

# Open Door

Multiple Sclerosis Trust

MS

Quarterly magazine of the MS Trust

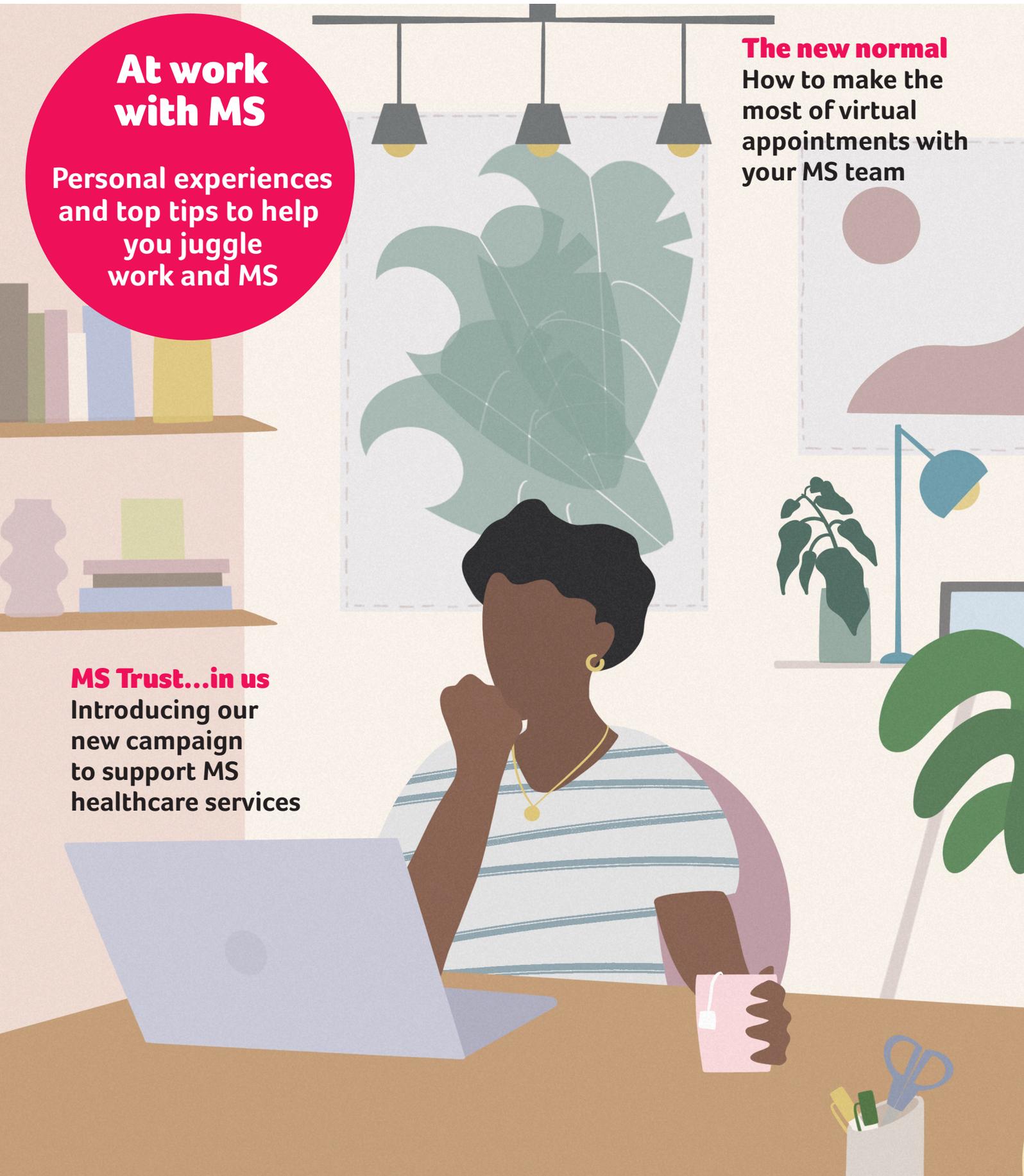
## At work with MS

Personal experiences and top tips to help you juggle work and MS

## The new normal

How to make the most of virtual appointments with your MS team

**MS Trust...in us**  
Introducing our new campaign to support MS healthcare services



# Welcome to the November issue of Open Door



This is the last Open Door of 2020 – and what a year it has been. It has been a rollercoaster ride for all of us, with an unprecedented number of challenges along the way, and I for one will be very pleased to see the back of it. Here's hoping for a

smoother ride in 2021.

As I reflect on the year gone by, one thing that really stands out to me is the humbling commitment and unstinting backing shown by all our incredible supporters. I would like to thank each and every one of you for your dedication to the MS Trust. Whether you ran the virtual London Marathon in the rain, skipped, hopped and jumped Miles for MS, or generously donated to our emergency appeal, we are so grateful for your support. We couldn't do what we do without you.

We promise to continue to do our utmost to ensure people with MS across the UK have the support and care they need and deserve.

One way we will be doing this is through our new 'MS Trust...in us' campaign (read more on page 16). This campaign will support MS healthcare services and people with MS during the pandemic and beyond; ensuring everyone can access the care they have a right to expect. We know that the Covid-19 pandemic has had a big impact on MS services across the UK. Our recent survey with the MS Society showed that 70% of health professionals feel that the service they work in, or with, is not currently able to meet

patients' needs to the extent it was pre-pandemic. Waiting lists were already too long for people with MS, and I am hearing first-hand how these waiting lists have got even worse during the pandemic. This is simply not fair. We are committed to doing all we can to help restore MS services in the aftermath of Covid-19 to make sure nobody has to manage MS alone.

Elsewhere in this issue, on page 14 you can read all about our brilliant new Staying Smart webzone, which provides everyday tips and tricks for dealing with thinking and memory problems in MS. On page 8, we share personal stories and top tips to help you juggle work and MS. On page 18, we have a really informative interview with Dr Jonathan Koffman on palliative care. And, on page 4, I reflect on what we are doing to be a more inclusive and diverse organisation, which fully represents the community we serve.

Don't forget if you, or a member of your family, have any questions about MS, the MS Trust Enquiry Service is here for you. You can call our friendly and knowledgeable team on 0800 032 38 39 or email [ask@mstrust.org.uk](mailto:ask@mstrust.org.uk).

All the best,  
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).

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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)

# Latest MS news

## Siponimod (Mayzent) approved for active secondary progressive MS in England, Scotland and Wales

The MS Trust is delighted that siponimod (Mayzent) has been approved by both NICE and Scottish Medicines Consortium for people with secondary progressive MS (SPMS) who continue having relapses or show MS activity on MRI scans.

The approval of siponimod (Mayzent), the first oral treatment for active SPMS, marks a significant advance in the treatment of progressive MS.

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

David Martin, CEO at the MS Trust, commented: "At the moment there are few options for someone whose MS is changing from relapsing remitting to secondary progressive, so this approval is very welcome and a big step forward. By slowing down disability progression and improving cognition, siponimod has the potential to allow people to carry on working, remain independent and stay connected with family and friends. More broadly, we hope that the availability of this new treatment will lead to a greater focus on services for progressive MS which would benefit a much wider group of people."



Caroline, who lives with SPMS, added: "This is fabulous news. While many of us won't meet the criteria, it is a game-changer for some and hopefully signals the start of more treatments for all with SPMS."

The MS Trust played an integral part in the appraisals. Nearly 400 people supported us by sharing their experiences and views, allowing us to give a compelling account of the challenges of living with SPMS and make a strong case for siponimod (Mayzent). Thank you to everybody who shared their experiences.

In Northern Ireland, NICE guidance is generally accepted once it has been checked by the Department of Health for any policy and financial consequences.



### What is active secondary progressive MS?

Many people initially diagnosed with relapsing remitting MS notice that, over time, they have fewer relapses and increasing disability, such as walking difficulties, poor balance and coordination, bladder and bowel problems. This is called secondary progressive MS.

The change from relapsing remitting to secondary progressive MS is gradual and people may continue having relapses or show signs of new and active lesions on MRI scans while at the same time their disability increases. This is described as active secondary progressive MS. Find out more at [www.mstrust.org.uk/spms](https://www.mstrust.org.uk/spms)

### What is siponimod?

Siponimod is taken as a tablet, once a day. In clinical trials for secondary progressive MS, siponimod delayed disability progression by 26% compared to placebo. Further analysis focussed on a subset with active SPMS – people who had relapsed in the two years prior to starting the trial or showed MRI evidence of MS activity. For the active SPMS subgroup, siponimod delayed disability progression by 37% compared to placebo. In addition to its effect on disability progression, siponimod can improve aspects of memory and thinking (cognition) through an improvement in the speed at which the brain processes information.

Side effects which have occurred more frequently in people taking siponimod include: low white blood cell count, increased liver enzyme levels, slower heart rate when starting treatment, macular oedema (swelling in the back of the eye affecting vision), high blood pressure, shingles, and convulsions. Find out more at: [www.mstrust.org.uk/siponimod](https://www.mstrust.org.uk/siponimod)

# Our pledge to be a more inclusive and diverse organisation

The response to the tragic death of George Floyd in the summer has led us to reflect on what we are doing to be a more inclusive and diverse organisation, which fully represents the community we serve. MS Trust CEO **David Martin** shares his promise to "amplify the voices of people who are marginalised."



Like many of us over the last few months I have been thinking more about the importance of equality and the impact this has on people's lives.

Both the Black Lives Matter movement and the disproportionate impact of Covid-19 on Black, Asian and ethnic minority people have shone a light on

issues of race and inequality, including the inter-section between inequality and health.

Racial discrimination and injustice remain all too prevalent across UK society and we all have a role in challenging and changing this. The MS Trust is here for everyone affected by MS - because anyone can be affected by MS. We aim to support all people affected by MS including Black, Asian and minority ethnic people.

We know we haven't done enough in this area in the past. Now we want to ensure that all voices and viewpoints are heard and to amplify the voices of people who are marginalised. To do this effectively we need to be proactive and ensure we look outwards, so that we understand and appreciate the diversity of people living with MS. We need to be an organisation which is inclusive and diverse, and which fully reflects the community we serve. I recognise that we have significant work to do on diversity and equality at the MS Trust and that we must find ways to address the systemic issues that exist in who we are and what we do.

I am grateful to everyone who has reached out to us to tell us about their experiences, to ask us about why we aren't doing more and to challenge us to improve. We have taken time to listen

and to reflect on these concerns and to start to plan how we will change.

## So what are we doing?

- We're making it a priority to work more closely with the whole MS community and to build our knowledge. We want to better understand who we serve and the problems that they face.
- We're looking hard at our services and our organisation to identify where we need to improve.
- We're working with our staff and trustees to agree a plan for change – and we will make sure that we put in the time and energy to follow it through and resource the actions we identify.

Every step of the way, we will continue to reflect and discuss. We will keep you updated with the changes we are making as an organisation and ensure the dialogue continues. We know we have a lot of work to do, but we are committed to making this change.

*"We need to be an organisation which is inclusive and diverse, and which fully reflects the community we serve"*

## Talk to us

We know that we have much to do and that we can't do this change alone. We need to work with and listen to our community. If you want to work with us as we change please get in touch at [hello@mstrust.org.uk](mailto:hello@mstrust.org.uk). If you'd like to share your story, please email us at [mystory@mstrust.org.uk](mailto:mystory@mstrust.org.uk).

# Flu jab season is here: what you need to know



If you have other questions or concerns about the flu jab and MS, you can read more details at [www.mstrust.org.uk/flu](http://www.mstrust.org.uk/flu)



## Can I have a flu jab if I have MS?

This year, all UK nations are expanding their flu vaccination programmes to encourage more people to have a flu jab and allow more people to have the flu jab for free. With Covid-19 circulating in the community, a surge in flu cases could overwhelm hospitals and other NHS services.

Flu can be a serious or even fatal illness, and each year causes thousands of people to become very ill. Like Covid-19, it is a viral infection that is passed on through coughs and sneezes. If you have MS, you're more at risk of becoming seriously ill from flu, even if you currently feel well.

By having the flu jab, you reduce your risk of having flu. If you do catch flu after having the vaccine, you are likely to have a milder illness. Having the flu jab also means you are less likely to have flu and Covid-19 at the same time, which could make you more unwell.

People with MS can have the flu jab for free every year. It is provided through pharmacies and GP surgeries, as well as workplaces and schools. You may be contacted by your surgery if you have been offered a flu jab in previous years, but you can also get in touch with them directly to book a flu jab for yourself.

Demand for a flu jab is high this year, and local services may need to prioritise the most vulnerable people

for their early supplies of the vaccine. However, the vaccine is delivered to GPs and pharmacies in several batches, as it needs to be kept refrigerated, and the NHS is confident there is a sufficient quantity available.

## Who can have the flu jab for free?

This year, the free vaccination is being offered to:

- adults aged 65 and over
- people with some medical conditions, including MS
- the main carer of an older or disabled person
- people who were required to shield from coronavirus – and anyone they live with
- pregnant women
- children aged from two to 11
- health and social care workers

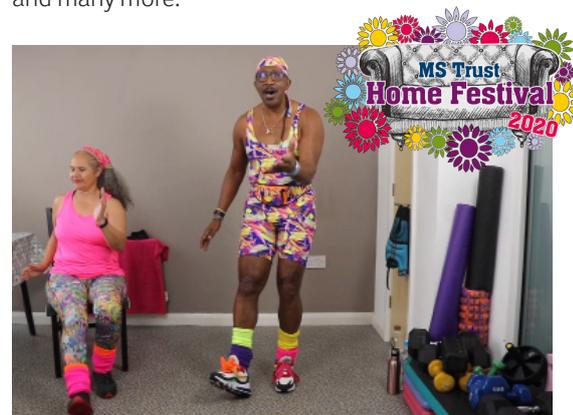
This year in England, Wales, and Northern Ireland, for the first time, the flu vaccine will be offered to the over-50s (over-55s in Scotland), once it has been given to those in the list above.

## Mr Motivator, John Shuttleworth and Mr Gee join us for a festival with a difference

With many festivals cancelled this summer, we decided to launch a new virtual festival fundraiser to help fill the void and bring a smile to the faces of our supporters in these uncertain times.

The MS Trust Home Festival took place back in August, bringing together a virtual line-up of comedy, music, yoga, dance, arts and a whole lot more, for supporters to enjoy from the comfort of their couch! With the added bonus of no queues for the loos!

The festival featured sets from stand-up comedian and radio presenter John Shuttleworth, fitness guru Mr Motivator MBE, spoken word poet Mr Gee, Royal Ballet choreographer Cathy Marston and many more.



We'd like to say a big thank you to everybody who attended the festival, and to all the amazing artists who gave their time for free. Thanks to your support, we raised nearly £2,300 to support people living with MS across the UK.

Discover more fun virtual events on our website, at [www.mstrust.org.uk/fundraising](http://www.mstrust.org.uk/fundraising)





## RESEARCH UPDATE

# A round-up of research from MS Virtual 2020

ECTRIMS (European Committee for Treatment and Research In Multiple Sclerosis) is the largest annual MS research conference. Every three years the event is held jointly with ACTRIMS, the equivalent American organisation. This year's joint meeting was held online under the title MS Virtual 2020. The following is a small selection of information presented.

### Prodrome

People who go on to develop MS will start using health services more frequently in the years before MS is recognised, according to Canadian research. Non specific symptoms and changes in health behaviour that happen before a definite diagnosis of a health condition can be made are called a prodrome. Information from medical records showed that people later diagnosed with MS were much more likely to have visited their family doctor, been prescribed medication or been in hospital in the five years before the first evidence of MS disease activity. Symptoms in this period included pain, headache, sleep disturbances and bladder problems, as well as mental health issues and skin complaints. Women who developed MS were less likely to have become pregnant than people in a non MS control group.

This reflects data from other recent studies around the world, where increases in different symptoms were seen in people later diagnosed with MS.

It's not yet possible to identify who will develop MS from these symptoms, which are also common in the general population. However, the development of better markers for MS, particularly with measures of proteins in the blood, may mean that in the future the condition can be identified sooner.

### Cardiovascular factors and atrophy

People with MS with cardiovascular risk factors are more likely to show signs of loss of brain tissue (atrophy), according to an Italian study. Gradual loss of brain tissue happens throughout life, increasing as we get older. People with MS tend to lose tissue at a

slightly higher rate than the non MS population. This study found that the rate was higher in people with MS with more than two cardiovascular risk factors, such as smoking, high blood pressure or high cholesterol.

People with MS who smoked had a higher level of neurofilament light chain (NFL) in their blood, according to a separate Swedish study. NFL is a protein that can indicate MS disease activity and poor response to treatment. People who currently smoked tended to have the highest levels of NFL. Levels fell in people who had given up smoking depending on how long since they had stopped. It took about ten years after stopping for levels to be similar to those of people who had never smoked.

### Bexarotene

A study of the cancer drug bexarotene in Cambridge and Edinburgh showed that it led to the regrowth of myelin in people with relapsing remitting MS. However, the dose needed to produce this effect also led to serious side effects including thyroid disease and potentially damaging levels of blood fats.

Although the fact that it is possible to encourage the regrowth of myelin in humans is a breakthrough and will lead to further research, the side effects mean that bexarotene will not become a treatment for MS.

The Cambridge team are planning another remyelination study using metformin (a diabetes drug) in combination with clemastine (a treatment for hay fever and allergies).

Read more about the latest MS research at [www.mstrust.org.uk/research](http://www.mstrust.org.uk/research)



## Disease modifying drugs (DMDs)

### Effective first DMD better than escalation

People whose first treatment was a more powerful disease modifying drug did better than those who started with a less effective drug and then moved to something more powerful if it didn't control their MS (escalation), according to an Italian study. The researchers used the EDSS scale to measure changes in disability over an average of eight and a half years. People who started on a powerful drug showed a smaller and slower increase in EDSS scores.

### DMDs and relapse during pregnancy

Women on more powerful disease modifying drugs were more likely to have a relapse during pregnancy than those on injectable or lower efficacy drugs, according to Australian research. This may reflect the fact that women on the more powerful drugs are likely to have more active MS. The researchers say that careful monitoring of these women may help to prevent relapse in pregnancy.

### Covid and DMDs

More early studies of the impact of Covid-19 are starting to appear. Several studies reported that people with MS who contracted Covid-19, including those on a DMD, didn't have a more aggressive illness and their outcomes were similar to people who didn't have MS.

## Treatments in the pipeline

### Ofatumumab

People with relapsing remitting MS who took ofatumumab had fewer relapses, less inflammation on MRI scans and longer time to disability worsening than people taking Aubagio, according to research presented by the drug's manufacturer. Ofatumumab



was approved by the FDA, the US drug regulator, in August. It is still being assessed by the European Medicines Agency. It will be marketed under the name Kesimpta.

### Siponimod (Mayzent)

People with early, active secondary progressive MS who took siponimod (Mayzent) throughout a clinical trial had a lower risk of disability progression and fewer cognitive symptoms than people who had started in the placebo group and switched to siponimod later. For more on siponimod, see page 3.

### Masitinib

An oral drug showed "positive signs" in non-active progressive forms of multiple sclerosis according to a French study. Where drugs for progressive MS such as Ocrevus and Mayzent seem to be more effective in people still showing signs of inflammation, the masitinib trial focussed on people who didn't show inflammation on MRI scans. The study found measures of disability increased less quickly and the time to 'first progression' was longer than for people on a placebo.



### Paru Naik, Director of Health Professionals Programmes at the MS Trust, reflects on her first virtual experience ofECTRIMS

This time last year, MS Trust CEO, David Martin, and I were in Stockholm for the 2019 ECTRIMS conference. The journey was pleasant enough, however my quest to do it on a minimal budget resulted in lost luggage and a three hour delay in arriving at my hotel with no luggage in tow. The upside was the weather, destination and shops for lost clothes were stunning. The Conference itself was a brilliant experience; by the end David and I came away with up-to-date news and an industrious list of MS world contacts through our resourceful networking opportunities.

This year the conference was the three-yearly joint American and European conference and the destination Washington DC, only virtual! It was great to hear from some of the best MS experts in the world without leaving the front door and not feeling guilty about adding to the carbon footprint. Swapping notes with David we both agreed that the MS sector is massively distracted by all things Covid-19 and that at such a time the inability to swap notes with other MS charities and pharma like we usually do at this conference is a real concern for us. We usually gather more intelligence and updates in three days at ECTRIMS than we do across the rest of the year.

A particular highlight this year was the update of the Atlas of MS showing that 2.8 million people are living with MS in the world. Research was a big focus and Professor Helen Tremlett, Canada Research Chair in Neuroepidemiology and Multiple Sclerosis, introduced us to a study on the prodrome phase, still a long way to go but it may allow us to predict whether a person will go on to develop MS much earlier on, intervene earlier, treat earlier and hopefully significantly improve outcomes.



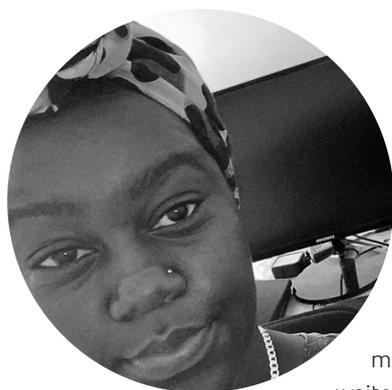
For more information on work and MS, visit [www.mstrust.org.uk/work](http://www.mstrust.org.uk/work)



## WORK AND MS

# At work with MS

MS affects everybody differently, but you may find that MS symptoms, relapses, disease progression, or in recent times, the Covid-19 pandemic, impact on your working life. Our work is a big part of our identity, it's more than just a regular pay packet, it can give us a sense of purpose, so it's understandable to feel anxious about having to give up such a big part of your life. With the right support in place, MS shouldn't stop you from working as long as you want to, but you may need to make some practical and emotional adjustments along the way. Here, we share the experiences of **Mike** and **Letisha** about how they deal with MS in the workplace, and answer some frequently asked questions about working with MS, from telling your employer to coping with fatigue.



## Letisha Charles-Thomas, PA

At the time of my diagnosis, I had to give up work for a few months. I had two relapses back to back and they both made it difficult for me to leave the house. I stopped working in May 2019, the same month I was diagnosed and waited until I had recovered from my relapse before seeking new employment.

Having to stop work and being diagnosed at the same time was tough, but I wanted to focus on getting better without the worry of work.

I found the job search process more draining and tiring than I ever had in the past, it felt like a full-time job! I had over 20 interviews – all different types; ones with tests, competency-based interviews, informal and formal interviews. Not once did I

reveal that I had MS.

At the time, I had only been diagnosed for 1-2 months, so my MS was very fresh and I was still coming to terms with it. I also found that as a black, young adult, it is quite hard for me to get a job in a corporate environment and I felt disclosing that I had a disability would only hold me back further.

During the job search process, I found my anxiety was increased. I wasn't sure if I should look for full-time, part-time or temporary positions. I was also worried about starting a new job and then being too fatigued to show up for work the next day, or experience a relapse and have to take time off and potentially lose the job.

After three months of unemployment and about two months of job searching and interviewing, I was offered a role as a full-time Personal Assistant in Central London, which fitted with everything I needed at the time. I didn't divulge that I had MS until I started my job. I didn't tell everyone, I only told people who I felt needed to know; my manager and a few other colleagues who I

work closely with. If I'm honest I felt nervous, awkward and quite anxious when disclosing my MS as I didn't even know how I would feel talking about it and what to expect from others, as it was new to me.

The main reason I decided to inform my employer is because MS is so unpredictable and you can't get the help and support you need if they don't know. It was well received and accepted. A few of my new colleagues know people who have MS or similar neurological conditions, so they are aware of some of the symptoms and challenges I experience.

I have been back in full-time employment for 10 months and overall, I manage well. I do have set backs and find it challenging

at times. Fatigue and cognitive issues are a real problem for me. I find it hard to concentrate at certain times of the day but I've found solutions to help me manage these issues better. I start and finish work earlier to avoid full-on rush hour, I have a healthy, filling breakfast and a later lunch so I don't start shutting down too early.

Another thing that really helps is the ability to work from home (currently I am working from home full time due to Covid-19). Prior to Covid-19 I worked from home 1-2 days per week, which really helped with my fatigue. Working with MS is a new challenge, one that I'm still adapting to.



## Mike Gale, police detective

One of the major challenges I faced when I was first diagnosed with MS in June 2019 was the uncertainty around how long I would be able to continue working. It's a question that nobody can answer; nobody knows what path the condition will take and we have all heard the line "everybody's MS is different".

For me it was something that was a big worry. I am a police detective and at the time of diagnosis I was working shifts and often long hours with little periods of rest in between. The job can be highly pressurised and the stakes are high as, ultimately, my actions and decisions affect people's lives. I also needed to have a good level of fitness as sometimes my job can be physical. In the police, you are expected to undertake and pass an annual fitness test.

The questions that instantly came to the fore when I was diagnosed were: What if I can't work, how will I pay the bills? Who will pay the mortgage? How will I buy cake? (Contrary to popular belief, most police officers prefer cake to donuts!). One of the difficulties that I encountered was how would I deal with the long hours of being a detective? Like most people with MS, one of my main symptoms is fatigue, it's something that hits you out of the blue and until you have experienced it you cannot describe it. Luckily, working for a big organisation they were able to accommodate me and give me a role that did not require me to work shifts and long hours. I was grateful for this and it has helped me get into a routine which assists with my fatigue.

It's still work in progress and awareness of working with a disability in the police still needs to be addressed more, but there are people working hard to achieve this and that can only be a good thing. To help, I have just signed up to the Disability Support Group within the organisation and I am hoping not only to get

support, but to be able to give support to others facing similar challenges too.

Moving on to the present when Covid-19 is a major part of everybody's lives, I have been working from home for the past six months. At first it was difficult and a challenge;

I no longer felt part of a team, a team which supported me with my issues and helped a lot, even if it was just teasing me to make me feel at ease! However, with the technology available these days, I have probably spoken to my colleagues more since I have worked from home than when I was sat in the same office as them! And I get more time to rest and can easily put on my weighted blanket sat at my desk to ease my restless legs without feeling self-conscious. I have learnt to embrace the positives that come with home working!

The advice that I would pass on to anyone, whether newly diagnosed or a veteran MSer: Ask for help from your employer, no matter how big or small the organisation, there is always something they can do for you, whether it's making adjustments through Access to Work, offering you a role which can accommodate any adjustments or changes to your working hours to enable you to get into a routine. There is always something that can be done to ensure that you can fulfil your role and continue to work to help maintain your independence... and more importantly buy cake!

*"There is always something that can be done to ensure that you can fulfil your role and continue to work to help maintain your independence"*

**On the next page we answer some of the most common questions around working with MS, from dealing with fatigue to telling your employer >>>**

## Q How do I manage my MS fatigue at work?

Fatigue can make many tasks seem overwhelming, but there are some simple changes, or 'MS work hacks', that will make a big difference. Here are a few ideas:

- Use your lunchtime to relax and save energy, rather than rushing around doing the shopping.
- Speak to your employer about changing your working hours, so you don't have to travel during rush hour and can avoid hot, stressful commutes.
- Ensure regular breaks throughout the day. Set a reminder in your phone to prompt you or build them into your outlook calendar.
- Do your most important work when you feel at your strongest.
- Pace yourself! You aren't superhuman. It's okay to say no to extra tasks if you just don't feel up to it.
- Many workplaces are now much more flexible when it comes to working from home, particularly since the Covid-19 pandemic. So if it's appropriate for the work you do, don't be afraid to start that discussion with an employer.



They may be able to advise on specialised equipment that could help. If you do not have an Occupational Health team at work, you and your employer can use the free Fit for Work ([www.fitforwork.org](http://www.fitforwork.org)) service for advice.

## Q Do I have to tell my employer about my MS?

You are not required to tell your employer about your condition unless there are specific health and safety risks, you drive as part of your job, or if you are in the armed forces. However, adjustments cannot be made unless an employer has been told, and early disclosure can be really important if you are to get the support you need.

Talking to your employer and colleagues about your MS may feel daunting. MS can often be misunderstood, and it's natural to feel worried about how they might react. You could point your colleagues to the MS Trust website, films and publications to learn more about the condition - our information sheet on explaining MS to others might be a good place to start. Do remember that if you tell your employer about your MS, you still have a right to confidentiality.

## Q What support can I access?

As part of the Equality Act, which protects people with MS (and other conditions) from any form of discrimination, employers are expected to consider making 'reasonable adjustments' for

employees with MS. There is no precise definition for what constitutes a 'reasonable adjustment' but examples might include changing your working hours, ensuring you have regular breaks, securing you a parking place close to the entrance, or providing a fan if you find your MS symptoms worsen in the heat. Your employer should not charge you for these adjustments. If the adjustments required to keep you comfortable at work are more costly than your employer would like, they can apply for a grant to cover the costs from the Access to Work service ([www.gov.uk/access-to-work](http://www.gov.uk/access-to-work)). You can also use this service if you are self-employed, to allow you to maintain your own business.

If it's something your workplace offers, you may find it useful to talk to an Occupational Health professional about your situation. Together, you can look at your workplace and see what you can do to minimise any issues you're experiencing.



## Q What can I do if my employer isn't being understanding?

If you feel your employer isn't providing adequate support, or you feel you're being discriminated against, there are further steps you can take and organisations you can turn to for advice. Before raising a complaint formally, you may want to consider talking to your employer first about your concerns. You could arrange an informal meeting with your manager to discuss these concerns and make suggestions on how they could be resolved. If conversations with your employer aren't successful, you could reach out to the organisations below for further advice.

- ACAS: [www.acas.org.uk/dealing-with-workplace-problems](http://www.acas.org.uk/dealing-with-workplace-problems)
- Equality and Human Rights Commission: [www.equalityhumanrights.com/en/multipage-guide/dealing-discrimination-employment](http://www.equalityhumanrights.com/en/multipage-guide/dealing-discrimination-employment)
- Disability Law Service has an MS Legal Line: [www.dls.org.uk/free-advice/ms-legal-advice-line](http://www.dls.org.uk/free-advice/ms-legal-advice-line)
- Citizens Advice: [www.citizensadvice.org.uk/work/problems-at-work](http://www.citizensadvice.org.uk/work/problems-at-work)
- If you're part of a trade union you could contact your union representative about your situation at work for further advice and support.



### Covid-19 and work

We know that many of you will have questions and concerns around work and Covid-19. It is an ever-changing situation, but you can find the latest up-to-date information on our coronavirus webpage at [www.mstrust.org.uk/coronavirus](http://www.mstrust.org.uk/coronavirus). Or get in touch with our Enquiry Service at [ask@mstrust.org.uk](mailto:ask@mstrust.org.uk) / 0800 032 38 39

## FOCUS ON

# Virtual appointments

The coronavirus pandemic has had a major impact on NHS services and how we contact our health professionals with more being done virtually now than ever before. Telephone and video appointments are quickly becoming part of our new normal, but they can feel very different from speaking to your MS team face to face. To help you prepare and get out of them what you need, we've put together some top tips for making the most of virtual appointments.

### Getting prepared beforehand

- Find the right environment. With virtual appointments it's down to you to find an appropriate setting for the call. Is there a quiet room in your house which would give you a private space to talk?
- Allow time to get the technology set up. Make sure your phone, tablet or laptop is fully charged. Test out the camera too – is there enough light in the room so you can be seen? If it's a video appointment and you need to download an app or log into another platform, then do this in plenty of time.

***"Make sure your health professional team has your telephone number. We all know that technology can go wrong and if, for example, it goes down in the middle of the video call your team will most likely phone you."*** – Consultant neurologist, Val Stevenson

- Consider the device you're using. If it's a video call and you want to show visible symptoms, such as changes to your walking, then using a tablet on a stand, a laptop or a webcam on a computer may be more practical than trying to balance your phone on pieces of furniture.
- Make some notes beforehand. Prepare as you normally would for a face-to-face appointment by writing down what you'd like to discuss. Have things changed with your MS? Are there particular symptoms you're struggling with? Are side effects from medication becoming a problem?

***"If it's a video appointment make sure you're ready five minutes beforehand to log on to the call."*** – Person with MS

### During the appointment

- Use your notes. Start by letting your health professional know what you want to talk about, then work through your list of priorities one by one. There may be other things your health professional raises which need to be discussed too.
- Be prepared to take notes. Have a notepad and pen ready so you can make notes during the appointment. If you're using your



For more tips to help you prepare for MS appointments, visit [www.mstrust.org.uk/appointments](http://www.mstrust.org.uk/appointments)



phone, consider using the loudspeaker function so you can take notes at the same time.

- Ask questions. Don't be afraid to ask questions if you're not clear on something your health professional has said or if you want a more detailed answer.

***"It's really difficult if people talk at the same time or interrupt each other on a video call. If the doctor, nurse or therapist is talking and you don't catch something or perhaps the sound freezes, using your hand as a signal is an easy way to stop them. Then you ask for a recap of what they've said."*** – Consultant neurologist, Val Stevenson

- Clarify what happens next. It can be helpful to finish the appointment with a quick summary of what's been discussed and the next steps that need to be taken.

***"Don't be afraid to ask them to change the set up so you feel more connected. In my appointment the nurse started looking to one side because of the different screens/webcam position, so it was like they were addressing someone else! I flagged it and they shifted so they were looking into the camera and we had eye contact."*** – Person with MS

### After the appointment

- Go through your action points. Maybe you need to pick up a prescription for a new medication or try some new management strategies for your fatigue.
- Review how the appointment went. Make a note of anything you didn't talk about so you can prioritise this next time.

***"I've had several positive video appointments. My MS nurse was able to share his screen and show me my MRI scans which was great."*** – Person with MS

**If you feel that a virtual appointment hasn't worked well for you then do speak to your MS team about the possibility of seeing someone face to face.**

## MY MS STORY

# "MS has made me determined to make a difference for others"

A "life-changing" diagnosis of MS in 1999 inspired **John Hambly** to set up a new therapy centre to improve his own situation and bring support to others living with the condition. Fast-forward 21 years and the Samson Centre for Multiple Sclerosis treats up to 200 people a week and provides 10,000 therapy sessions every year. Following the release of his new memoir **Samson Rising**, we caught up with John to find out more about his journey with MS and the inspiration behind the Samson Centre.

"It was like everything was in slow motion. I could see his mouth moving and that he was telling me things, but I was completely and utterly stunned." John Hambly remembers the moment his neurologist "dropped the bombshell" that he had MS like it was yesterday. The year was 1999 and John had a young family, a busy career as a partner in a surveying firm and an active lifestyle playing for his local rugby team. But he'd started experiencing "some strange sensations".

"It happened for the first time eight years before my diagnosis. I'd run the London Marathon and ended up in a bit of trouble in the last four miles with difficulty lifting my right leg up," John says.

This symptom came back again just before he was diagnosed. "I called it glue foot, because I couldn't lift the foot off the tarmac when I was running."

Initially doctors thought John had a viral infection of the spinal cord, but when he returned to the hospital, it became apparent John was having a second relapse and MS was diagnosed. He describes it as a "traumatic time."

"It really knocked me for six," John remembers. "The first thing I lost was sport. I was coaching at a rugby club and most of my social life was based around that. It felt like the world closed in a bit."

John tried to carry on as normal, "but I found it was a difficult balancing act. Because the more I pushed myself, the more MS hit back. I became frustrated because there wasn't much out there at the time in terms of MS nurses or a support network."

It was this frustration that led John to put the wheels in motion for a new support centre for people living with MS. At first he

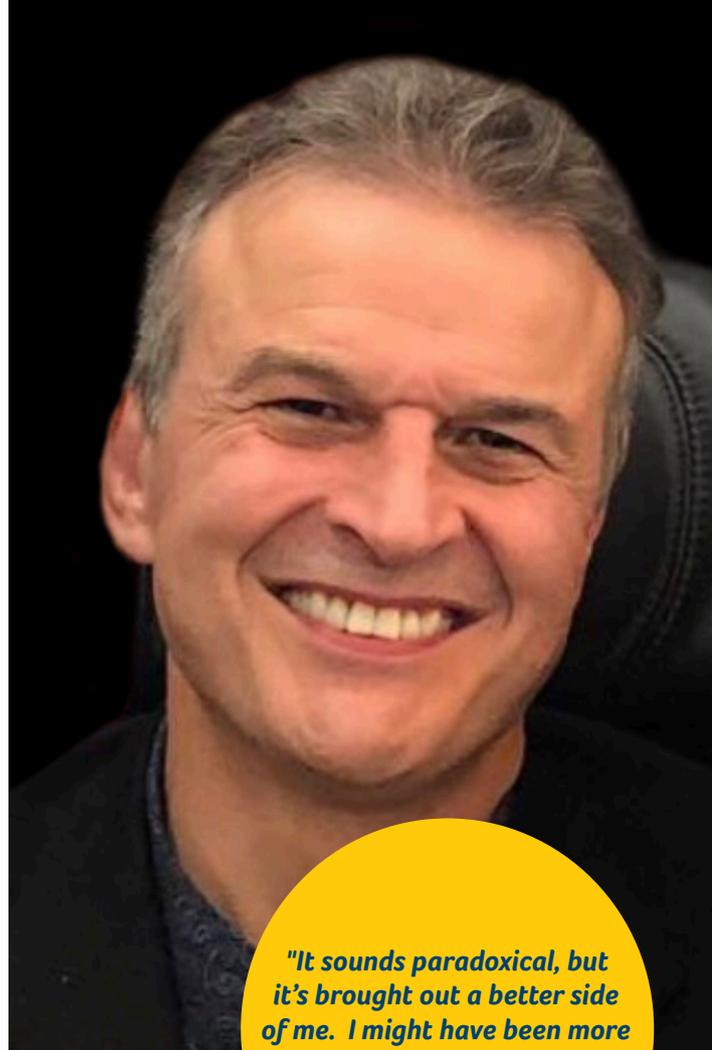
joined a small MS self-help group in Guildford. "We met in a village hall a couple of mornings a week for physio. But it was cold, there was a lack of equipment and it was shared with other groups. I realised that it was really useful, but could be so much better. So I spoke to the physios and asked if we could take it on a stage and get our own premises."

With a background in surveying, John knew how to put a building together, but what he didn't know was how to get the funding to pay for it. "I set off on the journey more in hope than expectation, with faith behind me. My rugby club was instrumental in getting it going. We had a couple of big fundraising events and with that came the belief that we could actually get it off the ground," John says.

The dream was to build a dedicated facility where people with MS could have one-to-one physio ("so we could help people who are disabled, like I am now, rather than them feeling like they're just sitting in the background watching others exercise"), as well as a variety of exercise classes, a gym and oxygen therapy.

Against all the odds, John spent the next 17 years, with help from his rugby teammates, charity trustees, family and friends, raising millions of pounds to enable the construction and development of the Samson Centre in Guildford, which now treats up to 200 people a week and offers 10,000 therapy sessions each year.

When John was diagnosed with MS, some health professionals



*"It sounds paradoxical, but it's brought out a better side of me. I might have been more selfish had all the cards fallen the right way for me"*

advised against exercise. It was felt that, since many people with MS experienced fatigue and found their symptoms worsened when hot, it was best to avoid activities that could be seen as tiring. Further research has changed that view and regular, moderate exercise is now known to be an important part of maintaining good health and wellbeing for people with MS. John has seen and experienced the positive impact exercise can have first-hand.

“21 years ago when I was diagnosed, it was very much ‘You’ve got MS, take it easy and don’t go pushing yourself’,” John remembers. “But I think we know now, and I’ve seen for myself, if you have an early diagnosis and you are still reasonably fit and well, if you can get on to an exercise programme that will keep you moving, it can have such a positive influence. I think sitting around watching telly all day, bemoaning ‘I’ve got MS’, that’s where the pitfalls are.”

The last 21 years have been quite the journey for John and one that’s inspired him to put pen to paper and write his memoir. The book is called *Samson Rising* and details John’s childhood growing up in Cornwall, his sports career, the life-changing diagnosis of MS and how that inspired him to follow his dreams and set up the Samson Centre. “I can’t believe I’ve written it,” John says. “I’m not an author and the only writing experience I had previously was big lumpy documents to refurbish buildings!”

The initial idea for the book came to John while he was in the oxygen chamber at the Samson Centre five years ago. “I’d nod off and get really vivid dreams and they were often dreams of things I’d forgotten. I describe it in the book as finding things on my cranial cutting floor. They were coming back to me and I started stringing them together. I realised that there were certain points in my life that I could identify as beacons; really important things that have happened that have guided me one way or another.”

John wrote the first 10 chapters, “but I put it aside for a while because I thought I was looking at pie in the sky – ‘why am I doing this? I’m not an author!’”

His friends and family disagreed. “Someone asked me how it was going and I said I stopped because I felt there wasn’t a story to tell. He read those chapters and said I don’t agree with you. He thought it had a certain style that made the reader feel like they were there with me in the book. So I kept going!”

What does John hope people take away from the book? “I’d like people to realise that whatever life throws at you, you can keep going. Adversity is there in everybody’s life at some point, just don’t give in and don’t be frightened to ask if you need support. Open up your arms and let it in; it’s amazing what you can do.”

Like many therapy centres, Covid-19 has hit the Samson Centre hard. But John and the team have put plans in place to ensure they can keep going; supporting the MS community post Covid-19 and beyond. Lockdown has given John a lot of time to reflect and he tells me how he thinks MS has changed him as a



### The Samson Centre for Multiple Sclerosis

person. “It sounds paradoxical, but it’s brought out a better side of me. I might have been more selfish had all the cards fallen the right way for me. What I’ve found is that it’s made me determined to make a difference for others so they don’t have the same helpless feeling I had when I was diagnosed.”

**You can find out more about the Samson Centre at [www.samsoncentre.org.uk](http://www.samsoncentre.org.uk).**

**John’s book *Samson Rising* is available now from a variety of different bookshops, including United Writers, Amazon and Waterstones.**

If you have a story about your MS journey you'd like to share, please get in touch at [mystory@mstrust.org.uk](mailto:mystory@mstrust.org.uk)



### What is an MS Therapy Centre?

MS Therapy Centres are local charities that provide a range of non-drug therapies for people with multiple sclerosis. Each Therapy Centre will vary in what it offers to people, but they typically include services such as physiotherapy, hyperbaric oxygen therapy, yoga, reflexology, pilates and more. Usually, you do not have to have MS to use the services.

MS Therapy Centres often also provide help through drop in sessions or support groups. In some UK regions, MS nurses have their offices and hold clinics in MS Therapy Centres as well. Most, but not all Centres belong to the umbrella group - Multiple Sclerosis National Therapy Centres.

MS Therapy Centres across the UK are shown on our searchable Map of MS services, which you can find here:

[www.mstrust.org.uk/map](http://www.mstrust.org.uk/map).



## MS SYMPTOMS

# Staying Smart

Ever forget where you've put your keys? Struggle to find the word that's on the tip of your tongue? Can't concentrate when there are lots of people talking around you? You're not alone. Thinking and memory problems affect more than half of all people with MS and can have a big impact on your day to day life. The MS Trust has launched a new, interactive web zone to provide everyday tips and tricks to help lift the 'cog fog'. **Claire Winchester**, Head of Information and Engagement at the MS Trust, tells us more.

We are excited to introduce to you a new, interactive zone on our website. Staying Smart is for people who want to learn more about how MS affects their thinking and memory, and take action to reduce the impact that cognition problems have on everyday life.

The new web zone, which builds on the work done by Professor Dawn Langdon and her team at Royal Holloway University, combines research evidence, expert advice, and peer support. We've designed it to be easy for people to read and we've ensured that it is accessible on all devices. You can check it out here:

[www.ms-trust.org.uk/staying-smart](http://www.ms-trust.org.uk/staying-smart).

'Cognition' is the general word that covers all aspects of thinking. It includes memory, concentration, and planning. Research suggests around half of all people with MS will have cognition problems at some time, although these may be more prevalent in black people with MS.

Cognitive difficulties can impact on all kinds of activities. They can affect how you feel about your abilities to work, your relationships with others, and your hobbies and other interests. Having memory problems can make it harder to manage your MS, for instance, if you forget to take medication or get to appointments. If you have trouble concentrating, you might find making decisions about your health care harder. Route finding problems can affect road safety and lead to falls.

Cognition problems in everyday life generally fall into one of six categories, so we've used these to help you navigate quickly to the right information. You can work out which type of thinking is tricky for you, and click on one of the everyday problems to take you directly to the expert advice, hints and tips

I forget where I have put things

Finding things



I can't say what's on the tip of my tongue

Language



At the end of the day I haven't got the important stuff done

Executive skills



I forget to take my tablets

Memory



I can't seem to concentrate

Attention



I forget the route to places I haven't been to in a while

Wayfinding



you can use yourself.

The most important new feature of Staying Smart is you! The new web zone gives you the opportunity to learn from other people with MS facing similar issues. On each of the six key information pages, you'll find a pop-up box with a prompt for you to share a piece of advice that works for you. You can click the box closed if you don't wish to add anything, but if you have a genius tip that has made all the difference to you, share it here! It might be just the nudge that someone else needs to help them.

The Information Team will check and moderate the tips and upload them to the site. There might be duplication, so we can't promise that every suggestion will be uploaded. But we are looking forward to reading every one, and learning from the real experts in MS, the people living with it every day!

You can find Staying Smart at [www.ms-trust.org.uk/staying-smart](http://www.ms-trust.org.uk/staying-smart)



## What can I do to improve my own thinking and memory skills?

-  Be kind to yourself and look after your mental health. Anxiety and depression can make your thinking and memory seem worse by taking up 'head space' with worry or intrusive thoughts.
-  Stop smoking. Research shows that heavy smokers tend to have worse problems with thinking and memory.
-  Review your medications with your MS team. Some drugs can make cognition problems worse, and so you might want to discuss alternative options.
-  Take a break. Fatigue can affect your concentration and thinking skills. Can you complete your tasks at a time when you have more energy?
-  Train your brain. Learning a new skill can help keep your thinking limber. A cognitive psychologist can help identify mental exercises tailored for any particular problems you have, or you can investigate some of the brain-training apps and games out there for yourself.

### Helena's story

When I was diagnosed with MS I didn't know much about cognitive problems. In fact, when I first read about them, I just ignored them. I didn't tell my neurologist about my symptoms. Forgetting words I blamed on fatigue and speaking two languages (I am from Sweden originally). The lack of concentration I tried not to think or talk about.

Words and communication are my job, and reading is one of my favourite ways to relax. Somehow the idea of losing out on these things, that I always used to be so good at, scared me more than the idea of ending up in a wheelchair.

But it got to the point where I had to admit to myself that I did have a problem, and it wasn't going away. I was sitting smack bang in the middle of an open-plan office, just by the telephones that rang all day. It was all very busy around me. I started feeling like I needed blinkers, there was so much going on, I lost my train of thought constantly. But I didn't want to say anything as it wasn't anybody else's fault, it was me losing concentration, it was me who started to fidget or talk to anyone that would walk past.

My work started to suffer, so I realised I just had to admit defeat and 'come out' about my cognitive struggles. During a one-to-one with my manager I told her that I found it really hard to concentrate, everything was taking too long to complete, and that I felt really bad about it. I felt like a failure and I never wanted special treatment because of my MS, but my manager was very understanding.

I am still in the same open-plan office, but now I sit on my own with a wall on one side that blocks out the sound a bit. I don't notice the phones ringing as much, or hear people talking or walking. There are still days when I struggle, so at these times I tend to go and sit alone in a meeting room, or ask if I could work from home, if I know I am going to need to concentrate.



**"Words and communication are my job, and reading is one of my favourite ways to relax. Somehow the idea of losing out on these things, that I always used to be so good at, scared me more than the idea of ending up in a wheelchair"**



## MS SERVICES

# MS Trust...in us



The Covid-19 pandemic has had a devastating impact on the whole MS community, with delays in specialist healthcare services and treatments, not to mention the isolation and loneliness of life in lockdown. We're launching our 'MS Trust...in us' campaign to help restore MS specialist healthcare services in the UK, getting them back on track to ensure people with MS can get the care and support they need and deserve, during the pandemic and beyond. **Paru Naik**, Director of Health Professionals Programmes at the MS Trust, tells us why this campaign is more important now than ever.

The plight of people with MS can no longer be ignored. The increase of the MS prevalence figure earlier this year revealed that more than 130,000 people in the UK are living with MS – a much greater number than the 109,000 people that the NHS are currently planning and providing services for. It confirmed what we already knew – that thousands of people with MS are without the support and provision they need.

Our MS Specialist Nurse and Advanced MS Champion Programmes are demonstrating with real world evidence the vital need for specialist care, in hospitals and the community, and that specialist intervention is required to improve provision for the MS community and provide care that is personalised, coordinated and enabling. We remain committed to funding new specialist nurses and champions across the UK – and we hope that local NHS trusts will join us in appointing their own champions once they see the huge impact they're making.

It is not only people with MS who need the support and attention of the MS Trust, but also our health professionals. Our educational programme provides training and support for MS specialists, and is needed more than ever. We are moving to an online offering in these times to make sure there are no gaps. We now need to extend that support by introducing a mental health module to provide professionals with even more tools and information to support their patients as the Covid-19 pandemic continues to threaten good mental health across the country.

The pandemic has stretched MS services to the limit, adding to

the existing delays, inequitable access and lack of joined-up care provision. Particularly at risk are the 52,000 people with advanced MS. Incredibly specialist knowledge is required to support people with advanced MS, and these specialists are few and far between across the UK, as are the care pathways that would help people receive the necessary care. Against all logic, many people with MS report they have lost contact with MS specialist services as their condition gets worse.

Our 'MS Trust...in us' campaign will support health professionals and the restoration of MS specialist services across the UK in the aftermath of Covid-19.

We will focus on three key areas:

**Education:** MS Trust...in us to train MS specialist health professionals in mental health, to help support the MS community during the coronavirus crisis.

**Community:** MS Trust...in us to ensure health equality for those with advanced MS through the funding of additional Advanced MS Champions.

**Support:** MS Trust...in us to fund even more MS nurses, and protect roles in MS specialist services while the NHS recovers from the pandemic.

**The impact of Covid-19 on MS services can no longer be ignored. You can trust in us to get vital services back on track, and to be there for you and your health professionals, today, tomorrow and every day after. But we need your support. Please join us and help ensure nobody has to manage MS alone.**

**70% of MS healthcare professionals believe the MS service they work in, or with, is not currently able to meet patients' needs to the extent it was pre-pandemic**

Your donation to the 'MS Trust...in us' campaign will help fund our second wave of Advanced MS Champions. We hear from **Maria** about the difference her Champion **Tania Burge** (funded by the MS Trust and appointed in June this year) has made to her life. And from Tania about why this programme is so vital.

## Maria

Maria is 46 years old and was diagnosed with MS in 2002. After studying business at university, she became a marketing manager and, in her spare time, enjoyed travel and water sports. She has a positive zest for life and before the Covid-19 lockdown tried helicopter rides, skydiving and gliding, as well as enjoying regular theatre trips.

Maria's MS has progressed rapidly, leaving her with no movement in her body, and poor speech and swallowing. She lives alone in a fully adapted house with 22 hours of care a day.

Maria's problems are complex and require a great deal of regular input from health and social care professionals. In the past, however, that care has often been fragmented and delivered by non-specialist staff who have no experience with MS.

But Tania has changed that. "Having an MS champion in my life has helped and assisted me tremendously. I can discuss any issue with Tania. She forwards it to the relevant person and my issue is dealt with efficiently and effectively. Having an Advanced MS Champion supporting me floods me with confidence to live my life - not just survive. Not all super heroes wear capes!"



*"Having an Advanced MS Champion supporting me floods me with confidence to live my life - not just survive. Not all super heroes wear capes"*

## Tania

The aim of the Advanced MS Champion is to improve people's quality of life, enabling them to live well with their MS and to reduce any unnecessary hospital admissions.

I'm really excited about this role as I feel that people with advanced MS will benefit from better coordinated services to manage their complex needs. This is a wonderful opportunity to be in a proactive role to improve service delivery and resolve some of the barriers to people with advanced MS accessing the services we know they need. This role will collaborate with and enhance the amazing work already carried out by other health professionals but we'll be able to provide specialist MS support, input and intervention.

In these uncertain times, Advanced MS Champions are more important than ever. We can support people with advanced MS who have struggled with the restrictions of lockdown and may have experienced reduced access to health professionals to manage their symptoms and the early interventions we know are vital. Thank you to the MS Trust for funding and supporting Advanced MS Champions like me across the UK.



**52,000 people with advanced MS need long-term specialist MS support from health and social care**



### How can I get involved?

- To find out more about our 'MS Trust...in us' campaign and to make a donation, visit [www.mstrust.org.uk/trust-in-us](http://www.mstrust.org.uk/trust-in-us).
- You can support our campaign via text to donate. To donate £10, text TRUSTUS to 70191. Or scan the campaign QR code on the right.
- To share your experience of MS services, please email us at [mystory@mstrust.org.uk](mailto:mystory@mstrust.org.uk).



## ASK THE EXPERT

# Palliative care

So often palliative care is associated with terminal or life-limiting conditions, despite these services being able to support people with other complex health conditions too, not just those nearing the end of life. To dispel the myths around palliative care and shed light on the support these services can provide people with MS, we spoke to **Dr Jonathan Koffman**.



### Q What is palliative care?

**Jonathan says:** Palliative care is primarily associated with improving the quality of life for people living with life-limiting or complex health conditions and, very importantly, their families as well. It's associated with relieving suffering from distressing symptoms. It also considers psychological issues as well as spiritual and existential concerns. Put simply, palliative care is about identifying the worst problems that person has on that day and trying to resolve them.

Most people associate palliative care with cancer, particularly at the end stages of the illness, but that is just not true. It can be invaluable in a whole range of other conditions, such as Parkinson's disease, chronic obstructive pulmonary disease, dementia, frailty in aging and MS.

It's typically delivered by a multidisciplinary team. This may include a palliative care doctor, a nurse, a social worker, a physiotherapist, an occupational therapist, and in some instances a speech therapist or a dietitian, a chaplain or a faith-based leader.

*"Palliative care is all about living. It focuses on improving quality of life and making the best possible hour, day, week or month for that person which means they can do stuff and be with people who they love"*

### Q Are there any misconceptions around palliative care which need dispelling?

**Jonathan says: Misconception #1: Palliative care is about glass half empty; it is about dying.**

Palliative care is all about living. It focuses on improving quality of life and making the best possible hour, day, week or month for that person which means they can do stuff and be with people who they love.

It can relieve suffering and improve wellbeing. That is associated with longevity; being around longer to do the things that individual wants to do, which may mean getting out in the garden, going down to the sea, being with people or stroking one's dog.

It's about adding life to years for that person and also, very importantly, adding years to life for family members. It's not just about dying; it's totally about living.

**Misconception #2: You have to stay in a hospice to receive palliative care.**

Palliative care can be provided in a whole range of different settings. It can be offered in hospital settings, as well as in the community and in your own home.

So, it's not just about hospices, although they are incredible places which are not solely about dying anymore. In fact, sometimes people will go into a hospice to sort out very distressing, complicated problems associated with their condition and they are discharged as quickly as

possible. Many people go to a hospice for rehabilitation. They might see a physiotherapist who helps them to do more and feel more confident against the backdrop of some of their physical problems. Hospices offer a range of lovely services – art therapy and music therapy – usually on a day case basis so people can go back home. They're not scary by any stretch of the imagination.

### **Misconception #3: Support and treatment from my MS team will stop if I'm referred to palliative care services.**

Absolutely not. MS teams do not wash their hands of you if you've been referred to palliative care. The perfect scenario is that, if there's a problem to be sorted out and it's outside the skill set of that neurologist or MS nurse, you would be referred to palliative care services and all the other care and treatment associated with your MS team should carry on as normal. These two things can run alongside each other. Palliative care can be involved and pull out at various points when it's either relevant or irrelevant.

### **Q In what ways would palliative care be able to help someone with MS?**

**Jonathan says:** MS is associated with a range of complicated symptoms, such as pain, breathing or swallowing difficulties, constipation, spasticity and mobility problems. There may be times when your neurologist or MS nurse may want some input from a specialist, such as a palliative care doctor or nurse, to help sort out these more complex MS problems that they may not have the skills or knowledge to manage.

Palliative care provides an additional layer of expertise in assessing troubling symptoms associated with MS. It can involve modifying or adding medications so they work better, particularly in combination with one another, and altering medications for symptom control that are causing unpleasant side effects. Very importantly, it also considers the psychological and social impact of MS on people's lives and their families.

Pain, for instance, can be felt in different ways; it's not always physical pain that gets people down. A good palliative care assessment will attempt to uncover the biggest issue(s) that person has and prepare a strategy to overcome it. Sometimes that can include just listening to that person and providing them with space and permission to share their fears and worries.

As a result, palliative care can reduce the physical and psychological burden of living with MS. When you're free from pain you can go for a walk, you can sit and focus on a book or a TV programme or just relax surrounded by your family. If you're anxious or depressed for a range of very legitimate reasons associated with your MS, palliative care can try to find a solution to that, either through medication or other methods like cognitive behavioral therapy or counselling, to reduce the burden of that psychological problem. It can help you focus so you're not consumed by worry or distressing feelings, so you can be with your family members, go for that walk, sit in the garden or admire a sunset or do whatever you want that brings you pleasure and happiness in that moment.

### **Q How can palliative care services support family members?**

**Jonathan says:** Family are often forgotten in the equation of care but they are indispensable. If carers put down their tools tomorrow this country would come to an absolute standstill.

Palliative care services can support family members too by understanding and listening to their concerns and needs, giving them a voice and providing them with the skills, knowledge and information they need to do the best job they can for their loved one.

Just as palliative care is relevant to the person with MS, it's relevant to that family member because it provides that additional layer of support that they can go to when they're struggling, if they have an issue or just want to vent because they might be pissed off about what's happening in their life. A member of the palliative care team would be there to listen to that problem and will have the time to try to find a solution.

Family members might also worry about money and resources. Palliative care social workers can signpost people to organisations that can help resolve financial problems. They can also help family members complete forms to apply for different benefits they may be entitled to.

Finally, should a family member lose a loved one as a consequence of the complications associated with MS, the palliative care team will support family members who are living with grief and travel with them for a period further down the path to make sure they're okay.

For more information on palliative care, visit [www.mstrust.org.uk/palliativecare](http://www.mstrust.org.uk/palliativecare)



**Dr Jonathan Koffman is a reader in palliative care at the Cicley Saunders Institute at King's College London.**



## GET INVOLVED

# It's business time!

**Jason Hodges**, Trusts and Corporate Fundraising Manager at the MS Trust, explains how your business could help make a difference for people with MS.



### What makes a typical business supporter?

The MS Trust is fortunate to receive support from businesses of all shapes and sizes - from nationwide logistics companies, to individuals selling jewellery on their Etsy shop. Terms like 'corporate partnership' can put off small business owners, who see themselves as anything but corporate, but at the MS Trust we welcome the support of businesses of all sizes.

### What does a partnership look like?

Some companies like to make a single donation with no further involvement, while others want help with fundraising ideas, promo materials, and a visit (virtual or otherwise) from an MS Trust team at company events. The small size of the MS Trust means that we steward our business supporters really well. We listen to what you want the partnership to look like, so that both sides benefit from the experience.

One idea that is becoming more popular is donating a percentage of your sales, or profits from a particular item. Our partners at [www.workforgood.co.uk](http://www.workforgood.co.uk) have made this really easy. They provide a template to set up the scheme, and even a toolkit to promote the partnership to your customers. It only takes a few minutes to set up, and saves a load of time.

### What do businesses get out of supporting the MS Trust?

Your support will make a real difference to people living with MS. MS is a cause that often gets overlooked for better-understood conditions that appear in the headlines more often.

We have places at all the big events like the London Marathon and Great North Run, but we also embrace innovation, so let us know if you have a unique fundraising idea. We love celebrating the support we receive from businesses with our 42,000 followers

on social media, **Team Captify conquer Mt Kilimanjaro for the MS Trust** some of whom might become your next customer.

### Any recent successes to share?

This August we hosted a 'home festival' – a virtual festival of music, yoga, comedy and a live DJ set. We wanted to bring a smile to people whose festivals had been cancelled due to Covid-19, or whose disabilities would prevent them from attending in person. The festival was sponsored by Briggs Equipment, whose annual 'charity of the year' process was on hold thanks to Covid-19. To our surprise, as the festival day approached they doubled their donation, which massively boosted the funds raised for people with MS.

*"We were pleased to support the recent MS Trust online festival and they were very responsive in ensuring that, as a main sponsor, our brand was well represented. We were proud to be involved in this fundraising activity"*

**Stuart at Briggs Equipment**

### Most people aren't business owners – is there a way for employees to help?

You may not be the chief decision maker at your company, but there are lots of great ways to help people with MS through your workplace.

- Many companies run a staff vote to decide where donations go. Nominate the MS Trust! We will help you present a strong case for the win.
- Take on a fundraising challenge! Office cake sales might be on hold, but we have some great fundraising ideas, even if you are working from home. Check if your company will match the funds raised - a great way to double your hard-earned sponsorship.
- Giving to the MS Trust through your payroll is a fantastic way to help. Ask your finance team to set it up for you, and your donation will come out pre-tax –so that's a bonus!

### Want to get involved?

Whether you are the head of a big company, a sole trader, or an employee, we'd love to have you on board to help provide people with MS with a safe place to turn for support. Contact: [fundraising@mstrust.org.uk](mailto:fundraising@mstrust.org.uk) or give us a call on **01462 476707**.

# The countdown to Christmas is on!



Christmas is fast approaching, and with everything that 2020 has thrown at us, we're sure many of you will welcome a little festive cheer. We've got just the thing to raise a smile... the MS Trust Christmas cards are now available to purchase, both from our new webshop ([www.mstrust.org.uk/christmas](http://www.mstrust.org.uk/christmas)) and our brochure, which is included in this issue!

The 2020 collection has a little something for everyone, from traditional to contemporary designs. Every single card sold not only raises vital funds towards our work supporting everyone affected by MS, but it also spreads awareness of MS and the MS Trust.

Claire Gambrell, fundraising officer at the MS Trust, helps to pick the card designs each year. She commented, "As we near the end of what has been an incredibly difficult year, this Christmas it is more important than ever to show our loved ones that we are thinking of them. What better way to spread a little joy than to send them one of our MS Trust Christmas cards? We have a fantastic range, from robins and Christmassy cows to beautiful snow scenes and sparkly trees."

Did you know that the MS Trust has a rather special connection to Christmas? In 1993, MS Trust co-founders Chris Jones and Jill Holt thought that the profits from Christmas card sales could be put to good use producing positive, practical and reliable information for people living with MS. So, armed with little more than a couple of cardboard boxes, a photocopier and a whole lot of passion, they set up a small charitable trust. . . The MS Trust.

From those very small beginnings, the charity has continued to grow and thrive, and a quarter of a century later, we still have the same passionate determination to ensure nobody with MS has to deal with it alone. Christmas cards still play a crucial role today in enabling us to carry out our vital work, with sales raising nearly £160,000 towards our work last year. Our cards (and diaries) are selling fast, so make sure you order your favourites now to show someone how much you care this Christmas.

## 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](http://mstrust.org.uk/fundraising) or call our team on 01462 476707.

### Crimbo Cake Off

Bake sales and bake offs are one of our most popular fundraisers, so why should that stop due to Covid-19?! This year we're going virtual! Don your apron, grab your mixing bowl and pre-heat that oven! Sign up to our first virtual Cake Off this Christmas and help us make sure nobody has to manage MS alone. For more information visit: [www.mstrust.org.uk/cake-off](http://www.mstrust.org.uk/cake-off)



### Virtual Christmas Jumper Day

Get your colleagues together virtually and wear your Christmas jumper (antlers, Christmas slippers or any other festive wear is also encouraged!) with pride on Friday, December 4. Have a catch-up, pour yourself a mulled wine and make a difference at the same time! For more information visit: [www.mstrust.org.uk/festive-jumper](http://www.mstrust.org.uk/festive-jumper)

### Santa Fun Virtual Run

Covid-19 will not stop Santa getting down that chimney! Take on your own virtual Santa Fun Run this winter: you pick the distance and you decide how you complete it – walk, skip, jog or even dance! No sign up fee required, all we ask is that you raise a few pounds to support people living with MS. Go on, spread some festive cheer on your next run! For more information visit: [www.mstrust.org.uk/santa-run](http://www.mstrust.org.uk/santa-run)



### Mission 100

Your mission, should you choose to accept it, is to raise £100 in 100 days to support the 100+ people diagnosed with MS every week. Whether it's dying your hair blue, holding a virtual quiz, or busking like Wesley (pictured), fundraise your way and help us ensure every single person diagnosed with MS has the information and support they need. For more information visit: [www.mstrust.org.uk/mission100](http://www.mstrust.org.uk/mission100)



### Do it your way

If you have any other virtual fundraising ideas, we'd love to hear them. Get in touch with us at [fundraising@mstrust.org.uk](mailto:fundraising@mstrust.org.uk) and we'll support you every step of the way.

15 MINUTES WITH...

# Laura Chapman

After five years at the helm, the MS Trust's Chair of Trustees is stepping down from her role. Here, **Laura Chapman** reflects on her time at the MS Trust and what she's enjoyed most about the role, and shares a message for the incoming Chair.



*"Being part of the MS Trust has been a great privilege for me"*

## How did you first come into contact with the MS Trust?

I first came into contact with the MS Trust when it applied to the grant-making charity where I was the CEO. I recall an extraordinarily impressive Director of Services giving an incontestable case for support for people with MS and telling me in no uncertain terms that the MS Trust was THE charity to meet that need. The grant was swiftly awarded. Then many years later, I was approached as part of the charity's search for a new Chair. The founder Chair was stepping down after 20 years and a replacement was needed. It was a role that I knew I would relish. From my close friends with MS, I knew what a huge difference the MS Trust made to their lives, and that it would be a real honour for me to become involved.

## Can you tell us a little about the role itself? What does being Chair of a charity involve?

Broadly, the primary role of the Chair of a charity board is to ensure that the charity has a clear understanding of why it exists, the impact that it wants to achieve and whether it is actually achieving that impact. The Chair is not the commander-in-chief, who makes unilateral decisions. The role is to encourage the members of the Board to reach collective decisions that are in the best interests of the Trust and its beneficiaries. The Board of Trustees that I joined in 2014 was a very impressive group of individuals who were knowledgeable, passionate and committed and not shy to express an opinion. Another important part of my role as Chair was to be a spokesperson for people with MS, raise awareness about their needs and seek to persuade decision makers to make the right decisions.

## What are some of the projects you've been most proud to have been involved with during your time at the MS Trust?

### The Specialist Nurse Programme

The Specialist Nurse Programme, launched in 2016 and working in partnership with the NHS, provides additional MS nurse posts in geographic areas of greatest need. The Trust has now placed seven new MS nurses and is committed to continuing this programme as the NHS resumes normal operations post the Covid-19 pandemic.

### Advanced MS Champions Programme

One of the key priorities identified in the Trust's ground-breaking research, Generating Evidence in MS Services (GEMSS) and in the Trust's state of the sector report, MS Forward View, was the need to provide specialist care for those with the most disabling and challenging symptoms of MS, typically known as advanced MS.

The Trust has now recruited six Champions. Early evidence from the evaluation of this new programme suggests that the role of the Advanced MS Champion is of huge benefit to those with advanced MS and offers significant cost savings for the NHS by avoiding unnecessary hospital stays.

## Response to Covid-19

Finally, the Trust's response to the Covid-19 pandemic has been fantastic. As the UK went into lockdown in March 2020, the charity responded quickly and effectively to the challenges of continuing to provide its much needed information support, with calls to the enquiry line and requests for additional information dramatically increased.

## What have you enjoyed most about your time as Chair?

My greatest enjoyment has been working with members of the MS Trust team and other MS advocates who are driven by their determination to improve the quality of life for people with MS. They are inspirational, committed, exceptional people who make such a difference to so many. Being part of the MS Trust for the past five years has been a great privilege for me. It is an exceptional charity that provides the highest quality of support that is not available elsewhere for people whose lives have been turned upside down by a relentless and unpredictable condition. The vision of the Trust's founders in 1993, to enable people with MS to live their lives to the full, is equally valid today, and I have every expectation that the MS Trust will continue to make that vision a reality.

## What would your message be for the Chair Designate?

The MS Trust will continue to be there for people with MS, building on the foundations that have been so expertly laid over the past 27 years and now to be led by an exceptional Chair, Caitlin Sorrell. Caitlin, who has a personal connection to MS, brings the best of the skills, expertise and passion that the MS Trust will need to meet its vision for people with MS to live their lives to the full. I have no doubt that under Caitlin's leadership, the Trust will become ever more effective and widely seen as the focal point to which people with MS turn for help.

*Give it,  
love it,  
wear it...*



Registered charity  
no. 1088353

to support people with MS this Christmas

Whether you're remembering a loved one or letting someone special know you're thinking of them this Christmas, simply make a donation and we'll send a limited edition MS Star pin badge & personalised certificate.



**You give it  
we'll send it  
they'll love it**

For more information visit  
[www.mstrust.org.uk/give-love-wear](http://www.mstrust.org.uk/give-love-wear)  
or call **01462 476707**

Please note- a minimum donation of £5 would be appreciated. Star pin badges are subject to availability due to limited numbers.



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Am I having a relapse? (IF513)



How can I live well with MS? (IF512)



Sex and MS: Men (IF356)



Sex and MS: Women (IF213)



Disease modifying drugs (DG442)  
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Primary progressive MS (IF352)



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Making Sense of MS (IF448)



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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](http://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](http://mstrust.org.uk/donate) or text to donate £5 via text, text MSTR01 to 70970.**

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