

February 2020

# Open Door

Multiple  
Sclerosis  
Trust

MS

Quarterly magazine of the MS Trust

## Feeling unsteady on your feet?

A physio answers  
your questions  
on balance  
problems  
in MS

## It's okay not to be okay

MS doesn't just affect your  
body, it can have an impact on  
your mind too. Inside, we look  
at the importance of taking  
care of your mental health  
when you have MS

## On your marks, get set, GO!

We share the stories  
of some of our  
inspiring London  
Marathon  
runners



# Welcome to the February issue of Open Door



Hello and welcome to the first Open Door of 2020 and of the new decade of course. It's a jam-packed edition as always, covering everything from balance problems in MS (page 18) to taking care of

your mental health (page 14). Hopefully there are some tips inside that everyone will find useful.

We've got plenty of inspiring stories too. On page 10 you can read about how a diagnosis of primary progressive MS inspired Alison Chubb to follow her horse-riding dream, and over on page 12, discover the stories of three members of our 2020 London Marathon team, each with very personal reasons for

taking on the iconic 26.2 mile route for the MS Trust. I'd like to take this opportunity to wish every single member of our team lots of luck with their training and on the day itself. Every stride you take will make such a difference for people with MS. Of course we know that running isn't for everyone and you can find lots of other ways to support our work on page 21. We really hope you like the new issue and if you have any feedback or suggestions for future content, do get in touch at:

**[opendoor@mstrust.org.uk](mailto:opendoor@mstrust.org.uk)**.

**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



### Answering your questions about MS

2019 was the busiest year ever for our Enquiry Service, with our team answering nearly 4,000 of your questions about MS. So whether you have recently been diagnosed, want to know more about a symptom you are experiencing, need information on the different MS drugs, or anything else that's playing on your mind, don't hesitate to get in touch. Our service is confidential and if we can't find the answer, we can direct you to someone who can. You can call us on 0800 032 38 39, email [ask@mstrust.org.uk](mailto:ask@mstrust.org.uk), or contact us via our Facebook page at [facebook.com/mstrustuk](https://facebook.com/mstrustuk). The Enquiry Service opening hours are Monday to Friday, 9am to 5pm.

### Helping people with MS access treatments

The MS Trust is committed to ensuring everyone with MS can access the treatments and services they need and deserve. We work collaboratively with MS charities, the NHS, and other decision makers to influence change and ensure the voice of the MS community is always heard loud and clear when it comes to the decisions that affect you. In 2019 alone, we contributed to 11 MS drug appraisals. Recently that meant explaining to the Scottish Medicines Consortium (SMC) why we think Ocrevus should be made available on NHS Scotland for people with primary progressive MS. We're delighted that the SMC listened and how now approved this treatment. Read more on page 6.



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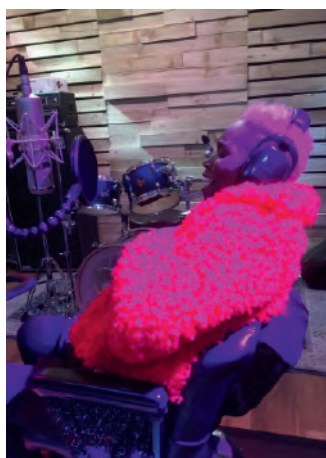


## Helping people with MS fatigue

Managing fatigue requires a very individual approach which can take patience and perseverance to develop. Our book *Living with Fatigue* talks through the strategies you can use to manage your fatigue, including tips to help you build up your energy levels and suggestions on how to use that energy in the best way. We've recently updated this book to ensure it contains the most up-to-date and relevant information. Alongside this, we've redesigned our web page on fatigue to give you more comprehensive information and a more personal journey. Order the new book at [mstrust.org.uk/204](http://mstrust.org.uk/204) or visit [mstrust.org.uk/fatigue](http://mstrust.org.uk/fatigue).

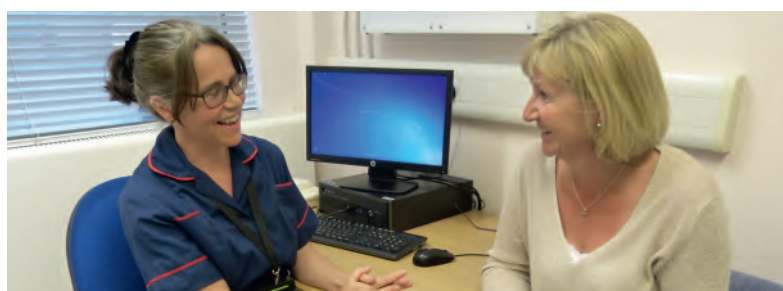
## Releasing a Christmas song

Back in December, we released a charity Christmas song called *Share Christmas With Someone*. The song was written and performed by our wonderful supporter Ruth Green, and was inspired by Ruth's journey with MS. We're delighted to reveal that the song has raised over £3,000 towards our work funding, training and supporting MS nurses across the UK, as well as raising vital awareness of MS. Thank you to everyone who got involved. You can listen to the song on all the usual streaming sites.



## Campaigning for more MS nurses

We believe that MS nurses are vital for people living with MS. They can help you adjust to diagnosis, consider complicated treatment options, manage a wide range of symptoms and learn to live well with an unpredictable, often debilitating, lifelong condition. But, worryingly, many people with MS are missing out on the support they provide, simply because there are currently not enough MS nurses in the UK and the nurses we do have are juggling unmanageable caseloads. Back in November, we launched our #FairMSCare campaign to help address the postcode lottery and fight to ensure everyone can access the specialist support and care they need and deserve. Find out more at: [mstrust.org.uk/fairmscare](http://mstrust.org.uk/fairmscare).



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# News



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)

## Supporting people with advanced MS

**We report back on the latest progress from our Advanced MS Champions Programme.**

Our ambitious MS Forward View project found that many people with advanced MS lose contact with MS specialist services as their condition gets worse. So we launched our Advanced MS Champions Programme, with the promise to bring much-needed support to those who need it the most.

Since 2018, it's been full steam ahead to ensure that promise is met. The first Advanced MS Champion, Lindsay Lord, was appointed at Salford Royal NHS Trust in October 2018, and the second and third Champions, Leanne Walters and Nicola Hyslop, started last summer in Swansea and North Cumbria, respectively.

We are now delighted to announce that our fourth and fifth Advanced MS Champions have started in post. Nicola Hare will cover the Poole area, while Ruth O'Regan is based in Norwich. Ruth and Nicola will bring invaluable support to people living with advanced MS in these areas by coordinating care across different services inside and outside the NHS, working across boundaries in the NHS and social care to ensure more joined-up care, and helping people with advanced MS, as well as their families and carers, to understand their condition and manage symptoms. Recruitment is ongoing for our

sixth Champion and we will bring news on this as soon as we have it.

We spoke to Ruth O'Regan about what she's looking forward to most about her new role: "I'm looking forward to having the time to spend with patients," Ruth told us. "All too often we are too rushed, so it's nice to have the opportunity to sit with them and listen to their needs and work more holistically with them."

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

In November 2019, we brought all five of the Champions together for an away day. This gave them the opportunity to discuss best practices, challenges and to exchange helpful tips for overcoming problems. Denise Middleton, who has worked as an advanced MS clinical specialist in Milton Keynes for around 20 years, led a Q&A session, which enabled her to impart her



*The Advanced MS Champion away day*

years of experience in the field.

At this meeting, we were also thrilled to announce that Lindsay Lord has had her role at Salford Royal NHS Foundation Trust made permanent. The positive impact her role has had on the region is highlighted in the evaluation of her first 15 months in post. This showed savings to the NHS of almost £250,000 through the avoidance of hospital admissions, with 79 potential hospital admissions avoided through Lindsay's interventions.

Other areas showing significant improvements as a result of Lindsay's role were reduced GP visits, reduced medicine budgets, preventing patients moving to continued healthcare funded placements and overall increased wellbeing of people with advanced MS.

We are in the process of measuring the impact of all of the Champions, so watch this space for the full evaluation soon.

## MS health professionals recognised at QuDoS awards

We were delighted to recognise some of the amazing health professionals making a difference for people with MS at the 2019 QuDoS in MS recognition programme back in November.

QuDoS in MS, which stands for Recognising Quality in the Delivery of Services in Multiple Sclerosis, highlights the very best examples of innovation in MS care, and recognises the incredible contribution of individuals and teams in improving the quality of life for people living with MS.

This year's winners included Karen Vernon from Salford Royal NHS Foundation Trust, who was awarded outstanding MS specialist nurse; Jody Barber from Central London Community Healthcare who was presented with the outstanding physiotherapist award; and the nutrition team at Chilterns MS Centre, who were recognised in the team of the year category. Congratulations to all the 2019 winners! For the full list of winners and nominees, see [qudos-ms.com](https://qudos-ms.com).

# Sativex cost effective in final NICE guideline

Back in November 2019, NICE published its final guidance on cannabis-based medicinal products, approving the use of Sativex for people with MS spasticity in England. This reversed the earlier decision made in draft guidance, which did not recommend Sativex because it was not seen as a cost effective treatment.

The guideline recommends that, providing the local NHS health authority is willing to pay for continued treatment, a 4-week trial of Sativex can be offered to people with moderate to severe MS-related spasticity which has not been improved by other treatments. At the end of the trial, if their spasticity-related symptoms have improved by at least 20%, they can continue taking Sativex.

"The MS Trust is extremely pleased that people with MS in England will have better access to Sativex," commented David Martin, CEO of the MS Trust. "As a charity, we have campaigned over a long period for Sativex to be widely available and we are delighted that NICE has listened to our calls for a fair assessment of its cost effectiveness.

"We know that access to this drug will greatly improve quality of life for many in the MS community. At the same time, we also recognise that some local health authorities will not be able to fund continued treatment with Sativex. The challenge ahead is to ensure that everyone eligible



*"The challenge ahead is to ensure that everyone eligible can access this treatment"*

**David Martin, MS Trust CEO**

can access this treatment."

Since this decision was made public, we've heard from many people with MS who are still not able to access this treatment. We will continue to work with the relevant bodies and the MS community to help remove some of the barriers and ensure everyone with MS can get the treatment they need. Keep an eye on our news pages at [mstrust.org.uk/news](https://mstrust.org.uk/news) for further updates.

## Here are five things you should know about Sativex

- 1** Sativex is a mouth spray prepared from cannabis plants and contains two chemicals - tetrahydrocannabinol (THC) and cannabidiol (CBD) - in equal proportions. The number of sprays is gradually increased each day until a dose is reached which relieves muscle stiffness but with the fewest side effects.
- 2** Sativex can only be prescribed by specialist doctors with experience of treating MS spasticity – consultant neurologists, consultant rehabilitation specialists and consultant pain specialists. For those who respond to Sativex, ongoing prescriptions can be managed by a GP.
- 3** Sativex is not yet available on the NHS in Scotland or Northern Ireland. In Wales, it is considered cost effective and is approved as an NHS treatment, although availability is still limited.
- 4** Common side effects include dizziness, drowsiness, constipation or diarrhoea, fatigue, memory or concentration problems, and a dry mouth or changed sense of taste. These side effects are more likely when you first start treatment and usually wear off within a few days. Speak to a health professional if you experience side effects as there may be steps you can take to minimise them.
- 5** As well as spasticity, Sativex had been studied for its effects on a number of MS related symptoms including: pain, bladder symptoms, tremor, and sleep disturbance.

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





# News

## Siponimod recommended by EMA

The European Medicines Agency (EMA) has recommended that a licence should be granted for siponimod (Mayzent) for the treatment of active secondary progressive MS (SPMS).

Active secondary progressive MS is defined as people experiencing relapses or showing signs of inflammation in MRI scans.

MS Trust CEO David Martin commented: "This is exciting news, as siponimod is the first oral drug to be licensed for secondary progressive MS in Europe. Secondary progressive MS has an impact on all aspects of people's lives – physical, emotional, social and economic – affecting not only the person diagnosed, but also their families. We hope that the availability of a new treatment will lead to a renewed focus on the needs of all people with

progressive MS and improve their access to services."

Caroline Smith, who lives with secondary progressive MS, added: "I am delighted that at last a treatment has been licensed for people like myself. For too long we have been excluded from services and been ignored. This decision provides an opportunity to slow our disease progression with the possibility of improving our quality of life immeasurably. Roll on NICE approval."

The next step in the approval process is for the European Commission to grant the licence, taking into the consideration the EMA's recommendation. Siponimod will then be appraised by NICE and SMC to decide whether it is a cost-effective treatment for the NHS.

## Ocrevus approved for primary progressive MS in Scotland

The Scottish Medicines Consortium (SMC) has approved Ocrevus (ocrelizumab) as a treatment for primary progressive MS (PPMS) in Scotland.

SMC has recommended that Ocrevus can be prescribed by the NHS for people with early, inflammatory primary progressive MS. This covers people who:

- have had symptoms of primary progressive MS for 15 years or less **and**
- are able to walk at least 20 metres or more, with or without walking aids (up to EDSS 6.5) **and**
- have evidence of MS activity on MRI scans.

"The MS Trust is delighted that Ocrevus has been approved for primary progressive MS," commented MS Trust CEO David Martin. "As the first approved

treatment for progressive MS in

Scotland, this is a landmark decision. But we know this is just the start. More treatments for progressive MS are still desperately needed, and we will continue to fight to ensure everyone with MS can access the treatments they need."

Ocrevus was approved as a treatment for PPMS in England last year. Roche is working with the NHS in Wales and Northern Ireland to make Ocrevus available throughout the UK. Ocrevus has also been approved as a treatment for relapsing remitting MS in the UK.

## Fampyra approved in Wales

Fampyra (fampridine) has been recommended for use by NHS Wales to improve walking for people with an EDSS score of between 4 and 7.

This means that Wales will be the first country in the UK to make Fampyra routinely available on the NHS to people with MS-related walking difficulties.

The All Wales Medicines Strategy Group (AWMSG) made its decision following a review of the clinical and financial evidence. If a medicine is recommended for use, the NHS in Wales is required to provide funding for the medicine within two months of the recommendation. This new decision reverses an earlier appraisal by AWMSG which found that Fampyra was not cost effective.

## Lemtrada should be restricted, says EMA

Lemtrada (alemtuzumab) treatment should be restricted to people with highly active relapsing remitting MS, according to a review carried out by the EMA's drug safety committee.

Highly active relapsing remitting MS covers people who continue to have relapses despite taking at least one disease modifying drug (DMD) or whose MS is worsening rapidly with at least two disabling relapses in a year and MRI scans show new MS activity. In addition, Lemtrada must no longer be used in people with certain heart, circulation or bleeding disorders or in people who have autoimmune disorders other than MS. The recommendations also include new measures to identify and treat problems that may occur after having a Lemtrada infusion.

The review of Lemtrada followed reports of side effects affecting the heart, blood vessels, liver and immune system. These side effects are rare but potentially serious.

Read about all the latest MS drug news at [mstrust.org.uk/news](https://mstrust.org.uk/news).





## Hair today, gone tomorrow!

Congratulations to our brilliant supporter Pete Davis for completing a year of fundraising for the MS Trust and raising over £2,000. Inspired to fundraise following his wife Shirley's MS diagnosis, Pete decided to grow his beard and hair for a whole year, before dyeing it MS Trust blue and tangerine orange (the colour of his football team, Oldham Athletic) for a spectacular finale at the end of 2019. Pete and Shirley have also been holding collections, parties and raffles in their local community to raise vital funds and awareness. Thank you to Pete and Shirley!

## Well done to our gaming heroes

A big thank you to everyone who took part in our very first MS: Play gaming challenge. Thank you for staying awake through the night and raising awareness of MS through your gaming channels. It was great to see some gaming inspired bakes too! If you would like to take on your own 24hr gaming challenge or tournament in 2020, visit [mstrust.org.uk/msplay](https://mstrust.org.uk/msplay) to find out more.



## A little help from our friends

The MS Trust is keen to develop a network of friends across the UK and we are delighted to announce that we have Friends of the MS Trust actively fundraising and raising awareness in Hertfordshire, North West of England, Staffordshire, Norfolk, South Wales and West Sussex. Look out for more information on how you too could become a Friend of the MS Trust in the next edition of Open Door. Find out more at [mstrust.org.uk/friends](https://mstrust.org.uk/friends).



## Lights, Camera, Action!

Back in November, we were delighted to premiere our new film, My MS Nurse is my Lifeline, which is all about the difference MS nurses make for people living with MS. The film featured Sally Fox, who is based in Bradford and was one of the first MS nurses we funded as part of our Specialist Nurse Programme, as well as her patients, Susan and Fahmeeda. Thank you to everyone who was involved in the making of this film. You can watch it on our YouTube channel at [youtube.com/mstrust](https://youtube.com/mstrust).



## Awards glory for King Kenny!

Intrepid MS Trust supporter Kenny Smith was the winner of the Best Charitable Initiative award at the prestigious 2019 Cycling Weekly Awards. Kenny was nominated for his epic 50-day solo cycle ride around the UK, which took place last summer and raised over £25,000 for the MS Trust. The ride was in memory of Kenny's sister Kathleen, who lived with MS. Well done and congratulations to Kenny for this incredible, and very well-deserved, achievement.



# Research update



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

## Risk of PML with Tysabri extended interval dosing

Tysabri (natalizumab) is very effective for people with highly active relapsing remitting MS but it carries the risk of developing a rare but very serious brain infection called progressive multifocal leukoencephalopathy (PML). While measures are in place to minimise the number of people developing PML, it has not been possible to eliminate the risk completely. Three recent studies looked at the effectiveness of Tysabri and risk of PML when the time between infusions is increased from the current four to six or more weeks.



### Extended interval dosing and PML risk

Researchers analysed data collected through the TOUCH program which monitors treatment with Tysabri and PML risk in the United States. Records of 35,521 people who were at risk of developing PML were selected. The investigators used three definitions of extended interval dosing (EID) to compare the risk of PML with standard interval dosing (SID).

For all three definitions, people who were treated with Tysabri EID were significantly less likely to develop PML. The risk of developing PML was between 88% and 94% lower for people on EID compared to SID.

### Is Tysabri still effective with a longer interval between infusions?

To evaluate effectiveness of the two dosing patterns, Italian researchers reviewed medical records from 14 MS clinics and identified 360 people who had taken Tysabri for more than two years. They were grouped according to the average number of weeks between doses; less than 5 weeks, SID; more than 5 weeks, EID. Relapse rates for both groups were very low and the researchers concluded that both dosing patterns reduced relapse rates very effectively.

### Do the effects of Tysabri wear off?

People taking Tysabri often report that symptoms, particularly fatigue and cognitive fog, are worse in the days leading up to their next infusion. Dutch researchers studied this in a group of 93 people. Just over a half (54%) of the group had experienced a wearing off effect at some point since they had started taking Tysabri and about one third (32%) reported a wearing off effect at the time of the study. The wearing off effect was more

that a longer time between infusions might reduce blood levels of Tysabri sufficiently to allow some immune cells to pass into the brain and prevent PML from developing.

Some commentators were surprised by the dramatic reduction in PML risk achieved by a small difference in dosing intervals and have urged caution in drawing conclusions from the study. One explanation could be that the JC virus that causes PML is very susceptible to a small increase in the number of immune cells passing into the brain.

These studies used historical medical records, which can introduce bias into the results. To obtain more reliable data, a new study is recruiting 480 participants to compare the effectiveness of Tysabri SID and EID over two years, measuring relapse rates, lesions seen on MRI scans and disability worsening. Because PML is a rare side effect, the number of participants in the study will be too small to give data on the risk of PML.

Read the full summaries of these studies, and all the references, at [mstrust.org.uk/tysabri-eid](https://mstrust.org.uk/tysabri-eid)

frequently reported with SID (39%) than with EID (19%) and was not associated with reduced Tysabri blood levels or binding to immune cells.

### What does it mean?

Overall, the studies do suggest that increasing the gap between Tysabri infusions from four to six or eight weeks does reduce the risk of PML, without loss of effectiveness. It has been suggested

Find out more about the JC virus and PML at [mstrust.org.uk/a-z/jc-virus-and-pml](https://mstrust.org.uk/a-z/jc-virus-and-pml)



# Do vitamin D supplements affect MS in people taking DMDs?

Low levels of vitamin D have been linked with an increased risk of getting MS, but also with more frequent relapses and increased disability in those with established MS. As a result, people with MS are often advised to take high doses of vitamin D. But there's been very little research to assess whether high dose vitamin D supplements affect MS activity. Two clinical trials (CHOLINE and SOLAR), which have just been published, investigated the effect of high doses of vitamin D in people with relapsing remitting MS already taking a disease modifying drug.



Read the full summaries of these studies, and all the references, at [mstrust.org.uk/vit-d](https://mstrust.org.uk/vit-d)

## The studies

**CHOLINE:** 129 participants already taking Rebif (beta interferon 1a) and with low blood levels of vitamin D were recruited at 27 MS clinics in France. They were randomly assigned to take either 100,000 IU vitamin D3 (equivalent to about 7,000 IU/day) or placebo, once a fortnight for just under two years. The main measure of the study was a change in the number of relapses.

**SOLAR:** 229 participants already taking Rebif were recruited from 40 MS clinics in Europe and assigned to take either 14,000 IU vitamin D or placebo each day for just under one year. The main measure was the proportion of people at week 48 with no evidence of disease activity (NEDA), a measure which combines no relapses, no increase in disability and no new lesions seen on MRI scans.

## The results

**CHOLINE:** Taking all those who started treatment, there was no significant difference in the number of relapses between the two groups. However, analysing data for just those who completed the study, in the vitamin D group there were fewer relapses, improvement in some MRI measures, and

lower disability progression.

**SOLAR:** There was no difference in the number of people with a NEDA status between the two groups. Analysing the data in more detail, the vitamin D group showed improvements in some MRI measures.

## What does it mean?

Disappointingly, these studies have not helped to establish appropriate doses of vitamin D, who is most likely to benefit and when treatment would be most effective. Neither study was able to show a clear benefit from taking vitamin D as an add-on to DMDs but did show some improvements in MRI measures, indicating there may be some improvements in MS activity.

A large number of participants, approximately 20% in each study, dropped out. Both studies coincided with the introduction of oral DMDs which made it difficult to recruit and hold on to participants; in both studies, people mostly dropped out because they had a relapse or wanted to switch from self-injecting to taking a pill. This high rate of drop-outs makes it difficult to draw firm conclusions; analysing data for just those who completed the studies could introduce bias into the results.

Researchers from these two studies collaborated to reflect on their findings and the results from other studies. They conclude that the effect of vitamin D supplementation is uncertain and less pronounced than suggested by the low blood levels of vitamin D observed during relapses and MS progression. Taking these observations at face value, you might expect there to be a huge treatment effect from increased blood levels of vitamin D when taking supplements but this does not seem to be the case. There could be a number of reasons for this discrepancy, for example, vitamin D levels and more active MS are unrelated but both are affected by some other unknown factor.

The researchers suggest that doses of 1000-2000 IU/day would be sufficient to ensure bone health, a well-established role of vitamin D. A dose of 4000 IU/day would be reasonable advice for people with MS in northern parts of Europe.

Find out more about vitamin D and MS at [mstrust.org.uk/life-ms/diet/vitamin-d](https://mstrust.org.uk/life-ms/diet/vitamin-d)



# Thanks to MS, I am learning to ride!

Alison Chubb was diagnosed with primary progressive MS in 2006. Despite the challenges her MS brings, last summer Alison competed in Riding for the Disabled's prestigious National Championships. Here she talks about how she's following her horse riding dream and learning to make the most of every opportunity that comes her way.



## Getting a diagnosis of PPMS

My diagnosis was a process of elimination. Retrospectively, I'd had symptoms for years. In the late 90s on holiday in Greece, I wasn't sure why I couldn't cycle like my husband did (in the heat!) – was I so unfit? Was I riding a duff hire bike? A couple of years later, during a walk in the lovely Yorkshire Dales, I came to a stile and I just couldn't lift my leg over it. I burst into tears, knowing something was wrong.

My GP referred me to a neurologist who began the arduous process of carrying out numerous tests. They were all to rule things out – stroke, motor neurone disease... to be honest, getting a diagnosis of MS in 2006 was a relief!

## My life growing up

I'm a dairy farmer's daughter and grew up on a farm in Northumberland. But, much to my consternation, I never had a horse and never learned to ride. Like many little girls, I was pony-mad. Schoolmates assumed I would have my own, but I had to explain Dad's annoyingly inarguable reason; "a horse eats more grass than a cow and doesn't give as much milk".

## Finding my local RDA group

Flash forward 40-odd years, and I have lived with MS for a few years, now. My husband and I are on holiday, staying with a family friend who happened to be one of the founders of the New Zealand branch of Riding for the Disabled Association (RDA). At home I'd

started reading Melanie Reid's articles in The Times Saturday magazine. After fracturing her neck in a riding accident, she is paraplegic, and her column extolled the virtues of RDA. Melanie recognised how beneficial riding could be for many disabilities, and she specifically mentioned MS. I felt someone was trying to tell me something...

Back at home, online searching led me to the Bedale RDA group. Within 6 months, I had – amazingly – won our regional heats and qualified for the 2014 National Championships. I didn't do very well, but I was just chuffed to be there, competing in the Countryside Challenge (a simulated hack, or walk on horseback, where you navigate various obstacles.)

## Making progress

Fast forward again, to 2019. I am now riding at the Richmond and Catterick RDA group. My trusty mount is Dexter, a gentle, piebald cob. I am now being encouraged to achieve my riding ambition, which is to rise to the trot. As I have no muscle memory, never having learned to trot pre-MS, my MS-damaged nerves mean my brain has to learn a new, albeit less efficient method. It's taking a while...! I often say that although my own legs hardly work, using a horse's four legs to walk is brilliant! The sense of freedom is great.

The Richmond and Catterick group invited me to compete again in the Countryside Challenge. I was

gobsmacked when it was announced that Dexter and I had won in the regional heats! So five years after my last triumph, I was back at the RDA National Championships! As I have primary progressive MS, to have held a place five years on is very positive progress to me.

## The big day arrived!

As Dexter didn't travel well, we borrowed a horse that I had only ridden once before the National Championships from Stokesley RDA – Jasper, a lovely bay ex-hunter. Jasper and I competed in the 50th Anniversary of the RDA in July 2019. With carriage driving, vaulting, dressage and show jumping, the National Championships is the biggest event for disability riding – even bigger than the Paralympics. Although I was a couple of points off winning a rosette, we all had a ball! The positive, encouraging atmosphere over the whole event was the epitome of the RDA motto: "It's what you can do that counts." Thank you, MS!

## My advice to others

If there are things you fancy doing and you can see a way to try them – go for it! If any readers have PPMS, like me – or have moved into SPMS – we all know there's no going back so we have to make the most of every opportunity that presents itself.

Find your nearest RDA group at [rda.org.uk](http://rda.org.uk). For more ideas on how to stay active with MS, visit [mstrust.org.uk/exercise](http://mstrust.org.uk/exercise).





## SUPPORTER STORY

# Introducing the MS MINI MINI

If you would like to follow the progress of the MS MINI MINI, head to the website for more details: [drivingwithnico.com/charity](https://drivingwithnico.com/charity)

***Our supporter Nicholas Martin has set himself a rather unusual challenge to raise money and awareness for the MS Trust – and it involves a very MINI MINI! Here, Nico tells us about what he's got planned and why supporting the MS Trust means so much to him.***

### My mother has MS

In 2015, my mother was diagnosed with relapsing remitting MS. For years we thought the constant fatigue and headaches were the result of bad sleeping habits and a poor diet. It wasn't until she started talking about a constant tingling sensation and other symptoms did we realise there was a much bigger problem.

When she was eventually diagnosed with MS, it was kind of a relief... because all the symptoms finally made sense. Sadly though, the symptoms have only become worse over the years, and she was later diagnosed with secondary progressive MS.

I wish there was something I could do to help my mother, but I've come to realise that the best thing I can do is help raise money and awareness for the MS Trust.

### Why the MS Trust

The MS Trust have done an amazing job supporting my mother with plenty of useful advice, and an MS nurse has always been

there for her when she needs it most. Sadly though, there are many people around the country living with MS who aren't as lucky, as there are simply not enough MS specialists to provide the support for everyone who needs it. It's great to see the commitment the MS Trust has to changing this, and it's only made possible through fundraising efforts.

My sister and her husband showed their support by running the London Marathon. I felt inspired and knew that I wanted to raise money and awareness too, but the idea of running a marathon is not something that appeals to me. I knew I wanted to do something car related (I have a YouTube channel dedicated to cars), so in 2018, I organised the very first MS Charity Drive, a 24hr scavenger hunt for car enthusiasts. Everyone who took part enjoyed it, and although it was only a small group of us taking part, we ended up raising around £2,000. That's when I knew that I was onto something special.

### Introducing the MS MINI-MINI

So what next? Just as a bit of fun, I bought a little pink toy MINI second hand with the intention of using it for a YouTube video, and at the time only planned to do a simple upgrade to make it go a little bit faster. However, when I drove it around at some car related events, it certainly turned

heads and made people smile when they saw a grown man riding around in a little pink MINI. It didn't take long to realise the potential that it had to raise money and awareness for the MS Trust, especially if I can make it go faster.

The plan is to modify the little pink MINI to reach speeds in excess of 25mph (it currently only goes 3mph!) and set some records in the process. On top of that, to help spread awareness, I intend to change the colour to blue and stencil spray the MS Trust logo onto it.

I've been given the green light to do some official speed runs during one of the most popular performance and modified car events, The Fast Show at Santa Pod Raceway, which is happening on 29 March. The MS Trust will be joining me at Santa Pod, and the MS MINI MINI will be on display at their stand. I hope it will draw in the crowds and allow people to learn more about the project and the MS Trust. At some point during the day, I will be hitting the drag strip with it in front of the crowds to find out just how fast it can go, and attempting to set a top speed record.

My goal is to raise at least £10,000 by the end of the year, and in order to help spread awareness, I plan on attending plenty of other events throughout the year. It may be a very small car, but I'm hoping it's going to have a **BIG** impact.



## LONDON MARATHON

# On your marks, get set, GO!

On Sunday, April 26, thousands of people will limber up for the 40th London Marathon. Among those taking part will be Laura, David and Gail, three amazing runners from Team MS Trust. With the countdown well and truly on, we caught up with the trio to find out how their training is going and their motivations for taking part.

***Gail Shore is an MS specialist nurse in Wolverhampton. Here she tells us why she wants to “give something back to the MS Trust”.***

### **How are you feeling about taking on the 2020 London Marathon?**

I feel very apprehensive as I've never run more than 10K! But I think it will be a fantastic achievement and doing it for the MS Trust gives me even more of an incentive.

### **What made you want to join the MS Trust's London Marathon team?**

I like a challenge and wanted to give something back to the MS Trust as they've been so supportive to me and my patients. My motivation is to not let anyone down! That includes my patients, family, friends and definitely myself. I am very competitive and once I have something in my mind I have to do it. I also struggle with my own weight and need to show my patients that I practice what I preach.

### **How does the MS Trust support your work as an MS nurse?**

In so many ways! I often use the MS Trust website and books with my patients. I have also attended the MS Trust Conference each year since I started my post which has been invaluable to my role - very informative, educational and great for networking and

getting new ideas. I have also attended the MS Development Module which again was a great start to my career in MS.

### **What do you find most rewarding about your job?**

Working in MS can be very complex. When I first started it became very apparent that I needed to know about everything. There are days when it's very hard, but then you get a thank you off a person with MS or carer and you realise your worth. It's always the little things.

### **What would be your main piece of advice for someone newly diagnosed with MS?**

Use the resources available to you - MS Trust, MS Society, MS UK, Shift MS, MS nurses and consultant specialists, GPs. The list is endless. Make the most of your appointments, as you don't get long and don't let MS win. It's an unpredictable condition, so do everything you can to take control. It's very easy to let it control your life.



*Gail Shore*

***Laura Marsden was diagnosed with MS in 2019. “I wanted something positive to focus on to remind me I can do anything I put my mind to,” Laura tells us.***



*Laura Marsden, right*

My main symptom is a numb left hand which makes anything

I was diagnosed with relapsing remitting MS in February 2019 after falling ill six months previously. I now know I had a relapse but the recovery and diagnosis was a very daunting and long process. The support from my friends, family and work colleagues was so important to see me through the tough days and being able to be honest with them about

my fears was very comforting.

that requires manual dexterity very tricky. I also experience fatigue and vertigo, but on the whole I am very lucky that my MS symptoms do not impact my day-to-day life too much.

Once I started to feel better after my relapse, I got into running by joining my local running group. I found that it helped focus my mind and learn about my body again. Staying active also improves my fatigue. It can be really hard to go out but I always feel better once I have been for a run. Thankfully, my amazing running club is great motivation for getting out regularly.

After my MS diagnosis, I felt like the future was uncertain and I really wanted something positive to focus on to remind me that I can do anything I put my mind to. This is why I signed up for the London Marathon. I know it will be tough but the sense of achievement will be totally worthwhile.

With my training, I just focus week to week on my goals and take it steady when I need to. My running group have given me a training plan to follow, allowing me to gradually build up my miles. It's going to be tough at times but I want to enjoy the training as much as the race, so I'm taking it slow and steady.

MS means I've learnt to listen to my body more. If I am tired I allow myself to rest as it's really important not to overdo it. In the same way, it's important not to use MS as an excuse not to get out. It's all about knowing yourself and I'm really clear that my goal is to complete it, not focusing on a time, so that I don't put additional stress on my body.

**David McDonald's reason for running is his wife Elise, who was diagnosed with MS four years ago. "Elise found the MS Trust's support and information a vital crutch," David says.**

#### **What inspired you to sign up to run the London Marathon?**

Four years ago my wife Elise was diagnosed with MS. I remember the day so well: not a great day. But in some ways Elise found it a relief to finally have a diagnosis. At long last she was able to put a name to the unexplained and at times frightening symptoms she had been experiencing over the previous three years – ever since the birth of our amazing son Charlie.

She accepted she had a chronic condition, acknowledging that there was no cure, and that over time her health was likely to deteriorate. She almost immediately adopted a positive mind-set and began a long process of self-discovery and enlightenment. Today, Elise is a stronger person than the woman I first fell in love with and I am in deep awe and admiration of her.

If I'm honest I didn't cope with her diagnosis anywhere near as well, which is a little embarrassing as MS wasn't happening to me. I felt completely powerless. All I wanted to do was look after her but I just didn't know how or what to do. My love for Elise has grown even deeper since her diagnosis and seeing her embrace her degenerative disease and turn it into a positive has been the inspiration for me to try and do something positive for other people who haven't been able to slow the progression of MS in their lives.

#### **Why do you want to run and raise money for the MS Trust?**

I'm proud to once again be a member of the MS Trust's London Marathon team. Every member of the team has a connection with MS and we all understand how a diagnosis can make people feel lost and alone. The MS Trust plays an important role in supporting people with MS from day one and every day afterwards. In the early days of her diagnosis Elise found the MS Trust's support and information a vital crutch and they played

I have chosen to run the London Marathon for the MS Trust because it was a great place for knowledge during my diagnosis and afterwards. The information available was key to helping me and my friends and family understand MS and it took away some of the uncertainty.

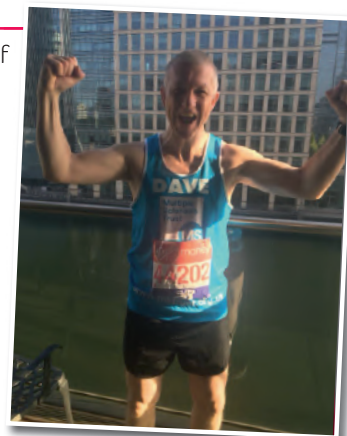
My advice for others diagnosed with MS is to always remember you're still the same person you always were. You might have MS, but MS doesn't have you. Sometimes it might feel like it, but talk to those around you to support you and keep you positive. You've got this!

an important part in her process of beginning to understand MS.

#### **What are you looking forward to most about running the London Marathon?**

The atmosphere at the London Marathon is totally amazing; it's unlike any other marathon that I've run and I'm sure as it's the 40th anniversary this year it will be even more

special. You can't fail to be moved by being part of an event where there's thousands and thousands of people who are running not only to raise money to help other people, but often for the memory of a loved one. It makes you realise that there's so much good in the world.



David McDonald

Running a marathon isn't for everybody, but there are lots of other ways you can support the MS Trust, making a difference for people with MS today. Get inspired at [mstrust.org.uk/fundraising](https://mstrust.org.uk/fundraising)



#### **What do you love about running?**

Running keeps me sane. Seriously. It's the thing that helps me cope with the stuff that life throws at you – and you don't even have to be very good at it.

#### **What's the best piece of advice you've been given about running a marathon?**

Remember to enjoy it. 26.2 miles is a long way and it can take a long time to finish but it can also feel like it's gone in a blur. So, I'm going to do my best to run with a smile even when it hurts and throw as many high fives as I can on my way around.

We'd like to wish all our London Marathon runners the very best of luck and say a massive thank you for supporting the MS Trust. To support our 2020 team by donating £10, text LONDON20 to 70191\*.



\*Texts will be charged at your standard network rate. For terms and conditions, see [easydonate.org](https://easydonate.org).

## COVER STORY

# MS and mental health

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. That's three times higher than for the general population. When faced with an MS diagnosis, it's completely understandable to feel depressed, anxious or stressed, but mental health problems can also be a direct symptom of MS, just like fatigue, balance and spasticity. This MS Awareness Week (April 20-26), we're focusing on MS and mental health, shining the spotlight on the problems that many people with MS, as well as their loved-ones, face and encouraging them to speak up and seek support. Remember, it's okay not to be okay. Here, **Carla King**, who lives with MS, share her experiences and offers some tips for managing mental health symptoms.



Carla King

I remember being in the consultation with my neurologist. It was like I was in a film: someone talking, slowly replaced by music growing to a crescendo, as I, the main character, processed my diagnosis. Many people hear about the Kubler-Ross Curve (commonly known as the five stages of grief)

at diagnosis. It's a

great, illustrative tool, used to help make sense of what we are feeling. I'd used the Curve as an HR professional, helping others through change. Here I was now searching for answers, and it finally resonated with me. But it would be another five years before I met my first MSer; another few before the reality set in.

Denial is the greatest trickster of all. It fools you into believing that everything will be as it was prior to diagnosis, which is true of some things, but not everything. The only guarantees with MS are that change will happen and that there are no certainties. The unpredictable, fluctuating nature of symptoms can lead to unexpected emotions.

MS didn't bother me for the first few years and even when it did, I soldiered on, struggling through life and work. Stress was the

main culprit behind relapses. I don't mean everyday stress, like not missing the train or getting the children to school. I'm talking about heightened, prolonged stress that keeps you awake at night and regularly occupies your thoughts.

We live in a world full of positivity, but when we're having a tough time, we feel pressure for not feeling this way. Many of us call ourselves fighters, but I've found that it's okay to let the MS bully win sometimes, trusting that I will eventually reset.

Denial, bargaining, frustration: I hadn't expected that I would revisit the Curve many more times during my journey with MS, any time there was a new challenge, new drug, new healthcare professional.

Last year, dealing with a particularly insidious new symptom, I began to experience panic attacks; the kind where you can't breathe. I couldn't work out why they were happening, and sought help from a psychologist. Through skilled questioning, we realised it was the MS and a difficulty in wrapping my head around change. I felt better when I started to address this – when you're faced with an unpredictable condition,

taking control becomes hugely important. I began to practise mindfulness and I discovered the therapeutic benefits of blogging.

So, how did I deal with these issues?

1. I feel better when I start to address things. If the source is not obvious, then find someone to help you uncover and deal with this.

*"We live in a world full of positivity, but when we're having a tough time, we feel pressure for not feeling this way"*



2. If you are feeling down all of the time, having outbursts of emotion such as anger, have begun to withdraw from friendships, find it hard to look forward to things, if your level of anxiety has increased and is interfering with your daily activities, talk to your GP. Medication can help, but the key can be counselling and finding coping mechanisms.
3. Be open about what you're going through, and find someone who cares enough not to judge. People tend to be more accepting when they know what's going on, and you are the best person to tell your story.
4. In online forums, people with MS are supportive of new members to this elite 'club' that connects us, and we genuinely understand what you're feeling as we've been there.
5. Mindfulness doesn't take long and can ground you, particularly when you can catastrophise, feel overwhelmed or like you're losing perspective. Find out more at [mstrust.org.uk/mindfulness](https://mstrust.org.uk/mindfulness).
6. As a way of dealing with change, I held on to things that make me happy. Find things that bring you genuine contentment like music, exercise, a good book. No matter how small my achievements are, even if it's just cooking a meal, I will figuratively pat myself on the back.

My approach is practical, but I know how hard it is to see the wood for the trees when you're overwhelmed. My feeling is that you have to put yourself first, and that if you don't deal with issues urgently, they have a tendency to spiral out of control. At the same time, I've realised that just as our MS is individual, so is our approach to it. For example, we wouldn't tell someone grieving to 'get over it.' If we continue to prioritise physical symptoms above mental health issues, we won't access support when we most need it. Strength and resilience come from recognising when something is not going well, as much as it is about celebrating achievements. We have the right to a better quality of life.

**Carla King was diagnosed with MS in 2008, having had her first relapse in 2005. Follow Carla on Twitter @CarlaKCoach or via her blog: [mysbullyandme.blogspot.com](https://mysbullyandme.blogspot.com).**



### ***What should I do if I'm feeling down or anxious?***

Feeling down or anxious is common in MS. It may be the result of dealing with your diagnosis, troublesome symptoms or the unpredictability of living with a long-term condition. However, depression and anxiety can be symptoms of MS in their own right if an MS lesion has occurred in an area of the brain associated with mood.

Depression or anxiety can come on suddenly or may creep up bit by bit without you realising. It's OK to deal with low mood in your own way to begin with by talking things through with family, friends or in online or face to face support groups. If you continue to feel down or are worried, then seek professional advice about treatments from your MS nurse or GP. Find out more at [mstrust.org.uk/life-ms/wellbeing](https://mstrust.org.uk/life-ms/wellbeing)



## **MS Awareness Week 2020: What we've got planned**

MS Awareness Week will run from April 20-26 and is a chance for us all to raise awareness of MS and the work of the MS Trust. MS is often misunderstood, with many people not realising what it's actually like to live with it. By speaking up about MS, in MS Awareness Week and all year round, we can change that.

### **How can I get involved?**

There are lots of different ways you can get involved:

- This year's MS Awareness Week focus is mental health and MS. We'll be encouraging people to organise a get together with friends, family and work colleagues to have a chat and a brew, and talk openly and honestly about MS, mental health and everything in between. To order a pack, which will include everything you need to organise your event, see [mstrust.org.uk/msawareness](https://mstrust.org.uk/msawareness).
- Download our MS Awareness Week graphics to share on your social media accounts and put up awareness posters in your local area. You can download them at [mstrust.org.uk/spreadtheword](https://mstrust.org.uk/spreadtheword).
- You could set up an MS information or fundraising stand at work, in your local library, your GP surgery, a local hospital or therapy centre, or anywhere that you think might reach people who would like to find out more about MS. Email [fundraising@mstrust.org.uk](mailto:fundraising@mstrust.org.uk) for more information.
- You could share your story, get in touch with us at [mystory@mstrust.org.uk](mailto:mystory@mstrust.org.uk).

**For more information, ideas and inspiration, visit [mstrust.org.uk/msawareness](https://mstrust.org.uk/msawareness).**

## FOCUS ON

# Self-compassion and resilience

Clinical psychologist, **Dr Sophie Day**, has been researching how people with MS adjust to having a long-term condition. In particular, her research focuses on the potential benefits of developing more self-compassion and resilience. Here Sophie talks about the findings of her research and provides some practical strategies which, through a little bit of self-reflection, encourage you to be kinder to, and more accepting of, yourself.

### What do we mean by self-compassion and resilience?

Self-compassion is the ability to be kind, accepting and understanding of oneself in times of difficulty. It's made up of several different factors.

- Mindfulness – evaluating negative emotions in a more helpful way so they don't become amplified or avoided.
- Self-kindness – showing care and compassion to yourself.
- Common humanity – the idea that other people may be going through a similar experience to you; you're not alone.

Resilience is linked to self-compassion in a way. It is focused on the ability to bounce back in times of stress or adversity and grow positively following challenging experiences. The idea is about you returning to the functioning you experienced before either a trauma or a diagnosis of a medical condition.

Another term looked at in this area is post-traumatic growth (also known as benefit finding) – the idea that people can actually go above the functioning they experienced before a trauma or a diagnosis by developing new behaviours and attitudes. Some theory suggests that post-traumatic growth is a stage above resilience, and we looked to test this in my research.

*"By developing more self-compassion, you actually become more resilient because you're able to deal with stresses and adversities in a more positive and less self-critical way"*

### How the study was carried out

The first part of the study was a review of the current literature of psychological growth and the impact on functioning. We carried out a quantitative review of research covering psychological growth (ie resilience, post-traumatic growth, benefit finding) in MS. We were looking at the relationship between these qualities and wellbeing and distress. Specifically we wanted to see whether

psychological growth was linked to reduced distress and improved wellbeing.

The second part of the research was an international survey which was completed online by over 200 people with MS. The survey encompassed a range of questions focusing on self-compassion, quality of life, stress, coping and perceived cognitive functioning to explore the relationships between these factors.

### What were the results?

Our quantitative review found that psychological growth was related to improved wellbeing and reduced distress, with greater effects shown for resilience than post-traumatic growth. This suggests that resilience is different to post-traumatic growth and may require fewer resources to achieve.

The survey study found that higher levels of self-compassion

were linked with improvements in quality of life and coping, reduced stress levels and fewer reported memory and thinking problems. The improvements in memory and thinking were found to be linked to reduced levels of stress.

Overall our research suggests that increased self-compassion and psychological growth are beneficial for improved adjustment to MS, and appear to have a positive impact on coping, quality of life, stress, memory and thinking, well-being and levels of distress in the context of MS.

### How to build resilience and be more self-compassionate

Self-compassion and resilience are often interlinked and many people have a lot of resilience already and resources they can tap into. There are however some simple exercises that can be a good place to start. It can feel hard for people in the beginning to understand what self-compassion is or how to practise it, so here is one example to demonstrate how you can adapt your thoughts to be kinder to yourself.

#### Example: Turning self-criticism into self-compassion

Often people will think about all the housework that needs to be done. If there are lots of jobs that need doing and you don't get them done, you might start thinking negatively about yourself.

You might think: "I've not done this so I'm really lazy. I shouldn't be resting, I should be doing the housework. Other people would be able to do it all and do it better than I can do it."

You can adapt your way of thinking about this problem to be more self-compassionate: "If I push myself I'm going to end up feeling worse than I feel right now. I've done the amount that I feel capable to do today and that's good enough. I can do the other bits when I have more time and energy. What I've achieved is good for me and comparing myself to others may not be helpful. It is ok to feel tired; I've used a lot of energy today."

**Could you apply this to a situation in your life and turn your self-critical thoughts into more self-compassionate ones?**

Practise self-compassion when you're able to – try not to become critical of yourself if you feel like you're not doing it often enough or doing it right. Try to notice times where you were self-critical and think about how that made you feel. How would you have felt if you'd used a bit of self-kindness instead?

Another really useful place to start with self-compassion is a website called **self-compassion.org** which was developed by researcher Dr Kristen Neff. Through a range of resources and exercises, it shows how self-compassion can be useful practically in daily life. Some of the practical exercises teach you how to treat yourself as you would a friend and how to reframe self-critical thoughts. It may feel a little alien to begin with but it's something many people find helpful – just keep practising!

By developing more self-compassion you can feel more able to cope with stresses and adversities in a less critical way, helping to build your resilience.

### Coping with the uncertainty of the future

It's really difficult to sit with that feeling of uncertainty about the future. You can start to feel quite angry about it, understandably, and want to actively do things to make things better or to reduce the uncertainty, but sometimes that's just not possible. You can be on a disease modifying drug, you can be doing exercise and lots of other things to keep well, but sometimes that uncertainty is still there.

Sometimes acknowledging that the future is uncertain is important for people. There's often this fight against it and sometimes people feel like they could be doing better or doing more. That is generally quite self-critical and the idea of self-compassion is being able to recognise that actually I'm doing the things that I can be doing, I don't really have control over what's going to happen next, but I can just try to manage that as and when I can. That's really important – acknowledging that the future isn't certain.

Only you can know what your journey is like and how it feels to live with MS for you, but acknowledging that you're doing the best that you can to cope with this unpredictable journey can help.



#### Recently diagnosed with MS?

Learning more about MS can help you take control and feel more secure in what can feel like uncertain times. Our Making Sense of MS core book covers some of the most commonly asked questions after diagnosis. Visit our website to order the book or read it online at [mstrust.org.uk/448](http://mstrust.org.uk/448).



**Dr Sophie Day is a clinical psychologist working in a neuropsychology team in Sheffield. She sees people with a range of cognitive difficulties caused by neurological conditions such as MS. Sophie is particularly interested in understanding what factors affect adjustment to long-term conditions like MS.**





## ASK THE EXPERT

# Dizziness and balance

Many people with MS experience problems with balance, dizziness, feeling unsteady and lightheadedness. These symptoms can be really debilitating and make it difficult to get on with simple daily activities. We spoke to neuro and vestibular physiotherapist **David Herdman** to find out about the effective strategies that are commonly used to help improve problems with dizziness and balance.

Q

**What's involved in maintaining a good sense of balance?**

**David says:** We use lots of different sensory systems for our balance and orientation. We use our inner ear balance which senses movement of our head. We also use our hearing and vision, and we use the sense that comes from our muscles and joints which tells us where our limbs are in space. The brain integrates all of these different senses and helps us to stay upright, balanced and orientated.

Q

**What causes balance problems in people with MS? What goes wrong?**

**David says:** A disruption in any of those different senses can lead to a sensation of dizziness or unsteadiness, so there's quite a lot of things that can cause it.

A common cause of dizziness is a condition within the vestibular system – the inner ear balance mechanisms. These have connections through the inner ear up to the lower part of the brain and into the upper part of the brain as well where dizziness is perceived. Demyelinating conditions can affect those pathways and cause dizziness.

For more information on balance problems in MS, visit [mstrust.org.uk/balance](https://mstrust.org.uk/balance).



We also know that people with MS are particularly prone to a form of vertigo called benign paroxysmal positional vertigo, or BPPV. This causes symptoms of dizziness when you lay down in bed, roll over in bed or tip your head up in these kinds of positions. The dizziness usually lasts for just a short period of time and is caused by a mechanical problem of the inner ear.

Q

**If you're referred to a physio because of dizziness and balance issues, are there any tests you'd usually carry out? What can people expect?**

**David says:** Usually a physiotherapist will ask you quite a number of different questions to try to establish what are the different characteristics of the dizziness – for example, when it might come on, what kind of movements trigger it and how long it would last.

Then they would typically do an examination which involves looking at your eye movements and certain reflexes of your head and eyes. There is a specific test for positional vertigo where they lay you down on a plinth and see whether that reproduces your symptoms. They may also look at your balance and walking.

After these tests they'll be in a position to recognise whether there's some exercises that might be able to help you or whether you might need some further investigation.

Q

## What would a physio suggest for treating problems with balance?

**David says:** Exercise is a key treatment for dizziness and balance problems. One of the interventions is called vestibular rehabilitation. Essentially this is an exercise-based therapy which involves different eye, head and body movements. Vestibular rehabilitation works by bringing on dizziness a little bit so that the brain can put it right. Over time, the brain desensitises to the movements and environments that at one time may have provoked the dizziness in the first place.

Q

## Is there any medication that can help?

**David says:** Generally we avoid medication to treat balance problems. Usually it doesn't really work and taking medication over a long period of time can sometimes worsen the problems of unsteadiness and balance. Medication that suppresses the vestibular system can actually delay recovery and affect the parts of the brain that we need to naturally recover. Usually we don't encourage long-term use of medication, although there are a few conditions where that can be helpful. If you're concerned about medication, it's worth speaking to your doctor..

Q

## Are there any types of exercise that can improve balance problems?

**David says:** Yes, outside of traditional vestibular rehabilitation, think about any kind of exercise that involves head or full body rotation or movements. Racket sports can be useful for this. Also there is some evidence towards Tai Chi due to its focus on balance and posture. Any kind of exercise that you enjoy can be useful, but it's got to challenge your balance. It's got to be quite difficult in order for you to improve.

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### Looking for exercises to improve your balance?

We have a range of exercises you can try on our website: [mstrust.org.uk/exercises](https://mstrust.org.uk/exercises). Do speak to a health professional if you're unsure what exercises are right for you.

Q

## If your balance issues are as a result of lesions on the brainstem, is it still possible to treat this with physio?

**David says:** The brainstem is a complex structure. It depends on what part of the brainstem is affected and how that might manifest. For example, there are some eye movement disorders that typically wouldn't respond to exercise. Nevertheless, in the largest study that's been completed to date they looked at vestibular rehabilitation in people with MS and they compared the results of people with and without brainstem lesions. They found similar levels of benefit from both of those treatment groups. That suggests that even patients with brainstem lesions might benefit from vestibular rehabilitation and physiotherapy to manage their dizziness problems.

Q

## If you could give three practical tips to someone who regularly experiences dizziness, what would they be?

**David says:**

1. Seek the appropriate help and try to see a specialist with knowledge of the vestibular system. That can be a nurse or physiotherapist or sometimes an audiologist. It's often a bit of a myth that dizziness is not treatable. In actual fact the vast majority of causes of dizziness can be treated effectively by trained specialists.
2. Try not to avoid those movements that bring on the dizziness. It's very natural and common that if something brings on dizziness you're going to try and avoid it, but actually bringing on that dizziness, even in the short term if it makes you feel a little bit dizzy, can help the brain to recover and reduce the response to dizziness over time.
3. Exercise is safe, even if it does bring on a little bit of dizziness. However, often people go in all guns blazing and then need to rest up for longer afterwards – that kind of boom and bust cycle doesn't necessarily help. When you're exercising, it's important to start off gradually with something very simple and easy, then gradually work up as you can tolerate more and more.

**David Herdman is a neuro and vestibular physiotherapist working in London.**



# Turn the skies MS Trust blue on World MS Day



*"It was truly one of those experiences I'll never forget!"*

**World MS Day is taking place on Saturday, 30 May this year and at the MS Trust we want to make this day extra special by inviting as many people as possible to take on an experience of a lifetime. Are you in?**

We would like to invite you, your friends, family or work colleagues to take a leap on World MS Day and sign up to a sponsored skydive for the MS Trust. We would love to get as many MS Trust supporters as possible skydiving across Britain on the same day, which will help us raise vital funds and awareness. Can we make the sky MS Trust blue for a day?

Tony (pictured) completed his skydive for the MS Trust last year. He said: "It was truly one of those experiences that I will never forget, all for the right reasons. The enjoyment of free fall, with the intense sound of wind rushing past your ears and dropping through the air at over 120mph was extremely strange but a fantastic feeling. The complete contrast to the peace and quiet of when the parachute opened and the gentle glide down to land. The whole day was such a memorable experience, with fantastic support from the MS Trust throughout. Together (with a colleague) we raised just under £3000".

The MS Trust's Director of Fundraising, Rob Carter, is taking the leap on 30 May and wants you to join him on this special day. He commented: "I've seen first-hand how cruel a condition MS can be, but I've also seen the amazing resilience it brings out in people. That's why I want to do my bit on World MS Day by taking part in the MS Trust skydive. Jumping out of a plane will definitely be taking me out of my comfort zone, but I'll do it with a smile on my face knowing that the money raised will help to provide incredible support for people with MS."

**Follow this step by step guide to find out how you can join Rob and other MS Trust supporters on this special day, at your nearest airfield. Don't delay, spaces are limited, so book now to avoid disappointment.**

Find out more at  
[mstrust.org.uk/world-ms-skydive](https://mstrust.org.uk/world-ms-skydive)

**Step 1:** Download our World MS Skydive pack for all the information you need about how you book at [mstrust.org.uk/world-ms-skydive](https://mstrust.org.uk/world-ms-skydive)

**Step 2:** After reading through the information and having any required medical forms signed, you can book your skydive for World MS Day on Saturday 30 May 2020.

**Step 3:** Once your skydive booking is confirmed, start collecting sponsorship to help those living with MS today. Our Fundraising Team will be on hand to help you along the way and will make sure you look the part on 30 May with your very own MS Trust t-shirt!



# A regular gift can make a BIG difference...



## A regular gift to the MS Trust enables us to plan ahead and support people living with MS in the UK.

All our services are offered completely free of charge. We receive NO Government funding to help us do this and much of our work is supported by voluntary donations and fundraising.

A regular gift allows us to plan ahead and underpins much of our work. It also provides an opportunity for you to support people affected by MS in a way that suits you. For example, you can choose how much and how often you would like to donate. A monthly gift of just £5 can help pay towards an MS nurse or Advanced MS Champion. It could help pay towards our information publications or time given by a member of our enquiry team. Rest assured that every penny you donate will be spent wisely and where the need is greatest.

***“My MS nurse is a rock, I can’t praise her enough. It is difficult to find someone who has the time to not only listen to what you have to say, but who can help with the problem.” Mark, living with MS***

We want to be there for everyone affected by MS, today, tomorrow and every day after, but we can’t do it without your help. You really can make a difference.

To find out how, visit: [mstrust.org.uk/regular-giving](https://mstrust.org.uk/regular-giving) or phone 01462 476707.

## Get involved!

There are lots of ways you can get involved and support our work helping everyone affected by MS. 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.

### My Garden Party

Spring is on the horizon! Start planning the afternoon teas and garden parties in the pretty spring blooms. Order your Garden Party pack from our website at: [mstrust.org.uk/mygarden](https://mstrust.org.uk/mygarden)



### Ultra Challenge Series

Looking for a walking challenge in 2020? The Ultra Challenge Series offers a variety of events and distances in many different parts of the country. From nature reserves, forests and the rolling hills of the countryside to coastal paths and historic trails, you can take in wonderful views. Or you could even pick the hustle and bustle of the capital and walk across 16 of London’s famous bridges. [mstrust.org.uk/ultra](https://mstrust.org.uk/ultra)

### Asics 10K London: 5 July 2020

Join Team MS Trust for this fun festival of running through the capital city. Make your New Year’s resolution stick, lace up those running shoes and don an MS Trust tee to make a difference for people with MS today. [mstrust.org.uk/asics-10k](https://mstrust.org.uk/asics-10k)



### School Awareness Pack

If you’re a teacher trying to explain MS to your class or a parent wanting to raise awareness at your child’s school, then look no further than our School Awareness Pack. Full of resources and fundraising ideas, you can download it for free from our website at: [mstrust.org.uk/school-pack](https://mstrust.org.uk/school-pack)

### Great North Run: Sunday, 13 September 2020

Join our team at the largest half marathon in the world and be part of the spirit of the North East. Take on this half marathon from Newcastle to South Shields with Team MS Trust and help make sure a life with MS isn’t a life defined by MS. [mstrust.org.uk/greatnorth](https://mstrust.org.uk/greatnorth)



15 MINUTES WITH...

# Professor Gavin Giovannoni

At the MS Trust's annual Conference back in November, MS Trust CEO David Martin caught up with leading neurologist Professor Gavin Giovannoni to talk about some of the challenges facing people with MS.



**Hi Gavin, thanks for talking with us today. What do you think are some of the biggest challenges facing people with MS at the moment?**

I think there are a number of challenges, from diagnosis all the way through to the advanced phases of the disease. But underpinning all that is probably access to services and good quality services, which vary across the country. So I would say the biggest issue we have is the variability in MS service provision in the UK.

**What do you think can be done to address this postcode lottery?**

I think we have to highlight the postcode lottery and then when we have the data, we use it in business cases to create policy statements and get politicians engaged. At the end of the day, politicians hate variability. They have to answer 'why isn't this part of the country as good as that part of the country?' and this creates at least the momentum for change.

There's also an enormous number of people that have just fallen out of the service. So when you go across the country, you find that anything between 10 and 25% of people with MS aren't even attached to a service. I think we need to get the message out to people that they need to become politically active. They need to lobby general practitioners, they need to lobby the MS service and lobby politicians to improve the services locally.

**The challenge might be getting even bigger because the prevalence of MS seems to be going up. So what can we do about that?**

We always underestimate the incidence and prevalence of MS and recently there was a study done in the Highlands and the Western Isles, which showed that in the last seven years the incidence and prevalence has gone up 30%. So I think there's actually an epidemic going on and we're not doing anything about monitoring this epidemic.

We know MS is potentially preventable and we really do need more research on MS prevention. We should be starting these studies sooner rather than later. Otherwise we're going to be letting down the next generation of people with MS. They shouldn't be getting this disease if we can prevent it.

**If you had a five-point manifesto for the MS community what would that be?**

A big funding push on prevention, a big funding push on improving services, and a big funding push on advanced MS,

getting those people that have been forgotten back into the services. That's going to need a big investment from the NHS, but at the end of the day, most of the MS services are just running flat out. We're just fighting fires. We don't have any spare capacity, we are on the bones in terms of what we can do and that's because of all the changes in the environment. I mean there is austerity Britain, most of our NHS trusts are under special measures, there is no finance for anything else, and they are expecting us to do more with less. You speak to MS nurses and half of them are burnt out because they just can't deal with the workload. So we really have to have a fundamental change in the way we approach MS.

*"We have to have a fundamental change in the way we approach MS"*

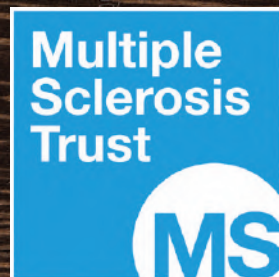
**And finally, what do you think can be done to help people with progressive MS?**

We've got to get rid of the dogma that if you've got more advanced disease that it is not modifiable. We've just got a drug licensed for primary progressive MS and there's potentially a drug coming for secondary progressive disease and we think the disease is modifiable throughout its course. We're starting two trials, one in primary and one in a more advanced secondary progressive MS, with the primary focus being upper limb function (more info at [multiple-sclerosis-research.org/trials-and-studies](https://www.ms-trust.org/trials-and-studies)). We think even when people are in wheelchairs, we could potentially modify their disease and slow down the worsening in terms of their upper limb function and keep them independent. So this dogma that's crept into the MS field that once you get to a wheelchair, there's nothing that can be done, it's not true. We need to challenge this dogma, encourage people with more advanced MS to get back into their services. It's not always about DMDs, it's about stopping them getting bladder infections, pressure sores, it's helping them with spasticity, it's improving their sleep at night. All these things improve quality of life and that's what a comprehensive holistic MS service should be providing.





# Write your will week



Reg charity no. 1088353

**16th – 20th March 2020**



From **16th – 20th March 2020** participating solicitors will be giving their time for free to write a basic will in return for a donation to the MS Trust.

Appointments are limited and available on a first come, first served basis. Terms & conditions apply.

For more information and to find a participating solicitor - visit **[www.mstrust.org.uk/wills](http://www.mstrust.org.uk/wills)** or call **01462 476707**







**Reviewed  
and updated  
for 2020**

**Newly diagnosed with MS? We're here for you. Today, tomorrow and every day after.**

Making Sense of MS is our resource for people recently diagnosed with MS. It covers what MS is, what happens after you're diagnosed, preparing for appointments with health professionals and how to live well with MS. You can order below or visit [mstrust.org.uk/publications](https://mstrust.org.uk/publications).

### 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)**

Managing your bladder (MS-429)

Managing your bowels (MS-430)

Sex and MS: Men (MS-356)

Sex and MS: Women (MS-213)



Living with Fatigue (MS-204)  
Revised edition

Primary progressive MS (MS-352)

Secondary progressive MS (MS-458)

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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