

February 2021

Open Door

Quarterly magazine of the MS Trust



Relationships and MS

Personal experiences of living with multiple sclerosis



Starting difficult conversations

Advice on discussing end of life planning with loved ones

Let's talk about sex

Tips from MS health professionals on sex and multiple sclerosis

Welcome to the February issue of Open Door



Hello and Happy New Year to you all. While the latest lockdown may mean that 2021 doesn't feel much different to last year, there are still plenty of new things to share with you in this issue.

This month, we've included a look at how MS affects relationships (starts from page 9), the latest news on Covid-19 vaccines (page 8) and advice on starting those, often difficult, conversations around end of life planning (pages 16 and 17).

At the end of 2020, we welcomed our new Chair of Trustees, Caitlin Sorrell. On page 14, Caitlin and her husband, Tim, discuss his recent transition from relapsing remitting to secondary progressive MS.

There's no denying that the new year is likely to bring new challenges, but we're looking forward to getting going at the MS Trust. We have our first virtual conference for MS health professionals taking place in February and we are already looking forward to MS Awareness Week from the 19 to the 25 April. This year we want to highlight the many different voices of people with MS and just how different everyone's journey with MS is.

We'll be showcasing as many stories as we can over the course of the week. If you'd like to share your story then do get in touch at **mystory@mstrust.org.uk**. For more information on our plans for the week keep an eye on **mstrust.org.uk/msawareness** and our social media pages.

If you would like to get involved with any of our fundraising opportunities throughout 2021, you can find more information on pages 20 and 21.

Most importantly, please remember that if you're finding lockdown especially difficult, there are lots of useful resources on our website and our Enquiry Service remains open 9am-5pm, Monday to Friday. You can contact them at **ask@mstrust.org.uk** or **0800 032 3839**.

As always, we really hope that you enjoy this latest issue of Open Door. If you have any comments or suggestions for future issues, please get in contact via **opendoor@mstrust.org.uk**.

David Martin, Chief Executive, MS Trust



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For T&C's, see
www.easydonate.org

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Affected by any of these news stories? Contact our Enquiry Service: ask@mstrust.org.uk



Keep up to date with the latest MS news by signing up for our regular email round-up mstrust.org.uk/keepintouch

Latest MS news

MS Trust awarded National Lottery funding for Covid-19 project

The MS Trust has been awarded £50,000 from the Coronavirus Community Support Fund. Distributed by The National Lottery Community Fund, the funding was given for our 'Supporting the MS community during Covid-19' project which will run for six months.

Since the pandemic started people with MS have been turning to the MS Trust in record numbers for support around Covid-19 and MS. This new funding has allowed us to expand the information we provide on MS, including up to date information on Covid-19, shielding, vaccines, and how to stay safe. The funding has also allowed us to continue delivering our Enquiry Service. Available 9am to 5pm, Monday to Friday (excluding bank holidays), the Enquiry Service hears daily from people who are unsure on what the latest government advice on Covid-19 means for people with MS, who want information about treatment options at a time when the pandemic has made accessing MS services harder than ever, or who simply

need more information on MS symptoms. We are also using the funding to make it easier for you to get in contact with the Enquiry Service and will be rolling out some changes shortly.

Finally we have been able to restart our community involvement programme, so we can talk to more people living with MS to find out how we can offer the best support during these difficult times.

David Martin CEO MS Trust says: "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. Like many charities, the MS Trust has been impacted at a time when demand for our services has never been higher. This funding from the Coronavirus Community Support Fund ensures we can continue to deliver vital support such as our Enquiry Service which we know makes a real difference to people living with MS. MS doesn't stop, and neither do we. We'd like to thank the National Lottery and the government for this funding."



Welcome to Caitlin Sorrell, our new Chair of Trustees

Caitlin will replace outgoing Chair, Laura Chapman, who has been at the helm of the board for the last five years and has decided the time is right to move on.

Caitlin Sorrell, has worked in a variety of marketing and commercial roles in retail pharmacy for over 20 years. She is currently working towards a qualification as a health psychologist. Caitlin's husband Tim was diagnosed with MS in 2009 and has recently been told his MS has become secondary progressive. They talk to us about the impact of his transition on page 14.

Outgoing Chair Laura Chapman says of her time at the Trust, "I am incredibly proud of the work the MS Trust has accomplished over the last five years. In particular the Specialist Nurse and Advanced MS Champions programmes, which have

made a real difference to people living with MS. 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."

On her appointment Caitlin says, "I'm thrilled to be taking over as Chair at such an important time for the MS Trust. The pandemic has significantly impacted MS services throughout the UK. We need to work together, to restore services and to continue to improve access to specialist care and information across the UK."

Virtual Summit 2021

Back in November, we held the MS Trust Virtual Summit study day for health professionals. Speakers attended from a range of services that are helping people with MS and it was great to hear them share their thoughts and experiences.

One of the primary aims of the Virtual Summit was to address how the pandemic has affected MS-related services, and how this can be used as a catalyst towards innovation.

The wellbeing of healthcare workers

It is not only people living with MS that need the support of the MS Trust; health professionals working to help individuals with MS need us too. In the current climate, we are ensuring we can continue to provide this support by moving online. We are now devoting more time and attention to mental health, to ensure there are no gaps when supporting healthcare professionals.

During the Virtual Summit study day, speakers placed significant emphasis on the wellbeing of these professionals.

In a presentation entitled '*NHS Heroes need help too*', Professor Subodh Davé, Consultant Psychiatrist and Deputy Director of Undergraduate Medical Education at the Derbyshire Healthcare Foundation Trust, highlighted the negative impact that the pandemic is having on healthcare workers who feel uncertain, fearful, and panicked about their occupation. He demonstrated the importance of professional care, such as a safe working environment, openness when it comes to emotions, how to manage information overload, as well as the importance of family and friends to wellbeing.

Innovation can be found in a crisis

We discussed how virtual consultations are here to stay and how they enable services to mix consultations and make clinic slots available for people with MS to come in when they need to. Virtual consultations have other benefits including reducing travel time, minimising the spread of Covid-19, and delivering a reactive service. In terms of the wellbeing and productivity of healthcare professionals, virtual consultations also reduce stress and increase the capacity of teams dedicated to supporting those with MS.

Conference news

The MS Trust Annual Conference plays a pivotal role in enhancing the care of people living with multiple sclerosis in the UK. The conference is designed to educate MS specialists and improve MS services across the country.

Typically, the occasion brings together around 300 nurses, physios, occupational therapists and other health professionals dedicated to providing the best care for everyone affected by MS. Unfortunately, due to the pandemic, we had to postpone the event in November 2020. But we are excited to be running the

first ever MS Trust virtual conference from 28 February to 2 March 2021.

Using a virtual platform we will provide health professionals with the same packed programme of presentations, seminars and networking opportunities, as they would expect from our face to face conference.

Better still, going digital means we no longer have to limit the number of attendees, this allows us to extend invitations to even more MS health professionals, who in turn take their learnings back to their services for people with MS.

Ozanimod (Zeposia) for RRMS has been rejected by NICE

The MS Trust is very disappointed that NICE does not recommend ozanimod (Zeposia) as a treatment for relapsing remitting MS in England and Wales. NICE acknowledges that ozanimod reduces the number of relapses and brain lesions compared to beta interferon (Avonex) but is unsure of ozanimod's ability to slow down disability progression. As a result, ozanimod is not considered to be cost-effective for the NHS.

This is NICE's initial decision and they have asked the manufacturer for more detailed evidence and analysis of the data. The MS Trust has been taking part in the appraisal of ozanimod and we will be replying to NICE's initial decision, before NICE makes its final decision later this year.

For more information on ozanimod visit mstrust.org.uk/a-z/ozanimod

Turning stars into donations

We were delighted to receive a donation of £1,350 from DrugStars recently.

Drugstars is a free app that allows you to manage all your medications in one place, set up reminders and track your progress. Every time you take your medication you earn stars and once you have 50 stars you can donate these to us. Stars turn into cash donations at no cost to you.

Thank you to everyone who is currently using this app and generating stars for us. We think you are all stars for supporting us in this way! We call it #GivingByTaking

To manage your medication and earn stars, scan the QR code to download the app.



Monkey Sox are back...

...and this time they have gone casual!

We are very excited to have partnered once again with Monkey Sox to bring you an exclusive MS Trust design.

James Carvell (who was diagnosed with MS in 2016) and his wife Lianne, set up Monkey Sox, to find a positive way to deal with having MS in their life, whilst raising awareness and money for charity.

The result was a range of colourful odd socks, representing how the body acts and feels different left to right, for those living with MS.

The odd socks theme is carried throughout their range and this new, exclusive design features Mr Monkey Sox himself on one sock, and the MS Trust duck on the other!



Order yours at
[monkeysox.org/
mstrust](http://monkeysox.org/mstrust)

They are super comfy and fun, with £3 from every pair sold being donated to the MS Trust. They would make a great present, or why not treat yourself?

We can't wait to see more MS Trust Monkey Sox strutting their stuff!

Alexander John Burnfield MBBS DPM FRCPsych 1944 - 2021

The MS Trust were deeply saddened to hear that former Trustee and dear friend, Sandy Burnfield passed away in January.

Sandy was born in Winchester in 1944. He qualified in medicine at the London Hospital Medical College, during this time he was diagnosed with MS. This caused him to change his specialism to psychiatry, believing that it this would be more accommodating to a potentially disabling condition. He helped to found Persons with MS International and establish it as a central part of the MS International Federation (MSIF).

He was influential in championing the then unpopular view that the person with MS should be at the centre of their own care. He held a particular interest in the emotional and relationship aspects of MS and disability and was author of "Multiple Sclerosis: A Personal Exploration" (Souvenir Press, London) and of many other publications, including those on the psychological impact on children when a parent has MS.



Exercise is good for your brain

It is well-known that exercise is good for physical and mental health, but it's less well-known that exercising also protects and repairs the structures of the brain. We've taken a look at this new piece of research and summarised below the animal and human studies which demonstrate the direct benefits of physical activity on the brain and on biological processes.

Background

In the past, 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.

Regular, moderate exercise is now known to be an important part of maintaining good health and wellbeing for people with MS. Physical activity also reduces the risk of developing other conditions such as cardiovascular disease. Research is now uncovering the direct beneficial effects of exercise on the brain.

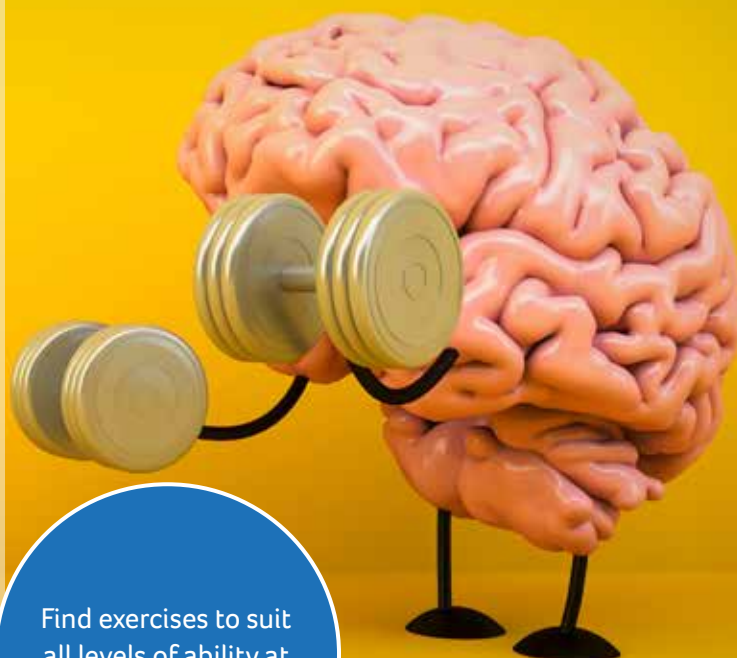
Lessons from animal studies

In animal models of multiple sclerosis, exercise, such as providing access to a running wheel, has been found to delay the onset or reduce the severity of the MS-like condition.

Physical activity increases the production of new neurons, improves the wiring which connects different parts of the brain, reduces demyelination and promotes remyelination.

Exercise achieves this by acting on a range of biological processes. It appears to increase the number and development of oligodendrocytes, cells in the brain and spinal cord which are responsible for producing the myelin coating of nerve cells. Exercise limits inflammation in brain tissue by altering the chemical balance, decreasing damaging cells and increasing repair cells. Physical activity strengthens the blood-brain barrier, preventing harmful immune cells from crossing from the blood stream into brain tissues.

One study combined exercise with clemastine, a drug used to treat allergies such as hay fever. Clemastine has been found to encourage immature oligodendrocytes to develop into cells capable of making myelin. Both exercise and clemastine on their own increased remyelination. But when the two were combined, this effect was enhanced; more nerve fibres survived and almost all were remyelinated. The authors propose the term "MedXercise" to describe this enhanced effect seen when physical activity is paired with medication and suggest that exercise creates conditions in the brain more favourable for the actions of a remyelinating drug.



Find exercises to suit all levels of ability at mstrust.org.uk/exercise

Exercise and the brain in people with MS

The effects of exercise in people with MS have been investigated using MRI techniques. These demonstrated improvements in the wiring within the brain as well as a reduction in brain volume loss, lesion numbers and activity in other brain areas that had been compensating for loss of function. Overall brain burden was decreased. Exercise improves cognitive symptoms and increases blood levels of brain-protecting molecules. Studies have also demonstrated the benefits of different types of physiotherapy on MRI measures of brain structure which suggest neuroprotection or even myelin repair.

What does it mean?

The reviewers conclude that data from animal models and from people with MS support the view that exercise improves brain and spinal cord structures and functions. They acknowledge there is still much to learn:

- Do age or disability level have an effect on improvements in the brain?
- What difference will the timing, intensity or type of exercise have on brain function?
- How can people benefit from exercise without causing other problems such as heat sensitivity or pain?
- Will people living with MS also benefit from MedXercise?

Authors: **Lozinski BM, Yong VW.**

Title: **Exercise and the brain in multiple sclerosis.**

Journal: **Mult Scler Relat Disord 2020;47:102607.**

[Epub ahead of print]

Read the summary: tinyurl.com/medxercise



RESEARCH UPDATE

Daytime sleepiness while driving

Daytime sleepiness is described as an inability to remain awake during the day and is considered to be distinct from fatigue. Although daytime sleepiness affects about one third of people with MS and can have a significant impact on daily life, it is often overlooked in the clinic and in research. It is well known that monotonous driving can increase daytime sleepiness so this study compared the effect of a simulated drive in people with and without MS.

The study

Researchers at an MS clinic in the United States recruited 15 people with MS and 15 people without MS; all had a valid driving licence and were driving regularly at the time that they took part in the study. The participants were asked to complete questionnaires to rate their levels of fatigue and quality of sleep. They also completed the Epworth Sleepiness Scale (ESS) to assess daytime sleepiness. The ESS has eight questions which ask about the likelihood of falling asleep or dozing off (in comparison to just feeling tired) in different everyday situations, such as watching TV, sitting and reading, or talking to someone. The scores are in a range of 0-24 and a score greater than 10 indicates increased daytime sleepiness.

Participants then completed a 25 minute monotonous simulated drive, similar to driving on motorways with low levels of traffic. When someone experiences a period of daytime sleepiness, their eyelid droops, so to measure alertness during the drive, a screen-mounted eye tracker recorded the amount of time that the eyes were 80% to 100% closed (excluding blinks).

The results

Responses to the questionnaires indicated that people with MS reported more symptoms of fatigue and poorer sleep quality. There was no difference in self-assessed daytime sleepiness between the two groups based on responses to the ESS questionnaire. During the driving simulation, real-time daytime sleepiness, measured by eyelid closure did not differ largely between the groups. In both groups, daytime sleepiness increased during the course of the drive; people with MS experienced a greater increase in daytime sleepiness towards the end of the drive. In people with MS, eyelid closure was closely associated with the total distance travelled out of the correct lane, either across the centre line or road edge.

What does it mean?

These results indicate that lack of mental stimulation from monotonous driving increases daytime sleepiness in people with and without MS. People with MS show increased symptoms of daytime sleepiness towards the end of the drive compared with people who don't have MS. The researchers conclude that monitoring eyelid closure while driving provides a valuable method for studying daytime sleepiness in MS. However, further studies with more participants and longer driving times are needed to confirm the results.

More about daytime sleepiness

Daytime sleepiness is defined as the 'inability to stay awake and alert during the day, resulting in periods of irrepressible need for sleep or unintended lapses into drowsiness or sleep'. Although fatigue and daytime sleepiness are two different symptoms, they are related; higher levels of daytime sleepiness were often accompanied by higher levels of fatigue.

Daytime sleepiness may be overlooked in someone who has fatigue, as it may be considered part of their fatigue, but could be a sign of poor sleep quality or sleep disorders such as sleep apnoea. Treating the underlying sleep problem could improve daytime sleepiness and potentially improve levels of fatigue too.

You can assess your level of daytime sleepiness at:
tinyurl.com/sleep-scale



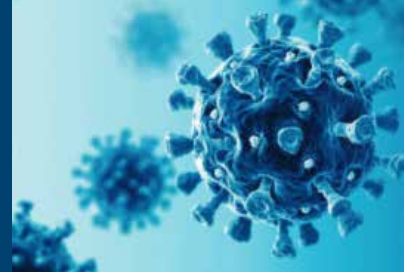
Authors: Devos H, et al.

Title: Real-time assessment of daytime sleepiness in drivers with multiple sclerosis.

Journal: Mult Scler Relat Disord 2020 Oct 31; 47: 102607.

Read the summary: <https://tinyurl.com/y4wqn744>

Covid-19 vaccines & MS



The independent Medicines and Healthcare products Regulatory Agency (MHRA) has approved three Covid-19 vaccines for use in the UK. The first was developed by Pfizer-BioNTech, the second by Oxford-AstraZeneca and the third by Moderna. Although the three vaccines use different technology, they all work to induce an immune response to the spike protein of the coronavirus. The vaccines are being made available through the NHS across the UK, although it's not expected that the Moderna vaccine will be available in the UK until the spring.

Q When will I get the vaccine?

The order of priority is based on individual risk, and aims to protect the most vulnerable people and the health and social care systems. This means that the main criteria for the first phase of the vaccination programme will be age.

If you have no other underlying health conditions apart from MS, we understand that you would be offered a vaccination at priority level 6. This is because the list of underlying health conditions considered relevant by the Joint Committee on Vaccination and Immunisation (JCVI) includes chronic neurological disease. The level also includes people on some disease modifying drugs (DMDs) or long term use of steroids. If you are older than 64 you will be invited to be vaccinated earlier.

If you're considered extremely clinically vulnerable, and have been asked to shield, you're likely to be included at priority level 4. Pregnant women and children under 16 may be included if they and their doctors agree that the benefits of having a Covid-19 vaccine outweigh the possible risks.

As of 5 January, the JCVI has revised its recommendations to say that unpaid carers of a disabled or elderly person, whose welfare may be at risk if the carer falls ill, should be prioritised alongside people with underlying health conditions.

You can view the full priority list as published by the JCVI, here: mstrust.org.uk/covid-19-vaccines

Q Are the vaccines safe?

The safety data checked by the MHRA indicates that all of the vaccines are safe and effective for the majority of adults, including older adults. None of the vaccines are live, so they cannot cause Covid-19 itself.

The MHRA has found no evidence of an increased risk of allergic reaction to the Pfizer-BioNTech vaccine among people with serious but unrelated allergies. They now advise that only people who had an allergic reaction to the first dose of this

vaccine, or who previously had reactions to any of its components, should not receive it. Anyone with any other allergies such as a food allergy can have the vaccine.

The Association of British Neurologists have advised that people taking Ocrevus or Lemtrada should discuss when to have their vaccine with their MS team. This is because these DMDs can affect how well a vaccine might work for you, so the timing of your infusions and vaccine will be important.

Q How will I get the vaccine?

You'll be contacted about your proposed vaccination, and invited to visit a local GP surgery, hospital hub or other location. In some areas, venues such as leisure centres or sports stadia may be used.

It's unlikely that you'll be given a choice of which vaccine you will receive, unless you have a history of allergic reactions. All vaccines are given as an injection in the upper arm. Two doses are required.

When will I be called?

If you are 70 or over, or extremely clinically vulnerable, and have not yet been offered a vaccine, you are encouraged to get in touch with your GP. Otherwise, you should wait for an invitation from the NHS.

If you think you've already had Covid-19, you'll still be invited to be vaccinated, as the protection from the vaccine may be higher than from natural exposure, and last longer.

Q When will I be protected from Covid-19?

For most people, immunity is complete around seven days after the second dose of the vaccine. A very small minority of people may not be fully immune, even if they are vaccinated.

If you're severely immunocompromised, the vaccine might not give you full protection, so you may still need to avoid exposure to others for a while to reduce your risk. You might be considered severely immunocompromised if you've had your spleen removed, have had cancer, an organ or bone marrow transplant or if you're taking a medication which suppresses your immune system.

The guidance suggests that your household contacts may be offered a vaccine to protect you if you are severely immunocompromised. This will not be the case for most people with MS whose household contacts will be offered the vaccine at their own priority level.

For more information on coronavirus and MS visit:
mstrust.org.uk/coronavirus

RELATIONSHIPS AND MS

Multiple sclerosis can have an impact on many areas of the lives of people with the condition and those close to them through romantic relationships, friendships or family bonds. In this section we hear how different relationships have been influenced by MS.

Dating and MS

Dating can often feel like a minefield. Throw in Covid-19 and multiple sclerosis and many people would be forgiven for not getting involved. **Dearbhla Crosse** discusses her surprise feelings of empowerment from allowing herself to be vulnerable.

A conversation with my grandfather last April, asking me when I was getting married, haunted me as I drove back to Dublin after four months of quarantining in rural Cork. His rendition of the wedding march ringing in my head, spurred me to reconsider entering the realm of online dating. Like most singletons, my dating life took a hit with Covid. Plus, a diagnosis of MS in 2019 meant I'd made the decision to remove myself from the dating world while I focused on juggling my various health issues. In hindsight had I known we were about to enter a global contagion; I may not have done so.

Telling a potential suitor you have MS means never being able to untell them. Yet, at a time when Covid is the 'kiss of death' for at-risk singletons, you inevitably have to reveal intimate details about yourself you'd never have disclosed pre-first date. Like many living with MS, I have to be cautious. My medication is an immunosuppressant, which compromises my ability to fight off infections. Therefore, attitudes to COVID-19 safety form the basis of any dating prospects.

Covid courtships

Dating for me means socially distanced walks in between doctors appointments. It has meant not really knowing how to move beyond date two or three and assessing my date's risk factors from work environments to common sense. I opted to tell my dates I was in the 'at-risk' category fairly early on to gauge their response. Initially, I worried about revealing my MS, but it has meant being more upfront from the start, which can be freeing. Since young people with underlying health conditions have been at the forefront of the national discourse, it didn't feel as daunting.

Covid courtships are predictably harder with a chronic illness. Dating can be utterly exhausting, especially when all you do is walk for miles. The frosty weather has also meant layering up like Pingu the Penguin, which admittedly isn't the most enticing look for a first date. I found myself judging my dates by their use of hand sanitizer and mask compliance; something I never thought would factor into decisions when choosing a future partner. I decided that I probably couldn't date anyone with flatmates because their bubbles were constantly shifting. It's a strange time for trust and it brings up questions about other people's value systems.



Explaining MS can be challenging

Explaining the hidden underlying factors of an invisible illness, as MS so often is, can be challenging and frequently misunderstood. Those of us living with MS have learned to make the most of the good periods, which can mean people presume we are absolutely fine.

It can be hard to explain to those you're dating that you woke up chronically fatigued after ten hours sleep or that your hand is twitching because you have overdone it. It can make for uncomfortable conversations, but ultimately the person I am with will have to curtail their life somewhat for me while Covid looms.

Surprise empowerment

Perhaps having to disclose my MS during this time has forced an honesty that wasn't there initially. I was overwhelmed by how open the men I met were and I have made some lovely friends because of distanced dates. Most people have a loved one they want to protect, whether it's their granny or a friend like me. I think it has made people more empathetic, as well as more conscious of health and hygiene, thankfully. So, to anyone who is worried about putting themselves out there, you would be surprised by how receptive people are. There is a bravery in being vulnerable and it can be incredibly empowering.



Talking to kids about MS

Colin Wallace lives in Aberdeen with his wife Judith, and is the father of two children, Evie and Alec. He was diagnosed with relapsing remitting MS in 2018. We talk to Colin and his family about the impact of the diagnosis and how they dealt with the difficult task of discussing MS with young children.



Colin, can you tell us a little bit about your diagnosis? How did you react to the news?

I was diagnosed in April 2018 when I was 32 years old. When I was younger I had repeated bouts of optic neuritis, the first of these occurred in 2005 when I was 20. After my second bout the consultant told me that I probably had MS, as a repeat of optic neuritis

can be a sign of multiple sclerosis. I wasn't ready to deal with this though, so put it to the back of my mind and got on with my life as normal. Although I had a few more episodes of optic neuritis over the years, I had no other symptoms and still managed to live a normal life. I rowed to a high level, competed in ironman triathlons, got married and started a family.

When I first started having other symptoms in winter 2018, including numbness and tingling in my left hand, along with balance issues, I still didn't really think about MS. I put it down to the cold of winter and being busy renovating our house. It was only after my dad, a former GP, asked for the fifth or sixth time how my hand was that it clicked with me and I thought it could be something more. I saw my GP, who referred me quickly and following an MRI, I was diagnosed with relapsing remitting multiple sclerosis. The news was devastating initially and I really struggled to come to terms with the it. I mourned the activities that I would no longer be able to do, was depressed for a few months and only told a handful of people what had happened.

However a few months on, after reading great publications from the MS Trust and other articles, I decided to tell everyone I could about my MS. The positivity that came back from them was incredible. Everyone was so kind and supportive and really helped me come to terms with the diagnosis. The second big thing I did (after my wife pushed me towards it) was to attend a Paralympic sports testing day. As a result, British Cycling have accepted me onto the foundation programme that is aiming towards the Paris 2024 Paralympics! These events and others have given me my unofficial motto of "turning my frown upside down".

How did your family respond to the news of your diagnosis?

My family were incredible. As a former GP, my dad was extremely knowledgeable and supportive. Mum was fab, just being there to give me cuddles when I needed them!

For more information about talking to your children with MS visit mstrust.org.uk/talking-with-kids



One of the hardest aspects was actually telling people I knew about my diagnosis, but luckily my dad and my wife, Judith, helped so much with this. Everyone was incredibly supportive and those that know me best trusted I would cope with whatever came my way and deal with it with positivity. My wife was sad when she found out, but has also said it was a relief to finally have an answer.

My daughter Evie was only two when I was diagnosed, so doesn't remember too much, but has admitted feeling worried about it as she got older. Alec was older than Evie, so was definitely more scared and worried about how our lives would be affected.

How did you go about explaining MS to your children?

Evie and Alec both got special books about multiple sclerosis which carefully told them what it is, why some people have it and also what it makes people with MS feel like.

Judith, came across the MS Trust books 'Talking with your kids about MS' and also 'A kid's guide to MS'. These are aimed specifically at children and made it so much easier for us to explain what was going on with me.

As a family how do you cope with MS?

Evie: For a while Daddy was taking medicine every day so I would help by reminding him to take it. Now he is on new medicine, so I have to be careful to not make him sick if I get poorly. I also give him a daily cuddle to make him feel better.

Alec: We know when he isn't feeling good so we are extra kind to him to make him feel better. We do fun things to make him forget about it, like going cycling together.

Judith: We take every day as it comes and continue to look to the positives this diagnosis has brought. He has the opportunity to remain involved in high performance sport, with the possibility of the Paralympics on the horizon. It has opened so many doors to us that we thought were closed forever. Colin is a great role model for the kids through his strength and determination to not let MS hold him back.

What questions do your children have about MS?

Evie: Is it going to stay with you forever?

Alec: How will it affect you when you get older? What does it feel like?

What advice would you give other children with a parent who has MS?

Evie: I talk to daddy when he doesn't feel good and we have our 'daily cuddle'.

Alec: We just talk about it lots and have cuddles if we are feeling sad.

Judith: Talk, talk, talk.

Double Diagnosis

Being told you have multiple sclerosis can put an understandable strain on a relationship. Finding out that your partner also has the condition is not something many people have to confront. In this article, **Julie** describes the shock of both herself and her husband, **Martin**, receiving the diagnosis. Despite this double blow, they are both determined to continue to get the most out of life.



In spring 1989, shortly after starting a role as a practice nurse in a GP surgery, I developed optic neuritis in my left eye. This lasted for about six weeks and was accompanied by pins and needles in my left arm and severe lethargy.

Thankfully I was working part time, near my home, meaning I could continue working. My

husband was working full time at that point, managing a motorcycle training school, and we also had two young daughters aged seven and four.

My second episode occurred a few years later. I had severe pins and needles and weakness in my left leg and arm. Following this episode, I was diagnosed with relapsing remitting MS. It was a huge shock. Immediately after my diagnosis, MS was all I could think about. I was convinced I'd end up bedridden by the age of 40.

I became adamant that this would not hold me back and continued working.

I went on to do a nurse practitioner degree and continued working in general practice for a further 27 years.

When I met my husband, he worked for the London Fire service. He later retired following a fall through a ceiling which injured his back. He went on to manage a motorcycle training school and eventually ran a successful business selling car engine products to the motor trade.

It was during this last career that he started to have falls. Initially he put these down to his new varifocal glasses. One of the falls damaged his knee, tearing the cartilage. Following that he continued to have weakness in the leg and knee pain requiring him to use a walking stick.

I was terrified that he had motor neurone disease.

My husband's situation came to a head when we were on holiday in Rhodes. He was unable to lift his right leg to climb a step. At that moment I knew that he had a serious issue, and was terrified that he had motor neurone disease. When we got home, we went straight to the doctors. Following several referrals to a variety of consultants, he eventually had a head MRI.

I will never forget the day we were given the results. The consultant gave the MRI result to ME rather than him. It clearly stated that his brain had several lesions consistent with demyelination. I put the result down and said "Oh shit!" Not once had I considered that he could have MS too.

Looking back he had probably had MS for at least five to ten years prior.

After further investigations, he was eventually diagnosed with primary progressive MS in 2012. Looking back he had probably had MS for at least five to ten years prior. Over time he gradually deteriorated and is now in a wheelchair full time. We sold our family home and moved to Essex to be closer to our daughters. We bought and renovated a bungalow and started a new (very different) life.

I retired a couple of years early due to my MS, but my life is as busy as ever. I volunteer in the local Crown Court as a Witness Service volunteer and for their outreach service, visiting and supporting witnesses at home. I also volunteer for Guide Dogs as a puppy walker. We hope to get an assistance dog one day. Plus of course I look after the grandchildren when required.

Despite us both having MS, we do try to live life to the full.

We have several wonderful friends who never get embarrassed if one of us falls over or is incontinent. In fact, I remember having lunch in London with some close friends a couple of years ago. Our friend forgot to put the brakes on Martin's wheelchair, so when Martin transferred, the chair went one way and he the other. He wasn't injured and all four of us fell about laughing (much to the shock of other diners).

We have recently bought a Trekkinetc wheelchair which enables Martin to go over rough terrain. He is slowly getting used to it and now can get out and about in the countryside.

Chaos generally reigns wherever we go. Nothing is simple, as I am sure all wheelchair users know. But the world is becoming more accessible, and once this dreadful virus has been controlled we are looking forward to exploring lots of places that were previously impossible in a wheelchair.

It isn't fair for anyone to have MS. I often think that if we both had to be given this stupid condition, the least God could've done is to give me primary progressive MS and my husband relapsing remitting MS. That way he could pick me up when I fall, and continue to do all the driving! But life is what it is. Our daughters help when Martin falls and needs extra help to get up. All I can say is, please focus on what you CAN do and not what you can't.



Falling for someone with MS

Pete and Shirley have been together for almost 16 years. We spoke to Pete about the closeness of their bond and why, despite the worsening of symptoms over the years, MS takes a firm second place to their relationship.

I first met Shirley in 2005. We were both happily divorced at the time and had said that we wouldn't get married again. However, when we met online in February 2005, we hit it off straight away. It was one of those things where we just knew that it was going to work. Even when she said to me, "Do you know what you're taking on, because I've got MS", I wasn't fazed. Although to be honest, at the time I didn't have the first idea about MS, but the relationship was so strong that it was not going to make any difference to me.

I found out early on that the illness was likely to progress.

I knew that as time went on it would become harder. Not just for Shirley, but for me as well, because it meant I would probably have to do more for her.

When we first moved to Bristol in 2007 we'd go to the local shops and the supermarket. With the aid of a shopping trolley to hold onto, Shirley would manage a good 10-15 minutes going around the store. But not anymore, instead we're using the wheelchair permanently outside our home. She's fine at home where it's familiar and we make sure the pathways are clear, but if I were to do something stupid like leave a coffee table in the way, she would fall over it. Due to her MS, she would see it and know it was there, but by the time the message reached her brain she'd have tripped over it.

Eventually the time came when we had to move again, because where we lived was inaccessible. We couldn't get a wheelchair through the front door. So with the help of South Gloucestershire Council we moved into an 'Extra Care' flat, which is independent living. The advantage is that Shirley has five or six hours of care calls a week. The care staff are on site and they are available 24/7 so if there is a problem, we can call them. For example, Shirley had a backwards fall onto the floor last year. I pressed the call alarm and a carer was very soon with us. She stayed until the paramedics arrived. Shirley had hospital treatment for a non-MS issue. It was serious neurosurgery, but we've come through this together, ready for the next MS challenge.

Shirley will have days where she can barely move a limb and have pain.

MS can be incredibly varied. A year ago she had trigeminal neuralgia which on its own is the most horrible pain. She's also had changes in medication which resulted in terrible side effects. Some



days you wonder if you're going to get the same symptoms two days running.

Shirley is a very bright, intelligent lady. She was a school teacher, robbed of a career by MS when she was only 41. The cognitive problems that MS causes are so far reaching that you can't pin it down to any one thing in particular.

You've got to have a good relationship to start off with, you've got to be extremely close to each other, because that's what generates the care. Anybody in this situation has to understand, that as time goes on the carer will be doing more and more. They may not always feel able to, because it is difficult. That's not to say I don't want to do it, because I do, but there are times when it's difficult. I accept it though, because that's the nature of the beast. The carers that we have are very good though and provide a break for me now and then.

Despite all that MS throws at us, Shirley is just great to be with.

As I said at the beginning, we hit it off straight away. The very first time that we met we just knew that it was right and that doesn't often happen. Relationships normally take a while to develop before you actually think yeah this is the person I want to spend the rest of my life with. It wasn't like that with us, it was pretty much straight away. We went out for a meal on the first night and it was just involuntary. I got up to go to the gents, walked away from the table, gave her a kiss on the top of the head and said "Won't be long". We're not just a married couple, we're lovers, we're friends, we're soul mates and we're mates. It's as simple as that. Yes, we have ups and downs, of course we do. The couple who never had any, never lived, but it gets dealt with and we've got a really good relationship. Whatever MS deals us in the future, we will tackle it together.

Friendships

Kaz Laljee was diagnosed with primary progressive MS 14 years ago. In 2011 he founded the online community Positive About MS which has over 20,000 members. Here he discusses the impact being diagnosed has had on his friendships and why his MS friends are so important to him.

I was diagnosed about 14 years ago when I was in my late 20s. I'd had symptoms for many years so ultimately it was good to finally get a diagnosis. When I was told that it was primary progressive MS and that's why I had been struggling to walk, along with other symptoms, I was just really glad to put a name to it and finally understand what had been going wrong with me.

After diagnosis I absolutely did not want my friends to know about it. I did not want a single person to know I had MS. I was afraid of being judged because of the condition and of people changing the way they were around me. I didn't want sympathy, nor did I want excuses being made for me. For the first year or so, I only told my direct family and my boss and maybe two or three very close friends.

Over the years my relationship with my friends has definitely changed as a result of having MS.

It's not because people don't want to be friends with you any more, it's just that when you have multiple sclerosis your habits and abilities change. It can have a devastating effect on your social life, when you can't do the things you once did. Slowly, slowly this results in being invited to less and less things. Not because people don't want you to come, but if they are doing something physical or they are going somewhere that's not accessible it can feel a bit awkward. With close friends however, I've eventually come to an understanding as they know my capabilities and realise that I can't attend every event.

I've also made new friends though. People with MS often end up making friends with other MSers. Initially I did this just to make sure I was normal. I was experiencing all these symptoms and struggles and to be honest it was nice to hear others going through the same thing. Eventually I ended up having lots of friends who had MS and I could share experiences with them and we'd help each other out.

I think that an MS diagnosis can change the way people see your value and what you can contribute. Sometimes it feels like your ideas and suggestions are dismissed, because of your disability.



With friends who have MS, it feels like we are part of an exclusive club.

For example we can share information about bladder and bowel weakness with each other, knowing that we won't be judged. We accept it and understand it, because we are going through it too. We can also share helpful hints and tips with each other. When I was first diagnosed I used to use chat rooms on the MS Society website. But now we are lucky to have social media. A quick search on Facebook helps you find local, national or even international groups that you can be a part of.

My advice for other people wondering how to talk to their friends about MS is, only share what you need to. It's good to let friends know why you can't do certain things, as it will help them to understand. Describing symptoms might also help them understand what you are going through. But I wouldn't really share symptoms with friends to make conversation, I think that's what our MS friends are there for.

Follow Positive about MS on all main social media channels @PositiveAboutMS

If you'd like to share your personal story of life with MS, then get in touch via email at mystory@mstrust.org.uk

TIM AND CAITLIN DISCUSS

Transition to SPMS

Discovering that the pattern of your MS is changing from relapsing remitting to secondary progressive can be a distressing and confusing experience for you and your loved ones. We talked to MS Trust Chair of Trustees, **Caitlin Sorrell**, and her husband **Tim**, who was recently diagnosed with secondary progressive MS, about that transition and how they have dealt with the emotional and practical impact the change in diagnosis has had.

Tim, can you tell us about what's changed with your MS over the last few months or years?

Tim: I first started getting MS symptoms in 2005, which was a few years before I was diagnosed in 2009. I've never really had a relapse, aside from the initial symptoms, so I've never had the classic spikes or symptom changes that you associate with relapsing remitting MS.

Over the years my symptoms have remained on a similar theme of loss of sensation and loss of strength. But in recent years, I've started to develop spasms and cramps in my calves that travel up my legs and thighs. I have widespread stiffness. Previously there would be periods without it but it's much more constant now. So when I had my last consultation, which was over the summer, the neurologist decided to shift me to secondary progressive from relapsing remitting.

Caitlin: We're both runners and I would say the biggest noticeable change from the outside is the increased number of trips and falls Tim has when he's running. To the extent that he now runs with knee and wrist guards.

Do you think you both recognised on some level that these changes were part of the transition to SPMS?

Tim: To be honest, I've never really identified as relapsing remitting. I've always felt a bit of a fraud because I've never really had relapses. There's no such thing as typical MS, but I've never really felt like I was a classic RRMS case. I've been very lucky and I guess you kind of hope that that means it's benign. But my symptoms have always been there and my symptoms have been on a sliding scale. So when the neurologist said, in the matter of fact way they do, "I want to move you to secondary progressive", it made absolute sense, because it feels like a better fit for me than relapsing remitting.



Some people refer to being diagnosed with secondary progressive as like being diagnosed all over again. It can feel quite traumatic, has that been the case for you?

Tim: I think if I'd been on a disease modifying drug and was then suddenly told, "You're secondary progressive, so there's no point in you taking this anymore", it would have been more of a wrench. But I stopped my DMD a few years ago following an allergic reaction. So from a medicines point of view, there's no difference as I wasn't on anything.

I think if I was taking something that felt like it was helping to manage my future progression and was then told, "There's no point taking this anymore", I think that would have been a much bigger struggle.

Caitlin: There was a part of me that was relieved to have this new diagnosis, because it fits better. I also think that his disease is getting worse. So there's an element of recognition that yes, he's getting worse. It's not just all in our heads or he's not just getting old.

We've got a label that feels more apt, but I'd be lying if I said it didn't feel like a big deal. The new label puts it into focus that yes, his disease has progressed from when he was first diagnosed. It's a reminder that even though Tim is relentlessly positive and still does absolutely everything that he can, there's a progression path with this disease and it's only going one way.

Tim: I said to Caitlin yesterday, it ultimately doesn't make any difference. It's just a label.

The way I feel hasn't changed. It's an absolute waste of time and energy railing against something that nobody can control. If there's something I feel I can control and I don't it will drive me crazy. With MS there's no point driving myself mad as there's nothing I can do. There's nothing anybody else can do, I have it. Maybe I'm lucky, in that I've always found it quite easy, not to wallow in the negative, because lots of people find it harder and lots of people struggle with more obvious problems as a result of their condition.

Looking to the future, do you see your life changing at all now you've been given this new label? Do you have concerns for the future?

Tim: I'm 46 years old, so I groan when I get out of bed, but I'm sure I'm not the only person that does that. I don't feel that there's very much to be gained by worrying about something I can't control. It's a cliché, but you have to cross that bridge when you come to it. We live in an end Victorian terrace and we've got a fairly steep set of stairs. There may come a point when I can't manage the stairs but there's no point in worrying about it now.

Caitlin: This is where we differ because I do spend time thinking about the stairs! Where we do agree is that, when you're given the diagnosis, you can focus on all the negatives and all the things that it might mean can change your life, or you can just keep living life to the full. If anything, Tim's diagnosis really encouraged us to live life to the full. We did a lot more travelling than we would have done without his diagnosis. I don't think we'd be running marathons. I certainly wouldn't be! Yes, there are lots of negative things that the future might bring because of his MS, but we'll just take them one day at a time. In the meantime, it's reminded us that life is for living.

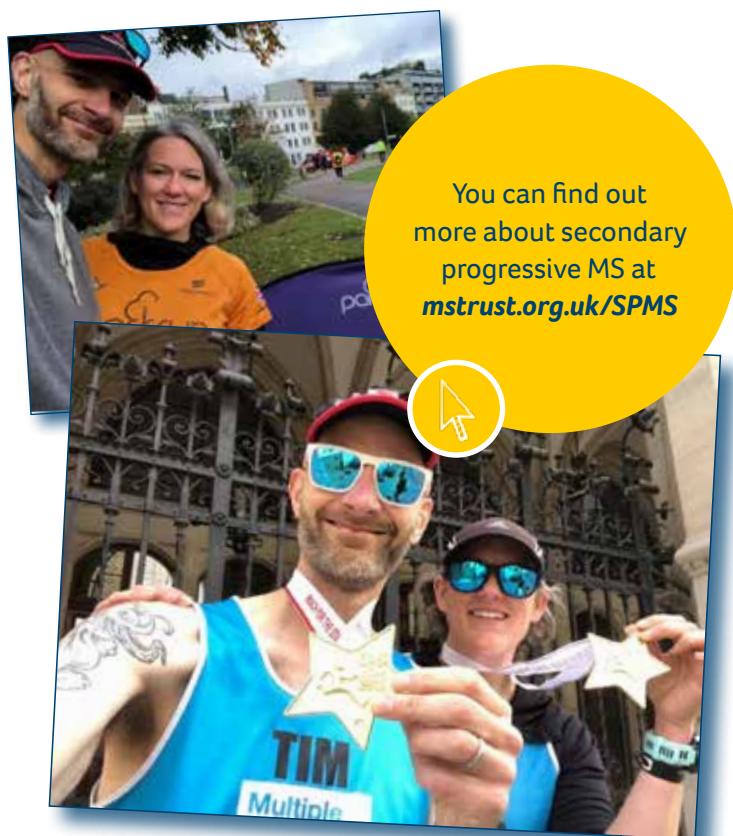
Do you have any advice, as a couple and as individuals for anybody else going through a similar transition?

Tim: The first thing to understand is that MS is different for everybody and everybody experiences MS differently. It's really easy to slide into a worst case scenario and think that your life's over. So my advice would be don't mourn what you might have lost or what you thought you were going to do, celebrate what you still can do. You need to look forward and think about what you can do, not what you can't do. When we're not in lockdown I do some guide running with visually impaired runners. I was running through a park with one man a couple of years ago and he said "I love running around here because the texture of the light changes as you go from the open parts by the lake, then into the woods." I just thought, "I completely take that for granted." I can see, and I completely take for granted how the light changes. I think we can all learn something from that.

Caitlin: My top tip would be to access all the help you can. We haven't been offered any treatment for secondary progressive, but the NHS has been fantastic in dealing with Tim's symptoms. They've helped us in trying to find solutions for bladder problems or spasticity or referrals to physio. Just because you don't have a pill to take or an injection doesn't mean that there aren't any solutions. Sometimes you have to ask several times to get referred for those solutions, but those solutions are available. Until there's a magic cure, then I think it goes back to what Tim was saying about focussing on what you can do and finding solutions for the problems that are in front of you.

Unlike Tim, I do spend a bit more time thinking about the future. One of the things I started doing when he was first diagnosed was thinking financially, what it might mean in the future if he wasn't able to work. There is a level of long-term planning that gives us contingencies for what happens next. Once that forward planning has been done, it enables us to live today a bit more. As a couple it's definitely helped us focus on what's important in life and to make the most of what we have. I also think it's brought us closer together. I've just started a PhD and I had a lecture on the strain that it will put on you and the impact that it can have on relationships. I felt like saying, I don't think there's anything a PhD can throw at me that we haven't already been tested with before.

I also find it really important to be able to talk to friends and family about Tim's MS when he's not there. When we got his diagnosis of secondary progressive, I needed to go and have a chat with some of my mates and my mum about what that meant and how I felt about it. So it's being able to have conversations together, but also acknowledging that it affects us both differently and that we both need to process, sometimes on our own and sometimes together.



END OF LIFE PLANNING

Starting difficult conversations



Although MS is a lifelong condition, it isn't considered a terminal one. But the truth is, none of us know what's waiting for us around the corner. Planning for the end of life is something we can all be thinking about, no matter our age or our health. Thinking about your wishes early, and making informed decisions about your preferences and priorities, is an important first step. Discussing these wishes with those closest to you, can help you feel more in control and give you peace of mind knowing that they understand how you'd like to be cared for in the final months of your life.

What do we mean by end of life planning?

End of life planning involves thinking in advance about your preferences and making decisions about the final months of your life. It can include:

- deciding how you'd like to be cared for
- thinking about where you'd prefer to die
- making it clear if there are any treatments you don't want to receive
- putting your affairs in order by making a will
- planning for your funeral.

Once you've thought about your wishes, it can help to share them with your close family so they're aware of your preferences. However these conversations can bring about a range of emotions and starting them in the first place can be a real challenge. Here are some suggestions to help you begin the conversation around end of life planning with your loved ones.

Decide what you want to say

Take a bit of time to think about your wishes and exactly what you want to tell your loved ones. You might want to talk about the type of care you'd like to receive and any treatments you'd prefer not to be given. If you feel comfortable, you may want to let them know your preferences about where you'd like to die.

As well as your future care, you may also want to talk about your funeral wishes and what you'd like to happen to your possessions. Make some notes on what you'd like to talk about – think about the things that matter to you most.

Choose the right time to talk

Have the conversation when you know what you'd like to say and, most importantly, when it feels right for you. You may want to let your family member or friend know in advance that you'd like to talk about end of life planning so it doesn't come as too much of a shock for them when you bring it up.

If you're not ready to have a face-to-face conversation yet, that's completely okay too. Perhaps you could try expressing how you feel and the things you'd like to talk about in a letter or recording something on your phone instead.

Find the right setting

Have a think about where you'd feel most comfortable having the conversation. You'll probably want somewhere that's quiet and private, and somewhere you won't be interrupted.

Have the conversation when you know what you'd like to say and, most importantly, when it feels right for you.

END OF LIFE PLANNING

That might be at your home or maybe while you're out for a walk. Choose a place where you'll feel most relaxed and at ease.

Start the conversation

Starting the conversation can be really difficult. You might want to plan how you're going to bring up the topic and have some phrases ready in your mind. You might want to open with a question, "Have you thought much about...?" or perhaps a statement, "I know it's a hard conversation to have, but I'd like to talk about..." Having these phrases ready can help you feel more comfortable getting the conversation started. Try not to worry about saying the wrong thing; there's no right or wrong way to deal with difficult conversations; the most important thing is you've been brave enough to start it.

Take your time

Don't feel like you have to cover everything in that one conversation. Spread it out into a few conversations over time. Talking about dying can be emotionally draining both for you and your loved ones, so break the conversations down into small chunks and take your time.

Prepare for different reactions

Everyone will respond to conversations about death differently. Some people will find it easier to talk about than others. Try to be respectful of people's reactions, keep calm and show you understand. If the person you're talking to is finding the conversation difficult, then you can always say, "Let's stop talking about this for now and come back to it another time."

Talk to your GP

It can be helpful to talk to your GP or another health professional involved in your care, about end of life planning. They can make you more aware of the options available to you. Let your GP know in advance that this is what you'd like to discuss. You could book a double appointment so the conversation doesn't feel rushed.

There isn't a right or wrong way to have a conversation about your end of life care. It's difficult to talk about dying. It's not something any of us necessarily want to be reminded about. But it's important to make your wishes known to those closest to you so they're aware of your plans and you have some peace of mind.

If you'd like to learn about how you can record your wishes, there are a number of organisations that offer information and support:

- **NHS – End of life care**
nhs.uk/conditions/end-of-life-care/
- **Compassion in Dying**
compassionindying.org.uk/making-decisions-and-planning-your-care/
- **Marie Curie**
mariecurie.org.uk/help/support/terminal-illness/planning-ahead/start-planning-ahead
- **Sue Ryder**
sueryder.org
- **MS Trust palliative care**
mstrust.org.uk/a-z/palliative-care





ASK THE EXPERT

Sex and MS

MS can affect relationships in a variety of ways. Having MS can change how you feel about yourself, how you relate to your partner and how you feel about sex and intimacy. Research suggests that sexual problems affect more than half of people with MS, but starting a conversation about them with a health professional, and with your partner, can often feel daunting. **Lesley Catterall** and **Denise Middleton**, two MS specialists who focus on sexual problems associated with MS, answer your questions.

Q

How common are sexual difficulties for men and women with MS and what problems occur the most?

Denise says: It's difficult to know exactly how many people with MS experience sexual problems. Research indicates sexual problems may affect 50–90% of men with MS and 40–80% of women. It's important to remember that people in the general population also experience sexual difficulties and that's quite common too: around 43% for men and 31% for women. Nearly three quarters of people who experience sexual difficulties with MS also report relationship difficulties. The most common problems for men with MS are difficulty achieving or maintaining an erection, sensation difficulties and fatigue. For women, reduced desire for sex, loss of sensation, reduced orgasm, less lubrication and, for some women, loss of orgasm can happen as a result of MS.

Q

How can I stop fatigue ruining mine and my partner's sex life?

Denise says: If fatigue is affecting your intimate relationships, there are three key areas you can work on: pacing, rest and activity. It's important to look at what you're doing during the day, and maybe what you've been doing the previous day, if you're thinking of planning a date night. By pacing yourself throughout the day and building in rest periods, you'll have more energy to use on the things you really enjoy rather than wasting it on unimportant things like doing the washing or the ironing. Having sex is much more important than that! Here are some other things to consider:

- **Timing** – pick a time of day when you're most awake.
- **Environment** – choose a setting that makes you feel relaxed and comfortable. Make sure the room isn't too hot.
- **Positions** – think about finding positions that use the least energy, such as spooning. You could also try the stop-start method to save some energy or maybe a "quickie" if that works for you!
- **Body temperature** – if your core body temperature increases by even half a degree when you have MS, you may feel weaker and more fatigued so it's important to try and stay cool. You could have a cold shower beforehand to reduce your body temperature. It can be invigorating!

Q

MS has left me with some numbness in my genital area making it difficult for me to become aroused and reach orgasm. Do you have any tips to help with this?

Lesley says: Sometimes people can get bogged down worrying about achieving an orgasm. It's rare in general for partners to achieve an orgasm at the same time. Intimacy is just as important; things like touching, holding hands, spending time together.

To help arousal you might plan a date night, setting the scene with candles, soft music, mood lighting, and using fragranced massage oils. There is a technique called body mapping which can help with finding out which parts of the body become more sensitive during intimacy.

When you have MS those areas might change because of pain or muscle stiffness so it's good to communicate with your partner and just explore each other's bodies to find out which bits help you get turned on.

There are lots of websites you can look at for sex toys now, and there are also intimate massagers which have been designed specifically to help women who have difficulties with sensation. Masturbation can help because you can feel more in control and decide on the rhythm and speed which can help in achieving an orgasm.

Q

Spasticity in both my legs is making sex a real challenge. Is there anything me and my partner can try to make sex a bit easier for us?

Denise says: Firstly, it's important to understand the triggers that can cause your spasticity or spasms to worsen. Those triggers can be things like constipation, bladder problems or an infection. If these things are addressed with your MS nurse and managed appropriately that can be a real help.

It's good to experiment with positions because positioning is key. For some people, the missionary position is a real no-no because it can set off extensor spasms, where the legs go straight out and become locked solid. That can be quite painful for both partners. Some people find spooning better because the legs are flexed towards the body. Pillows under the knees or under the bottom, or positioning a rolled-up towel to support your lower back can be useful too.

If you take medication for your muscle stiffness and spasms, it can help to take some before you have sex. Massage, relaxation techniques and stretching before sex can help too.

Q

I've been experiencing some bladder and bowel problems because of my MS and I'm really anxious about losing control when being intimate with my partner. How can I stop these symptoms getting in the way of our sex life?

Lesley says: Firstly, if you're experiencing any bladder or bowel problems it's always worth mentioning it to your MS nurse so you can be referred on to specialist continence services. If you're particularly worried that it's going to interfere with your sex life, try not to be embarrassed and share your concerns openly with your partner. When you experience MS symptoms like this, a little bit more planning is required before you engage in sexual activity.

With bladder problems, there are a few things you can try to help you feel more confident. Emptying your bladder

before having sex may reduce some of your anxiety about losing control. If you're really worried you're going to have an accident you could always put a black or red towel down just so it's a bit more discrete.

Similarly, if you self-catheterise perhaps plan to empty your bladder before you become intimate with your partner. Indwelling catheters shouldn't inhibit you from being able to have a healthy sex life. Men with indwelling catheters can use a condom so it doesn't get in the way during sex and women can discretely tape it to one side. If you have a suprapubic catheter fitted, this shouldn't get in the way at all during sex.

If your MS has caused bowel problems, make sure you go to the toilet before you have intercourse. If constipation is an issue, speak to your MS nurse about medications that can make emptying your bowel a little bit easier. If you're worried about your bowels emptying unexpectedly, there are things called anal plugs that are discreet and can be inserted into your rectum to prevent any accidents happening.

Q

I'm single and feel as though no one will be attracted to me now that I have MS. How can I build up my self-esteem so I have the confidence to start dating again?

Lesley says: When you're diagnosed with MS it can really knock your self-esteem and change the way you feel about yourself. Some people feel less confident and start thinking negatively about themselves. The important thing to remember is that even though you've been diagnosed with MS, it doesn't change who you are as a person. Raising your self-esteem can take time, but there are a range of steps you can take to build up your self-esteem and start thinking more positively about yourself. You might find it helpful to write down a list of the positive qualities that you like about yourself. You could also think about the good things that family members and friends say about you. Write them all down and keep the list somewhere you can see it.

For more strategies on raising your self-esteem, you can find further information from the NHS and Mind:

- [nhs.uk/conditions/stress-anxiety-depression/raising-low-self-esteem](https://www.nhs.uk/conditions/stress-anxiety-depression/raising-low-self-esteem)
- [mind.org.uk/self-esteem](https://www.mind.org.uk/self-esteem)

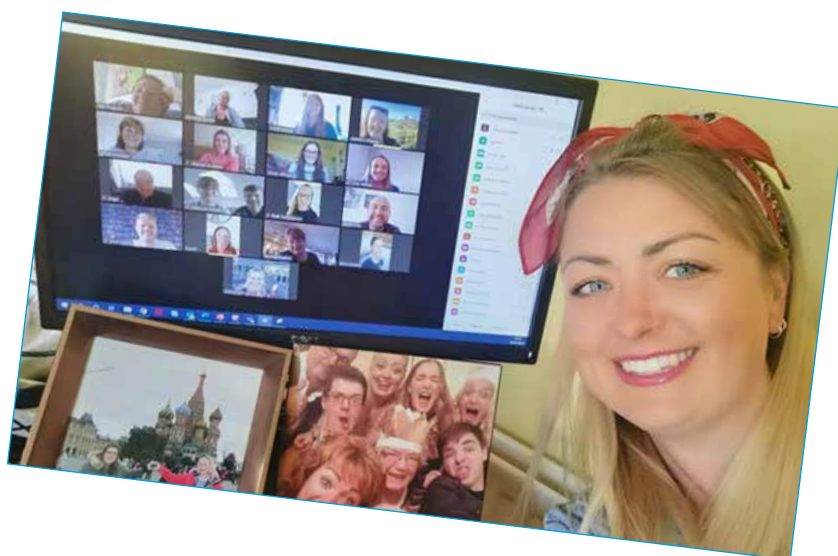
Lesley Catterall and Denise Middleton both work for the Central and North West London NHS Foundation Trust. Denise is an Occupational Therapist with expertise in MS and Lesley is an MS Specialist Nurse.

For more info
order or download
our books
Sex & MS: a guide for men
mstrust.org.uk/356
Sex & MS: a guide for women
mstrust.org.uk/213



GET INVOLVED

Miles for MS – summer 2021



We're excited to announce that Miles for MS will be back for summer 2021, from May to July.

To take part, all you need to do is set your own Miles for MS distance challenge to complete throughout summer, and raise sponsorship to support people living with MS. Whether it is half a mile or 100 miles, you pick how far you want to go and do it your way. You can walk, wheel, run, row, scoot, swim, and so much more... the choice is yours! You don't have to do it alone either, why not get a team together – you can get your office, friends or family involved too.

We know that keeping active is important for everyone's physical and mental health, so we hope that this challenge will help motivate you to keep moving! We surveyed some of our previous Miles for MS participants about what they gained from taking part in the event. 91% of those who took part in our survey said they "intend to exercise more as a result of taking part in Miles for MS". Exercising is known to release positive endorphins and, according to the survey, those who took part in Miles for MS felt happier, more confident and found that their focus and concentration improved too.

Claire was one of our fundraisers who took part in Miles for MS in 2020. She was diagnosed in 2018 with relapsing remitting MS and is trying to take on a challenge every year to do her part and keep active.

Last year, Claire and 27 of her friends and family members (the Movers and Shakers) took part in Miles for MS, making it all the way to Greece, virtually. "Our original challenge was to walk 334 miles, the circumference of Northern Ireland. As the team grew, we decided to take off from Belfast and virtually make our way across Europe, with our final destination as Athens, Greece!" Claire says, "I absolutely loved it. I think recruiting or joining a team is a brilliant idea, it kept me so much more motivated."

Theresa, who lives with MS, also told us how her daughters gathered a team of 16 young adults who all wanted to take part in the Miles for MS challenge. The team was called 'No MSing Around' and between them they raised over £4,200, completing 1,133 miles. Theresa explained how each individual undertook challenges in their own way, including running, walking and cycling, and completed them independently over the first lockdown. She said, "I would like to say how proud I am of all of them; their camaraderie and ambition to complete their miles was outstanding and they all succeeded in raising a huge amount for charity."

Last year, our Miles for MS stars covered an amazing 19,000 miles together and raised over £90,000. This year will be the fourth year of Miles for MS and we'd love for even more people to get involved. Sign up from the end of February for just £15 via mstrust.org.uk/miles and you will receive an MS Trust t-shirt, your own personalised online page where you can track your progress and raise funds, and a certificate when you finish. If you raise over £150, you'll also get a Miles for MS medal to wear with pride.

If you are interested in taking part and would like to find out about more accessible ways you could get involved in this event, please do get in touch at fundraising@mstrust.org.uk

Discover more fun virtual events on our website, at mstrust.org.uk/fundraising



PLEASE NOTE: You need to be over 18 years old to register for Miles for MS. If you are under 18, please ask a parent or guardian to sign up on your behalf.

Get involved!

There are lots of ways you can get involved and support our work helping everyone affected by MS. For details of all our great upcoming events, which are regularly updated, please visit the website at mstrust.org.uk/events

Here is just a small selection of the events you can get involved in...



Ultra Challenge Series

Looking to get in shape and re-energise in 2021, or perhaps you are a keen walker or runner looking for a new challenge? If so, one of the Ultra Challenge events could be the one for you!

Whether it's enjoying the great outdoors along stunning coastal paths, or on historic trails in beautiful countryside, all events are at Covid safe venues. Pick your event and distance now at mstrust.org.uk/ultra

Be Bold in Blue

Be Bold in Blue gives you the freedom to fundraise your way for people with MS. Whatever you do, no matter how big or small, the money you raise really will make a difference for people with MS. Download your fundraising guide at mstrust.org.uk/blue

Skydive

This year experience the thrill of skydiving from 10,000 ft and freefalling at around 120 mph before parachuting back to the ground. Find out how you can take part at mstrust.org.uk/skydive

MS Trust Running Club

On your marks, get set – go! After a challenging year, running events should be back on track for 2021. Organisers are doing their utmost to ensure the events are safe, following all guidelines and restrictions. There are lots of great running events planned and places are already on sale, so set yourself a challenge and sign up. For more information on upcoming running events visit mstrust.org.uk/run

"Both my mother and sister have forms of MS, so it is a part of my family's life. I chose to support the MS Trust in my fundraiser because the best way I can help their work is by raising money through a gaming livestream."



Power up for the MS Trust

Are you or someone you know a keen gamer? Would you love to be able to raise money to help people living with MS, whilst enjoying your hobby or passion for gaming? Well the MS Trust has just the thing for you!

Take part in **MS:Play** and choose your gaming challenge. Play solo for a 12hr or 24hr marathon, or sign up with a squad and make it a tournament! Pick your favourite games and stream these on a console of your choice, or on your mobile phone. Then power up by collecting sponsorship as you play.

Our fundraising team will be in regular contact to help you start fundraising and to share fundraising tips. We will also be able to provide information on how to stream your game play, link your Just Giving page and how to prepare for your gaming challenge.

So what are you waiting for? Get ready...

Pick the date, choose your **MS:Play** challenge and let's go – before it's game over!

For further information and to sign up to MS:Play visit mstrust.org.uk/msplay



Mission Completed!

A big thank you to everyone who took on the virtual Mission 100 to raise £100 each. It was fantastic to see all the different ways you raised money at home including a mince pie sale with over 400 mince pies baked and sold – amazing! We are keeping Mission 100 open for 2021 to anyone who would like to get involved. How could you raise £100? For more information please visit mstrust.org.uk/mission100

15 MINUTES WITH...

Paru Naik

We are all aware of the huge impact the pandemic has had on MS services. Over the last few months **Paru Naik**, Director of Health Professionals Programmes at the MS Trust has been working tirelessly to get these vital services back up and running. She has also been adapting our support packages to ensure MS health professionals continue to receive the support they need.

What does your role at the MS Trust involve? How has it changed during the current pandemic?

In my role as Director of Health Professionals Programmes at the MS Trust, I work as part of the Senior Management Team for the whole organisation. I have worked in senior NHS roles for many years, but I feel that this is the best opportunity I've had to influence MS services and improve access.

Unfortunately, the pandemic has had a profound effect on MS programmes, as nurses and therapists are stretched and many are redeployed to help combat Covid-19. As a result, our Enquiry Service has seen a huge increase in traffic and we have had to divert our attention to surviving as a charity due to significant losses in our fundraising activities.

MS services across the country have been stretched for many years. How has the pandemic further impacted services?

The pandemic has exposed pre-existing weaknesses, including underinvestment in MS services and healthcare professionals. It also revealed the deep-rooted health inequalities we face, as well as spiralling out of control waiting lists and appointment backlog.

What do you see are the biggest challenges in getting MS services back up and running across the country?

The biggest challenge will be to readjust to 'the new normal' and to become comfortable with this. The coordination of MS services is complex and, frankly, almost impossible without increased funding. It will require significant reforms to address the gaps in care for MS patients. We also need to understand the full effect of Covid-19 on MS healthcare services. In the near future, we will be conducting our own mapping exercises to find out exactly what is required.

Our healthcare professionals are continuing to work incredibly hard to provide the care that those with MS deserve, and we're doing all we can to assist them.

How are the MS Trust working to reinstate services following the pandemic? And how are they working to improve services in general?

While the crisis has been challenging, it has also brought innovation and an appetite to permanently change the way MS services work. We will soon be restarting our programmes to place more Specialist Nurses and Advanced MS Champions where they are needed most, and we will be supporting them every step of the way.

We are also determined to keep our education and training services



"With so much going on, I would say be persistent in getting through to someone who can help you."

for Specialist MS Nurses and therapists running. In October we were proud to run our MS development educational module via Zoom for the first time and received really positive feedback. Although we had to postpone our annual conference in 2020, we are excited to be holding the very first MS Trust virtual conference from 28 February to the 2 March in 2021. A programme that is as packed and innovative as ever.

What are the key things that need to happen in the coming months to achieve this?

There is no doubt that the road to restarting services post-Covid will be a steep climb. We still have to get through the latest round of restrictions and a workforce that is exhausted and needs support. We need to continue the support that we give to health professionals.

We will do this by keeping up the fight for the resources and tools that are needed. However, we can't do this without our incredible supporters. A donation to the MS Trust provides the help needed to get MS services back on track during these uncertain times. To get involved, visit: mstrust.org.uk/get-involved

What advice would you give to people with MS who are still struggling to see their MS nurses and neurologists due to the pandemic?

Please know that we are here for you. Even though many services have been devastated by the pandemic, we are doing all we can to help. We have a range of useful information and up to date news at mstrust.org.uk. You can also contact our **Enquiry Service on 0800 032 38 39 or ask@mstrust.org.uk**

With so much going on, I would say be persistent in getting through to someone who can help you. This may well be in the form of a virtual telephone call with your GP, family, friends and/or carers. Talk to those who you can raise concerns with and they will help direct you to the right place.

In the UK, 130 people are diagnosed with MS every week, and we must do what we can to help them. 40,000 people in the UK are living with advanced MS and require a specialist to help them with their condition. They should not be denied the care that they deserve. No one need be alone when it comes to dealing with MS.

Promise today, change tomorrow

Leave a gift to the MS Trust in your Will.

After taking care of your loved ones, a donation in your Will is a lasting gift for someone living with MS.

A gift in your Will could help fund more MS Nurses in NHS hospitals across the UK, more Advanced MS Champions supporting people in the community or our invaluable, free enquiry service.



"I am leaving a gift in my Will to the MS Trust so I know that my legacy will make a difference to people with MS"

Carla, MS Trust supporter



For more information or to find out how you could write your Will for free visit

www.mstrust.org.uk/wills

fundraising@mstrust.org.uk

+44 (0)1462 476707

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We'll send them directly to your mobile or tablet with our MS publications app.



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Got a question about MS? We're here to help



I have just been diagnosed with MS, what happens now?

How can I manage the effects of fatigue?



What does research I've seen in the press mean for me?



What treatments are available for MS?

Got a question about MS? We're here to help

Email: ask@mstrust.org.uk Call: 0800 032 38 39 (voicemail)