

August 2020

Open Door

Quarterly magazine of the MS Trust

Multiple
Sclerosis
Trust

MS



**"I wasn't going to
let MS stop me"**

Emily Padfield shares her
adventures on the BBC2 show
Win the Wilderness: Alaska

Welcome to the August issue of Open Door



We hope you're all keeping safe and well.

At the time of writing, some lockdown restrictions have been lifted and we're all getting to grips with a new kind of normal. But we know there's still a lot of anxiety

and worry out there, particularly for those people with MS who have been shielding. In what is an ever-changing and uncertain situation, we're doing our best to keep you updated with all the latest information and guidance on the coronavirus and what it means for the MS community. If you have any questions or concerns, please don't hesitate to get in touch with our Enquiry Service at ask@mstrust.org.uk / 0800 032 38 39.

MS doesn't stop for a global pandemic and neither do we. In this issue of Open Door, we have all our usual MS news and research, practical tips to help you live well with MS and inspiring real life stories from the MS community. One such story is that of Emily Padfield, who earlier this year appeared on the BBC show **Win the Wilderness**. Read about Emily's experience on the show and her journey with MS on page 8. For those of you who find that your MS worsens in hot temperatures, fellow MS'ers provide their top tips for dealing with heat sensitivity on page 14. There's also advice for sorting the facts from the myths in the era of fake news on page 10 and steps we can all take to improve our resilience to illness on page 12.

As has been the case across the charity sector, the Covid-19 pandemic has created a massive challenge for the MS Trust to

ensure that we are able to continue to support people with MS. In the 27 years since we were first formed, we have never known a year like it. I'm going to be honest with you, it's never been so tough. We receive no government or NHS funding and around 80p in every pound we spend every year comes from traditional fundraising like skydives and cake sales. Lockdown stopped them almost overnight in one of the busiest fundraising periods of the year.

The MS community needs us more than ever - and we need your support to ensure nobody has to face MS alone. On page 16 you can read about the different ways you can get involved in our work and help support those living with MS in these uncertain times. Thank you, as ever, for being in our corner. We promise to always be in yours.

Take care and stay safe.

David Martin, Chief Executive, MS Trust



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

Texts will be charged at your standard network rate. For terms & conditions, see www.easydonate.org.

What's inside?

3 News

NICE rejects Siponimod for secondary progressive MS, new report on progressive MS and sixth Advanced MS Champion starts in Bristol

6 Research

A round-up of the latest research on Covid-19 and MS

8 Cover story

The winner of BBC2 show *Win the Wilderness*: Alaska shares her MS journey

10 Fact or Fiction?

Simon from the MS Trust's Information Team has some tips to help you sort the facts from the myths

12 How to improve your resilience to illness

Steps we can take to give ourselves the best chance to recover from Covid-19 infection

14 Ask the expert: Heat sensitivity

Advice from MS'ers to help you keep cool in the summer months

16 Get involved

Fundraising in lockdown, supporting the MS Trust while you game and the latest on our emergency appeal

18 15 minutes with Megan Roberts

The MS Trust's Head of Health Professionals Programmes talks about the impact of the Covid-19 pandemic on MS services

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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](https://www.mstrust.org.uk/keepintouch)

Latest MS news

Siponimod for active secondary progressive MS rejected by NICE

The MS Trust is very disappointed that the National Institute for Health and Care excellence (NICE) is unable to recommend siponimod (also known as Mayzent) as an NHS treatment for active secondary progressive MS.

Back in June, NICE announced that it would not be approving siponimod as an NHS treatment for people with active secondary progressive MS (SPMS) in England and Wales.

NICE acknowledges that there are very limited treatment options for secondary progressive MS, and that clinical trials have shown that siponimod can slow the worsening of disability in SPMS.

However, NICE has concluded that they are unable to recommend siponimod as a cost-effective treatment for the NHS for England and Wales without more detailed evidence and analysis of the data.

David Martin, Chief Executive of the MS Trust, commented: "We are hugely disappointed by this initial decision. Time and time again, we hear from people with secondary progressive MS struggling at home, feeling like they have been forgotten. Just earlier this month, a new report (see page 4) has highlighted the significant gaps in support and services for people with SPMS. Not everybody will be eligible for siponimod, but we hope that the availability of a new treatment will lead to a renewed focus on the needs of all people with SPMS."

People on the MS Trust's social media pages have reacted angrily to this decision. One person commented, "Those of us with progressive disease are frequently pushed aside... I'm glad the MS Trust recognise the lack of treatment for progressive MS and hope that they succeed in convincing NICE to license this drug." Another commented, "All NICE do is put barriers up which deny people with MS {the chance} to lead a better life!"

The MS Trust is reviewing NICE's decision and we will continue to make the strongest possible case for NHS approval. NICE will meet again to review this decision in the light of comments received and further evidence from the manufacturer; the date for this meeting has not been confirmed.

The Scottish Medicines Consortium has also scheduled an appraisal of siponimod but this is currently on hold. In Northern Ireland, the Department of Health reviews NICE guidance.

To read more about siponimod, visit www.mstrust.org.uk/a-z/siponimod



The impact of Covid-19 on MS services

We've worked with the MS Society to survey MS healthcare professionals across the UK and find out the impact Covid-19 is having on MS services.

We found that seven in ten MS healthcare professionals (70%) believe the MS service they work in, or with, is not currently able to meet patients' needs to the extent it was pre-pandemic.

Nearly three quarters (73%) think neurological rehabilitation services have been impacted by the pandemic, with appointments having been limited, delayed or cancelled – 76% said resuming these vital services back to pre-Covid-19

capacity must be a priority.

Alongside workforce redeployment, MS healthcare professionals identified a number of ongoing challenges MS services are facing in getting back to pre-Covid capacity safely. Three in four (75%) said a backlog of patients was a challenge, more than two thirds (66%) said a lack of physical space to deliver care safely was problematic, while three in five (60%) said patients being reluctant to attend appointments was having an impact.

Megan Roberts, Head of Health Professionals Programmes at the MS Trust, commented: "We're hearing first-hand

from people with MS who feel that their health and wellbeing has deteriorated during the pandemic because they have been unable to access the life-changing rehabilitation services they rely on. Healthcare professionals are going above and beyond to support people with MS in these uncertain times, but they are facing huge challenges. We stand with the MS Society in urging the NHS to address the current gaps in treatment, care and support and ensure nobody is left to face MS alone." Read the full report on our website, at www.mstrust.org.uk/news.

"When is the NHS going to stop ignoring people living with secondary progressive MS?"

Are people living with secondary progressive MS being forgotten? Yes, says a new report. MS Trust CEO David Martin, who was involved in putting together the report, writes about what must be done to help the 'forgotten many'.

Read the report at:
[www.mstrust.org.uk/
forgottenmany](http://www.mstrust.org.uk/forgottenmany)



Time and time again, I have heard stories of people with progressive MS struggling at home, feeling like they have been forgotten. One told me they felt they had been discharged because there was little else that could be done for them.

Admittedly, there is not currently enough capacity in neurology services to manage this group of patients without services working differently. But that shouldn't lead to the health needs of 60,000 people living with secondary progressive MS (SPMS) being largely ignored or overlooked. That is quite simply wrong in 21st century Britain. No patient with secondary progressive MS should be left behind.

The Forgotten Many: A 2020 Vision for Secondary Progressive Multiple Sclerosis is a compelling new report published in June that I helped create. It identifies for the first time the total numbers of people now living with SPMS.

The MS Trust has come up with a partial solution to some of the issues. Our Advanced MS Champions Programme is piloting how best to provide guidance, support and coordinated care for those people living with advanced MS, both secondary and primary progressive. The six pilots are expected to save the NHS £3million while improving the quality of life for so many people.

Beyond the Champions, there are four simple steps the report highlights in particular that would transform the lives of many of the people living with SPMS:

- We need to find 'the forgotten many' and then offer them a holistic service to improve their quality of life
- Guidance for SPMS diagnosis would aid prompt diagnosis and help integrate psychological support.
- Every person with SPMS should have a review every year to monitor their symptoms and assess which treatments they could benefit from.
- A national agreed integrated pathway should be developed for people living with SPMS.

Yes, some of this will cost more money. But at the moment, the report highlights how £86 million was spent on emergency hospital admissions for people living with MS in 2018/19 – surely there's a better way to use that money?

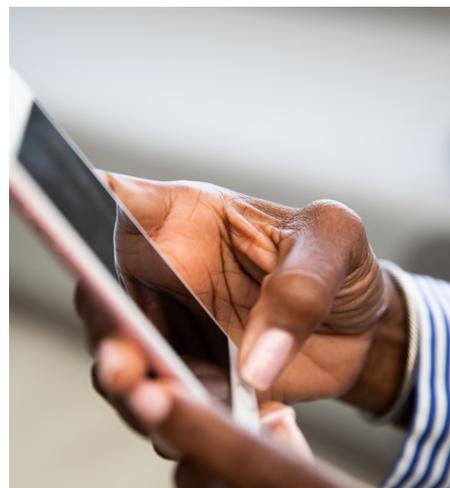
In the meantime, we all have to find ways to ensure that the people living with secondary and primary progressive MS are no longer ignored. And a great start to that would be if NHS England would lead an appropriate and targeted awareness campaign to increase understanding and awareness.

MS Trust launches new app

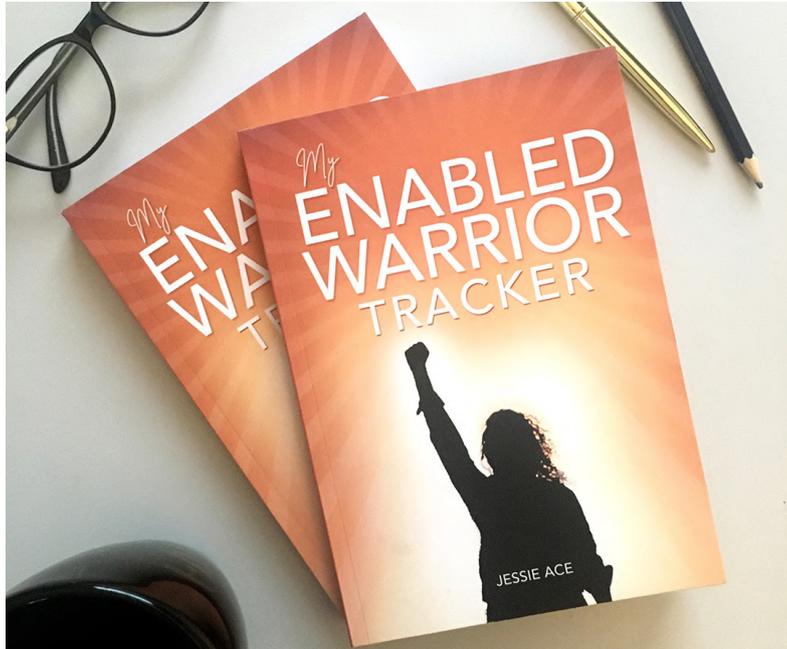
We are really excited to announce the launch of our new app to support people with MS, their families and health professionals.

At the MS Trust, we are always looking for ways to improve and expand the ways in which we offer information and support to the MS community. The 'MS Library' app allows users to access the latest issues of Open Door, as well as many of our most popular information resources, on their smartphone. Features include the ability to zoom in and size text to make it a comfortable reading size, automatic updates when we add new resources and links which take you straight through to our website.

To download the app, simply search for MS Trust Publications in Apple and Android stores. Once you've downloaded the app to your device, please get in touch at hello@mstrust.org.uk to tell us if you no longer wish to receive a printed copy of Open Door.



A new way to track symptoms and support the MS Trust



We're really excited to have partnered with Jessie Ace, who is donating 50% of the profits from her ENabled Warrior Symptom Tracker book to the MS Trust.

The book has been inspired by Jessie's own journey with MS. When she was diagnosed seven years ago, Jessie used to record her symptoms by scribbling them down in notebooks, "but I realised those scribbled notes weren't helping me track my symptoms or put the information across in a way that was helpful for doctors," Jessie explains.

Jessie decided to create her own solution, working with doctors and people with chronic conditions to produce something that was "helpful and effective" for everyone.

And so, this year, The ENabled Warrior Symptom Tracker book was born. The aim of the book is to help those living with MS, as well as other chronic conditions, to track their symptoms, spot triggers and make

the most of appointments with health professionals.

The book takes around 10 minutes per day to fill in and has other helpful tracker sheets like food, hydration, exercise and menstrual cycle. It also contains gratefulness, journaling, 'I AM' positive statements and top three priorities which is what Jessie uses herself every day to focus on the good and stay positive.

"This book has the power to help so many people so I wanted to take it one step further. Through the challenging times we've been in just lately, I wanted to give back to the MS Trust who need more donations to continue the amazing work they do to help so many other people like me," Jessie explains.

To order your book, and support the MS Trust at the same time, visit: mmini.me/mstrustbook.

Sixth Advanced MS Champion appointed in Bristol

We're delighted to announce that our sixth Advanced MS Champion has now started work at North Bristol NHS Trust.

The appointment of Tania Burge means the pilot phase of the Advanced MS Champion Programme is complete, with Champions in post in Bristol, Salford, North Cumbria, Poole, Swansea, and Norwich.

Advanced MS Champions help people with advanced MS get back in touch with the support and care they need, and save them from unnecessary hospital stays. This saves the NHS hundreds of thousands of pounds each year.



Tania Burge, Advanced MS Champion for Bristol

Over the next two years, the MS Trust aims to demonstrate how the Champions can make a real difference in delivering efficient, equitable and joined-up MS services that work for people with MS and save the NHS money by reducing emergency hospital admissions.

The final report of the pilot is expected to be published in spring 2021, and we believe this will make the case for these posts to be rolled out across the NHS so that no one has to manage MS alone. Megan Roberts, Head of Health Professionals Programmes at the MS Trust, commented: "Our work over the past five years has shown that people with advanced MS and their families all too often miss out on vital specialist care. We've set up the Advanced MS Champions programme to change this narrative and help transform the lives of people living with advanced MS and their families."

RESEARCH UPDATE

Coronavirus, Covid-19 and MS: A round-up of the latest research

Authors Sormani MP, et al.

Title An Italian programme for Covid-19 infection in multiple sclerosis.

Journal Lancet Neurology 2020; 19(6):481-482

Read the summary <https://bit.ly/38j44nR>

Authors Fan M, et al.

Title Risk of Covid-19 infection in MS and neuromyelitis optica spectrum disorders.

Journal Neurology, Neuroimmunology and Neuroinflammation 2020; 7(5):e787

Read the summary <https://bit.ly/3igCXhH>

Authors Louapre C, et al.

Title Clinical characteristics and outcomes in patients with coronavirus disease 2019 and multiple sclerosis.

Journal JAMA Neurology 2020; June 26 [Epub ahead of print]

Read the summary <https://bit.ly/3ePE2ep>

The coronavirus pandemic has generated an enormous amount of research, with over 40,000 papers published in the first six months of 2020. We've been sifting through the research up to the end of June to bring you a round-up of the studies that give an idea of what coronavirus means to people with MS. This is a rapidly evolving topic and we'll update you with any further news in future issues of our Research Update emails - sign up at www.mstrust.org.uk/keepintouch.

Most of the studies so far have reported data on single cases or a small number of people. They do give a general indication but we need to interpret them with caution. Around the world, registries have been set up to capture information supplied by neurologists and people with MS. Analysis of data from larger numbers of people will give us a better picture of how people with MS are affected by coronavirus and Covid-19. The UK MS Register has launched a survey to look at how people have coped with guidance from the government as well as to capture data on confirmed or unconfirmed cases of Covid-19 in people with MS. Whether you have had symptoms of Covid-19 or not, you can contribute your experiences by signing up for the survey at www.ukmsregister.org.

Does MS affect your risk of catching coronavirus?

As coronavirus began to spread globally, one of the first questions to be asked was would people with multiple sclerosis be more likely catch coronavirus.

Based on our understanding of the biology of MS, we would not expect someone who has MS, and is otherwise healthy, to have a greater risk of becoming infected compared to the general public; MS does not weaken your immune system. At this stage, we don't have data from sufficiently large numbers of the population to absolutely confirm this, but there's been no indication that people with MS are more likely to catch coronavirus.

Does MS affect the severity of COVID-19?

Italy was the first European country to see a rapid rise in the number of people with Covid-19. Italian researchers set up an online registry to record and collect data about people with MS who have been diagnosed with Covid-19 or have developed symptoms (suspected Covid-19). MS neurologists across Italy were asked to input data and share patient outcomes.

Their preliminary data included 232 people with MS who tested

positive for Covid-19 (57 people) or had suspected Covid-19 (175 people). 211 were taking a disease modifying drug (DMD).

The data recorded the severity of Covid-19 in these people:

- 222 (96%) had a mild infection
- 4 (2%) had a severe infection
- 6 (3%) had a critical infection

Of those who were critical, one person recovered and five people died. The people who died tended to be older (50+) and have other health conditions.

A French registry has also published data on people with MS with confirmed or highly suspected Covid-19. Of the 347 people in the study, 73 (21%) needed hospital care and there were 12 deaths (3.5%). Age, disability and obesity were most strongly linked to a more severe course of Covid-19.

Although the numbers reported are fairly small, they suggest that having MS doesn't increase your likelihood of a more severe Covid-19 infection and that the majority of people with MS who do develop Covid-19 are likely to have a mild infection, the same as the general population.

Data gathered from the wider population has identified other factors which can increase the risk of having a more severe course of Covid-19, such as an older age and having underlying health conditions, particularly those affecting the heart or lungs. If you are more severely affected by MS, for example if you have difficulty with swallowing, clearing your lungs or are prone to chest infections, you will also be at greater risk of developing complications from Covid-19.

Do disease modifying drugs affect the risk of coronavirus or severity of COVID-19?

Disease modifying drugs (DMDs) work by damping down your immune system in a number of different ways, so there is a

possibility that they might make you more susceptible to infection with coronavirus or affect the course of Covid-19. Much of the research published so far has focused on this aspect of coronavirus and MS.

At the beginning of the pandemic, teams drew on expert opinion to publish recommendations on starting, continuing or suspending DMDs. Guidelines from the Association of British Neurologists have formed the basis of advice in the UK. For more detail visit www.mstrust.org.uk/coronavirus.

Data from around the world is now being published and this may lead to refinements to the initial guidelines. The Italian and French registry studies assessed the impact of DMDs on the course of Covid-19. In the Italian study, 211 people (91%) were taking a DMD; in the French study, 284 people (82%) were taking a DMD. In both studies, taking a DMD did not appear to cause more severe Covid-19 but both research groups acknowledged the small number of people taking any one drug made it difficult to draw firm conclusions.

A further set of data on the risk of Covid-19 in people with MS has been collected by neurologists in China. A survey reported details of 1,836 people with MS, of whom 882 (49%) were taking a DMD. None of those taking a DMD were diagnosed with Covid-19.

Finally, a number of studies have reported outcomes for individuals or a small number of people who developed Covid-19 while taking one of the DMDs (including Ocrevus, Tysabri, Gilenya, Lemtrada, Aubagio). In all of these, there has been no evidence to suggest that taking a DMD increases your risk of developing more serious complications.

Taken together, these studies provide reassurance that taking one of the DMDs does not lead to a more serious course of Covid-19. Combining data from registries and carrying out further, detailed analyses will shed further light on the impact of coronavirus and Covid-19 on people with MS.

Read more of the latest MS research at www.mstrust.org.uk/research



Find out more about coronavirus, Covid-19 and multiple sclerosis

As a group, coronaviruses are common across the world. In general, they cause mild respiratory or sometimes gastric symptoms. The new strain of coronavirus has been named SARS-CoV-2. In this article, we use coronavirus to describe the virus and Covid-19 for the disease it causes.

The main symptoms of Covid-19 are:

- a new, continuous cough – this means you've started coughing repeatedly
- a high temperature – you feel hot to touch on your chest and/or back
- shortness of breath
- a loss or a change to your sense of taste or smell

If you have any of the main symptoms, you should stay at home (self-isolate) and get tested for coronavirus as soon as possible. For more information, visit www.mstrust.org.uk/coronavirus.

COVER STORY

Our adventures in the Alaskan wilderness

When farmers **Emily Padfield** and **Mark Warner** applied for a new TV show promising an “off-grid experience in the Alaskan wilderness”, they never once imagined they would actually end up appearing on the show, let alone winning it! We caught up with Emily to hear more about the couple’s experience on the BBC2 show ‘Win the Wilderness’ and why it was her MS that persuaded them to take on this ‘crazy’ adventure.

I’ve never had a great memory for things. Some people can remember an infinite amount of moments, circumstances or reminisce about childhood or the past, but I must have limited brain capacity to store this sort of stuff. But I do remember acutely the moment I was diagnosed with multiple sclerosis 15 years ago.

At the time I was working as a parliamentary stagiaire (or intern) in the European Parliament in Brussels. Walking to work each morning I had started to get tingling legs every time I moved my neck, and it was steadily getting more noticeable. I had no idea what it might be, thinking that I had done something to my neck or back by falling over some time before.

By chance, my boss at the time pointed me in the direction of a neurosurgeon (the health system works a bit differently over there and luckily with my job I had health insurance). Within a week, following several brain and spine scans, I was back in his office on a Friday night being told I had MS.

Back then, there was no widespread mobile internet and I lived in a shared apartment with one phone, so I went back to my little office at work and started Googling.

I wouldn’t encourage anyone to Google MS following diagnosis. It’s inevitable that you will, but I urge you not to try and take everything in. Everybody’s MS is different and you will not find a case study that fits your symptoms or progression exactly. I guess we all feel happier when we have a box we can fit in, but it’s just not possible.

After my diagnosis I returned home to my parents in the UK to get a bit of a handle on things. I guess for the next two years I ran from my diagnosis. Newly graduated, I applied for jobs and was

open about my diagnosis and didn’t get interviews, after never being turned down for anything before. I soon learned to keep it to myself until I could prove myself, how legal or not that is I don’t know. I know I am lucky when it comes to my disease and I have always felt that. Soon after my return home I signed up for a lambing job (12-16 hour days) that pushed me greatly physically before then going on a harvesting gang where we would regularly top 18 hour days. That was my ‘running’ time as I describe it, when I was running from my diagnosis rather than turning to face it.

Since then I have been incredibly fortunate to have studied for an MSc, established myself as a journalist and PR consultant as well as enjoying a busy and rewarding life farming sheep and beef alongside Mark, my partner of nearly 10 years.

When I saw the opportunity to live off-grid in the Alaskan wilderness advertised on a farming forum, it immediately appealed to me. I couldn’t wait to get home and tell Mark.

The advert was quite short. It just asked, “would you like to experience living off-grid in the Alaskan wilderness?”. The short answer to that was yes, and Mark seemed up for it too. Little did we know at that point that

there was a house to win at the end of it, that all came later.

For those who haven’t seen it, the premise of **Win the Wilderness: Alaska**, is six couples competing to win the chance to inherit a property (owned for the past 35 years by Duane and Rena Ose) deep in the Alaskan wilderness, braving sub-zero temperatures, wild bears and predators along the way!

During the decision process I can honestly say having MS didn’t even come into mine or Mark’s reckoning. I am lucky, I know



Emily (far left) and Mark (middle right) with Duane and Rena Ose

"Everybody's MS is different and you will not find a case study that fits your symptoms or progression exactly. I guess we all feel happier when we have a box we can fit in, but it's just not possible"



Emily and her partner Mark

this. My MS flares up in the form of numbness, fatigue, pins and needles and sometimes I do feel I am not perhaps as sharp in the mind as I once was. I do need a nap from time-to-time (doesn't everybody!) and I now take Gilenya having moved from Copaxone injections around 18 months ago.

Having been accepted to go on the show (remarkably!) I did worry that my physical fitness and MS might not be up to the challenge. We didn't really know what the whole process would involve and I guess I was thinking more Who Dares Wins (the SAS show) as opposed to how it turned out. I enrolled in a gym (much to Mark's amusement, he put no training in at all!) and tried to get more in shape. I do think I underestimated my fitness levels. Working on the farm gives you an inert level of fitness and strength but I am definitely no marathon or even 5k runner!

During the filming of the BBC2 show (still available on iPlayer and also globally on Netflix) I realised I needn't have worried. Most of the other couples were a good bit younger than me and I didn't feel left behind in the slightest. I guess that's what I struggle with sometimes, judging my activity against others. I have always overcompensated because of MS in everything I do. I guess I feel like I need to prove to myself that I can still do just as much if not more than others to feel like I am topside of it.

There are so many more people worse off than me, with MS or with many other debilitating diseases. I always think that of the things to have, MS is one of the better ones for me currently. I know I am lucky. I don't know how long I will be this lucky so that's why I take on crazy things like *Win the Wilderness: Alaska*. Right

until the end I didn't know if we would win or not (which amazingly we did!!). But not once did I think it would be my MS that stopped me.

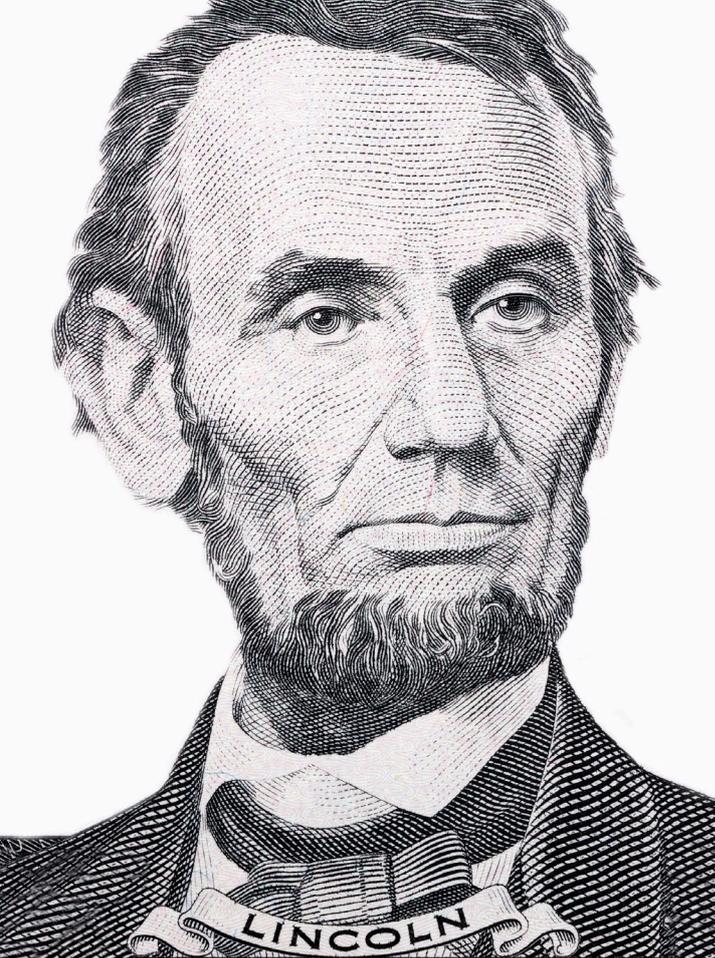
I can't believe it's been a year since we took part in the show, pretty much to the day. We returned to Alaska in the autumn and had supposed to be back there in May, but like many others, Covid-19 has prevented us from travelling. We very much hope to make it out there this summer but we are just waiting for the US to open its borders for UK citizens.

Our plans for Ose Mountain are to spend as much time as we can there, but also to open it as a veteran and first-responder therapy resource for wilderness-based rehabilitation. We can't wait to get back there and have even ordered a sawmill for delivery in order to get started on producing the lumber needed to finish the build!

"Right until the end I didn't know if we would win or not (which amazingly we did!!). But not once did I think it would be my MS that stopped me"

If you have a story about your MS journey that you'd like to share, please get in touch at mystory@mstrust.org.uk





"Don't believe everything you read on the internet just because there's a picture with a quote next to it"

- Abraham Lincoln

FOCUS ON

Fact or fiction?

We live in an information age. Now more than ever before we have ready access to an enormous quantity of data about health, treatments and research - from the internet, through the press, and on social media. But how do we know how to trust and understand what all this information is telling us? Simon from the MS Trust's Information Team has some tips to help you find health information you can trust.

Question what you read

Approach what you read with an open and questioning mind - neither immediately believing nor disbelieving what it tells you.

Ask yourself, who is telling me this and why? Does the author have an agenda? Are they trying to sell a product or an idea? Are they trying to make you think in a particular way?

For instance, advertisers will naturally want to make their product look good and appealing. While what they present won't necessarily be wrong, they may be selective in the information that they choose to give - emphasising the good points of the product and avoiding less convincing elements.

Some information, particularly in social media, may be plain wrong or deliberately misleading. This can be an intentional effect for malicious or mischievous ends. It can also happen unintentionally, where someone shares misunderstood information, which circulates and takes on a life of its own.

Let the story try to convince you of its argument and if something sounds surprising or unusual, double check the information. See if it has been covered in other sources and

how it has been described there. If you think something may be fake news, sites such as FullFact and Snopes exist to fact-check news stories and social media content and are a good way to recognise hoaxes that are circulating.

Read the article

With so much information presented to us every day there is a tendency to only skim headlines or to read the opening sentence or two of a story. Whilst this can give a general idea of what's going on, important details may be missed.

News thrives on dramatic headlines about miracle cures or ground-breaking advances. Often important but less eye-catching details appear several paragraphs into the story. For instance, apparently exciting research may only be in the early stages of laboratory tests or animal studies, or the link between this research and an effect in humans may be theoretical and certainly hasn't been tested yet.

While the research will have scientific value, it will have no immediate effect for people with MS and may not justify the bold statement in the headline.

Check the date

A story can be true when first published but the facts may change later. Particularly online, information can remain available for some time after it was originally published. Old stories can be circulated - accidentally or maliciously - and cause concern or outrage about something that is no longer current or correct.

Check the source

Most of the information we read will have been filtered through other sources. A press release by the original researchers is picked up by a press agency, then by a newspaper or website and then may be shared and commented on in a blog or on social media. Each stage has the possibility of reinterpretation of the original material.

Consider the source that you are reading and whether you find it trustworthy. If it is from a source that you don't recognise, check how they have approached other topics to get an idea of their general approach to issues.

A website that focusses on alternative treatments may present information on medication and supplements in a different way to a site based on conventional medicine. A site that reports pharmaceutical news may have a different slant again. Although based on the same material, the elements

that each source chooses to emphasise will colour the message within the article.

If the original source of the story is mentioned, try and find that to see how the coverage of the information matches with what was originally said.

As well as bias in the sources of information we need to be aware of our own biases. We all have our own opinions, prejudices, and areas of interest. There is a tendency to be drawn towards information that fits with these - known as confirmation bias. We like to read things that agree with our point of view and tend to avoid those that disagree.

To counter this, try and find the information from sources that give a more balanced or neutral view - acknowledging different sides of an argument. It won't mean that you change your mind on the topic, but it may help you see it in a wider context.

"Approach information with an open mind and ask yourself - do I trust this? Do I believe this? Can I check this?"

In a nutshell

Approach information with an open mind and ask yourself - do I trust this? Do I believe this? Can I check this?

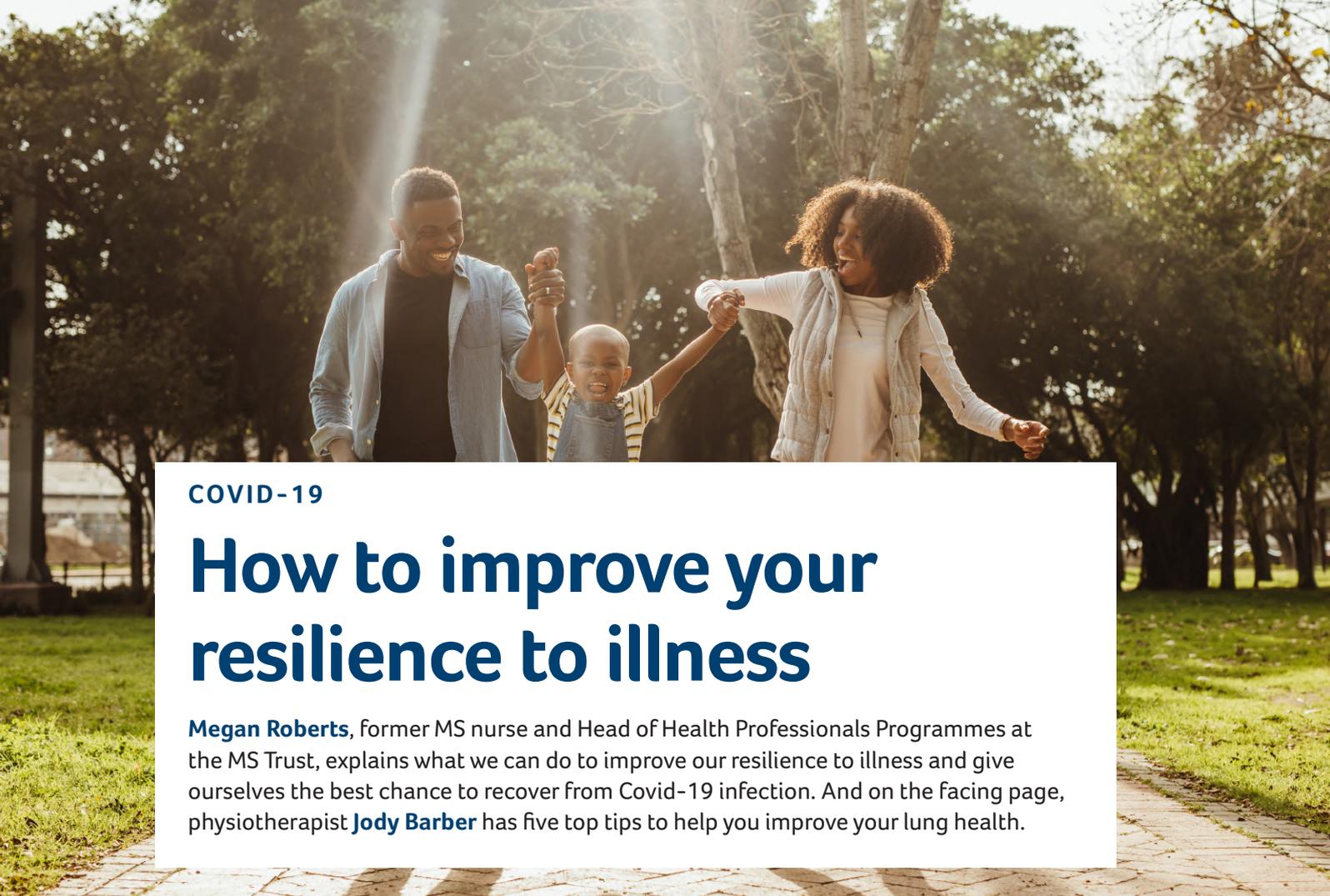


Information you can trust

***"10 years ago the MS Trust was there for me with helpful, accessible and easy to understand information just when I needed it most, when I felt there was no-one else to turn to. Understanding brings strength and empowerment, and this is what the MS Trust provides, then and now."* Liz, person with MS**

In an era of 'fake news', finding information you can trust is so important, particularly when it comes to health information. Wherever you are with MS, the MS Trust's information service is here for you when you need it. We believe in providing the best help and support so you can take control and live a life with MS, not defined by MS. We produce practical, reliable, evidence-based information, online, in print and in video, covering a whole range of topics. From lifestyle tips to MS symptoms; explaining MS to kids, to drugs and treatments. To find out more about our work supporting people with MS, visit

www.mstrust.org.uk/infoteam. If you have a question about MS, email our Enquiry Service on **ask@mstrust.org.uk** or call 0800 032 38 39.



COVID-19

How to improve your resilience to illness

Megan Roberts, former MS nurse and Head of Health Professionals Programmes at the MS Trust, explains what we can do to improve our resilience to illness and give ourselves the best chance to recover from Covid-19 infection. And on the facing page, physiotherapist **Jody Barber** has five top tips to help you improve your lung health.

Should I be preparing now in case I catch coronavirus? The quick answer to this is yes!

More of us than not are going to catch the coronavirus at some stage over the next 12-24 months – some estimates are that as many as 80% of us will contract the virus. The good news is that there is a lot you can do in advance to give yourself the best chance of reducing the risk of any serious illness developing as a result of catching the virus.

Stopping smoking has to be top of the list – if you smoke then stop! You are 14 times more likely to die if you get coronavirus and smoke. There is a lot of support available to you if you want to stop smoking – the NHS website has lots of tips and links to support services, your local pharmacy may also be able to help you. Start by telling friends and family of your plans – they can be your greatest allies and motivators. We have more information on quitting smoking on our website.

The commonest serious complication of coronavirus is viral pneumonia so, apart from stopping smoking, making sure your lungs are working as well as possible is one of the most helpful things you can do. All of us should be doing what we can to strengthen our lungs right now and on the adjacent page you can read our five top tips for improving your lung function – and having some fun at the same time!

Eating well and healthily can feel like a bit more of a challenge

than usual at the moment but is important, as much to help us keep a positive outlook as to keep us healthy. We should all be aiming for a well-balanced diet with plenty of fruit and vegetables. Being obese is known to increase your risk of developing serious complications; if this applies to you then trying to lose some weight will help. The NHS Eat Well, Live Well website (www.nhs.uk/live-well/eat-well) is a really good place to start and there is plenty of help and advice available out there.

As well as improving your physical health, your mental wellbeing is also really important. Many of us are struggling a little more than usual with our mental health at the moment but there is lots of help available and many things you can do to help yourself. Some of the things we have already mentioned such as exercise and eating healthily will help your overall well-being. Getting outside and being around nature can be very helpful – even if you can't get far, sitting on a balcony with a few plants around or in your back yard can help. When did you last really look at a dandelion – they are amazingly beautiful!

Staying connected is more important than ever right now – we are all getting much more expert at using video calling technology and there are online groups or classes you can join if you don't

" The commonest serious complication of coronavirus is viral pneumonia so, apart from stopping smoking, making sure your lungs are working as well as possible is one of the most helpful things you can do."

have any close friends or family you can speak to regularly. You might also like to try mindfulness exercises, meditation or listening to some of our relaxation resources. The NHS have created a mental health website which allows you to create your own personalised plan for improving mind and body. There are also many different apps available which you can download depending on what appeals to you most. Don't forget of course that the MS Trust enquiry line (ask@mstrust.org.uk / 0800 032 38 39) and organisations such as the Samaritans or Mind are always there for

you if you just need to talk.

It is worth reflecting that Covid-19 is a mild to moderate illness for most people, that the evidence from Italy (see page 6) is that people with MS are not excessively affected and that it is by no means certain that you will need to go to hospital if you catch it. Most people who are infected can recover completely at home.

Physio Jody Barber has five top tips to help you improve your lung health (featuring a kazoo!)

Regular respiratory exercise will help you avoid deconditioning, which is where your breathing muscles get weaker with inactivity, but will also give you the best chance of coping with a Covid-19 infection. Physical exercise is the first thing people think of when they are thinking of ways to get fit or expand their lungs, but we know that many people with MS struggle to exercise to the point where they can get a little out of breath. Here are some other options that will make a difference to your lung health, and perhaps also keep you entertained...



- 1 Stop smoking.** The serious news is that smokers are 14 times more likely to die of Covid-19 than non-smokers. The good news is that you can improve your blood circulation, immune system health and oxygen levels in the blood within 2-12 weeks of stopping. The NHS has excellent resources for you if you want to take this as the perfect incentive to quit. Read our page on smoking and MS at www.mstrust.org.uk/smoking.
- 2 Sing!** Belting out a show tune, football chant or pop hit does wonders for your mood as well as your lungs and breathing muscles. Under normal circumstances, joining a choir can be a brilliant way to socialise, but in the meantime, you could try joining a virtual choir.
- 3 Laugh!** There's nothing like a belly laugh for chasing the lockdown blues away, and laughter is good for lung health too. Find your favourite comedians or comedy shows online or on TV, tune in to a comedy podcast or radio show, or just have a knock-knock joke competition with your family.
- 4 Simple breathing exercises,** done several times a day, can significantly expand your lung capacity. Our website has breathing exercises you can try (www.mstrust.org.uk/breathingexercises). Your physiotherapist may have some specific recommendations for you, or you can try the stacked breathing exercise demonstrated by Jody on our website (www.mstrust.org.uk/lunghealth).
- 5 Kazoos aren't just toys for kids** – making music with one of these buzzy little instruments really gets the far reaches of your lungs stretched and active. Cheap and readily available online, can you and your family perform a favourite tune for us on a kazoo ensemble? (See also tip number 3) Share your musical talents with us at mystory@mstrust.org.uk and spread that happiness around!

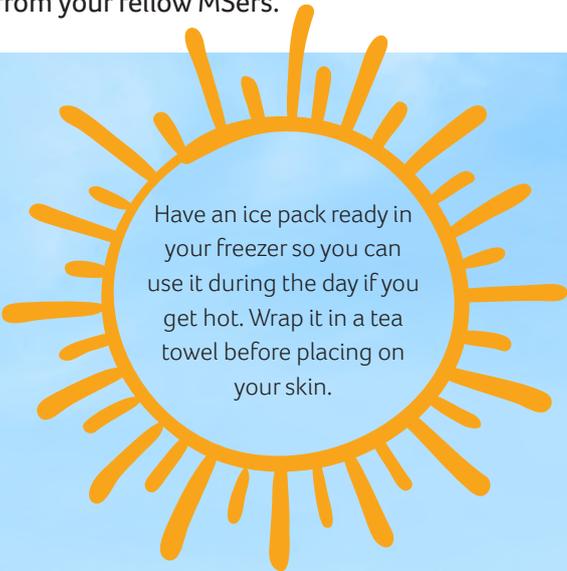
You can find the MS Trust's information on coronavirus and MS at www.mstrust.org.uk/coronavirus



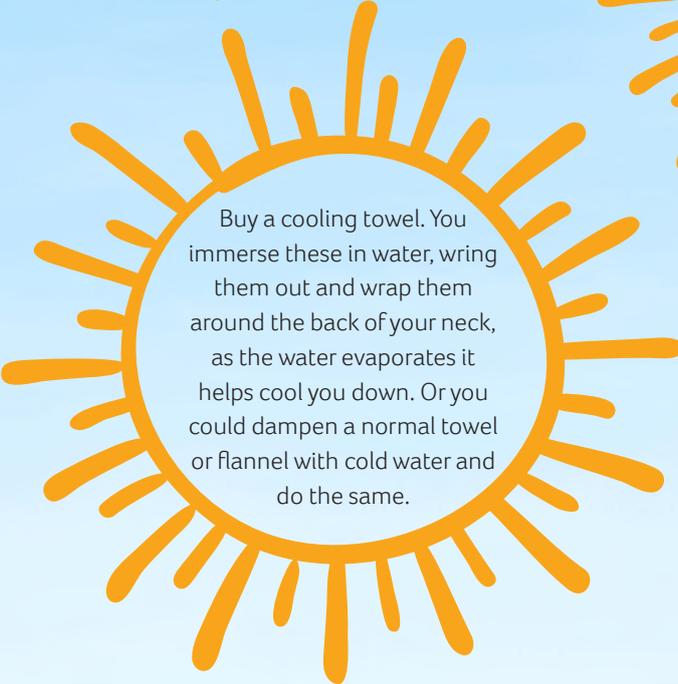
ASK THE EXPERT

Heat sensitivity

Long, sun-filled days and muggy nights mean summer is well and truly upon us. It may be the highlight of the year for some, but for people with MS summer is not always such a welcome arrival. Rising temperatures can cause MS symptoms to worsen – in the heat, fatigue can become overbearing, the ability to think clearly may be lost and movement and coordination may become more difficult. In order to deal with the heat, people with MS have to quickly become experts at keeping cool. So, for this 'Ask the Expert' feature, we decided to ask the real experts on how to keep cool during the summer months – you! Here are some tips from your fellow MSers.



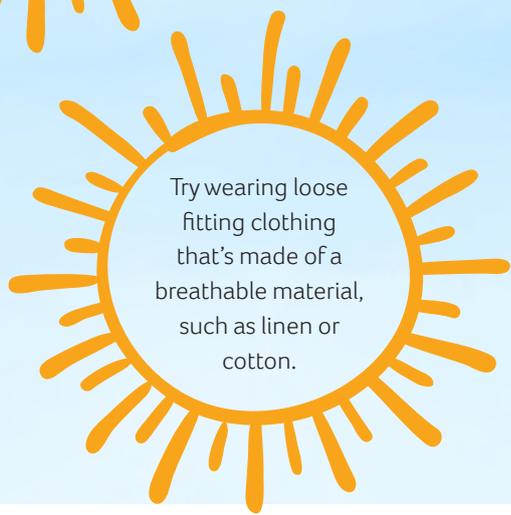
Have an ice pack ready in your freezer so you can use it during the day if you get hot. Wrap it in a tea towel before placing on your skin.



Buy a cooling towel. You immerse these in water, wring them out and wrap them around the back of your neck, as the water evaporates it helps cool you down. Or you could dampen a normal towel or flannel with cold water and do the same.



Soak some sweatbands in water, wring them out, put them in the fridge and then wear them on your wrists and ankles.



Try wearing loose fitting clothing that's made of a breathable material, such as linen or cotton.



Choose cold food and drinks, like salads, frozen yoghurts, ice cream, and iced drinks.



Stay hydrated by drinking cool drinks throughout the day.



Keep curtains and windows closed in rooms directly facing the sun during the day.



Put a bowl of ice in front of your fan so the air is cooler. Homemade air con!



Put your pillow case in the fridge an hour or so before you go to bed.



Fill a hot water bottle with ice cold water and put it at the bottom of your bed to keep your bed cool.



Have a tepid shower before bed to reduce your temperature and help you sleep.



Consider wearing sports clothing, such as a running top with wicking properties. These tops pull moisture away from your skin and into the fabric, allowing it to dry out quickly and help you regulate your body temperature.



Avoid hot tubs!



Wear a wide brimmed hat when outside and try to stay out of the sun by finding shaded areas. You could also soak your hat in cold water to keep your head cool.



Dip your feet in a bucket of cold water.



You can find the MS Trust's information on heat sensitivity and MS at www.ms-trust.org.uk/heat

The science behind heat sensitivity

It's thought that heat sensitivity (also known as Uhthoff's phenomenon) can happen for a number of reasons in MS. Firstly, when your body temperature increases it can affect the speed at which messages travel along nerves that have previously been damaged by MS. The messages travel along the nerve more slowly, and are sometimes even blocked completely, when you get too hot. This results in a noticeable worsening of your MS symptoms.

Heat sensitivity can also be caused by MS lesions in areas of the brain that control and regulate your body temperature. This can hinder your body's response to increased temperatures. For instance the message telling your body to produce sweat might not get through properly. If you are sensitive to the heat, you should notice your MS symptoms subside once you've cooled down.

GET INVOLVED

We're all in this together

Even in these tough times, it's been amazing to see some of the unique ways our supporters have been raising funds and awareness from home. From virtual running challenges to crafty fundraisers, we'd like to say a huge thank you to all of you!

Looking for inspiration to start fundraising from home?
Visit
www.mstrust.org.uk/home-fundraising



Sew-cially distanced fundraising



Over a discussion on the MS Trust Community Facebook group, we discovered that MS Trust supporters Anne (from the North East) and Anna (from London) have been spending their time in lockdown creating beautiful face masks for friends in their area. We were even more thrilled to hear that they had made this into a great socially-distanced fundraising

opportunity, exchanging the masks for donations to the MS Trust. "I wanted to do something during lockdown that would be helpful. As I'm social-distancing due to my MS, making masks at home from my big stash of fabric seemed like a good idea," explains Anna. Thank you SEW(!) much Anne and Anna!

On your marks, get set, GO!

Siblings Helen and Ian planned to take part in the Asics 10K to support the MS Trust. But like so many mass participation events, this event has been postponed. Rather than be disappointed, they have decided to put their weeks of training to use and run their very own 10k anyway! "If you are thinking of supporting the MS Trust in these difficult times, we would encourage you to do it! These uncertain times mean that you may need to be a bit more creative, so team up with a family member, or a friend and do a challenge 'together' remotely."

Team work makes the dream work

Back in May, Claire and 27 of her friends and family members (the Movers and Shakers) took part in Miles for MS - and they virtually made it all the way to Greece. "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. "Whilst taking part, I had a bad bout of fatigue which completely floored me for over a week - I was completely housebound. The team got me through and told me to rest up and recover and they would pick the miles up for me. It meant the world to me to have their support."



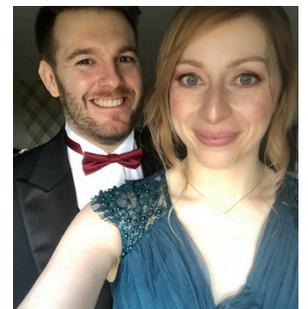
Say cheese!

It was great to see some of the fab ways supporters got involved in the 2.6 Challenge - a campaign which encouraged people to raise money for charities by taking on a challenge which involved the number 2.6 or 26 on the day when London Marathon would have taken place. We particularly enjoyed watching Syd and Rachael have a game of tennis in their dining room with cheeseboards. It even got a mention on the BBC news!

Power Up to help the MS Trust

In October 2019, we had our first MS: Play gaming weekend, encouraging MS Trust supporters to use their passion for gaming to help support those living with MS today. Since then, more than 80 gamers have taken part in various gaming challenges and raised over £17,000 to support our work.

Audrey (pictured right with husband Jon), took part in her own gaming challenge and raised over £700 for the MS Trust. She said: "I'm a huge girl gamer and had already been looking at ways to fundraise, but I'm not one for running long distances or throwing myself out of planes. It just so happened that the date the October challenge fell on was my birthday. So what better way to spend my birthday than doing something I love whilst raising money for a charity that gives so much? The MS Trust has helped me massively since my husband Jon was diagnosed with MS last year. He had been ill with suspected labyrinthitis for eight weeks and was eventually admitted to hospital to be told there were lesions in his brain and spine, and that it was probably MS. As soon as the neurologist left the room the first thing we did was Google what MS actually was and we came across the MS Trust website. It has been a wealth of knowledge for all things MS related since his diagnosis."



Are you a gamer? Why not set your own challenge to support people with MS? The next MS: Play weekend is taking place on 24-25 October. Find out how you can get involved at: www.mstrust.org.uk/msplay.

MS doesn't stop. Neither do we.



'MS doesn't stop. Neither do we' has been the message of our emergency appeal, and of the MS Trust, since the Covid-19 outbreak. While the confusion and uncertainty of lockdown continues worldwide, MS doesn't stop. So the MS Trust will not stop either.

Covid-19 did not only impact the MS community, but also the MS Trust as a charity. Demand for our services shot up, while our income dried up. Our CEO David Martin, wrote: "The Covid-19 emergency has created a massive challenge for the MS Trust to ensure that we are able to continue to support people with MS... In all of the highs and lows in the history of the MS Trust, it has never been this tough".

Since it launched in April, the 'MS Doesn't Stop' campaign has been imperative in enabling us to continue to support the MS community. Whether it's through our enquiry service, or funding MS nurses and Advanced MS Champions, donations have been a lifeline to people with MS.

As the country reaches a 'new normal', those with MS have been left behind. With disruptions to health services and delays in treatment, people with MS need support now more than ever, and our MS Doesn't Stop campaign will strive to source the necessary funds. Christine, who has MS, describes her 'new normal': "Before, I was attending six-monthly visits at a London hospital for a clinical trial of a possible drug for secondary progressive MS. In this new normal, the visits have been replaced by a phone call... Meanwhile, I feel my MS has worsened, no-one can stop it and I'm increasingly scared for the future. I have held one Virtual Cuppa and raised some funds for the MS Trust because without charities like them, we would be lost."

We are so grateful for supporters like Christine, and all of our donors. The MS Doesn't Stop appeal has raised over £40,000 for people with MS, but this is just the beginning. With no government or NHS funding, your support means more to us now than ever before. Together we can ensure people with MS aren't left to face MS alone. **To support our appeal, please visit www.mstrust.org.uk/ms-doesnt-stop.**

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 or call our team on **01462 476707**. (N.B. All of these events were going ahead at time of writing, due to Covid-19, some may have since been cancelled or postponed. Please make sure you check with us or event organisers).

Be Bold in Blue

Be Bold in Blue gives you the freedom to fundraise your way for people with MS. From baking blue cakes to holding a blue-themed virtual quiz night, whatever you choose to do, just make it blue.

www.mstrust.org.uk/beboldinblue



MS:Play weekend - 24-25 October

Take part in a sponsored gaming marathon to support people living with MS. Play solo or sign up with a squad and pick your favourite games for this 12hr, 24hr or tournament challenge – you decide! Stream your game on a console of your choice or on your mobile phone and power up by collecting sponsorship as you play.

www.mstrust.org.uk/msplay



Get Your Sparkle On

Whether it's sparkly nails, glitter in your beard, or that sequin dress you've been waiting for an excuse to wear, ditch the joggers, don your sparkle and spread a little joy on your next video call. It's all about having fun, feeling fabulous and supporting people with MS across the UK. Sparkle,

donate and nominate! **Text SPARKLE to 70970 to donate £5.**

#GetYourSparkleOn

Christmas cards

We know it's rather early, but with everything that's happened in 2020, we think now is a perfectly acceptable time to get in the festive spirit! As ever, we have a fantastic selection of cards available and all profits raised help support people with MS today. Our cards will be coming soon to shop.mstrust.org.uk, so keep an eye out!



Looking to 2021?

There are a great selection of treks that you can take part in across the UK to support the MS Trust, including Snowdon at Night.

www.mstrust.org.uk/events-2021

15 MINUTES WITH...

Megan Roberts

Megan Roberts is the Head of Health Professionals Programmes at the MS Trust, supporting MS health professionals to provide the best possible care for people with MS. We caught up with Megan to find out about the impact of Covid-19 on MS services, how the MS Trust is helping to bridge the gaps in MS care and what she loves most about her role.



Find out more about our work funding, training and supporting MS health professionals at www.mstrust.org.uk/about-us



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

I work as the Head of Health Professionals Programmes – which is a bit of a mouthful but really means that I work closely with MS health professionals to provide support, training, advice and funding to help them improve services for people with MS. During the pandemic things have changed a little – especially as many of the MS health professionals were redeployed during the peak months of the pandemic. I have been working with them to make sure that there was at least a minimum service available to people with MS throughout and to help them now rebuild their MS services.

What are the biggest challenges MS services are currently facing and how is the MS Trust helping to support MS teams with these challenges?

Before the pandemic started we know that many MS teams were under resourced, short staffed and finding it difficult to provide the services they wanted to due to lack of funding. Many MS health professionals were redeployed during the peak of the pandemic and some MS services were put on hold. MS teams are now being released from their re-deployments and are starting to rebuild their MS services and to catch up with all those people with MS who should have had appointments, started treatments or who have had problems over the last few months. There are still too few MS nurses, therapists and neurologists and we at the MS Trust are working hard to support and encourage service growth and development through education, training and funding.

How do you think Covid-19 will affect the way MS care is delivered going forward?

I think that in the short term it will continue to be difficult for everyone as services try and catch up with the large backlog of appointments and reviews that have been lost during the crisis. However, as MS services are able to rebuild their services, I think we will see a lot more flexibility with just about every team continuing to offer virtual appointments for routine reviews and monitoring to those who want them. We are also encouraged to hear that some MS teams have been able to reach out to more people with advanced MS through virtual appointments which is enabling a few people to access services which they find difficult to otherwise.

What is the MS Trust doing to address the gaps in MS services across the UK?

We continue to support MS health professionals who come to

us asking for specific help around service development or training. We are still planning to run our annual Conference and our course for new in post MS health professionals.

In addition to training, we have so far funded and supported seven MS nurses in different teams, increasing their capacity and helping them to improve their service provision locally. We have had to put a hold on this programme at the moment due to the pandemic but are planning to pick this up again early next year. We are also piloting six Advanced MS Champion roles around the country which we are funding, supporting and evaluating – we are aiming to publish our report on these roles in summer 2021.

What would be your advice to someone who doesn't have access to an MS nurse?

We know that not everyone has access to an MS nurse and where this isn't possible then do use your GP. Also remember that whilst there may not be an MS nurse available, there may well be other services such as neurorehabilitation teams or neurology nurses who will also be able to help. The MS Trust Enquiry Service is also always here and able to answer pretty much any questions that you may have – you can email them (ask@mstrust.org.uk) or phone (0800 032 38 39).

You began your career as an MS nurse, what would be your main piece of advice for someone living with MS?

I think it would be to make the most of each day we have. There is a phrase used by Albus Dumbledore in Harry Potter and the Chamber of Secrets – 'It is our choices, Harry, that show what we truly are – far more than our abilities' which has always resonated with me. We should each focus on what we can do right now rather than dwelling on what we were able to do in the past and live our lives to the best we can today. I know that's hard sometimes – and I would be the first to say that I don't always manage to stay positive – but I do find there is usually something which I can find in each day to take pleasure in.

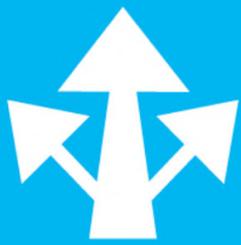
What do you love most about what you do?

I love knowing that I am making a difference to MS services and so, through them – to people living with MS. I was an MS nurse for many years so have a good idea of how difficult living with MS can be – anything we can do that helps to make that a little easier is worth doing.

From everyone at the MS Trust,
a heartfelt thank you to all the
frontline heroes who have been
working so hard to look
after us all.

Multiple
Sclerosis
Trust

MS



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)

Order MS Trust publications

Some of our recently updated publications are listed below. You can find our full list of publications at: shop.mstrust.org.uk

Am I having a relapse? (IF513)



How can I live well with MS? (IF512)



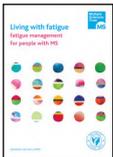
Sex and MS: Men (IF356)



Sex and MS: Women (IF213)



Living with fatigue (IF204)



Primary progressive MS (IF352)



Secondary progressive MS (IF458)



Making Sense of MS (IF448)



Delivery details

Title First name Last name

Job title (if health professional)

Address

City/Town Postcode

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

This will not stop any existing communications you receive from us. You can unsubscribe or change your email and postal preferences at any time online at mstrust.org.uk/preferences 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 or text to donate £5 via text, text MSTR01 to 70970.

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