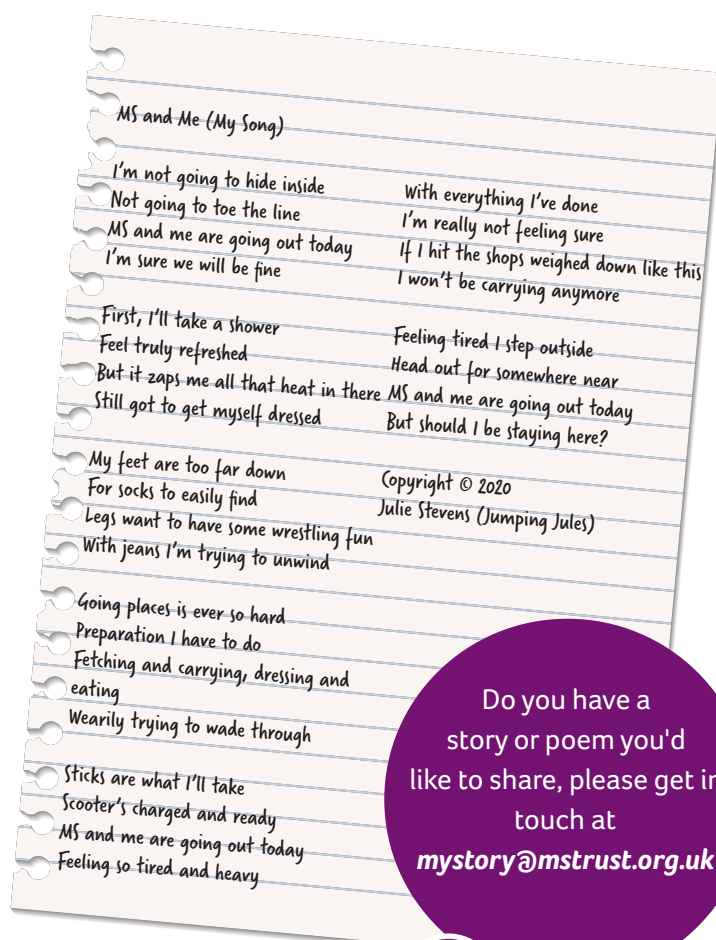
After 14 years, now in the secondary progressive stage, I took ill-health retirement. MS was leaving me with extremely weak legs and awful fatigue. My balance was causing problems too. A hard decision to make, but with a young son, this enabled me to spend time with him. I concentrated on that.

Thirty years after onset, I have two children, walk with sticks, and use a wheelchair, or mobility scooter when going further. I wasn't sure about mobility aids, but am so glad I have them. They make a huge difference. I don't have to worry about my legs giving up on me on a shopping trip or day out. My poem 'MS and Me (My Song)' came from this change.

I started writing poems just over a year ago and now have well over one hundred. MS has given me so many ideas! Going into my own world and putting thoughts down is very relaxing. I have now even started sharing some of them on a website and social media. Reading comments about how people relate to them and enjoy them is great. One lady told me how my poem explained a symptom so well, she was going to show everyone. "You have the words I cannot find to describe how I'm feeling," she said. It's amazing that I'm able to help someone with a poem.

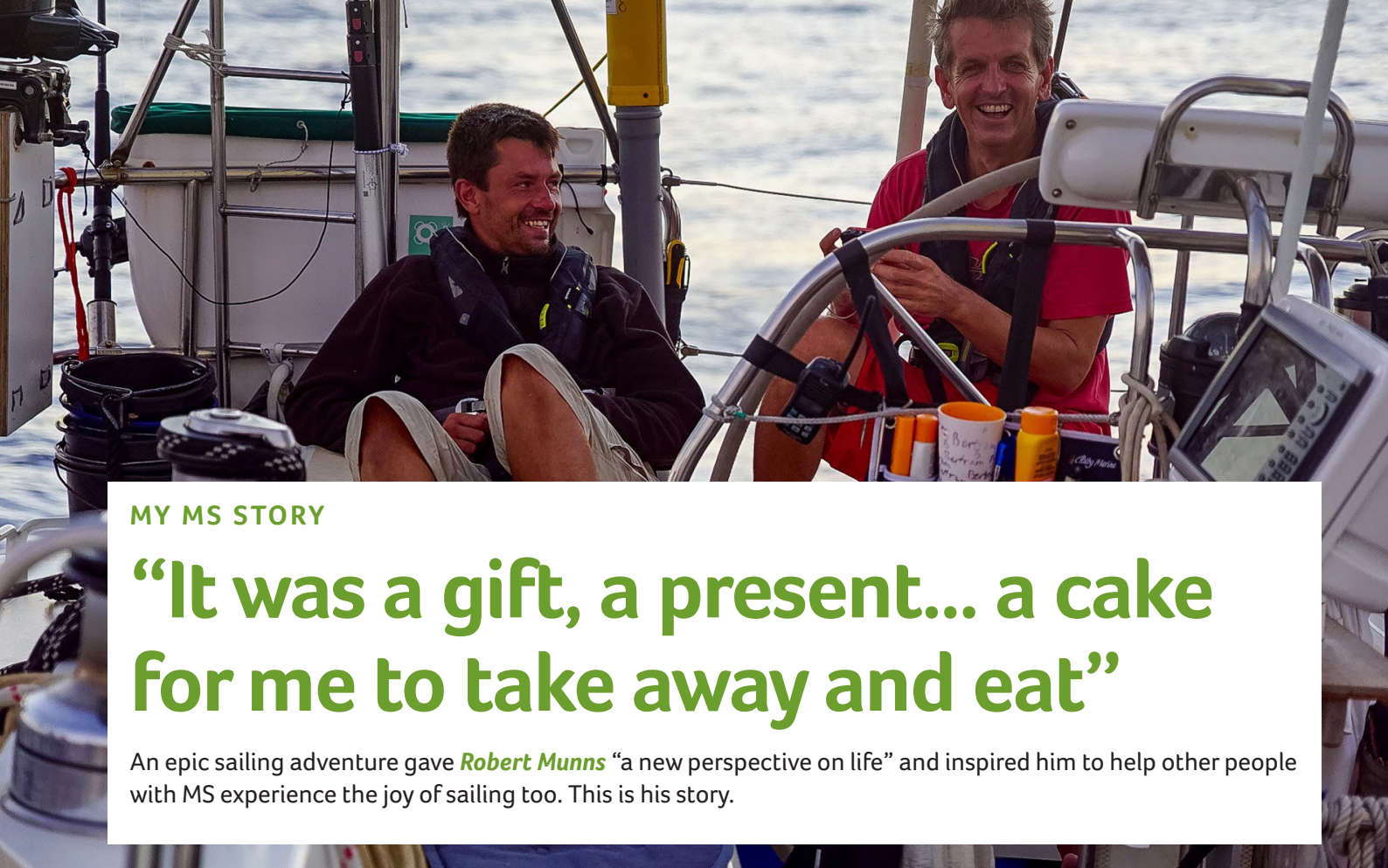
A lot of my poems are based on my experience of having MS and they really have got people talking about it: "I didn't know it affected you like that" I'm often told. Having been published

now in several poetry magazines, I hope it's not too long before I can publish a book of my poems. MS has led me into the world of writing, open mic events and much more! Jumping Jules is the name I publish under and I definitely am jumping for joy with all the happiness this has brought. You can read more of my poems on my website at [jumpingjulespoetry.com](http://jumpingjulespoetry.com) with links to all my social media platforms.



Do you have a story or poem you'd like to share, please get in touch at [mystory@mstrust.org.uk](mailto:mystory@mstrust.org.uk)





## MY MS STORY

# “It was a gift, a present... a cake for me to take away and eat”

An epic sailing adventure gave **Robert Munns** “a new perspective on life” and inspired him to help other people with MS experience the joy of sailing too. This is his story.

People who don't know that I have MS cannot really tell. I do consider myself lucky, but they don't see the real story. You see, I'd never really been ill before.

To be hit with an inexplicable attack (double vision, speech issues and electrical impulses through my body) and then to be told after all the many tests that this is what 'I had' was devastating at the time. I was in the prime of my life. The world was my oyster and I was enjoying the ride. In 2008, however, all that was brought into question: EVERYTHING was petrifying. And for me the fear has always been the killer. What's causing this pain? Why can't I sleep? Why am I so tired? Why do I ache? I must admit that for someone with MS, this is not unique.

Then in 2014, I stumbled over a crazy scheme to sail around the world with a crew of people with MS. Oceans of Hope it was called, "out into life" they said. As a pretty experienced boat person, my knee jerk reaction was to apply.

In December 2014 I was accepted for the Pacific leg of the circumnavigation. I then made my travel plans and resigned from work (hasty, I know) and by February 2015, I was on board Oceans of Hope in the Galápagos Islands with a full complement of MS crew bound for Tahiti. It was to be a journey of just over 4,000 miles with a

couple of stop offs at small islands mid Pacific.

During my time on board, I learned a lot about MS and my relationship with it. What I'd learned was mainly twofold. Namely how much I'd been disconnected from life and secondly how important humour is.

I had not been engaging in life since 2008, which was quite clearly depressing. Being on the boat made me realise how much I had not been present. Life was happening to others, I was just standing by, not my whole self. What also struck me as important was humour. I've always enjoyed laughter (who hasn't?), but it took some time, space and good people on board Oceans of Hope to make me realise how much I had missed laughter for some considerable amount of time.

Once I left the boat, I had some time to absorb and reflect on my journey so far with MS along with the new positive perspective on life. This new perspective was given to me on board Oceans of Hope. It was a gift, a present... a cake for me to take away and eat.

That summer, I was compelled to continue with this journey and I decided that this gift, this cake that I was given, needed to be replicated. More people with MS had to have the same opportunity as me, so I founded Oceans of Hope UK.

That was 2015... it's now 2020!

With the help and support of great people we are still striving to achieve this. Since 2015 we have been organising sailing trips, taking over 400 people sailing with us so far. Since 2018, we have been a UK registered charity Oceans of Hope UK. For people that haven't come sailing with us yet, it's important to say that it really does make a difference to people's lives. It's that simple.

You can find out more about Oceans of Hope and how you can get involved at: **[oceansofhope.co.uk](http://oceansofhope.co.uk)**. Search for Oceans of Hope UK on Facebook, follow on Twitter at **@OOHChallenge** and Instagram **@oceansofhopechallenge**.

If you would like to find out more about the different ways you can stay active with MS, visit **[mstrust.org.uk/exercise](http://mstrust.org.uk/exercise)**



# “It’s brought us closer together”

The emotional impact of an MS diagnosis can be hard to deal with for the whole family. *The Bunby’s (Natasha, Marc, Deon and London)* tell us about the ups and downs of living with MS, how they support each other and their advice for other families.

## Natasha

I did feel extremely scared when I was diagnosed with MS as I didn’t know anything about the condition and when I looked it up on the internet, all I could find were really negative things. I was put in touch with our local MS nurse and she was an incredible person. She provided me with lots of information from the MS Trust. It takes time to come to terms with an illness, but over time I’ve learnt my MS is a tiny part of who I am and it won’t ever be the most interesting thing about me.

My MS has been very active and not responsive to multiple treatments, which is not the case for most people, so I’ve been very unlucky. I can now no longer walk and I struggle with my hands functioning and I’m also bladder and bowel incontinent. But there are so many incredible adaptations available now that help me to live a very independent life despite these problems. I’ve had to learn to adapt and everyday I focus on the things that I can do, not the things I can’t do.

Coping with MS as a family is hard at times, but we’re a close family and we support each other. We have all learnt to adapt together. When it comes to juggling parenthood and MS, I am careful with how I plan things and I have to be very organised. My son London spends the most amount of time with me as he is only 12 and he sees my struggles a lot more than anyone

*“I’ve learnt my MS is a tiny part of who I am and it won’t ever be the most interesting thing about me”*

else does. I try to keep positive, especially for my children as they are my world. Deon is a teenager so he is off out a lot and I’m pleased that he still does normal teenager things and is happy. London and I spend lots of quality time together; we go to

the cinema, out for coffee, I take him swimming and bowling or he takes his bike out and I go out in my wheelchair. They both can’t

remember me before I had MS, so for them me being in a wheelchair is our normal.

My advice for other families living with MS is to be there for each other. Don’t push each other away and if your children don’t always want to talk to you, don’t force them to. Take strength from each other and use all the resources and information that’s out there to support you. MS has changed me but it’s not taken away my life – I won’t let it do that. As a family we still have a great life together and we will keep going together, united to keep living our best lives.



Natasha with Marc, Deon and London



## London

I can’t really remember my mum not ever having MS, as I was so young when she was diagnosed.

If I was describing MS to others, I would say it’s scary sometimes as it stops my mum’s arms and legs from working properly but it doesn’t stop her doing things

with me. We still have lots of fun and laugh a lot together.

Our family life has changed, as we now have a stair lift, hand rails and a wet room in our house. It’s made us change our car as we have a special family car with an electric ramp where you

press a button and the boot opens and the ramp comes out. Mum drives it via hand controls instead of her feet. There have been positive changes too; we have done fundraising for the MS Trust which I really enjoy as it makes me feel like we’re helping other families like ours.

To support my mum, I help with washing up, make mum drinks and sometimes I help her put the shopping away. These things make me feel helpful.

My advice for other young people who have a mum or dad with MS is to talk about your worries as talking really helps. If you can, do small things to help them, as that will help to make you feel good as sometimes MS can be tough and make you feel helpless when you see a person struggling. I talk to mum a lot as she makes me feel better when we talk and we have lots of cuddles.



## Marc

I'd heard of MS when Natasha was diagnosed but never really understood it, and we are all still learning together.

We try to keep as normal a family life as we can as we don't want the kids to miss out on anything. The biggest challenge we've faced is getting Natasha the help and treatment she needs. She hasn't had any treatment for nearly 18 months and has no neurologist. MS nurses do all they can, but it's heartbreaking to see that she's been left with nothing and we really worry what's next. We are very lucky to have the NHS, but the system is just so stretched and you don't notice it until you have someone who can't access the support they need. Where we live it's a postcode lottery.

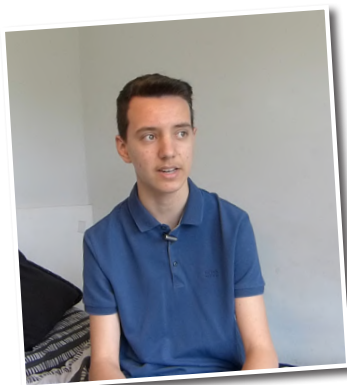
Following the diagnosis, you initially question why her? Why us? Natasha is very unlucky as she has very active, aggressive MS, and this absolutely isn't the case for most people. We both know that as time goes by the condition is going to get worse so we

do try to cram in as much now as we can. I believe it has made us stronger and closer as a family. Like any family we have good days and some very challenging and tough days, but I wouldn't change her for the world. She is everything to me and the boys.

MS is a terrible disease but it doesn't change your partner. There is help out there, from the MS Trust and the MS Society, so I would say to other families, don't give up. Keep asking for the help you and your loved-ones need. I find support through Natasha mostly, she always knows what to say and she always makes me feel better, when it should be the other way around.



*"You initially question, why her? Why us?"*



## Deon

I felt confused and upset when I found out about my mum's MS diagnosis, because I didn't understand what MS was and it didn't seem like anyone could explain it to me. I would now describe MS as an

illness

that won't go away. MS stops people's bodies working properly because their brain can't tell their body what to do.

Since mum's diagnosis, we have had to move to an adapted house and mum has an adapted car. I help my mum by doing bits around the house and do those little tasks which will be easy for me but very difficult for my mum.

MS has brought our family closer together and made us realise how lucky we are to do everyday things that able-bodied families can do.

My advice for other young people who have a parent living with MS is not to overthink things and make sure that you ask questions and talk to people as bottling up all of your emotions will not be good in the long run.

*"Try not to bottle up all your emotions"*

## Dealing with MS as a family

MS affects not only you, but those around you as well. If you have children in your family, you may feel a little worried about how and when you should talk about your MS with them. Try not to worry! On the whole, discussing your diagnosis with your children in an open and honest way can help the whole family get used to MS and understand what it means for them. You will need to judge when this conversation would be appropriate and how it should take place, but we have resources to help you. On our website ([mstrust.org.uk](http://mstrust.org.uk)), we have lots of information to help you start the conversation, and have answers to common questions that children and teenagers may ask. Our free publications, *Talking with your kids about MS* and our *Kids' guide to MS* are written to help children and young people understand MS and what it might mean for the whole family; you can order or download a copy at [mstrust.org.uk/publications](http://mstrust.org.uk/publications).

If you're the partner of someone with MS and reading this, you might feel a little concerned about how MS will impact your relationship and how you can be supportive, while also giving your partner space to adjust. There is no formula for what is the best approach as everyone is affected differently. A willingness to listen and help, and sensitivity to their individual needs and wishes, are the cornerstones of providing appropriate support. Our resource, *Someone I know has MS* has information to help you both come to terms with the diagnosis and what it might mean for your life together. Download or order your copy for free at [mstrust.org.uk/publications](http://mstrust.org.uk/publications).

## MY MS STORY

# "I've learnt so much about myself"

When former professional cricketer **Chris Paget** was told he had MS in 2017, he didn't know which way to turn. Feeling isolated and alone, he spiralled into depression, refusing to open up even to the people closest to him.

Thanks to the love and support of his family and friends, Chris was able to emerge from the darkness and today, three years later, he says he's "never felt stronger". It's been quite the journey to get to this point and one that's inspired Chris to launch Milestone, a new initiative to help normalise the conversation around mental health. We caught up with Chris to find out more.

### Hi Chris. Thanks for talking to us. Can you tell us about the moment you were diagnosed with MS?

I was given a suspected diagnosis in 2013 following a period of neurological symptoms in my hands and feet. These sorts of symptoms weren't that uncommon for me. Between 2004 and 2008 I was a professional cricketer for Derbyshire CCC (albeit not a very successful one!!) and during this time I experienced a fair amount of nerve related issues which I'd always interpreted as general wear and tear of professional sport. As it turns out it was probably more than that. However, given these types of symptoms weren't uncommon I had been rather blasé, perhaps even arrogant, throughout the testing and I was completely underprepared for the news that they suspected I had MS in early 2014. I wasn't formally diagnosed with MS until 2017.

### What are some of the main MS symptoms you experience day-to-day?

They aren't immediately obvious: they are primarily in my hands, feet and lower left leg. While they are largely sensory – often like that slightly painful feeling you get when you are coming out of an episode of pins and needles – I also experience muscle spasms, fatigue, the so-called hug (not that friendly) and bladder weakness. My lower left leg is particularly uncomfortable, especially when I'm tired and can cause problems sleeping. They have kind of become my new normal, but I definitely notice a deterioration when I'm tired.

### How did the diagnosis impact you?

Whichever way I look at it, MS has had a profound effect on me. Now I feel comfortable saying that the effect has been a positive one, but for a long time that wasn't the case.

When I was diagnosed, I knew very little about MS and I was happy to stay in the dark in that regard so did nothing to address this. I was in denial. I kept my diagnosis private other than with my very closest friends and family. This was where I can now see where I went wrong.

At first this 'secret life' was something that I felt I was able to live with and, in public, at least, I was. Until very recently I was able to carry on my job (as a sports and entertainment lawyer and partner at Sheridans) without my firm knowing. However, the diagnosis and the associated psychological impact of hiding it were taking their toll both publicly and privately.

### How did the diagnosis affect your mental health?

I felt an overwhelming sense of shame. I was isolated and alone and I had created a situation where I was without an outlet where I could openly discuss my feelings and fears. I was depressed but too ashamed to seek help and support – I didn't feel comfortable exposing my growing vulnerabilities.

I lived inside my own head in private and put on a mask in public. Privately, alcohol became an outlet, which had a compounding effect on my mental health. I feared judgment,



*"I felt an overwhelming sense of shame. I was isolated and alone and I had created a situation where I was without an outlet where I could openly discuss my feelings and fears"*



and I particularly feared demonstrating any vulnerability and exposing 'my secret'. Without my amazing wife, Harriet, and her continued attempts to get me to open up about my feelings and my state of mind, I would still feel isolated and alone. Whereas now, and notwithstanding the diagnosis and potential prognosis, I have never felt stronger: I have learnt so much about myself, what I consider important and how I want to live my life, I have reconnected with friends that I had subconsciously pushed away and I have been able to re-prioritise what is important.

I know I have a long way to go and that I have to work on my mental health on a daily basis but it was taking the initial step that was comfortably the hardest. The birth of our little daughter, Orla, four months ago has certainly put things very quickly into perspective. I think parenthood does that whatever your situation.

### What would your advice be to others dealing with an MS diagnosis?

Communicate, try to be proactive in processing and learning to accept the diagnosis and use the support networks that you have (whether family, friends, colleagues and of course the MS Trust!). Basically, do everything I didn't! It was only when I began to communicate that I was able to process the full range of emotions that I had harboured and then things began to feel easier. It felt like a huge weight had been lifted off my shoulders.

### Tell us about Milestone. What was the reason for setting up the charity and what would you like to achieve through it?

I suppose it was my experiences of dealing with my own mental health, along with my experiences of hearing how my close friends and family have suffered (or in some cases are still suffering). I hope Milestone can play a small part in the push for all people to get comfortable with not always feeling 100% in control but, likewise, feeling comfortable in asking for help. Milestone is really about trying to help normalise the conversation around mental health and mental wellbeing and using sport as the conduit to be able to hopefully achieve this (the tagline for the charity is 'tackling setbacks through sports').

### How will Milestone look to do this?

We've identified three broad aims of Milestone:

1. Milestone being a resource: to help educate and raise awareness around mental health and mental wellbeing, including its interplay with chronic disease;
2. Milestone bringing people together: through a variety of initiatives and events to try and inspire others (especially men) to be comfortable to communicate their feelings, emotions, concerns or worries without fear of judgment, shame or a perception of weakness; and
3. To fundraise: for the MS Trust and two other charities, CALM and the Professional Cricketer's Trust

### Why is Milestone supporting the MS Trust?

First and foremost, to highlight the amazing work that the MS Trust does and the support that the charity provides. I hope that



Chris, Harriet and Orla

Milestone, in conjunction with the Trust, will assist in continuing to raise awareness of the services, support networks and outlets available to anyone with MS and, in some respects, continue to work on rebalancing the narrative around MS as a condition.

### What are some of the events Milestone has planned?

We've got some pretty big plans! Everything we are doing is aimed around the central purpose of normalising the conversation around mental health. Bringing people together through sporting events and sporting conquests feels like the best way of doing this (while also having some fun along the way!).

There are a number of events this year, including a golf day (all details are on the website) but the main event will be an 18 day endurance event next year starting in Durham and finishing at Lords in central London where we will be taking in all 18 professional county cricket grounds in 18 days. Running a marathon one day and doing a 100-mile odd bike ride the next. I'm going to be doing each day, but it is hoped we will get as many people as possible to join us for a leg or maybe two.

Exercise and the associated holistic physical and mental health benefits have been massive in my shift in approach to my disease. I know this is something that lots of other MSers feel too, and so, I would absolutely love to get as many people who read this or support the Trust to come and join us for a leg and in turn raise money.

**MILESTONE** | TACKLING  
SETBACKS  
THROUGH  
SPORT

To find  
our more about  
Milestone and how  
you can get involved, visit  
[teammilestone.co.uk](https://teammilestone.co.uk), or  
follow on social media  
[@team\\_milestone](https://twitter.com/team_milestone)



## FOCUS ON

# Ageing and MS

In a recent blog, leading neurologist Professor Gavin Giovannoni wrote about ageing in MS and predicted that, with the MS population increasing, this could be an important topic in 2020. Simon from the MS Trust's information team looks at some of the challenges of growing older with MS and the support that's available.

MS is a lifelong condition and issues associated with growing older will present challenges to people also living with multiple sclerosis. As most people are diagnosed in their twenties and thirties, MS is sometimes described as a young person's condition. The new figures on the number of people with MS in the UK (see page 4) reconfirm that this is not the case, with more than half of people with MS aged 50 or older.

As well as coping with the continuing, possibly increasing, effects of MS, you are more likely to develop other health issues (or comorbidities) as you grow older. Common age related conditions include arthritis, reduced memory, vision or hearing, high blood pressure, osteoporosis and heart problems.

Even in the absence of other health conditions, the effects of ageing may match or amplify MS symptoms. It can be difficult when dealing with issues such as weakness, temperature control, fatigue, bladder control and poorer balance to separate what is caused by MS and what is due to age. Not everything is due to MS and there is the risk that treatable conditions are lumped together with long-term conditions and so not adequately managed.

Social isolation can be a problem in both age and long-term illness. Being unable to maintain friendships and contact with

other people can lead to low mood and depression. This can lead to a cycle of isolation as feeling down can make you disinclined to try to make contact.

Your independence may be affected by physical and cognitive changes and by increasing care needs. This, again, may restrict socialising.

The effects don't only apply to people with MS. A couple where one partner is a carer will be ageing together and both may be

finding their abilities becoming more limited. The care needs may proportionally increase and the carer, who could have their own health issues, needs to look after their own physical and social health.

Age can bring some advantages. Studies have reported that some people find age helps them manage their MS. On one hand, you have more experience of what MS might do and how you might cope with some of the problems it can present. Equally, people expect someone who is older to be less active or walk with a stick, maybe less cognitively with it. They may better make allowances for these symptoms in older

people than they do for people at a younger age.

***"Social isolation can be a problem in both age and long-term illness. Being unable to maintain friendships and contact with other people can lead to low mood and depression"***





*"Volunteering in a local service or charity shop may give you new opportunities to meet people and to help out in your community"*

## What can be done to help oneself?

### 1 Watch what you eat and drink

A good diet is important at any stage of life to maintain health and energy. A good basic diet will be low in saturated fat, with lots of fruit and vegetables, oily fish. Keep fatty, sugary and salty foods to a minimum. And drink plenty of water.

### 2 Stay active

Doing some degree of activity every day is important for fitness, for general health, and for mood and self-esteem. This needn't be exercise in a gym sense, but building in activities to your daily routine will help. Approaches such as chair yoga or Pilates are gentle but helpful exercises to try. See our website at [mstrust.org.uk/exercise](https://mstrust.org.uk/exercise).

### 3 Look after your general health

If it becomes harder to get out, general health issues such as dental checks, sight tests or podiatry can be neglected. If problems are allowed to build up, this can also have an impact on your MS and worsen symptoms. If getting to health services is difficult, look into visiting services that can come to you.

### 4 Stay in touch

Having contact with other people is good for general wellbeing and for putting your concerns into perspective. This may involve keeping in touch with family and friends who have moved away, or taking part in social groups and meetings. Of course, the group needn't

be anything to do with MS or

with age. Find something you enjoy and get involved. Volunteering in a local service or charity shop may give you new opportunities to meet people and to help out in your community. If getting out is a problem, Age UK and The Silver Line run befriending services, both over the telephone or visiting befrienders. You may prefer to volunteer as a befriender contacting other people.

### 5 Plan ahead

Concerns about what might happen in the future are natural, but thinking through what you might do in certain situations can be helpful. Turning concerns into strategies can give you some control and make fears seem less threatening.



### Find out more:

Making decisions and preparing for the future is an important element of self-management. Although MS is unpredictable and it's difficult to know how it will affect you in later life, you can begin to develop self-management skills which will help you to anticipate problems and find ways to resolve them. The MS Trust booklet, *MS and me* looks at setting goals, problem solving and healthy living. You can download it for free at [mstrust.org.uk/publications](https://mstrust.org.uk/publications).

It can be helpful to discuss issues relating to living with multiple sclerosis with other people with first-hand experience. There are a host of support groups, both online and face-to-face, where you can share your own experiences and benefit from those of others. Find out more at [mstrust.org.uk/support](https://mstrust.org.uk/support).

Adopting a healthy lifestyle will keep you as healthy as possible and put you in the best position to deal with the challenges that MS brings. We have lots of tips to help you live well with MS at [mstrust.org.uk/lifestyle](https://mstrust.org.uk/lifestyle).



## ASK THE EXPERT

# Pregnancy and MS

MS is often diagnosed in women at a time when they're considering starting a family. Many women, and their partners, will have questions around the impact of MS on pregnancy and vice versa. To answer some of these questions, we spoke to consultant neurologist, **Ruth Dobson** who is one of the experts involved in developing pregnancy care guidelines for women with MS.

### Q Does MS affect my chance of conceiving?

**Ruth says:** As far as we know, MS doesn't affect your chance of conceiving. It's hard to know this for sure as we don't really know how many people in the UK are trying to conceive at any one time and how many people with MS are trying to conceive. But based on the information we have got, there doesn't seem to be a significantly lower conception rate in MS or a significantly higher miscarriage rate in MS either.

### Q If I had children, are they at higher risk of getting MS?

**Ruth says:** The risk of you getting MS is slightly higher if you've got relatives with the condition.

If a child's mum or dad has MS, the child's risk of getting MS is around 2%. This means that around 2 in every 100 or 1 in every 50 children may go on to develop the condition.

However it's really important to note that those children are much more likely not to get MS during their lifetime than they are to ever get MS.

### Q Are any of the DMDs safe to take whilst trying to conceive and during pregnancy?

**Ruth says:** First of all if you're thinking about starting a family, it's best to speak to your neurologist or MS nurse about your DMD options. Often decisions are made on a case-by-case basis depending on your personal preferences around the different DMDs and how active your MS is.

The information we have shows that Avonex, Betaferon, Extavia, Rebif, Plegridy and Copaxone are safe to take both whilst trying to conceive and during pregnancy. These medications are likely to be safe during breastfeeding as well.

For women with more active MS, the medication that's most likely to be safe, or potentially used during pregnancy, is Tysabri. There's increasing evidence around this but the risks and benefits need to be carefully weighed up for each person in discussion with their neurologist. Another option is using medications that are used infrequently, such as Lemtrada or Mavenclad, then waiting for a while after taking the medication before trying to conceive. If you decide to do this, it is important that you talk to your neurologist about how long to wait after taking the medication before trying to conceive.

Some drugs are really not safe to be taken whilst trying to conceive and during pregnancy. It's therefore advised that women who are taking Gilenya should stop this medication at least a couple of months before trying to conceive.

Similarly Aubagio should be stopped before trying to conceive. It can take a while for this medication to leave

For more information on pregnancy and MS, visit [mstrust.org.uk/pregnancy](https://mstrust.org.uk/pregnancy)





your system so this needs to be discussed early with your neurologist.

For more detailed guidance around what DMDs are safe whilst trying to conceive and during pregnancy, see the UK consensus on pregnancy in multiple sclerosis: <https://bit.ly/2WLiQU>.

## Q Is it safe for a man with MS to be on a DMD if they're trying for a baby with their partner?

**Ruth says:** This area hasn't been properly addressed by research, so unfortunately information is extremely limited. We know that small amounts of Aubagio are detected in the fluid around the sperm of men with MS. There have previously been concerns that this may be associated with a theoretical risk although there's no real evidence to back that up.

With Mavencard, both men and women should use adequate contraception whilst taking the drug and for some time afterwards. Men should make sure they are adhering to this as well as women because we know that it does interfere with sperm quality – and there is a risk that this could be a problem for any baby that was conceived around this time.

## Q I've heard that women with MS go into remission while pregnant and relapse after birth – is that true? If so, why?

**Ruth says:** On average women with MS have very few relapses during pregnancy. The chance of you having a relapse lessens the further through pregnancy you get. The reasons for this aren't particularly well understood, although we do see a similar pattern in other diseases of the immune system. We think this happens because when you're pregnant your immune system is slightly lowered as a way of trying to protect the baby from the mother's immune system. This is probably what's having the effect on the MS as well. Hormones are also likely to play a role in these changes, and they may impact on the mother's MS.

After the baby's born, research shows an increased risk of relapse in the first three months postpartum. This is thought to be due to the immune system reactivating and/or hormonal changes during this period.

## Q What if I have a relapse when I'm pregnant? Will it harm my baby?

**Ruth says:** Whilst relapses are horrible things to have, and they can cause problems for the mum, they are not harmful to your baby.

Steroids can be used during pregnancy to treat relapses and help you recover quicker. We prefer to use steroids later in pregnancy rather than earlier on because during the first three months lots of important parts of the baby are being formed.

Whether you choose to use steroids or not is something that will need to be discussed with your MS team. It will involve weighing up the risks and benefits, and a consideration of the severity of the relapse and how much it's affecting you.

## Q

## What is the recommended dose of vitamin D for a woman with MS who's pregnant?

**Ruth says:** Vitamin D may be important for the developing immune system of the baby. There are no agreed guidelines for the appropriate dose of vitamin D for women with MS who are pregnant.

The Royal College of Obstetricians and Gynaecologists has recommendations for vitamin D in all women who are pregnant, but these are not specific to MS. They recommend that all pregnant women should take at least 400 units of vitamin D a day and those that are at high risk of deficiency should take 800 units of vitamin D a day.

Trials have shown that there's no evidence of harm to the mum or the baby in pregnant women who take higher doses of vitamin D than this (up to around 4,000 units). However you should speak to your MS team about the appropriate dose for you.

## Q

## Can I breastfeed?

**Ruth says:** Yes, women with MS can breastfeed. However, if you have highly active MS it's important to discuss the pros and cons of breastfeeding versus restarting a disease modifying drug with your neurologist.

There's some evidence that breastfeeding may be very mildly protective against relapses, but it's certainly not as good as taking a DMD. Some of the medications are safe for use in breastfeeding, in particular Avonex, Betaferon, Extavia, Rebif, Plegridy and Copaxone.

It's important to discuss your options around breastfeeding with your MS team during pregnancy so you know what your plan is in advance.

**Ruth Dobson is Clinical Senior Lecturer of Preventative Neurology at Queen Mary University of London and Consultant Neurologist at Barts Health NHS Trust, London.**



# Meet our new Friends!

We have Friends! Our Friends of the MS Trust network is growing! With dedicated and enthusiastic supporters around the UK, flying the Blue MS Trust flag in their local communities, we are reaching even more people with MS. From organising collections in local supermarkets to putting posters up in local doctor surgeries, our Friends are vital in helping the MS Trust to do what we can to ensure a life with MS isn't a life defined by MS. Here we introduce some of our new friends!

"I want to give back to the resources I used to help me get through the early days of the diagnosis. In fact, I still use the site and recommend articles to other people I now know who have MS"

**Lauren Walsh, Friend of the MS Trust in Glasgow**



"Since becoming a Friend of the MS Trust, I have made friends with people in my area, organised some amazing fundraising events and I have also learnt new things about MS"

**Anne Thompson, Friend of the MS Trust in the North East**



"I agreed to become a Friend of the MS Trust as I wanted to raise awareness of MS and the MS Trust in my local area. I was diagnosed with MS at the end of 2016 and wanted to say thank you to the Trust for their help since my diagnosis. I also wanted to support the Trust and ensure that they are there to be able to help those who receive their diagnosis, and their friends and family, in the future"

**Cathy Forbes, Friend of the MS Trust in Staffordshire**



"I am so excited to support our Friends of the MS Trust, sharing their ideas and seeing their areas grow. Becoming a Friend of the MS Trust may sound a daunting task but I am here to provide all the help and guidance to turn ideas into a successful fundraiser. Why not join us?"

**Kelly Boston, Senior Community Fundraiser at the MS Trust**



"Being a Friend of the MS Trust makes me feel so proud that I am giving back to a cause that has been so supportive to me"

**Sam Bromfield, Friend of the MS Trust in Norfolk**



## Want to get involved?

Visit [mstrust.org.uk/friends](https://mstrust.org.uk/friends) and complete the online form and Kelly will contact you with further details. Do we have Friends in your area? Check out our interactive map on the link above.



# Love is in the air



**Your wedding is one of the most important days of your life, and what better way to celebrate it than to give a little something back to a charity that is close to your heart? That's what our supporter Lisa Hickingbotham did. She shares her love story.**

"Our wedding day was everything we dreamt it would be and more. One of the biggest reasons for this was because my mum was there to see my dad give me away.

Mum is now in the latter stages of MS, which has affected her since her 20s, but was only diagnosed in her mid-30s. We were encouraged to prepare for the inevitable last summer which made the wedding even more poignant. All I kept thinking to myself was that she wouldn't miss this day for the world. So of course in true mum style, she looked beautiful in the front row, with a sparkle in her eye. To see my mum alert, smiling and in full view of me whilst I was taking my vows, was like a miracle and intensely emotional.

I am so incredibly proud of her, she is the most resilient and the strongest lady I know.

We decided to support the MS Trust on our wedding day because of mum. We managed to raise £1,650 through generous donations from our incredible friends and family as wedding gifts, and our wedding favours were the MS Trust badges, which all our guests loved and wore throughout the celebrations.

We know that charities like the MS Trust can make a huge difference to people affected by MS and we want to support them in any way we can. I hope this may encourage others to do the same and give a little something back on their special day."

**If you'd like to find out more about supporting the MS Trust at your wedding, or at any other celebration you're planning, visit [mstrust.org.uk/celebrate](https://mstrust.org.uk/celebrate).**

## Get involved!

There are lots of ways you can get involved and support our work. Here are just a few ideas. To find out more, visit [mstrust.org.uk/fundraising](https://mstrust.org.uk/fundraising) or call our team on **01462 476707**. (N.B. All of these events were going ahead at the time of writing, due to the coronavirus some may have since been cancelled or postponed. Please make sure you check with us or event organisers).

### Asics London 10k

Get ready for this spectacular summer event. Be part of our team, run through London and see some iconic landmarks whilst enjoying the unbelievable atmosphere. Whether you are new to running or have experience, you are welcome on Team MS Trust!

[mstrust.org.uk/asics-10k](https://mstrust.org.uk/asics-10k)



### My Garden Party

Host a party in your garden later in the year and choose from traditional cream teas to bottomless brunches – the choice is yours! Your garden can be big or small, or perhaps friends or family could host it for you. [mstrust.org.uk/mygarden](https://mstrust.org.uk/mygarden)

### Snowdon at Night

Join our midnight trek under the stars and climb to the summit of the highest mountain in England and Wales. See the sunrise across Snowdonia National Park, take in the breath-taking views, and then finish with a celebration breakfast. [mstrust.org.uk/snowdon-night](https://mstrust.org.uk/snowdon-night)

### Miles for MS (inside edition!)

Set your own Miles for MS distance challenge to complete during May and raise sponsorship to support people with MS. There are lots of home-based exercises you could do. From climbing the stairs to dancing in your garden! Sign up for free at [mstrust.org.uk/miles](https://mstrust.org.uk/miles)

### Great North Run: 13 September 2020

Don't forget to join our MS Trust Team taking part in the world famous Great North Run half marathon in the North East. Registrations close soon, so don't miss out on this iconic event to raise money for the MS Trust.

[mstrust.org.uk/greatnorth](https://mstrust.org.uk/greatnorth)

### Ultra Challenge Series

Pick from a variety of events and distances, in some of the most picturesque areas of the country, like the Peak District and South Downs Way. You can run, jog or walk – the choice is yours. Take a look and pick the challenge for you! [mstrust.org.uk/ultra](https://mstrust.org.uk/ultra)



15 MINUTES WITH...

# Podcaster Jessie Ace

**Jessie Ace** is the host of the DISabled to ENabled podcast, which aims to inspire those living with chronic illness. Here she talks about coming to terms with her MS diagnosis and why she's determined to turn it into "something positive".



## Hi Jessie, can you tell us about when were you diagnosed with MS and how you came to terms with your diagnosis?

The morning of my last day at university – typically the very LAST day – I didn't quite feel 'right'. I'd been working to exhaustion most days so the fact that the left side of my body had gone weak, numb and wobbly sort of made sense to me. I was just stressed. Wrong. It was still numb and weird after a week, so my boyfriend begrudgingly dragged me to the GP for an appointment. Nothing could be wrong, though, I was 22. I was perfectly healthy and had never, ever been sick; I was just exhausted and stressed, that's all. When the doctor announced, she thought I'd had a hemiplegic migraine (which causes localised weakness and numbness) it made total sense. "It'll probably come back in a few weeks", the doctor told me.

Little did I know that an hour later, that feeling – and the diagnosis for that matter – would completely change. My phone rang just as I got home. It was the doctor. She'd been talking with a colleague, and together they came up with the idea I could have had a stroke. She ordered me to go to Accident and Emergency at the hospital, right now.

'Oh my god', I reacted. A stroke?! I thought she was crazy, but at the same time, I'd been working so hard that it made sense, plus it meant it had already happened right? So it couldn't possibly get worse from here. It got worse.

After coming out of the hospital, a week later with a diagnosis of multiple sclerosis; I thought my life was, indeed, over. What the heck was multiple sclerosis?

It took a good few years to accept my diagnosis. A good few years of feeling sorry for myself, blaming myself for not looking after myself more. Always complaining, "Why me?!" or "What did I do to deserve this?" People that I was friends with no longer wanted to know me. They didn't understand what MS was. Neither did I. "What do I do now?" I thought. I've got to turn MS into something positive.

## And how did you turn your diagnosis into a positive?

I decided to use my diagnosis to help others to understand the condition and to help inspire other people to know that their life is not over, in fact, I wanted to tell them it's only just beginning. Firstly, I created the ENabled Warriors. An alternative, positive group, to help people who are young and newly diagnosed.

I then started blogging for the National MS Society, MS Society, and MS-UK.

Most importantly, I wanted to bring people with chronic illnesses together to share their empowerment stories. I created the DISabled to ENabled podcast and have interviewed people such as CEOs, famous radio DJs, even Paralympians, and Ironmen!

But it wasn't easy to get to this stage. At the start, I had zero confidence. I couldn't hold a conversation – I didn't know how! For years I'd been quiet and un-confident with who I was. I didn't want to live that way anymore; I wanted to be the confident person in the room, the one not afraid to speak to anyone. Over time I taught myself to be confident. I taught myself to manage my anxiety. I taught myself to manage my symptoms (without extra medication). I want to pass on what I've learned to others.

## How has being diagnosed with MS changed your outlook on life?

I have far more of an appreciation for life now. I appreciate how good it feels to type with two hands when I can and to be able to take my dog for a long walk in the sunny woodland — listening to the birds chirping in the trees and the fresh early morning air against my face. My eyes finally see what is around me for the first time and it's opened my eyes to how inaccessible our world is and how society judges people who are differently-abled. I believe it's us with these conditions who have to speak up, educate others and share our stories. I am grateful for everyday that I have MS.

## What would be your advice for others diagnosed with MS?

My advice would be to allow yourself to feel what you need to feel at that moment in time. Focus on today. Don't put pressure on yourself or allow people to put pressure on you for not accepting your diagnosis instantly. It could take days, weeks or in my case years to feel at a point where you feel ok to even speak about it. It is natural to go through a grief cycle after a traumatic event like a diagnosis; so when we are faced with a traumatic event, understand that you can't control what happens to you, you can only control how you respond to that situation.

Find Jessie's podcast at  
[www.DISabledtoENabled.com](http://www.DISabledtoENabled.com).





# Vintage Gi♥ing

Easily donate your old and vintage items  
using our **FREE** service to help  
raise money for **MS Trust**.



**Box it.** Fill a box with vintage or old items – up to 30kg.



**Send it.** Drop off at a Post Office for **FREE**, or book a **FREE** home collection.



**Donate it.** Donated items are turned into funds and paid directly to **MS Trust**.



## Items we accept

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**Writing Instruments**

**Pewter/Brass/Copper**

**Watches/Clocks**

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**Pipes/Lighters**

**Old Coins & Currency**

**Medals & Militaria**

**Costume Jewellery**

**Old Toys/Games**



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**MS doesn't stop.  
Neither do we.**

*Please give to our emergency appeal to ensure that we can continue to provide our vital services. Together, we can be there for those with MS today, tomorrow and every day after.*

**Donate now at:  
[mstrust.org.uk/MS-doesnt-stop](https://mstrust.org.uk/MS-doesnt-stop)**

### Order MS Trust publications

**Some of our recently updated publications are listed below. You can find our full list of publications at: [mstrust.org.uk/shop](https://mstrust.org.uk/shop)**

Am I having a relapse? (MS-513)    How can I live well with MS? (MS-512)    Sex and MS: Men (MS-356)

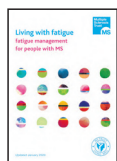
Sex and MS: Women (MS-213)



Living with Fatigue (MS-204)    Primary progressive MS (MS-352)    Secondary progressive MS (MS-458)

Revised Feb 2020

Making Sense of MS (MS-448)



#### Delivery details

Title  First name  Last name

Job title (if health professional)

Address

City/Town  Postcode

We would like to send you information about MS, the MS Trust and the work we do as a charity, and updates as to how you can get involved and help to support us. Would you like to receive this information from the MS Trust? (please tick)    By post ☐    By email ☐

This will not stop any existing communications you receive from us. You can unsubscribe or change your email and postal preferences at any time online at [mstrust.org.uk/preferences](https://mstrust.org.uk/preferences) or by calling 01462 476700.

**Please return to MS Trust, Spirella Building, Bridge Road, Letchworth Garden City, Herts SG6 4ET**

**Remember, if you have any questions about MS you can call our free enquiry service: 0800 032 38 39**

**All our information is free, but we can only continue to offer our services thanks to donations.**

**If you'd like to support our work, visit [mstrust.org.uk/donate](https://mstrust.org.uk/donate) or text to donate £5 via text, text **MSTR01 to 70970**.**

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