



Research matters

The latest developments, innovations and achievements in MS research

Autumn 2018 • Issue 016

Experts in the hot seat

Supporters
quiz our leading
scientists on
current hot topics



MS progression, cannabis, vitamin D, exercise and more...



Welcome to Research Matters

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Redactive

MS IS A COMPLICATED
CONDITION – and the
research into it can be
confusing. So we've
dedicated this issue of Research Matters to
exploring some of the big questions that
people have about MS research.

We worked alongside members of our
Research Network, a group of people personally
affected by MS, to decide on the research areas
to cover. As you can imagine, the list of topics suggested was very long... so we
held a workshop with our volunteers to whittle the questions down to the
articles in this magazine.

For each topic we've found expert researchers who were happy to sit
in the hot seat and be grilled by people living with MS about their work.

We hope you enjoy this edition of Research Matters, covering topics
including medicinal cannabis, vitamin D, the gut microbiome and the
emotional impact of MS.

And be sure to turn to **page 14** to read a special interview with Professor Alan
Thompson about progressive MS. Alan is chair of the Scientific Steering
Committee of the International Progressive MS Alliance and has unique
insights into where research is heading.

As always we'd love to hear what you think about Research Matters. You'll
find contact details on left hand side of this page. And you can find out how to
get involved in the next issue of Research Matters on **page 22**, including how to
suggest future topics to be featured.



Susan Kohlhaas

Director of Research

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If you'd like to talk to someone in confidence about any of the topics raised in the magazine, the MS Society Helpline is there to listen. You can call them for free on **0808 800 8000**, or email **Helpline@mssociety.org.uk**

Research Matters is available as an audio download. For details, telephone **020 8438 0999** or visit **mssociety.org.uk/Research-Matters**

Vitamin D and MS

We know the sunshine vitamin is good for us - but could it treat MS?

Research Network member **Fay Mansfield** (pictured) gave **Dr Ruth Dobson**, researcher and neurologist at Queen Mary University, a call to learn more about vitamin D and MS.



What made you get involved in vitamin D research?

From the start of my MS research career I've had a big interest in understanding why people develop the condition, whether we can predict who's going to get MS, and if we can prevent it. Vitamin D has long been a candidate for investigation in MS, so it was a case of following my passion really!

Can taking vitamin D supplements prevent people from developing MS?

We don't yet know if taking vitamin D can have a significant impact on the risk of developing MS. Finding this out would require following tens of thousands of people (or more) from early childhood through to adulthood over a period of about 30 years. This is something that is very hard to do!

That's not to say that research isn't happening. Scientists in Australia are looking at skin markers to sun exposure and their

correlation with MS. There do seem to be hints that people who go onto develop MS have less sun exposure in childhood. But the findings are far from conclusive – it's something we need to look at in more detail.

What about vitamin D and MS progression – can it stop it?

We don't know if taking vitamin D supplements will have an effect on MS progression. Any evidence at the moment is mostly circumstantial, as, to the best of my knowledge, there aren't any big conclusive studies looking at vitamin D and MS progression.

Studies in mice have linked vitamin D to the immune system and myelin repair, so there's definitely potential for vitamin D to play a role in MS treatment, but we're not there yet.



What's your current research looking at?

We're looking at the pattern of people's vitamin D levels across the UK. We know in general that people with MS have lower levels of vitamin D than the population as a whole, but there are still large gaps in our knowledge. So many things can influence vitamin D levels in the blood, including supplements, levels of sunlight, ethnicity and genetics. Put all this together and we really don't have a true representation of whether people with MS are actually vitamin D deficient.

How will finding this out help people with MS?

The ultimate goal is to run a study to see if taking vitamin D supplements helps people with MS. Before we can do this, we need an accurate picture of vitamin D levels across the MS

population in the UK, and the factors that can influence this.

Our current study is also a kind of 'trial run' to see how best we can collect the data with minimal disruption to people's lives.

Sounds good! So, how can people get involved in your research?

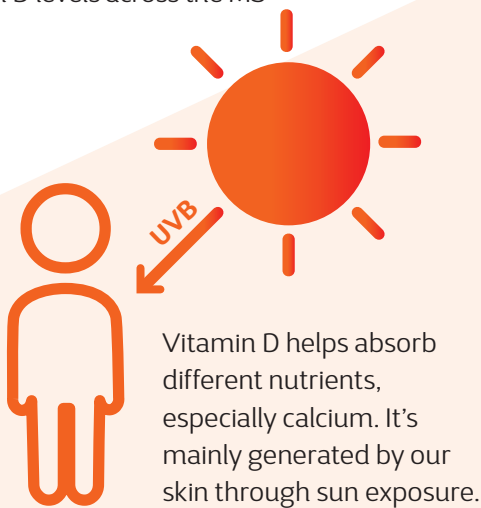
We're recruiting through the MS Register (visit ukmsregister.org for more information). When you sign up, you'll be asked to complete a questionnaire about your MS and lifestyle choices that could affect vitamin D levels. You'll also be asked to send us a finger prick blood sample and cheek swab through the

post (we'll provide everything you need for this). These samples will allow us to measure vitamin D levels and look at whether certain genes can affect it. We want to make it as easy as possible for people to take part, without having to attend a hospital or clinic in person.

What's the criteria to get involved?

The only criteria are that you're over 18 and have an MS diagnosis. It's a chance for people who aren't normally able to take part in research to get involved, regardless of age or disability.

Turn to page 12 for Ruth's expert advice on vitamin D supplements.



MS is more common in countries further away from the equator.

Researchers have found a link between vitamin D levels and a gene associated with MS.



Investigating vitamin D supplementation as a disease modifying treatment is one of our top 10 research priorities.



We need clinical trials to see if vitamin D supplements could be a safe and effective treatment for people with MS.

Vitamin D is found in



Vitamin D deficiency is a risk factor for MS

BUT... Too much vitamin D can cause nausea, abnormal heart rhythm and kidney stones. If you're concerned about your vitamin D levels, consult your GP.

Photo: iStock



Medicinal Cannabis for MS

Cannabis-based medicines are now legal but access is restricted

On November 1, the UK Government changed the law to make cannabis for medicinal use available on the NHS.

Beth Shorthouse (pictured), who has MS, reports on what led to this milestone decision and what now needs to happen to make sure those who could benefit have access.

A taboo subject

Let's face it: there's a stigma around cannabis. The association with recreational drugs is a hard one to break. And the fact that it's illegal and often smoked doesn't help.

But experts think that medicinal cannabis could help around 10,000 people with MS who have pain and

muscle spasms.

What is medicinal cannabis?

Natural cannabis contains over 80 active compounds, called cannabinoids. The levels of these can vary quite a lot across the different cannabis-based products. Two of these compounds, CBD and THC, are thought to be important for the therapeutic effects reported with medicinal cannabis.

In the UK, medicinal cannabis (that's cannabis used for medical reasons rather than recreational use) must be manufactured under

strict pharmaceutical conditions. This means the exact dosages of THC and CBD are known, while avoiding unknown and harmful ingredients and fungi that could be present in street cannabis. Until now, it's been illegal to prescribe most cannabis-based products.

Sativex is currently the only cannabis-based drug that's licenced to treat muscle spasms and stiffness in MS. However, its availability is limited – you can't get it widely on the NHS except in Wales.



A change in attitude

Earlier this year, the Home Secretary announced a two part review into medicinal cannabis. An assessment of the evidence by the Chief Medical Officer concluded that cannabis-based medicinal products have therapeutic benefits for some medical conditions, including for treating chronic pain and spasticity in MS.

This report was followed by the


Advisory Council for the Misuse of Drugs reviewing the legal status of cannabis. They recommended it

Photos: iStock/Alamy



Understanding cannabis - based products


Medicinal cannabis

What's in it? Varying known levels of CBD and THC, made to a pharma grade standard. 

What's the evidence? Research suggests that cannabinoids could help MS pain and muscle spasms.


Is it legal? Yes, it can be prescribed on a strict case-by-case basis, once all other treatment options have been considered.

Sativex

What's in it? An equal mix of CBD and THC. 

What's the evidence? Clinical trials found that it can help to manage MS muscle spasms.


Is it legal? Yes. It's licensed to treat MS muscle spasms, but NHS access is limited.

Commercial CBD products 

What's the evidence? There's little evidence to show that commercial CBD products on their own help with MS symptoms.

Is it legal? Yes, but commercial CBD products can't legally be sold as medicine; they're available in shops as food or health supplements.

Street cannabis

What's in it? THC, CBD, and other (unknown) ingredients. 

What's the evidence? None.

Is it legal? No.

be 'rescheduled' so that cannabis-based medicinal products can be made available on the NHS.

The law changed on 1 November 2018 to make cannabis for medicinal use legal under prescription by specialist doctors, including neurologists.

How did we get here?

To find out why it's taken so long to get to this point, I spoke with **Dr Waqar Rashid**, a consultant neurologist and expert medical advisor for the MS Society.

'Naturally occurring medicines have been used by man since the year dot really. But with cannabis, the issue got complicated. As cannabis was illegal, it's been hard to test in clinical trials. And this made it difficult for medical professionals and licensing bodies to make a call on the risk-benefit balance of the drug.'

'However, the MS Society carried out a detailed evidence review on medicinal cannabis. This led us to estimate that around 10,000 people with MS could benefit from the legalisation of medicinal cannabis.'

'Now the law has changed, we must ensure that those who could benefit are able to access medicinal cannabis.'

Why access may be restricted

Despite the change in the law,

it's unlikely that anything will change in the short term for people with MS.

This is because interim guidance released by NHS England and the Royal College of Physicians discourages specialist doctors from prescribing medicinal cannabis. And unfortunately, the guidance doesn't address spasticity in MS and doesn't recommend medicinal cannabis for pain.

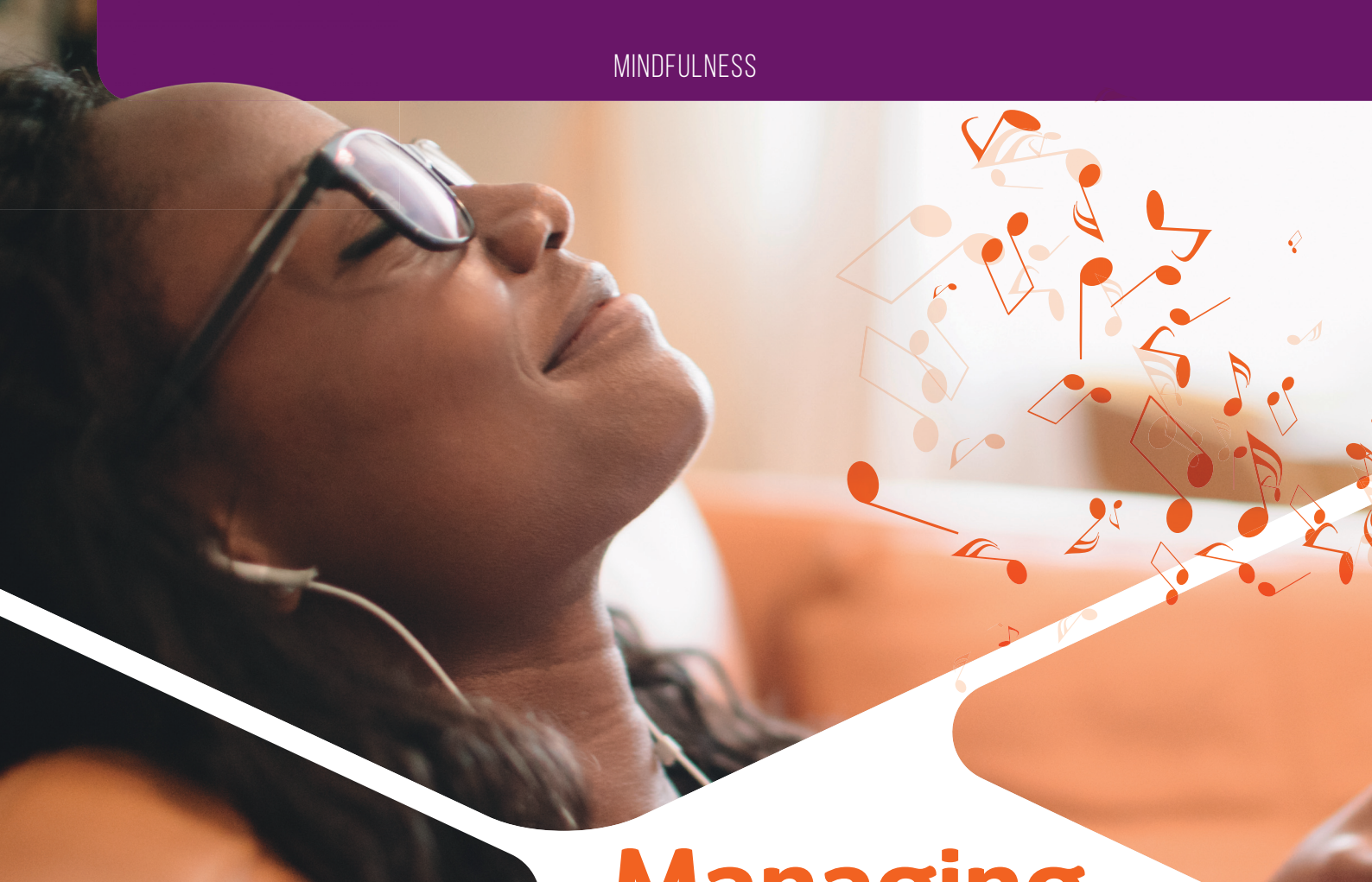
The campaign continues

Genevieve Edwards is Director of External Affairs at the MS Society. She says that the change in the law is an important moment for the MS community, but the interim guidance for doctors needs to be revisited.

'For this change to have a real impact, everyone who could benefit must be given access in a safe, responsible and fair way, with specialist doctors properly supported to make decisions around prescribing.'

'We're calling on NHS England to revisit this guidance urgently and engage with neurological experts at the earliest opportunity to ensure people with MS are not left disappointed and unable to access cannabis treatments.'

You can read more about our campaign to improve access to medicinal cannabis on page 11 of MS Matters.



Managing MS with mindfulness

Coping with the mental challenges of living with MS

It can be stressful to live with MS. Uncertainty about the future, coupled with symptoms such as pain and fatigue, can have a huge impact on a person's quality of life.

You might have heard about using mindfulness to help manage mental well-being. But what's the evidence it can help people with MS?

Take a break

Often, we go about our daily lives on auto-pilot and without stopping to think about how we feel. This can lead to us feeling stressed and

overwhelmed – and the day-to-day experience of living with MS can add to these feelings.

Mindfulness is the practice of paying attention to the present moment – to your own thoughts and feelings, and to the world around you. Supporters say that taking some time – even just a few minutes a day – can help them to feel more in control of their mood.

Mindfulness won't stop you from having negative thoughts or difficult days. But it can be a tool to cope with them better.

Can mindfulness help my MS?

Scientists have looked at how mindfulness could help people with MS. A review of the research found that mindfulness-based interventions can help improve the



Photo: iStock

Mindfulness and Me



Caroline Howlett tells us how she uses mindfulness to help manage her MS.

'I'm far from a perfect mindfulness practitioner. I don't manage to live continually and blissfully "in the moment". I still get worried about rationing my energy usage to get the best out of this scant resource.

But mindfulness has provided me with a toolbox I can use to create stillness and calm. This is important for someone with an often busy mind.

I have re-engaged with my love of nature and poetry. Performing a three minute "listening meditation" or closely observing the activity at my birdbath helps to restore my sense of proportion. It makes me thankful for what I do have – not what I don't.

Mindfulness is now a part of me.'

can practice mindfulness.

Finding something that you enjoy is key. If you're creative, you could spend some time on a mindfulness colouring book. You could listen to a mindfulness podcast on your commute home from work, or start your day with a mindfulness video. Some places also offer courses in mindfulness.

But you don't need any equipment. You can take some time to yourself almost anywhere to focus on your thoughts and emotions, and how your body feels.

Mindfulness can be a really useful tool to help manage your emotional well-being, but it isn't the answer to everything. If you're concerned about how your mental health is affecting your day-to-day life, you should talk to your doctor. There are lots of different options out there, including medicines, which can help you to manage your emotional well-being.

Turn to page 18 to read about Rona Moss-Morris' work on the emotional impact of MS.

quality of life and mental health of people with MS. It also showed that mindfulness can help improve some physical health measures like fatigue and pain.

One study found that people with MS who took part in an 8 week programme of mindfulness training showed improvement in a range of symptoms, including feelings of anxiety.

But it's hard to do scientific experiments to see whether mindfulness is effective. It's a very personal thing, and we don't have any biomedical way of measuring the outcomes. So the results often rely on participants reporting how they feel.

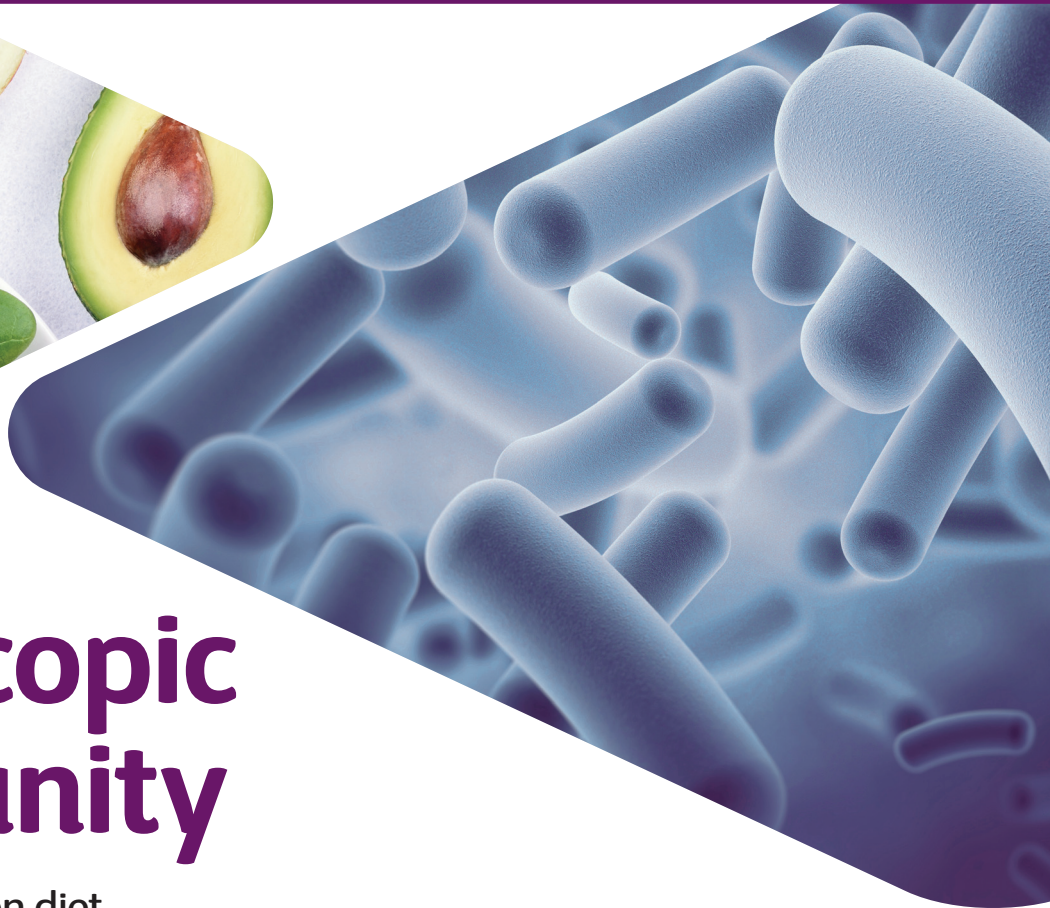
Starting your own mindfulness journey

There are lots of different ways you



Read how mindfulness helped Noor after her MS diagnosis:

**[mssociety.org.uk/
community/mindfulness-
diagnosis](https://mssociety.org.uk/community/mindfulness-diagnosis)**



A microscopic community

The link between diet,
gut microbes and MS

The gut microbiome is the name given to all the bacteria, fungi and other microbes that live in our digestive system. Research Network member **Pam Ward** quizzed University of Edinburgh neurologist **Dr Peter Connick** (both pictured right) about why he thinks this hidden community may hold the key to treating MS.

Why is a neurologist interested in the digestive system?

Over the past decade or so, we've begun to appreciate how much communication there is, both ways, between the brain and the gut. They're in contact all the time.

On top of this, there's the gut

microbiome. It's strange to think about, but there are actually more bacterial cells inside the human body than human cells! These bacteria can change how we behave and how our bodies work, including the immune and the nervous system.

What does microbiome research tell us about MS?

If we're ever to prevent MS, we really need to understand what causes it. 50 years of research has taught us that genes are important but not the whole story.

Scientists have identified a number of environmental and lifestyle factors, including vitamin D, smoking and infections. But even taking all

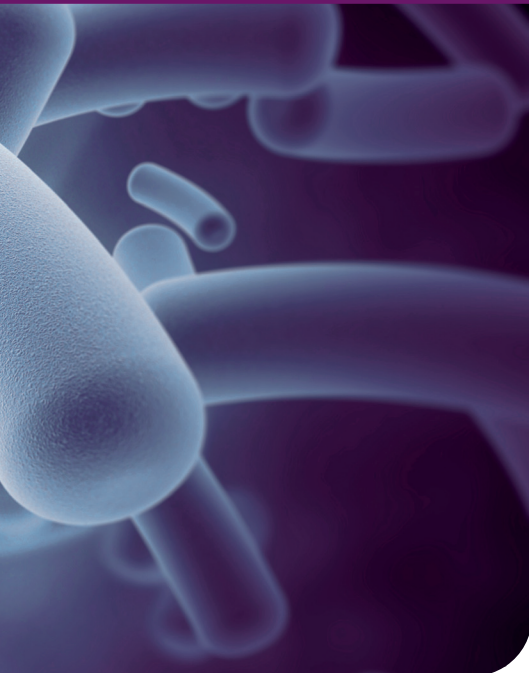
these factors into account doesn't tell us for certain who will develop MS.

That's where we think the gut microbiome has a role - perhaps by triggering or ramping up the immune system's faulty response in MS. Recent experiments suggest that this is an important area to explore.

A landmark study in germ-free mice found that there was a connection between the microbiome, the gut, the brain, and disease. Mice who received bacteria

learn

Find out more about the International MS Microbiome Study at **IMSMS.org**



finding what a good diet looks like, because there probably are no simple fixes.

The World Health Organisation (WHO) recommend people consider probiotics as a way to improve human health, but there is little evidence that people with MS should be spending money on this. Unfortunately probiotics are not like medicines – they vary by brand and batch – so we’re not really talking about one thing here.

Is there a diet to help avoid or manage MS?

Testing diets is complicated and most studies so far have been quite small, so we don’t have a clear answer yet.

But while we don’t know if there’s an ideal MS diet, we know you don’t want to have another condition on top of your MS. So a healthy diet that looks after your heart and the rest of your body is definitely important.



Photos: Shutterstock/IBM research

Microbiome Study. We’re looking at their diet, their genetic makeup, and their microbiome composition to see how these factors all play a role in MS.

Is it extra or missing bacteria that are the problem?

Great question! At the moment we don’t know if it’s one or two bacteria causing the problem, or whether it’s the ratio of types that’s important. But we hope to answer this by looking at the microbiome of a large number of people across the world.

The other problem we have is working out how to fix any negative imbalance. We all change our bacteria populations when we switch diet or take antibiotics. But these changes are not precise.

So if our large population studies identify a bacteria that might be important, we’ll probably need to go back to animal research to confirm exactly what that bacteria does.

Should people be taking probiotics?

I think our emphasis should be on

from people with MS were more susceptible to developing an MS-like condition than those given bacteria from people who don’t have MS.

This, alongside other pre-clinical data, was enough to inspire the work we’re doing now, to see how the bacteria inside us influence the development of chronic inflammatory conditions.

We’re recruiting 4,000 people with or without MS from across the world as part of the International MS

read Take a look at the latest advice on special ‘MS’ diets at mssociety.org.uk/special-diets-and-ms

I have MS and I'm worried about chickenpox and shingles. Is it safe for me to have the shingles jab?

Shingles is caused by the same virus that causes chickenpox. Most people get chickenpox as children. However, after the illness has gone away, the virus remains dormant in the nervous system. It can become active at a later stage in life, and it's this reactivated form of the virus that causes shingles.

The shingles jab is a live vaccine. This means it contains a weakened form of the virus that causes chickenpox and shingles. Live vaccinations are not usually recommended for

people with MS - having a weakened immune system can mean the person develops the infection the vaccine is meant to be protecting against.

However, as most people get chickenpox as children, they already have the virus in their bodies. This means that, as long as they've previously had chickenpox, the shingles vaccine is generally safe for people with MS.

When considering vaccination, it's important to take into account your individual circumstances. You should speak to your MS specialist

about the risks and benefits of the shingles vaccine.

Can I be around someone who has chickenpox?

It's recommended that you should avoid contact with people who have active chickenpox or shingles if you've not had the virus in the past. If you've previously had chickenpox, it's safe to be around people with chickenpox or shingles.

Getting the right advice

Our research staff are not medical professionals. This page is designed to provide general information. If you have specific health questions, please talk to your health care professional.

Your questions answered

Vaccines and vitamins in MS



ask

If you'd like to talk in confidence about any aspect of living with MS, you can call our Helpline free on **0808 800 8000**, or email **Helpline@mssociety.org.uk**

Could high doses of vitamin D be a treatment for MS?

We know having too little vitamin D is a risk factor for MS, but there's currently no strong evidence that taking high doses is helpful if you have the condition.

We're aware that some lifestyle programmes, such as the Coimbra protocol, recommend taking extremely high doses of vitamin D (e.g. 40,000–300,000 IU) as a treatment for MS. But the European Food Safety Authority suggest that, for adults, only doses up to 4,000 IU are definitely safe, although slightly higher doses are probably ok.

We don't recommend taking ultra-high doses, as we don't know if it will help people with MS and it can be bad for you. Having too much vitamin D can lead to a build-up of calcium in the blood, causing kidney stones, bone pain, vomiting, and abnormal heart rhythms.

Photos: Shutterstock



Vitamin D: practical advice

Dr Ruth Dobson, consultant neurologist, talks to us about vitamin D supplementation



What's the ideal dose of vitamin D to take?

There's no perfect dose for everyone.

The NHS recommended daily intake for adults and children over the age of one is 400 IU. This is to prevent vitamin D deficiency and promote healthy bones.

For people with MS, many clinicians recommend that people take a much higher dose of vitamin D, around 4,000–5,000 IU a day. This dose won't do harm and importantly it may actually do some good in MS or for those who may be at risk of MS, such as family members or those prone to vitamin D deficiency. But make sure to check with your neurologist or GP before taking this higher dose.

Should we be changing how much vitamin D we take across the seasons?

Vitamin D does fluctuate with seasons, but actually, with modern lifestyles keeping us inside more, it's probably better to take all supplements all year round, especially as they do no harm at the recommended doses.

What foods are good to eat to increase vitamin D levels?

Oily fish, including sardines, mackerel and wild salmon, are very high in vitamin D. Eggs are also a reasonable source of vitamin D in food. Plus, margarine, some breakfast cereals, infant formula milk and some yoghurts have added (or are fortified with) vitamin D.

I have MS – should I be giving my children vitamin D supplements?

We don't know if taking vitamin D supplements can prevent MS, but we know that, at the recommended doses, supplements don't do any harm and are beneficial for bone health. So I would advise if you are a parent with MS, make sure your children take vitamin D supplements.

Guy Mortenson (pictured below) was diagnosed with primary progressive MS some years ago. He is keen to find out when research will deliver treatments for people with progressive MS, and how attitudes are changing around managing the condition. Who better to ask than **Professor Alan Thompson** from University College London, lead scientist of the International Progressive MS Alliance.

Scientific progress to stop MS progression

Progressive MS affects over a million people across the globe, most of whom currently have no treatment options



I suppose the first question I'd like to ask is - what exactly is primary progressive MS?

Primary progressive MS gets its name because it's progressive in nature from the first (primary) symptoms. A person with primary progressive MS will see their symptoms gradually get worse over time, rather than appearing as the sudden attacks, or relapses, we see

Ocrelizumab

Ocrelizumab (brand name Ocrevus) is the first drug licensed to treat early primary progressive MS. It works by targeting specific immune cells, called B cells. In a clinical trial, ocrelizumab reduced the risk of disability progression in people with early

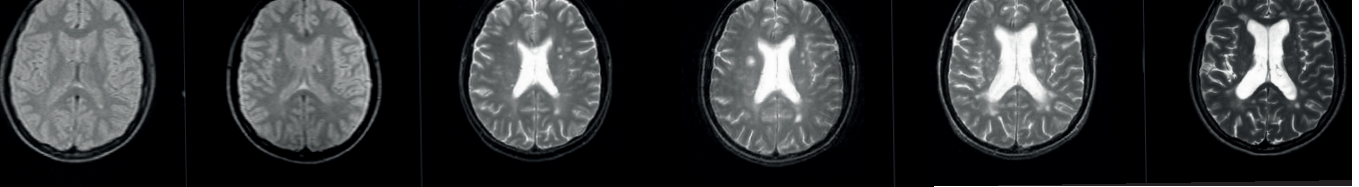
primary progressive MS.

In September 2018, NICE rejected making ocrelizumab for primary progressive MS available on the NHS. The MS Society is campaigning to change this.

Turn to page 10 in MS Matters to find out more.

Photo: Karen Chung

MRI SCANS CAN BE USED TO LOOK AT MS PROGRESSION



in relapsing MS. It differs from the more common secondary progressive MS, which follows on from relapsing MS.

But, when you look more in depth at what's actually happening to the nerve cells, the differences between primary and secondary progressive MS are still not entirely clear.

We've seen some great breakthroughs in treating relapsing MS. Why are there no treatments available for progressive MS?

In the past, the focus of MS research was to target the immune system – because its attacks on the nervous system were an obvious and important problem. Stopping these attacks has been a very successful way to treat relapsing MS. And this method can also help treat early progressive MS, as we've seen recently with ocrelizumab (see information box).

But progressive MS is mainly characterised by the nerves themselves being damaged or lost, rather than by inflammation. And the problem we're facing, not just in progressive MS, but also in other neurological conditions such as Parkinson's and Alzheimer's, is

that the body can't regenerate nerve cells once they are lost. So any disability resulting from nerve damage becomes permanent.

To try and fix this, we need to find treatments that put the protective myelin back on the nerve cells and make sure the nerves are as strong as they can possibly be.

What's the International Progressive MS Alliance?

The Alliance is a collaboration of around 18 MS charities, including the UK MS Society, which has come together to jointly support research into progressive MS on a global scale.

The creation of the Alliance was borne out of the frustration of people living with progressive MS being able to do little, if anything, to influence their deteriorating condition.

Since its creation in 2012, the Alliance has brought researchers and people with MS from around the world together to drive forward treatments for neurodegeneration.

My fervent hope from this global collaborative focus on progressive MS is that in the near future, we won't be saying that this condition is

untreatable, and we'll be well on our journey to finding treatments that work for everyone with MS.

There can be mental and emotional effects that come with a diagnosis of MS. Has there been much research into this area?

I run a diagnostic clinic, so I witness first-hand the impact that a diagnosis of MS can have on a person. And we know that there are specific issues involved when telling someone they have progressive MS.

There is an awful lot more going on in that area than there used to be. If you go back to when I started in this field about 35 years ago it's completely changed. The impact the condition has on every aspect of the individual is now carefully considered.

You can read more about the emotional impact of MS on page 18.

read Find out more about what we're doing to stop progressive MS: mssociety.org.uk/research/progressive-ms



Fighting fit

Exercise can reduce fatigue and improve wellbeing – but what exercise is best for you?

Many people with MS find staying physically active helps to manage their health. Exercise has been shown to improve many symptoms common in MS, particularly fatigue and balance. And recent research recommends that exercise should be part of treating MS.

Living well with MS

It may sound odd that exercise actually makes you feel less tired, but research has shown that keeping active can help fight MS fatigue. We don't know exactly why this is, but it may be that "fitter" cells cope better with the extra demands that MS places on them.

Early research has also found that resistance exercise (such as building up strength by lifting weights) causes changes to the connections between nerve cells in an area of the brain called the caudate. This specific region of the brain is thought to be involved in MS fatigue, giving researchers another clue about how exercise may help battle this common symptom.

Preventing MS

There's no evidence that exercise directly reduces the risk of getting MS – one US study involving over 190,000 women found that exercise didn't protect them against developing the condition.

However, animal studies suggest

that physical activity can be good for the brain as well as promoting general health. One study found that mice with brain damage had better levels of myelin repair if they were physically active.

And we know that exercise contributes to a healthy lifestyle, which could be beneficial in the fight against MS. For example, we know that obesity increases the risk of developing the condition.



read

Take a look at our 'Moving More with MS' booklet, available free at mssociety.org.uk/publications/moving-more-with-ms

Best against MS

Researchers are busy trying to work out what exercise is most beneficial for different symptoms. Right now there's only limited evidence about the value of different types of exercise. So the best advice currently is to do what works for you.

Fighting fatigue

A comparison of a large number of studies found that aerobic exercise (exercises that get your heart rate up) reduces levels of fatigue by about half on average, versus no exercise, and can be more effective than medication.

We're funding Professor John Saxton at the University of East Anglia to test whether a resistance exercise programme (using exercise bands) could work as treatment for fatigue in MS.

Staying cool

Heat sensitivity is another common symptom of MS. For some, a rise in body temperature can make MS symptoms worse, making aerobic exercise an unwelcome suggestion. But research suggests that aqua-therapy might be a good alternative, since it keeps your body cool compared with exercising on land. The benefits of the exercise itself appear to be the same.

Balancing act

Studies have shown that core stability training, weight training, and posture activities like Tai Chi can help people with MS who have balance problems. Our researchers also found that computer games systems like the Nintendo Wii could be adapted for special MS exercises that improve balance, pain and fatigue.

Photos: Brendan Foster/ Amit Lennon / Susannah Fields

Easier said than done

Exercise is good for everyone. But most of us struggle to do enough, and that's before you factor in the extra challenges that MS presents. Our research programme is working to find safe and effective ways for people with MS to fit physical activity into their daily lives.

iSTEP-MS from London

Dr Jennifer Ryan at Brunel University is developing a new way to support people with MS to get more active. Participants will test Jennifer's programme using pedometers to track their progress, as well as testing how easy it is to stick to the programme over time.

MS-LEAP from Cardiff

Getting physically active can be particularly hard for people with advanced MS. Professor Monica Busse's team at Cardiff University are working with physiotherapists and people living with progressive MS to develop and test a new web-based lifestyle programme called LEAP-MS. It's hoped the programme will help everyone achieve a level of exercise that's right for them.

Active Together with you

We've developed a special programme with experts to help people get more active. "Active Together" is a range of work-out videos designed to match your ability. So whether you feel your mobility is not affected by your symptoms, have trouble walking, or use a wheelchair, there's a work-out video for you.

watch

Our simple **Active Together** workout videos have been designed with you in mind: mssociety.org.uk/simple-workouts-for-ms





Living with MS

Research is helping people cope with the emotional impact of MS

Living with an unpredictable long term condition like MS can be difficult. **Professor Rona Moss-Morris**, a health psychologist at King's College London, spoke with our Research Network about the emotional impact of MS and the work being done to help people manage it.



A natural cycle

The support people affected by MS will want or need often changes with time. Sometimes people have good social support or are able to find their own way, but Rona doesn't think it should be left to chance. She is working to ensure that symptom management and emotional support are offered to everyone as standard, throughout the course of their condition.

Right help at the right time

Getting a diagnosis of MS can be frightening, overwhelming, or, for some, even a relief after so long of not knowing. It's important that support is available at this time.

But for many people with MS, the hardest time can be when symptoms become visible, such as if you need to start using a walking aid. This can be because it changes your perception of yourself, and may affect confidence. It's normal to need a period of adjustment for this.

Photo: Simon Rawles

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Find out about the research taking place at the University of Nottingham, working to improve the experience people with MS have at diagnosis: mssociety.org.uk/research/support-at-diagnosis

Distress is normal

Rona says it's important not to assume that everyone in distress needs treatment. It's normal to be upset when you're dealing with a diagnosis, have a relapse or are experiencing disability progression.

Showing signs of distress is a coping mechanism and can be a way of breaking down barriers, opening up the support of friends and family.

It's when that distress stops you from being able to do what you want to do that support such as Cognitive Behavioural Therapy (CBT) can be important. The saMS trial, funded by the MS Society, showed that CBT really benefits people who are in distress.

Talking is important

Being able to talk to others about your MS may also help you adjust to living with the condition. Working with children with MS who experienced fatigue, Rona found that keeping their MS secret may have

Our Helpline is here to listen

We know everyone's MS is different and the impact of MS can change over time. We also know that MS affects more than just the person with the diagnosis. We support people with MS, people worried about MS, those going through the diagnostic process and those who are newly diagnosed. We also support carers, friends and family, employers and professionals.

Freephone **0808 800 8000, Monday to Friday, 9am to 7pm** except bank holidays. All contact to the MS Helpline is confidential.

contributed to the fatigue itself.

Though you can never guarantee someone's response, it can be a relief when you do tell others about your condition.

Managing unpredictability

Some people handle uncertainty better than others, and are happy to live in the moment. But for many, the uncertainty of MS is one of the hardest things to cope with. Rona's team is working to understand why some people living with a long term condition are more resilient to unpredictability than others, to help everyone live with it better.

Taking time to adjust

Dr Angeliki Bogosian at King's College London is learning from people with progressive MS about how they adjust to their diagnosis. She has found that many people cope by scaling back goals and focusing on one or two critical areas. That doesn't mean giving up on their dreams, but often involves prioritising the things that give them joy.

Specialist support

Many people feel that standard programmes for anxiety and depression don't properly acknowledge the specific challenges of having a long term condition like MS. So Rona and her team are developing an online CBT treatment called COMPASS, to help people navigate their condition.

This programme is being created jointly by expert psychologists and people with long term conditions. An important part of the programme is ensuring it can be properly supported by health care providers. Once COMPASS is up and running, the team hope to start developing condition-specific versions, such as for MS.

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Find out more about how people adjust to their progressive MS diagnosis: mssociety.org.uk/adjusting-to-life-with-progressive-ms

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Meet the next generation of researchers

We're proud to fund PhD studentships to invest in the MS scientists of the future

Grace Birch (pictured below) is a PhD student at Imperial College London. We went to find out more about her work and why she's interested in MS research.

Hi Grace! Could you tell us a bit more about your PhD project?

I'm looking at a type of cell called a natural killer cell (NKC) in people with MS. These cells fight viral infections, and we now know that they play a role in autoimmune conditions. In our lab, we found that the NKCs change in people with MS who are experiencing an acute relapse,

compared with people who are stable. My work focuses on learning more about the role NKCs play in relapsing MS.

I'm really happy that the MS Society has given me the opportunity to study for my PhD at a world class research institute alongside experts in MS and immunology.

I hope my research will add to the growing knowledge surrounding MS. We know that T immune cells have a role in MS, and it looks like NKCs are important for controlling T cells.



Where do you hope your work will lead to?

I think all research is extremely valuable even if it doesn't immediately lead to a new drug. As we learn more about our immune system we realise that it's a highly complex system with lots of cell types that each have specific roles to play. I hope that my project feeds into this and opens up new roads to finding treatments for MS.

What made you want to work in MS research?

When I was young, my mum was diagnosed with MS. At the age of seven, I made every effort to learn all about it – and decided then that I was going to be a scientist and find a cure for MS!

I went to university and studied Biomedical Science, where I got to learn more about MS, alongside other conditions such as Alzheimer's disease.

I've always been closely involved with the MS Society through my mum, so when this PhD position popped up I leapt at the opportunity.

What have you learned during your PhD?

Doing a PhD really helps you to grow. I've been able to develop my own ideas as a scientist with the support of experienced post-docs and supervisors, and I think I've developed into a more mature and independent scientist as a result.

I've also developed as a public speaker and a teacher too. I've been able to perfect my presentation skills, and had the opportunity to teach Masters and undergraduate students.

On top of this, being able to attend events such as the MS Frontiers conference have helped me to become a clear communicator, and – I hope! – a good representative for the MS Society. I believe that these experiences have been invaluable for my personal development and I am very grateful to the MS Society for all of the opportunities that they have granted me.



You can help us fund more researchers like Grace by visiting mssociety.org.uk/get-involved/donate



AND FINALLY...



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This is your MS Society. Whether you have MS, or care about someone who does, our community is here for you through the highs, lows and everything in between. We put your thoughts and contributions at the heart of everything we do. And that includes Research Matters.

Our research programme

is driven by your priorities and we'd like our magazine content to reflect this. We want to showcase and explore the research areas you consider to be most important.

So for future issues of Research Matters, we'd like to hear from you.

● Is there an area of MS research you want to

know more about?

- Do have a question for an MS researcher?
- Would you like to contribute an article yourself?

However big or small your involvement, it will all help to produce a magazine that works for our community. So, we'd love to hear from you!

Get in touch

Send your suggestions or questions to researchmatters@mssociety.org.uk or write to **Research Matters Editor, MS Society, 372 Edgware Road, London, NW2 6ND.**



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