

New Pathways

Your **MS** magazine of choice

May/June 2020 Issue 121



“

Taking things one day at a time helps me remain focused and in the present

Mary Wilson

”

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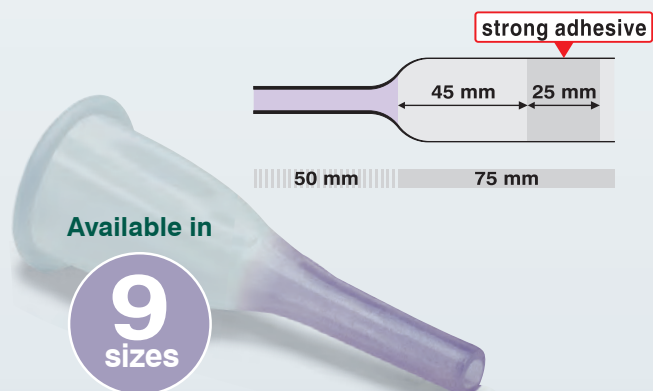
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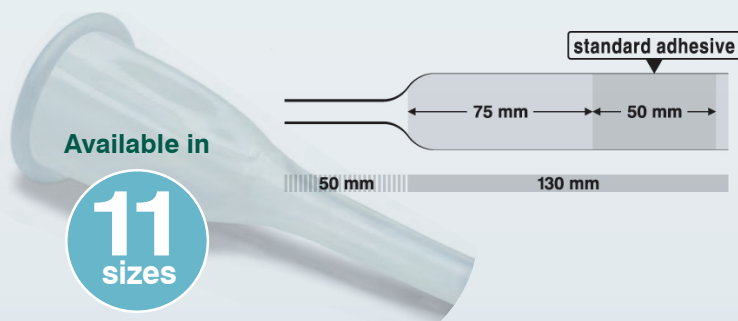
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Hello,

Welcome to the May/June issue of New Pathways, I hope it finds you well.

The year so far has been dominated by COVID-19 and life as we know it has completely changed for many of us.

Unfortunately, with almost all fundraising events cancelled, our revenue dried up almost overnight. We estimate that we will lose £300,000 of our normal income, which has a huge impact on a small charity like ours. That's why we've launched our urgent appeal, so we can keep working hard to help everyone living with MS. If you would like to make a donation, please visit www.justgiving.com/campaign/MS-UKAppeal - we are so grateful for any help you can give.

This issue, we hear how lock down has affected MSers, and Feature Writer Ian Cook investigates a possible link between coronaviruses and MS. And of course, you'll find all the latest news, research and advice. Enjoy!



Allison



Contents

Regulars

- 04 Top stories**
The latest news in MS
- 38 Your letters**
Here's what you had to say
- 43 Charlie Gee**
His take on lock down
- 44 Q&A**
Your questions answered
- 46 Scott's final say**
Our columnist on his diagnosis

Support

- 14 Coronavirus and MS**
Ian Cook investigates a possible link
- 20 How to breeze the menopause**
Natural helpers to carry you through
- 24 Stay active at home**
Our wellness coaches offer some simple exercises

- 32 Cook's report**
Ian Cook revisits the aluminium connection
- 35 Work and MS**
How measures taken during lock down may benefit MSers at work
- 37 Denial**
Why this is both friend and foe

People

- 12 Mary's Smasher**
The Paralympian on how lock down put her dreams on hold
- 16 My journey so far**
Joanna Livermore on her shock diagnosis
- 22 These things I know**
Gary Williams looks back on 35 years of MS
- 26 The new normal**
Amanda Dulieu was a high-flying banker when she fell ill

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SUBSCRIPTIONS: 01206 226500, or visit www.ms-uk.org/newpathways

PUBLISHED BY:

Direct Solutions Ltd.
7 Faraday Close Oakwood Industrial Estate, Clacton-on-Sea
CO15 4TR **Call:** 01727 893 994 **F:** 01727 893895
Email: enquiries@centuryonepublishing.uk

ADVERTISING SALES: Jack Green

Call: 01727 739196

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ART EDITOR & DESIGNER: Ami Williams

All images are used for illustrative purposes only.

Registered Company Name:

Multiple Sclerosis-UK Limited, trading as MS-UK

Company Number: 2842023

Registered Charity Number: 1033731

VAT Number: 632 2812 64

Registered Office: Unsworth House, Hythe Quay,
Colchester, CO2 8JF

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In the News

All the latest must-read MS research and stories

Obesity linked to faster optic nerve degeneration

Top Story

Being obese is linked to a faster degeneration of optic nerve tissue in people with multiple sclerosis (MS) compared to those of a normal body weight, a new study has found.

Researchers at Johns Hopkins University, who conducted the study, say that because optic neuropathy indicates greater brain nerve cell loss, tracking retinal changes could help them understand if lifestyle choices and behaviour can improve MS development.

Degeneration in part of the back of the eye called the ganglion cell and inner plexiform layer (GCIPL) has a correlation with worse disability, disease activity and brain atrophy. The researchers investigated whether obesity in people with MS increased damage in this area of the eye.

There were 513 participants in the study. By measuring their body-mass index (BMI), they were classified as either being of normal weight, overweight, or obese.

Researchers assessed damage to the optic nerve using a method called optical coherence tomography (OCT), which acquires cross-section images of the retina using light waves. This allows them to measure the thickness of layers in the eye. In the first assessment, participants of normal weight tended to have lower GCIPL thickness than the overweight and obese, because they had had more severe optic neuritis.

Participants then had a follow-up a (mean) average of 4.4 years later. Researchers found that obese participants had a much faster atrophy in the GCIPL layer than the people who were of normal



per cent in the normal weight group. Comparison between the overweight and normal weight group was not statistically significant, though.

These findings suggest that diet and lifestyle changes to reduce body fat could improve



Diet and lifestyle changes to reduce body fat could improve the outcomes for people living with MS

weight. The obese people's rate of GCIPL thickness reduction each year was 0.57 per cent, compared with 0.42

the outcomes for people living with MS. For information and advice on obesity, visit www.nhs.uk/conditions/obesity

MS therapies being trialled to treat COVID-19

Several disease-modifying therapies (DMTs) currently licensed for people with MS are being investigated as possible treatments for COVID-19.

The first drug being tested is beta interferon, which can reduce, and may prevent, the inflammation that damages

the nerves in MS.

The second therapy being investigated is fingolimod, which stops immune cells reaching nerves in the brain and spinal cord. Fingolimod is being tested as a possible treatment for the severe breathing difficulties that some people with

COVID-19 experience.

Thirdly, ibudilast is a drug being developed by MediciNova which is currently planning a phase 3 trial for those with secondary progressive MS without relapses. It's also being trialled for use with COVID-19 patients.

Spasticity scale test not enough to show Sativex benefits

A new study from Italy has found that Sativex, a type of medical cannabis licensed in the UK for some symptoms of MS, eases symptoms related to spasticity, even in those with no significant improvements in a validated spasticity scale.

Previous studies have suggested that spasticity scales might not be enough to measure a patient's response to Sativex or reflect the true benefit to the person.

Spasticity can be associated with other symptoms such as nocturnal cramps and spasms, jerking movements and sleep disorders.

Studies have found evidence that the severity of spasticity directly correlates with people's wellbeing and overall quality of life. Anti-spasticity medications are available but unfortunately many people are resistant to them.



At the moment, Sativex is approved for use as an add-on therapy for moderate-to-severe spasticity, but only in those resistant to first-line treatment. Evidence is increasing that Sativex, which is taken as a mouth spray, offers benefits beyond spasticity. But currently, if patients don't show at least a 20 per cent increase in the 0-10 spasticity numerical rating scale (NRS) after a month's trial, they are not allowed to continue the treatment and are classed as non-responders.

The Italian researchers said their study confirmed the therapeutic benefits of cannabinoids may extend beyond spasticity, and improve spasticity-related symptoms even when there was no improvement in the NRS figure. They said this evidence highlights the inability of NRS to catch all the facets of MS spasticity.

Future controlled studies are needed to confirm these potential benefits in patients considered to be unresponsive to Sativex, based on changes in a spasticity scale.

People with MS may not have higher risk of severe COVID-19 infection

An early study from Italy suggests people with MS may not have a higher risk of getting a severe COVID-19 infection.

Although the researchers said caution must be taken because it is still too early in the pandemic to draw solid conclusions, the results should bring some reassurance for those living with MS.

What is particularly unclear at present is whether people taking immunosuppressive therapies, which are among the main treatments for MS, have increased susceptibility to developing a severe COVID-19 infection, or whether their treatment might help protect them against the huge immune and inflammatory response that's associated with severe

complications of the virus.

The findings were drawn from an international platform online called MuSC-10 (multiple sclerosis and COVID-19), which exists to collect clinical and demographic data about MS patients who have the signs and symptoms of the virus.

Its goal is to understand better the relationship between COVID-19 and MS, and how factors including age, sex, comorbidities, and treatments affect how those who catch the virus react to it.

New technique to detect early-stage MS

Scientists have developed a new technique to diagnose early-stage MS and distinguish it from a similar autoimmune condition called neuromyelitis optica.

Brazilian researchers used a nanobiosensor, which was originally created to detect pollutants like herbicides and heavy metals, and developed a

method for watching myelin basic protein peptides when they were put with samples of antibodies from patients. This was observed under an atomic force microscope.

If antibodies in the patients' cerebrospinal fluid are attracted to the peptides, researchers say this indicates a person has MS.

The researchers wanted to find

a way to diagnose MS quickly because it is usually done clinically, based on the symptoms presenting, and then an MRI scan to look for lesions. They say that the method they have developed is more accurate and costs less. The earlier someone is diagnosed, the sooner they can begin treatment and hopefully slow disease progression.

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New subset of monocytes offers hope for MS treatment

A new mouse model study has suggested targeting a subset of monocytes, a type of immune cell, might be a better way to treat MS than targeting all of the immune system's cells as is currently done.

Monocytes are immune cells which start out in the blood and then infiltrate tissue, and fight off threats by engulfing them. They destroy parts of the central nervous system in people with MS.

At the moment, MS therapies that dampen immune reactions against myelin put people at risk of infection. But scientists in Germany found that by depleting a newly identified subset of monocytes they could reduce signs of MS without affecting the body's ability to fight off infection.

The scientists say that if what they are hypothesising is true, future MS treatment could deactivate the Cxcl10+ monocytes rather than targeting the T or B cells of

the immune system.

The research team believes that Cxcl10+ monocytes may have an even bigger role than anticipated, being the immune cells that open up the blood-brain-barrier to help other immune cells enter the CNS, and then recruiting and activating other immune players in the disease.

"If that is the case, in the future most forms of MS could be treated by specifically deactivating the Cxcl10+ monocytes instead of targeting the T- or B-cells of the immune system," they said. "This would protect the body's immune memory and prevent many side effects of current MS therapies."



MS increases vascular mortality risk

New research has found that having MS is associated with an increased risk of acute coronary syndrome (ACS), stroke, and death, and the

findings cannot be explained by traditional risk factors.

Scientists found that participants with MS had a 28 per cent higher risk of ACS, 59 per cent increased risk of cerebrovascular disease, and 32 per cent increased risk for any macrovascular disease when compared to a healthy control group. Researchers also

noted a 1.5-fold higher risk of cardiovascular disease mortality, and a more than three-fold increased risk for all-cause mortality.

The researchers said the results show that vascular risk assessment and management in people with MS is very important, given the increased risks noted.



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MS-UK are excited to announce we've been named sixth best charity to work for in Britain.

We scooped the accolade in Third Sector's Best Charities to Work For, which recognises employers in the charity sector that have created outstanding workplaces.

The awards are a collaboration between Third Sector, a news and jobs portal for charities, and Best Companies Group, an organisation which promotes workplace excellence.

Staff at MS-UK have a range of benefits which have led to us securing such a high score. "There is a big focus on wellbeing at the charity, as well as courses on stress management, so our colleagues know how much

they are valued." says Amy Woolf, CEO. "Our staff have paid time off for medical appointments, regular team days, and opportunities for training and development."

Part one of the assessment (which counted for a quarter of each workplace's score) consisted of the Best Companies Group Employer Questionnaire, which was used to collect information about each employer's benefits, policies, practices and other general information.

Part two of the assessment (which counted for three-quarters of the score) involved the confidential Employee Engagement & Satisfaction Survey, which was used to evaluate the employees' workplace experience and culture.

The BCG experts then conducted an in-depth analysis to determine which organisations made the list.

Second hand smoke exposure in adolescence raises MS risk for females

Female adolescents exposed to second hand smoke may have an increased risk for developing MS, a new study has found.

It is already known that cigarette smoking is an environmental risk factor for MS. Second hand smoke exposure has also been linked to a greater risk for developing

MS, but previous research has focused on adulthood.

People were asked about their involvement with cigarette smoke.

For men who were active smokers after the age of 19, the risk for MS increased by roughly 59 per cent. For males who did not become active smokers after 19, adolescent passive smoking did not



significantly change MS risk.

For females who were exposed but did not become active smokers after 19, the risk for MS was around 43 per cent higher.

Fruit peel compound may promote myelin repair

A compound found in the peels of some fruits, such as apples and prunes, may reduce neuron damage and promote myelin repair, a new mouse model study has found.

Scientists used laboratory-grade, purified ursolic acid and tested mice which were at the chronic stage of the condition – most mouse model studies test on mice in the acute stage when it is just beginning or peaking.

Researchers studied the effect of ursolic acid on cells

and observed that it seemed to stimulate stem cells to produce new oligodendrocytes, which make myelin sheath and are depleted in people with MS. Investigators say that while

this doesn't mean it's a cure, they are hopeful that if the effect is replicated in humans it could improve quality of life.

There are still several safety tests that must be done before human clinical trial stage.



Early MS cognitive impairment not linked with ethnicity

A new study has found that ethnicity doesn't appear to have any influence on the severity of cognitive impairment in people in the early stages of MS.

Researchers already know that changes in cognitive function during a person's early stages can help to predict more severe cognitive impairments later down the

line. The study was looking for other factors that may be able to help predict which people were at greater risk.

The researchers evaluated cognitive function using the Symbol Digit Modalities Test (SDMT) which measures attention, processing speed, and working memory.

Researchers analysed data from 1,174 people. Of the group, 71 per cent were women and average mean age was 40.

The SDMT tests showed that people with MS had lower scores compared to a control sample across all of the ethnicities, but no evidence was found that MS causes more cognitive impairment in Hispanic or black people than in white people.

Headaches are a common side effect of IFN-beta treatment

Headaches are a more common side effect of interferon-beta (IFN-beta) treatment than medical professionals previously thought, a new study has found.

Published in the Journal of Pain Research, the research analysed data from 796 people with relapsing remitting MS. Of these, 283 were male and 513 were female. The average age of participants was 30.84 years and all were treated at one of various centres in Egypt.

Out of everyone studied, 34

per cent already suffered from headaches before being diagnosed with or starting treatment for MS. From this group, 55 per cent reported their headaches became more frequent, more intense, and/or longer in duration within a month of beginning IFN-beta treatment.

Thirty four per cent of people in the study had no history of headaches before they were diagnosed with MS, but then went on to start experiencing them about the time they were diagnosed, with 45 per cent of these

people saying that the headaches worsened after they began taking IFN-beta.

Another 29 per cent had no history of headaches but developed them just after starting IFN-beta.

Overall, 55 per cent of people in the study reported new or worsened headaches after beginning the drug.

The results had no significant differences in terms of sex, age, condition duration, type of MS or family history of headaches.

IFN-beta therapies such as those with the drug names Avonex, Rebif and Betaseron are already known to cause side effects which include flu-like symptoms, fatigue, and injection site reactions.

Long-term fingolimod treatment may lessen disability

Long-term treatment with fingolimod results in lesser disability in people with relapsing remitting MS, a new study has found.

People treated with the drug for eight or more years had smaller increases in disability over the course of 10 years than those who used fingolimod for a shorter amount of time.

Longer use of the treatment saw fewer people transitioning to secondary progressive MS, a reduced reliance on walking aids, and lesser disability progression over the 10 years.

Published in the Multiple Sclerosis Journal – Experimental, Translational and

Clinical, the study saw a research team at the University Hospital Basel and the University of Basel, Switzerland, examine 10-year follow-up data on 175 people who were enrolled on a phase 2 trial of Gilenya (fingolimod's branded name) by Novartis, the company that developed the drug, and which also funded the follow-up study.

People were divided into low-exposure and high-exposure groups. Those in the high exposure group were treated with Gilenya for an average of 11 years, and the low exposure group for

an average of 3.3 years.

Across all the study's participants, disability scores, measured with the Expanded Disability Status Scale (EDSS) rose by 0.83 points from the start of the study to 10 years ahead. For those in the high exposure group, the rise was much lower – a mean average of 0.58 points, compared with those in the low exposure group, which had a mean average rise of 1.17 points. Over 10 years, 34.7 per cent of those in the high exposure group had disability progression, compared with 56.1 per cent in the low exposure group.

Gilenya prevents immune cells from leaving lymph nodes and invading the central nervous system. It was first approved for use in 2010.

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Mary's Smasher

MSer Mary Wilson explains how the COVID-19 pandemic has put her Paralympic dreams on hold

Mary was an army mental health nurse and completed four foreign tours before being discharged due to multiple sclerosis (MS).

Then, aged 53, she began competing as a para badminton player, with her sights set on the Tokyo 2020 Paralympics. Since the games were postponed for a year due to COVID-19, she talks us through her training schedule and how the postponement has derailed her plans.

Competing

My plan for this year was to enter all Paralympic badminton qualification internationals to give me the chance of gaining as many selection ranking points as possible. The ground work to be able to do this was a cardio vascular and strength and

conditioning gym session six out of seven days, plus being coached and playing games with my sparring partner.

It has taken many years to understand the boundaries that I have physically, initially being diagnosed with relapsing remitting MS and then being re-diagnosed with secondary progressive MS as my condition deteriorated. The condition is such a fluid and eclectic mix of different symptoms, such as lack of coordination, fatigue, pain, problems with sight, weakness in muscles, and memory loss. Trying to keep my training on an even keel depends on how I feel each day. Within 10 minutes of waking I will know what kind of day it will be for me and I take it from there. Balancing training with health is pretty much

common sense. I eat well when I can, rest for a couple of hours in the afternoon if needed and try and get at least eight hours' sleep per night.

However, I do find it difficult to eat breakfast, so often I would either go without or have to force myself to have cereal. Sometimes I would be too tired after training to cook and I would eat easy junk food or nothing at all.

On an average week, I'd train six days out of seven, with coaching, working out in the gym and sparring with my partner.

The decision to postpone

Since the postponement of the Olympics, my training regime has been blown apart due to the



My advice

To anyone newly diagnosed, I'd say try not to be scared. I know I was when I received the diagnosis and unfortunately, I was just left to get on with it. I had a couple of days of feeling sorry for myself and then decided I had the choice of giving up or taking it on and showing that it would not define who I was. People would say to me, "you can't do that," or "you will hurt yourself," but that made me even more determined to challenge myself and see just how far in life and sport I could go.

Try and get used to having the diagnosis, and then ignore it. Make a plan of what you are going to do about it. You can do anything you set your heart on and, with your determination and courage, which you may initially believe you do not have, you can take small steps to begin with have a go at what it is you want to do.



lack of sports facilities and being unable to associate with other players and my coach. I do believe it was the correct decision for the government to make, but one that I think should have been made much sooner.

Keeping self-discipline, a positive attitude and motivation is proving to be an extreme challenge. In the big scheme of things, I need to keep reminding myself that people are dying all over the world and that sport and 'my world' must come second to what is going on just now.

One day at a time

I have made a weekly calendar and take each day as it comes. One day at a time helps me remain focused and 'in the present'. This helps me achieve what I have set out to do for that day. I have put together an indoor gym session which is for strength and conditioning. I also take my dog out for a brisk walk for an hour of cardiovascular exercise each day. As you can imagine, this is nowhere near what I need and I am very worried about losing my skills, fitness, and court movement. Other countries such as China

are already back training and this will give them a head start over countries who are still in and will remain in lock down for longer.

Sponsorship challenge

Any sponsorship I secured was extremely tough to get. I contacted over 200 companies, but none were interested, or were already sponsoring able-bodied elite athletes. The charity Path to Success empowers and supports 14 disabled female athletes across four major disability sports – para badminton, para-powerlifting, wheelchair tennis and wheelchair basketball. They were the only charity who came forward and accepted me as one of their sponsored athletes. They believed in me and what I was trying to achieve.

I receive a yearly payment from them to help with travel, accommodation, entry fees and specialist physiotherapy. I could not have managed financially without their support, encouragement and friendship. I also have a local butcher called Crombies of Edinburgh who made a special sausage, which I named Mary's Smasher, and they give me a percentage of the monthly takings on the sale of the sausage.

It makes me so proud having the local community supporting me in my quest. As to my ranking, we are waiting to hear when there are going to be more qualification internationals as all of them have been cancelled or are suspended. So it remains to be seen.



Coronaviruses and MS

A possible connection?

One of the curious consequences of the COVID-19 pandemic is that it has re-awakened interest in viruses as a cause of multiple sclerosis (MS) and, particularly, coronaviruses, which cause the common cold as well as COVID-19.

COVID-19 is a member of the coronavirus family of viruses and, for a long time, it has been speculated that viruses may be the elusive environmental factor

that, along with genes, cause auto-immunity that starts MS. For years researchers have looked at the Epstein-Barr virus (EBV) as the most likely culprit. But, is it possible that coronaviruses, or a particular member of this family of viruses is involved, rather than, or as well as, EBV?

And could the current COVID-19 pandemic lead to renewed interest in coronaviruses as a factor in causing MS?



Feature Writer **Ian Cook** investigates an interesting theory

The research

Research into coronaviruses and MS has been going on for at last 40 years. A paper published in 2000 in the Journal of Virology titled “Neuroinvasion by Human Respiratory Coronaviruses” observed that upper respiratory tract infections of viral origin could be an important trigger of MS attacks. Moreover, it was said that coronavirus seasonal patterns fit the observed occurrence of MS relapses.

In another paper published in 2019 in the journal Viruses and titled “Human Coronaviruses and Other Respiratory Viruses: Underestimated Opportunistic Pathogens of the Central Nervous System?” it was observed that several respiratory viruses have neuro-invasive capabilities, being able to spread from the respiratory tract to the central nervous system (CNS). The 2019 paper said the following - “Like other well-recognised neuro-invasive human viruses, respiratory viruses may damage the CNS as a result of misdirected

Dr Pierre Talbot has authored research papers on the connection between coronavirus and MS



host immune responses that could be associated with autoimmunity in susceptible individuals and/or viral replication, which directly causes damage to CNS cells (known as virus-induced neuropathology).”

One academic with an interest in the coronaviruses and their possible role in MS is Dr Pierre Talbot, Director of the Laboratoire de neuroimmunovirologie at Armand-Frappier Santé Biotechnologie research centre in Laval, Québec, Canada. Over several decades, Dr Talbot has authored a number of academic papers including the above two which look at the coronavirus and its possible role in triggering MS.

Brain evidence

In a third paper, Dr Talbot detected the presence of coronaviruses in the brains of MS patients. Dr Talbot’s research team have also determined that neuronal cells and cells of the glia in the brain can be infected by human coronaviruses. In a paper published in the *Annals of Neurology*, he identified a striking human coronavirus-myelin cross-reactive T-cell response in MS patients, but not in those without the condition. Studies in progress at Dr Talbot’s research laboratory currently deal with the neurotropism of human coronaviruses (their ability to attack the nervous system) and the possibility that coronaviruses can trigger autoimmunity, leading to neurodegeneration.

Anti-viral drugs

Ultimately, if a link between coronaviruses and MS is established, then it is likely that there will be a new search for an anti-viral drug to be used as an MS therapy.

Several anti-viral drugs have been used to treat influenza viruses which are closely related to COVID-19. Could one of these treat MS? In the US there are four Food & Drug Administration (FDA) licensed influenza drugs.

Of these four, none has been in clinical trial for MS although, intriguingly, oseltamivir (Tamiflu) was given to a group of children and adolescents with acute disseminated encephalomyelitis (ADEM). This is an immune-mediated disease that produces multiple inflammatory lesions in

the brain and spinal cord and bears many similarities to MS. A study carried out in Turkey and published in the journal *Paediatric Neurology* in 2013 found that in 13 of 15 ADEM patients treated with Tamiflu, all neurologic signs and symptoms resolved after treatment. This begs the question whether it is time for a clinical trial of this drug or another flu drug in MS.

Dr. Talbot is not sure that Tamiflu would work on MS and, at present, there are no coronavirus-specific anti-viral drugs so a new drug would need to be developed but he believes it is possible that when an anti-Covid-19 drug is developed it could be used for MS and it might even work. He says he certainly hopes it does.



My journey so far

My first symptoms started back in 2010. I'd not long moved up to Greater Manchester from Essex. I felt my feet suddenly start tingling. I remember walking from my car to work one morning and I was wearing ballet pumps. I couldn't keep them on my feet – all sensation was gone from them and they just felt really cold. That sensation gradually travelled further up my legs, and I kept switching between feeling hypersensitive to feeling nothing from the waist down. I went to see my GP, who referred me for an MRI scan. I never heard anything back from the scan. I didn't chase it so I assumed it wasn't anything serious or worth worrying about. Whilst that sensation I was experiencing is nowhere near as bad as when it started out, it's never really left me.



Early clues

Between 2010 and 2017 I continued to pick up on odd bodily quirks. For example, I experienced random leg buckling, losing my balance without explanation, and even what I now know to be the multiple sclerosis (MS) hug (a common symptom where you feel as if there is a tight band around your chest).

I could explain away everything easily though, from working too hard in the gym, to a sensitivity to caffeine.

Joanna Livermore talks us through her long road to diagnosis, embracing lifestyle changes and the positives she's taken from having MS

I distinctly remember one relapse where I spent about two weeks with my head over the toilet as I was persistently and violently sick from vertigo and double vision. Even at that point, aside from my GP suggesting that I might have had a stroke, it never seemed to cross anybody's mind that I had MS.

That all changed in June 2017 when I lost my vision in one eye. After seeing my optician I was referred to St Paul's eye unit in Liverpool and after three months, a lot of tests and loads of people asking me if I had tingling in my legs, I was told that I'd had optic neuritis and that I might have MS.

In limbo

After the initial shock of being told that I might have this condition, honestly – I didn't expect it at all – my world fell apart. I didn't get my confirmed

diagnosis of MS until four months later and that period of time between being told that I might have it and it being diagnosed was the toughest wait I've ever experienced.

What it did do, though, was give me the time and space to process that I was going to be diagnosed with a serious medical condition, whether that be MS, or something else. I had counselling through my work's employee assistance programme to come to terms with what was ahead, which really helped me to prepare for it mentally.

When the diagnosis finally came, it was a relief. Limbo had felt worse than the reality. You can't do anything in limbo. Life is uncertain. You can't move forward.

I was put on a waiting list for Lemtrada and had my first round in June 2018. It turned out my MS was quite active and there are a lot of lesions on my spine. My reserves were

low so there was a huge risk that my next relapse would be disabling.

Lemtrada has been great for me. It's a tough therapy to go through, but now I'm nine months post round two, I'm starting to feel a lot more like me again. The bad days are less frequent and I'm starting to feel more energised. The best bit is my last MRI came

back with no evidence of disease activity. That means that in the time that I've known I've had MS, I haven't had a relapse. It feels strange, but is really positive.

I regularly attend my local MS therapy centre and there I discovered reiki (a holistic form of energy healing which can ease both physical and mental dis-ease) which has been life-changing for me, not just in terms of MS but my life in general. I've also moved to a pescatarian diet (a meat-free diet but one that includes fish), although I'm not sure if that's had a positive impact as it's difficult to say what would have happened if I hadn't.

I'm now trying to transition to the Overcoming MS Plan as

life if it wasn't for my condition. I'm a lot kinder to myself, too. I'm not running around at 100mph any more. I stop when my body is telling me to. I have a better work-life balance.

Good is often good enough, so I no longer put unrealistic pressure on myself to constantly deliver perfectionism, both in and out of work. The biggest thing for me is to just take each day as it comes. Some days I can't get out of bed. Others, I feel energised. I try to make the most of the days where I feel good.

My advice

It's an emotional rollercoaster and you need to allow yourself to feel however you need to feel. Go to your local MS Therapy Centre and find people like you – people around you that get it are really invaluable.



Now I'm nine months post round two of treatment, I'm starting to feel a lot more like me again. The bad days are less frequent and I'm starting to feel more energised.

people talk about that having a really positive impact on their MS – but I have to be honest, I'm struggling to give up cheese at the moment!

So many positives

MS has given me a lot more than it's taken away. I have so many new friends, all with MS and who I wouldn't have in my

Social media is great for that, too. Try not to live in a space of fearing or worrying for the future. Live for today and know that it takes time to adjust to your new normal. For me, advocating about MS and talking openly about it is cathartic and helps me to process it, but that doesn't work for everyone. Find what works for you.



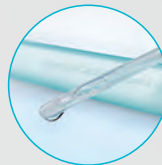
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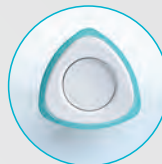


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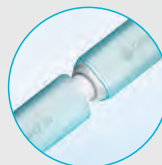
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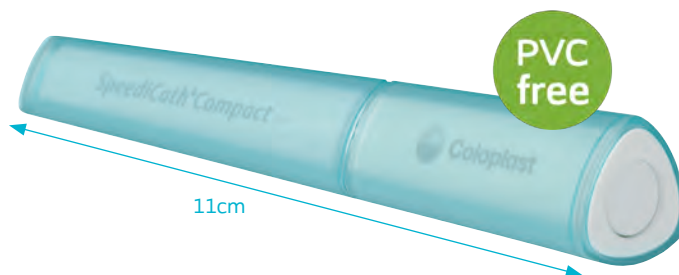


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"It's discreet. I can just be myself."



My name is Liselotte, I'm 53 and I'm an office assistant and living in Hillerød with my fiancée. Between us I have a son and he has a daughter.

Ten years ago I was told that I had multiple sclerosis (MS). One of the complications associated with MS is urinary incontinence. For me the issues started very early. I always had to carry incontinence pads around with me, even though pads didn't work when the bladder suddenly emptied. This meant that I needed to take a big suitcase with me wherever I went, for the security of having a change of clothes with me. It was very humiliating when suddenly I would have an accident and because of that I just stopped going out.

One day I met another MS patient, and she said: "Why don't you use a catheter?" At first I thought I couldn't, but I spoke to my MS nurse who told me there was a treatment I could have, which would enable me to use a catheter. So I convinced myself I had to try it for myself.

By using a catheter I have gained a world of freedom. I have got rid of the pads, and of the constant stress. Suddenly, I felt that I was just like everyone else again.

The design of the catheter and the way it looks is very important to me because it's become part of my daily life. With SpeediCath Compact Eve -

it's clever, it's small and resembles a mascara for your clutch. I can simply carry it in my hand, I don't need a bag. Or I can stick it in my pocket and take it with me everywhere I go. If people see it, they don't think it's a catheter. The fact that it looks so discreet and feminine and not medical meant that it didn't scare me and it definitely helped me to accept it.

As an MS patient you may not have a lot of strength in your hands or they may be tingling, but with SpeediCath Compact Eve's triangular shape this makes it very easy to grip and to open.

The fact that you can re-close it is also very important, as you may be in a place where you can't easily dispose of it, instead you can conceal it and not have your condition exposed.

Using SpeediCath Compact Eve has given me a freedom that grows every day. I'm more myself once again.



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CC_MSPATHWAYS_19/20

Breeze the menopause, **naturally!**

Take charge of symptoms with these holistic steps

Are you experiencing symptoms of the menopause? Hot flushes, fatigue, and low mood are just some of the effects that can hit women mid-life but, thankfully, there are many natural ways to help ease your way through this turbulent time.

Hot flushes

What you eat can have a big effect on the frequency and intensity of hot flushes, which occur due to fluctuating hormone levels. Red meat and alcohol can exacerbate the problem, as can caffeine and chocolate (sorry!). Try to eliminate these as much as you can, or at least avoid consuming them all within the same meal. The same applies to spicy foods which will heat up your body.

It's thought that eating plant oestrogens can have a mild oestrogen-like effect in the body and reduce symptoms such as hot flushes. Try tofu, which is made from soy milk and high in phytoestrogens (plant oestrogens).

Try to follow a Mediterranean-style diet, with lots of vegetables and wholegrains, as studies have proven women who eat this way experience less hot flushes than those who ate less nutrient-dense diets.

Herbal helpers

Never underestimate the power of medicinal herbs. Taking herbal supplements is something you should consult with your doctor about, as the chemicals in plants can be very potent, and some can interact with medications you may already be taking. Providing a medical professional agrees that it is safe, you could try some of the following.

Black cohosh – this wild flower helps to lower levels of luteinising hormone, which helps to balance oestrogen and progesterone. Clinical trials have found black cohosh can have a positive effect on menopause symptoms, helping to relieve hot flushes, low libido and mood swings, plus

boosting sleep.

Sage - this has been shown in a study to reduce the frequency of mild hot flushes by 46 per cent and severe flushes by 79 per cent, and also contains polyphenols which can inhibit perspiration.

St John's wort - known as the sunshine herb, it has a natural antidepressant effect. In a study on menopausal women, 60 per cent of those who took it for three months reported improved libido, and 82 per cent had better mood, less anxiety and irritability, hot flushes and disturbed sleep.

Sea buckthorn

- this can help give your sex life a boost. Symptoms





such as vaginal dryness and atrophy (where the tissues thin) can put a serious dampener on bedroom activity. But sea buckthorn oil may help – especially if you can't use oestrogen creams. In one study in Finland, women who took sea buckthorn oil daily for three months had less vaginal dryness, burning and itching. The oil is full of fatty acids which could help boost cell barriers.

Nutrition

Good nutrition becomes even more important during this stage of life, and you should prioritise heart-healthy foods. This is because oestrogen has a protective effect on the heart, but it declines sharply after the menopause. Try to eat a portion of oily fish every week, such as sardines,

mackerel or salmon for their omega-3 fats, which are known to help raise good cholesterol and lower bad.

Bone loss affects one in five women over 50, so it's important to eat calcium-rich foods like low-fat milk, cheeses, dark, leafy vegetables and beans. You should also consider taking a vitamin D supplement, which assists with calcium absorption in the bone.

These things I know

Gary Williams charts his life from his MS diagnosis 35 years ago



putting my arms around their shoulders and telling them everything was going to be fine. I suppose we were all stumbling around in the dark, as no one knew what we were dealing with. No one really thinks about these things until they actually affect you or someone close to you personally.

Back on track

As sure as night follows day, eventually MS caught up with me. First it was a stumble, then it was a fall, then stumble and fall became a way of life. It was at this point, at about 43 years of age, that I made what, to me, was a momentous decision. I decided I was making a huge mistake trying to beat MS and the only way forward was to work with it, to accommodate it without letting it either beat me or overwhelm me. Now that ain't easy for someone like me, who had always lived my life on my terms, with no reverse gear and no compromises.

I had been in various relationships but had always ended them because the dreaded MS was always in the background and I never wanted to saddle anyone with the problems I knew were piling up down the road. But, by some miracle, out of one of my relationships my son appeared.

I was 28 when I was diagnosed with multiple sclerosis (MS). That was in 1985, in the decade that fashion forgot, but one that sticks forever in my mind.

My symptoms started a year earlier. I was having a shave one morning and noticed that the pupil in my right eye was huge, whereas the one in my left was tiny. Unusual for a Tuesday, I thought, and when I blinked and looked again, the pupils had changed and the left one

was huge instead.

I started having spasms and my body would cramp up quite painfully. To cut a short story long, I had all the usual tests, a lumbar puncture, and it transpired I had MS.

Early days

The first six weeks after my diagnosis were strange. It seemed to affect others far more than it did me. I spent most of that time comforting people,

My focus

He was the best thing that ever happened to me, and became, and still is, the focus of my life. His mother and I are still good friends. I reckon, over the years up until he was 18, we spent 99 per cent of our weekends together. It was during this time I decided to do something with my brain, such as it was.

Back to school

I'd completed a university degree after school but never used it. Then I went back at age 47 and did a masters in social work. I was offered a PhD but decided I had already pushed my luck too far. The irony was that I had discovered something which I really wanted to do but, as luck would have it, just at that time, my body began to splutter.



I spent my life building emotional walls, because I thought I knew what was best for others. It turns out I was wrong

Treatment

Initially I was excited by beta interferon, looked into it, and got on the programme. I felt it worked at first but, once again, the MS was stronger. Next up was low dose naltrexone. I really thought this helped but, over time, the monster prevailed and things regressed. By the time I got to my 50s, the concept of stem cell treatment grabbed my attention. Expensive, but

definitely worth selling your house for, if it would give you your life back. I'm still interested but have yet to see tangible results which would get me to put all my assets on the one bet. So, I am where I am – 62, with the mind of a five-year-old and the ambition of an 18-year-old.

Onwards and upwards

I am trying to take more exercise. I have a home gym and attempt to use it every day. I say attempt, because I'm not always successful. Still, I use it a lot and it stops me from looking like Mr Creosote. I also try to watch my diet – it's too easy to eat for the sake of it. I know, I've been there and done that. After this lockdown, I am looking into wheelchair tennis and basketball. I have been curling

and quite enjoyed that so may well go down that road as well. For the past few years I have been playing with a street drumming band called Dezibel Drummers. It's great fun. The past three years have been somewhat of a write off as, over that period, I have been in and out of hospital with pneumonia, TB, sepsis and E. coli. Not a very pleasant time but, as long as I can avoid this COVID-19 malarkey, it's onwards and



upwards. I now subscribe to the theory that what doesn't kill you makes you stronger, literally.

My advice

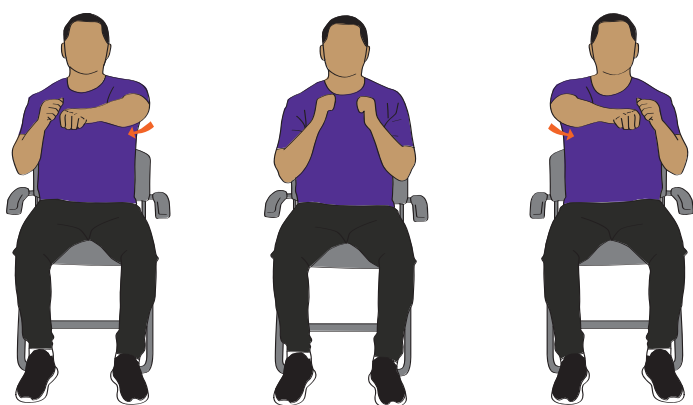
On reflection, the only advice I would give to the 28-year-old me is don't push people away – they are hurting as much as you are. Don't stop someone coming into your life, and don't assume you know what is best for them. I spent my life building emotional walls, because I thought I knew what was best for others. It turns out I was wrong. I have reached a stage in my life where I would love someone to share it with, but I don't know how to. Let's face it, I'm not the traditional package. I wake up with more hair on my pillow than on my head. On the plus side, I have a wicked sense of humour and love going on cruises.

So, if there are any younger MSers out there reading this, don't do as I did. MS doesn't have to be an anchor – sure, it's an impediment, but make it work for you. If you approach it right it makes you a powerful, strong individual. You gain mental strength and tap into inner resources you may never have known you had.

Keep **active** at home

These accessible aerobic exercises are designed to achieve sustained movements and get your heart rate up

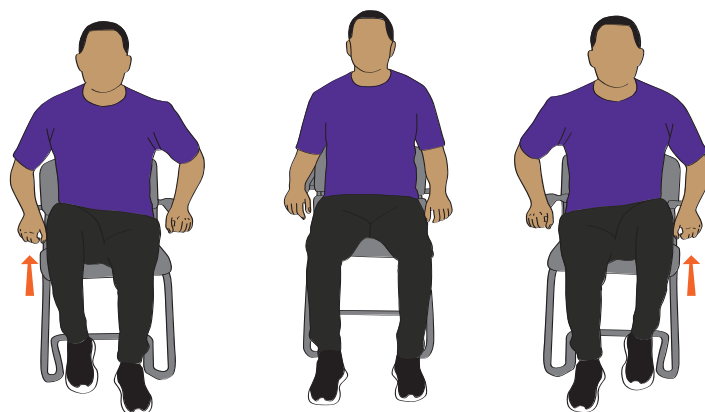
Seated punching



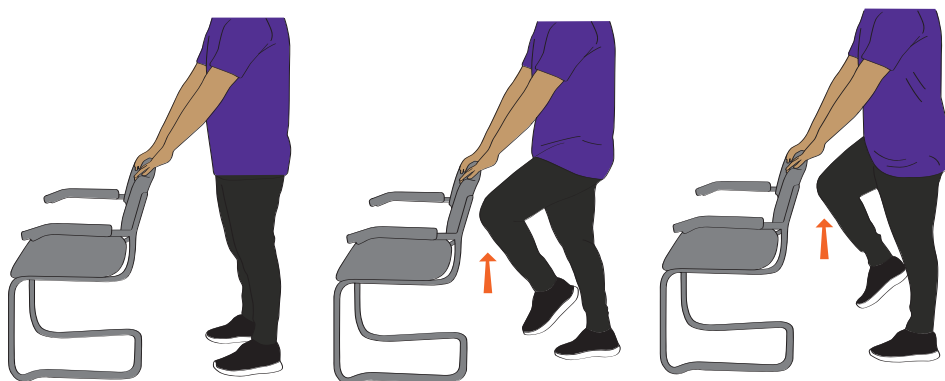
- Punch out in front for 30 seconds at a time alternating left and right
- Keep hands at shoulder level
- Punch directly in front of you
- Set tempo at your own pace

Seated marching

- Sit on the edge of your chair. Raise knees off the floor, alternating left and right
- Continue for 30 seconds. Use your arms to support your torso and posture
- Control leg lifts – try not to drop your leg down each time



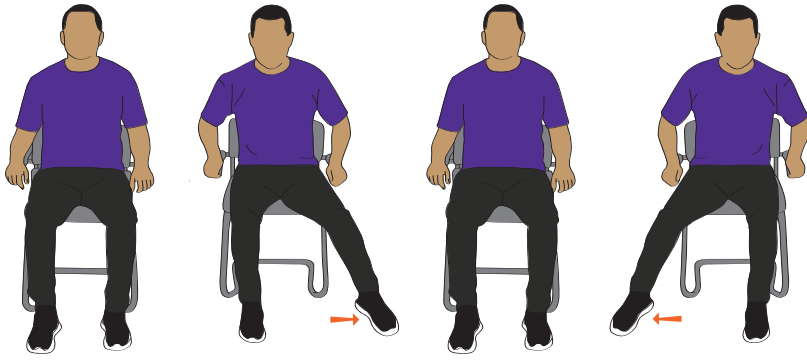
Supported standing marching



- Stand behind and hold onto a firm object such as a heavy chair
- March on the spot, raising your legs as high as you can
- Maintain for 30 seconds or more

If you have more stability and want a higher leg lift, use just one hand for support and turn to the side. Try aiming to lift your leg to waist height each time.

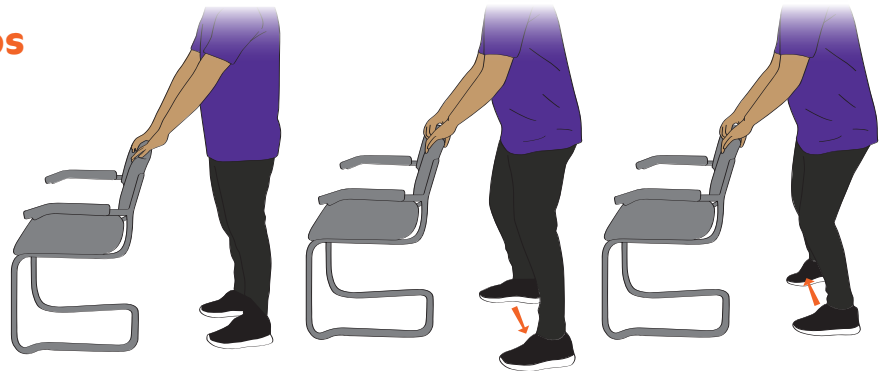
Seated side steps



- Sit on the edge of a chair. Move your left leg out then bring back to the centre
- Do this for 15 seconds at your own pace.
- Repeat with other leg for a further 15 seconds

Supported standing side steps

- Hold on to a firm object such as a heavy chair or kitchen worktop
- Step each leg out to the side and back for 15 seconds each side
- Work at a tempo that suits you



Seated reaching up and down

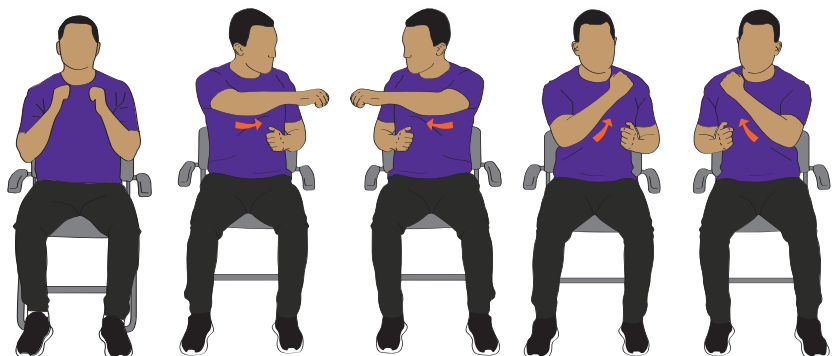


- Sit on the edge of a chair
- Reach down to the floor then bring the arm back up to reach over head
- Work for 15 seconds on each arm
- Be careful with any dizziness you may experience and stop if you feel any

If you haven't got full range of movement, you can reduce the motion so your hand reaches mid shin level when reaching down and ear level when reaching up.

Shadow boxing

- Sit on the edge of a chair with an upright posture



This move can be done in repetitions or duration.

Repetitions

10 x punching forward, alternating left and right
 10 x hooks – think about twisting the torso too
 10 x upper cuts. Continue to work through 3 or 4 sets

Sequence 2 x forward punch, 2 x hook, 2 x upper cut, rotate round for 30 seconds or a minute

The new

normal

Amanda Dulieu was a high-flying banker when she was diagnosed with MS. Here she charts her journey from coming to terms with it, and how it pushed her to live life in the moment

I was diagnosed less than a month before my 30th birthday, back in May 2002. Only four days before, my twin sister Deb had given birth to her first baby in hospital in Yorkshire, and I was in hospital in Germany wondering what was wrong with me. I even briefly wondered if it was a 'twin thing' and I was 'coming out in sympathy' with Deb? It's bizarre, the thoughts that go through your mind when you feel ill but can't explain it.

My husband Neil and I were living in the financial hub of Frankfurt, Germany at the time and we were working for a German investment bank. Eight months before, we'd married in our home county of Essex and since our honeymoon in the USA, I'd found long walks exhausting, was falling asleep after my gym visits, had had constant pins and needles in my feet, and the odd shooting pain from the soles of my feet up through my spine. Then, during a visit home for the early



May bank holiday weekend, I lost control of my bladder and bowel while I was walking along a street in the City of London.

Something wrong

We flew back to Frankfurt later that afternoon and I felt increasingly odd – there really was nothing explicit, just a feeling that things were not right. I said to Neil that I would have a hot bath and get an early night. I really struggled to get out of the bath and as I got into bed, I told Neil, "If I don't wake up in the morning, you do know I love you, don't you?" Unsurprisingly he was completely freaked out and wanted us to go straight to

hospital, but I said I didn't know how to explain how I was feeling in English, let alone German! So I insisted I would go to bed and would be fine for work the next day. When I woke up the next morning, I couldn't feel my legs from the waist down.

I was sent to a neurologist. Two days after being admitted to hospital and after countless tests, MRI scans, intravenous steroids and a lumbar puncture, my doctor came round one evening with his colleagues in tow and sat on my bed. I thought it was an extremely un-German thing to do and I immediately knew something was up. He addressed me and said in German, "Unfortunately we can confirm that you have multiple sklerose." Even with my limited medical German, I knew what the translation was.

"Oh. Is there anything I can do?" I asked. "Anything I can do to help myself?" "No," he replied firmly. Being honest and straight is extremely important to Germans – there was no bedside manner! "There is no

known cause and no cure. Get some rest and I will come back to see you tomorrow.”

From that point on, we were on a mission to learn more and get some control back. My family and friends back in the UK were all completely stunned but amazingly caring and supportive. My sister and mother-in-law called the MS-UK helpline for guidance and secured lots of leaflets.

Anger

Unfortunately, my diagnosis was much harder on those closest to me, especially Neil. He fell to pieces. He was so angry that the diagnosis was mine – he wanted to take it from me. His mum recalls a phone call to her when he just cried and cried with despair.

Despite this despair, he was only ever worried about me and promised me we were still a great team and we would tackle MS together. He has stuck to that promise – he’s amazing.

Positive changes

In retrospect, I’m not sure it was a completely conscious decision, but we have definitely lived our lives more in the moment ever since my diagnosis. We tend to say yes to everything, which means our lives have been packed full of positive experiences, many of which I don’t think we would have done, had I not had MS.

We decided that I would start taking the beta-interferon drug Rebif and thus we had to put any thoughts that we might have kids on hold. My health was more important at that time. I



had eight relatively good years while on that drug. I worked hard and achieved promotions at work, getting to director level.

Seizing opportunities

I was asked to move to Singapore for three years with my job and Neil and I eventually decided to go for it, even though I had to pay for my Rebif out there (which was around £100 per syringe) when in the UK it was free via the NHS.

It meant that it wasn’t quite the financially lucrative move that others experience when they move to Singapore, but it was the right decision for us in so many ways. I worked long hours during the week but at weekends and during holidays we travelled extensively around the region – Bali, Thailand,

Cambodia, Indonesia, Australia, Malaysia, Japan – the list goes on and we went to many of these places over and over again. Whether we knew it or not, we were living our 30s to their maximum and squeezing every last opportunity out of them while I was relatively well. In the back of our minds we knew that one day it might become a lot more challenging to do things, so our attitude was, why put them off?

Life now

Life is very different for me these days, but it is positive and happy. Almost eight years ago now, as I approached my 40th birthday, and literally 10 years after my initial diagnosis, my health started, without warning this time, speedily deteriorating.



My bladder and bowel were so unreliable that most days, I would have three to five accidents while working in the office. I was constantly in fear of it happening in public or trying to hide when things did happen and getting out of the office, home for a shower and clean clothes and then coming straight back into the office.

I always bought three or four versions of my suits so that I had spares to change into and could go back into the office looking exactly the same.

I changed roles, I then altered my work contract hours so that I could come in later and try to deal with my bladder and bowel issues at home before I started the day. This time, though, I wasn't recovering after being ill and in September 2012, I was diagnosed with secondary progressive MS. I started working from home more and that helped for a while, but in early 2013, we agreed that I was simply too ill to continue with my role and needed to focus on my health and recovery.



I was devastated and felt a huge sense of failure and inadequacy. It probably took me a couple of years to come to terms with the fact that my career in finance was over. It truly hurt me because my self-esteem was completely wrapped up with my achievements in the workplace. The 'balance' was all wrong, but it took a long time to move on and work out what my 'new normal' would and could be.

Making adjustments

Neil and I moved out of London to a quieter semi-rural location and moved my parents to live next door to us in our annexe. I can keep an eye on their health but, just as much, they keep an eye on me! Neil has changed his career again and is now a teaching assistant so that he can be close by and look after me (his words not mine!) as much as possible. So many of my family and friends have done fundraising activities to raise money for MS-related causes. They've

done marathons, walks, yoga sessions, coffee mornings... between them they've raised thousands of pounds. Neil ran 2018K in the year 2018 (effectively a marathon every week) and finished with his first ever marathon on his last day, which was also his birthday. His goal was to raise £2,018 and he ended up raising £3,250. He made me so proud that day.

My advice

For anyone newly diagnosed, I would encourage you to gather and absorb as much information about MS as you can, using the many resources available, including MS-UK's Helpline and Choices booklets. If you can, try to speak to anyone you know who has MS. It really helps to have others reassure you that you can still have a positive and plentiful life with MS.

While we are all different with our symptoms, we can all empathise with your specific challenges and we can help support you and give you optimism in those early days. Rest assured that MS is something you can live with – it really shouldn't stop you doing what you want to do with your life and as with my experience, it can have a surprisingly positive impact on your life, too.

Focus on what you can do not what you can't do. I recently did an indoor skydive that my friends booked for me – again, something I don't think I would ever have done if I didn't have MS. The condition has enriched my life – it has made me value what I have and really appreciate and live in the moment.

Symptom spotlight

Dizziness and vertigo

Here's all you need to know about this common MS problem

Feeling lightheaded and dizzy is very common among people who have multiple sclerosis (MS). If the feeling is more intense, with the feeling that your surroundings are spinning, it is called vertigo.

Vertigo can make you feel very unsteady, fall over and feel, and even be, sick. It can sometimes be accompanied by ringing in the ears, vision problems, and hearing loss.

Coping with vertigo

Vertigo can be quite a frightening experience. If you feel it coming on, sit still until you feel it easing, keeping your head and body position the same. When you begin moving again, take it slow. Don't try and read, and dim any bright lights. Avoid using the stairs as you may be unsteady, and don't drive until you are confident the episode

has passed.

Vertigo can happen during the night while you are in bed. You should turn on dim lighting and sit up straight, trying not to move until it has passed. If lying flat causes you problems with dizziness, a reclining chair is an option.

Your environment

Because it can make you unsteady on your feet, get rid of trip hazards around such as loose rugs or carpets. A cane can help you steady yourself, a chair in the shower can help while washing, and consider installing handrails.

Managing vertigo

It is quite an unpredictable symptom which can come and go, and last for just minutes, or hours, or days. Some ways to manage it

include trying acupuncture, physical therapy for help with balance and coordination, and staying physically active as exercise can help.

Causes

Dizziness and vertigo in MS is normally caused by a lesion on the brain stem or cerebellum, which is the area that controls balance. You must always see your doctor to determine the cause of dizziness and vertigo as this symptom has a range of other potential causes.

Treatment

Once your doctor has established the cause, they can prescribe over-the-counter anti-motion sickness medicine, and if the vertigo is severe, steroids can sometimes help.

The cook book

Try this speedy lunch and delicious dinner from Simone Anderson

Serves 4

Cauliflower Tabbouleh

Ingredients

- 1 head cauliflower, roughly cut into florets
- 2 spring onions, sliced
- 1 punnet cherry tomatoes, halved
- ½ cucumber, finely diced
- 1 cup chopped parsley leaves
- 1 cup chopped mint leaves, plus extra to serve
- ¼ cup extra virgin olive oil
- 2 tbsp lemon juice
- sea salt and freshly ground black pepper to taste

To serve

- 4 hard-boiled eggs, halved
- 100g crumbly feta
- 4 tsp sliced almonds

Method

- 1 Place the cauliflower in a food processor and whizz until it resembles small grains of rice.
- 2 Place the cauliflower in a large bowl with all the other ingredients and stir to combine.
- 3 Transfer to serving bowls, top with the egg, and serve scattered with crumbled feta, almonds and extra mint leaves.



Parmesan-crumbed fish with tomato ragu

Ingredients

Roast potatoes

- 1 kg baby potatoes
- 2 tbsp olive oil
- sea salt to taste
- 2-3 sprigs rosemary

Tomato ragu

- 2 tbsp olive oil
- 1 red onion, thickly sliced
- 3 cloves garlic, minced
- 1 red capsicum, deseeded and sliced
- 2 courgette, sliced
- 1/2 cup pitted kalamata olives
- 1 cup tomato passata
- 400g can chopped tomatoes
- sea salt and freshly ground black pepper to taste

Fish

- 1 egg, lightly beaten
- 1/2 cup panko crumbs
- 1/4 cup finely grated Parmesan
- 2 tbsp finely chopped parsley
- 4 white fish fillets such as gurnard or terakihi (about 450g)
- 1 tbsp rice bran oil



To serve

- 100g baby spinach leaves
- lemon, cut into wedges

Method

1 Preheat the oven to 200°C and place a roasting tray inside to heat. For the roast potatoes, halve or quarter any large ones.

2 Place the potato pieces in a large pot of cold salted water. Bring to the boil and cook for 10 minutes until beginning to soften. Drain well and place on the hot roasting tray.

3 Drizzle with the olive oil and toss to coat. Season with salt, throw the rosemary on top and cook for 10-15 minutes until crispy.

4 For the tomato ragu, heat the olive oil in a large frying pan over medium-high heat. Add the onion, garlic, capsicum and courgette and fry until golden. Add the olives, tomato passata and chopped tomatoes, season, reduce the heat and cook for about 10 minutes until the vegetables are tender.

5 While the ragu and potatoes are cooking, prepare the fish. Place the

egg in a bowl and combine the panko crumbs, Parmesan and half the parsley in another bowl.

6 Coat each fish fillet with beaten egg, then dip it in the Parmesan crumbs. Heat the rice bran oil in a large non-stick frying pan over medium-high heat, add the fish and cook for 2-3 minutes each side.

7 Divide the spinach among serving plates. Top with potatoes and ragu and serve the fish on top, garnished with the remaining parsley and with lemon wedges for squeezing.



So Delish! by Simone Anderson (£17.99, Allen & Unwin).

Photography © Melanie Jenkins (Flash Studios), 2020

Urgent Appeal

An update from MS-UK CEO **Amy Woolf**



Dear readers,
I sincerely hope you are keeping well during these times.

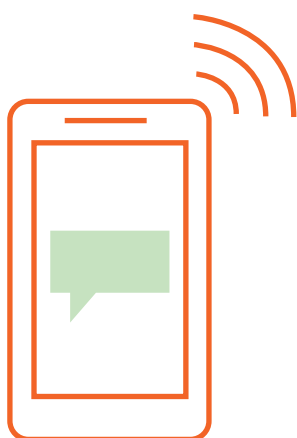
Here at MS-UK we are adapting to the current situation as rapidly as possible in the hope that our services

can continue uninterrupted.

Thank you so much to those of you that have donated to our urgent appeal. Unfortunately, most of our fundraising comes from mass participation events such as the London Marathon and, because of this our charity has lost a huge amount of its income, we estimate a

£300,000 loss. If you have not seen the appeal, or would still like to donate, visit www.justgiving.com/campaign/MS-UKAppeal. You can also send a cheque to FREEPOST MS-UK or follow the steps below. Thank you.

Amy



Donate by text

To give **£5** text **URGENT5** to 70456

£10 text **URGENT10** to 70456

£20 text **URGENT20** to 70456

You will be charged £5, £10 or £20 by your network provider plus one message at your standard network rate. MS-UK will receive 100 per cent. **By texting your gift e.g. "URGENT10" to 70456 you are agreeing to us contacting you by phone and SMS to tell you more about our work and how you can support it.**

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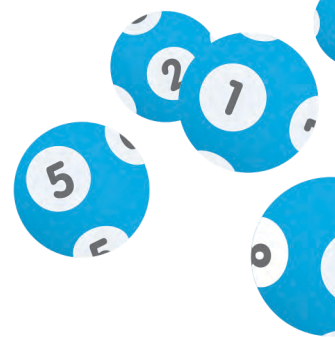
Pays for a year's subscription to New Pathways magazine

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Pays for a single counselling session for someone struggling with their mental health

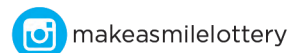
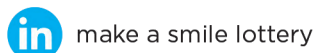
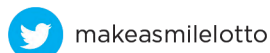
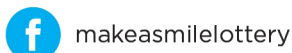
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New opportunities



MSer and HR expert **Rebecca Armstrong** reflects on how lock down could lead to positive progress in the workplace

As I write this article we are mid lock down during the coronavirus crisis. Hopefully, when you are reading this, we will be further through this and less restricted.

During this period the world has had to adapt overnight. Restrictions have meant that work for many has looked very different and employers have had to embrace this and put measures in place. In this article, I reflect on how this may help employers understand multiple sclerosis (MS) and similar conditions and, importantly, how this might create benefits for people with MS longer term.

Resilience

When it comes to resilience (that is, the ability to bounce back) and how able we are to cope with changes, we could argue that MS gives us a head start. We have been training for this since diagnosis and are used to having to adapt to new circumstances, often with very little notice.

The changes that may be helpful

Here are a few things that occur to me

- One of the most significant changes most employers made was to allow people to work from home if they could. This really challenged the mind-set of many employers who opposed working from home. In my experience of working with people who have MS to help them obtain reasonable adjustments, this has been a consistent barrier, with many employers reluctant to take the step. As we reflect back, this period in history has served to prove the homeworking model can work. On the whole, people have been able to carry on and do their job to a good standard from their own home.
- This creates an opportunity for people with MS to consider whether, as a reasonable adjustment, working from home would be helpful in making their job accessible. Perhaps you

have asked before and been refused, or have found it helpful during this period. You can start to have an open dialogue with your employer about this and request it as an adjustment.

- Every one of us with MS was labelled as vulnerable early on in the pandemic. Some of us went on to being classified as extremely vulnerable, with the advice being to shield. Whilst these were very stressful times, this not only helped to keep us safe, it has given employers insight into the gravity of the condition. This creates a platform for conversations around reasonable adjustments and vulnerability. As you have been doing your job well to date, this shouldn't raise questions about your ability to continue to do so, but does show the need for extra support and help. As we bounce back, think about what would help you moving forward.



My MS Marathon

From 01-31 July 2020, do it your way for MS-UK

Have you ever dreamed of completing a marathon? Well, this July it's your time to shine! Take part in the UK's most assessable marathon to support MS-UK. Plus, if you raise over £100, you'll earn your own exclusive My MS Marathon medal

Get involved

All you need to do is think of a fun challenge that's based around the number 26. That could be 26 meters, minutes, hours or even cupcakes! Whether you knit, walk, run, dance, read, wheel, lift, hop or craft, the choice is yours. My MS Marathon is the UK's most accessible challenge and absolutely anyone and everyone can get involved.

Thank you in advance for your kind support. We can't wait to hear your ideas.

Join today!

It's quick and easy to join our challenge. Simply

- 1) Dream up your activity based around the number 26
- 2) Register to take part at <https://mymsmarathon.ms-uk.org> your fundraising page will automatically be set up for you
- 3) Share your fundraising page with your friends and family
- 4) Have fun doing your challenge during July (be sure to take photos or make videos of you in action!)
- 5) Raise over £100 and claim your exclusive my MS-Marathon medal

Help those in need

By taking part in My MS Marathon you will be raising vital funds for MS-UK's

telephone counselling service, the only one in the UK specifically for people living with MS. Our team of professional counsellors understand what it is like to live with MS.

Whether it's coming to terms with a diagnosis, dealing with a relapse, or helping with mental health issues such as anxiety, low mood or depression, our counsellors are there to help people make sense of life with MS. People like Clive Whyte, above, who was struggling to cope. "The diagnosis hit me like a tonne of bricks. I found the counselling sessions helped me release the feelings I had trapped inside. The mind and body have a way of catching up with you and stopping you in your tracks, and there were a lot of things inside I needed to heal after the initial shock.

"My confidence has grown since having counselling, and I'm much more comfortable in situations at work or with friends. Before, I would try and avoid people. This service has been a gift for me, and I'm very grateful."

Your help ensures we can support more people like Clive.



For more information about My MS Marathon please visit <https://mymsmarathon.ms-uk.org> or contact Isabel in the Fundraising team on 01206 226500.

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Why denial is both friend and foe



It can be common to experience denial says MS-UK Counsellor **Mark Howe**

What is denial and how to manage it?

Denial is a powerful defence mechanism. It helps us protect ourselves by not accepting the truth about a situation that may be frightening. It allows us to avoid emotional pain and helps us cope. A diagnosis of multiple sclerosis (MS) can often cause feelings of fear, grief and loss. Denial is the first stage in the process of grief.

When we are in denial we may refuse to accept a feeling, thought or an event has happened, even if there is strong evidence that it did. It may also take the form of minimising or down-playing a feeling, thought or event, for example 'other people have it worse than me' or 'it isn't that bad really'. How often when we are feeling upset and someone asks us how we are, we say 'I'm fine'? These are all examples of denial.

How to tell if you're in denial

- People may say you are
- You try to avoid any big emotions or not let yourself think about things that are upsetting
- When someone asks you how you are you automatically answer that you are fine
- You may feel 'stuck'
- You take the easy option without really thinking

What problems can denial cause?

Being in denial can leave us feeling that we are stuck in our lives. It may impact our mental wellbeing and we may feel depressed or anxious. It can have an impact on our self esteem, it may start to have an impact on our relationships and it might also mean we are not able to live our lives as fully as we could as we are not

getting the help and support we need.

What if someone I love is in denial?

Before we demand that they do something about it, it can be helpful to step back and ask - do they just need a bit more time to work through it?

Don't force them. Let them know that you are open to talking about the issue, listen and offer support. This could be what they need to feel safe and secure enough to move forward.

How can counselling help?

If you are in denial then you are probably not facing the painful feelings. Working through them with a counsellor can help you to validate, understand and accept them. By doing this we are able to take control and find other more helpful, longer-term ways of coping.

To access MS-UK Counselling, visit www.ms-uk.org/counselling

Your letters

Whether it's gripes or groans, a pat on the back, or hints and tips, we want to hear from you



A hands-free challenge

Dear New Pathways,
I am reliant on voice-activated systems to keep me in contact with the world.

I have been trying to find a genuinely hands-free, voice-activated mobile that does not require able-bodied people to be around to keep me connected, but without success to date. I have a Samsung Android phone which is set to answer automatically when anyone calls me. This is paired with an Mpow M5 headset. Once the phone is switched on and the headset connected this works reliably.

If the person who has called ends the call, there is no problem. However, if I am in a queue or on hold, I can't end the call myself, as I am unable to press the screen. Also, if the screen has gone into screensaver mode I am unable to press the power button to reactivate it.

Secondly, I am very limited in my ability to initiate a call by voice alone. I have Google Assistant installed. It is patchy

in getting it to make calls, and I have yet to succeed in getting it to ring a number I dictate. I can't reel off a number in a single breath, but when I pause it immediately goes off to look up the stub of the number. Thirdly, I am unable to overcome the power saver mode. When this kicks in I have no way of reactivating the display as I am unable to press the power button. This makes Google Assistant inactive, so I have no way of making a call.

What I am looking for is a phone and software that can do the following

1) Automatic answering of incoming calls when I have a Bluetooth headset on. Not every Android phone has this function



installed, as I found out to my cost when I bought a Motorola G7 recently.

2) A voice-activated option that allows me to end a call without touching the screen.

3) A voice-activated option that allows me to dictate a full number even when I need to pause.

4) A set-up that allows Google Assistant to remain active when the phone is in power saver mode. I have read that the newer OLED displays may allow this. It would be great to find out whether this works reliably.

If anyone has an OLED phone, or is making a lot of use of voice activation on their smart phone, I would be interested to hear which makes and models work most successfully.

If anyone can help, I'd be grateful if you could email ms@bmsct.org or call 01189 016000.

Thank you,
Sam, Berkshire



Contact us

Write to "FREEPOST MS-UK"
(no stamp is required)

Call 01206 226500

Email newpathways@ms-uk.org



Sleep suggestion

Dear New Pathways,

I have just read your March/April issue and noticed the articles on insomnia. My wife Kerry, who has had MS for 23 years, takes a drug called low-dose naltrexone (LDN). It boosts your immune system so Kerry never gets the little coughs and colds that can knock you back if you have MS.

She has been on LDN for ten years now and always sleeps like a log. If I didn't wake her, she would sleep until 10am. The point is, she always gets eight or more hours of sleep a night. LDN is a cheap drug that's available on the NHS, and our GP prescribes it for us. If your GP won't prescribe it, Dr Robert Lawrence of Dietary research UK based in Wales will write a private prescription. We did this for the first three years until our GP saw the value.

I'd also suggest considering a wheat and dairy-free diet.

Hope this helps,
Chris,
Bodmin



Holiday help

Dear New Pathways,
I have MS and recently had a relapse which means I now need carers twice a day. We have always enjoyed our holidays but now we need to find holiday cottages or hotels that can provide carers with a hoist. Can anybody suggest anywhere please (for when we come out of this lockdown)?

Regards,
Andrew,
Warwickshire



Water difference

Dear New Pathways,

My carer suggested that a water filter might help so I bought one with a four-litre capacity and the results have been incredible. No longer do I have to squeeze daily the debris that builds up in my clear plastic tube. Now I do it fortnightly, if that. My catheter is now changed by appointment every 12 weeks – the maximum length of time allowed – and not when I have a blockage. I also do a washout with my carer once a week as well.

I hope this tip may help other New Pathways readers.

Best wishes,
Philip, Northamptonshire

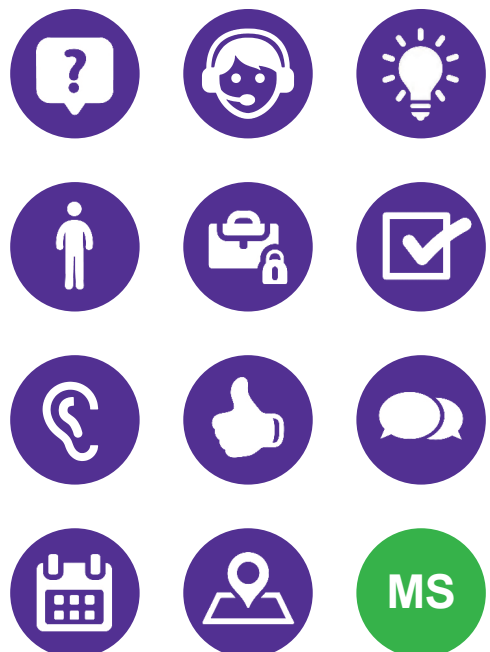


MS-UK Counselling

Our counselling service is focused on helping you understand yourself in light of your MS and exploring its emotional impact on your life. It is available to anyone living with multiple sclerosis aged 18 and over, and is completely confidential.

Counselling is a process that invites you to talk about your thoughts and feelings with a qualified professional. Counsellors do not give advice but help you explore your experiences so that you can find your own way forward.

MS-UK counsellors are BSCP registered or accredited with knowledge of MS and its impact on mental wellbeing. Your sessions will be weekly, last 50 minutes, and be delivered over the phone.



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Aluminium revisited



Feature Writer **Ian Cook** looks back and asks – is it time for more research?

More than 100 years ago, aluminium was first linked to Alzheimer's disease, and then around five years ago it was linked to multiple sclerosis (MS). This MS link was largely due to work carried out by Prof. Chris Exley of Keele University.

Aluminium toxicity

Last year I interviewed Prof. Exley about his work. The interesting thing about this professor is that he looked not only at aluminium toxicity as the possible environmental factor in MS, but also at how to remove aluminium from the body when it reaches potentially toxic levels. In 2017 he carried out a study which looked at how drinking silicon-rich mineral water could lead to lower levels of aluminium by removing it from the body in a process known as chelation. His study followed 15 people with secondary progressive MS

who drank chelating silicon-rich mineral water daily for 12 weeks to remove aluminium. Last year, I too drank 1.5 litres of silicon-rich mineral water daily for 12 weeks, during which time my aluminium levels would have dropped quite considerably.

Bigger studies needed

I did notice a slight improvement in my bladder and it's only anecdotal evidence but sadly there wasn't any major change in any of my other symptoms. Despite this I think the aluminium theory deserves further investigation. As Professor Chris Exley says, "While it is too early to confirm a role for human exposure to aluminium in the aetiology of MS, the significant observations of elevated urinary excretion of aluminium in individuals with the disease and excessive accumulation

of aluminium in brain tissue post-mortem suggest that it cannot be ignored. In addition, burgeoning anecdotal evidence of the benefits of silicon-rich mineral waters in individuals with multiple sclerosis may suggest a future non-invasive therapy." It may be rewarding to research this possibility further.

Population study

My idea for further investigations

As a start, researchers could look at whether there is less MS in areas where silicon-rich water occurs naturally, such as the Auvergne area of France where silicon-rich Volvic comes from. This research might be cheap and easy to do and may take the theory further, perhaps even resolving the issue of whether this environmental factor influences MS.

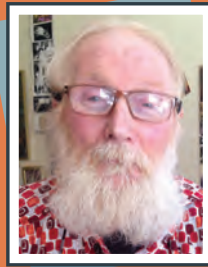
Look on the bright side



What a bummer, I didn't see that coming. I entered this year thinking the world was my oyster. I would be going to at least two festivals. I would be looking to see if there were any good football matches at Burnley, which is about six miles away from my home. I have some friends from the 1970s and 80s that are avid Burnley fans and I was going to arrange to meet up with them. We were on strike together in the 1980s and it is amazing how close you become when you're involved in a struggle.

I would also be going to the annual general meeting of the United Patients Alliance, where we would try to think up more strategies for legalising medical cannabis. Then the beast from the East hit us with this sucker punch and the coronavirus arrived!

These are strange days. The world has become a totally different place from pre-virus times. The news keeps on scaremongering, so I have



When COVID-19 derailed Charlie Gee's 2020 plans, he turned to positivity and hope to get himself through

taken to watching things that make me happy, such as repeats of Red Dwarf, The Good Life and Dad's Army. If we are going to be isolated, it is better to fill our heads with joy and laughter than fear.

The upside

Interestingly, the lock down is having some wonderful effects on the environment. River and air pollution have gone right down and the general fall in consumption has led to a big reduction in toxic and unnecessary waste. The governments of the world told Greta Thunberg and the rest of the eco-warriors that it would take years to slow down, never mind put an end to, the destruction of the planet. I hope we use this unintended world holiday to

take a step back to reassess what is truly important, and not go rushing blindly back into the hectic materialism of the lives we had before.

Finding Calm

As the world enters uncertain and precarious times, I find it important to have a philosophy which makes you feel better about the situation and, that is what I have. I gave up being afraid of death in the 1970s after reading books by Alan Watts. He died in the 1970s but had the foresight to record most of his lectures. The most accessible I have found is called "out of the trap". In a calm reassuring voice he explains the meaning of life and I recommend you look into his videos. His work can be found on YouTube.

QA

Questions and Answers

Ryan and Laura want to hear from you

Q I am looking for information on dentistry for people with multiple sclerosis (MS). I have had MS for 24 years. In the last few years my teeth are coming out one by one (at a fast rate!). I want to know if there are any colleges or universities that do dentistry either cheaply or free as part of their training.

A A study by Spanish researchers published in 2012 showed that people who live with MS have higher rates of tooth decay and gum disease. Poor oral health and hygiene may lead to infection, which can worsen MS

symptoms. Tooth loss impacts not just chewing ability, but also a person's smile and appearance, which, as we know, play a role in feeling good about yourself. There are colleges or universities that offer dental care as part of their students' learning and yes, there are some dental hospitals that offer free or low-cost dental treatment. The website for the Association of Dental Hospitals has a page giving information about dental treatments by students. There are 17 hospitals, mainly in the larger cities in the UK. Visit www.dentalhospitals.org.uk/about-us/dental-treatment-students/

Q I was diagnosed with MS 10 years ago after experiencing optic neuritis, and my neurologist has suggested it's possible I have benign MS. Can you explain what this is?

A Benign MS is a form of relapsing remitting MS (RRMS). A person is likely to be initially diagnosed with RRMS and after time – perhaps 10-15 years – a neurologist may suggest that their MS is 'benign'. By this they mean that there has been insignificant disease activity and the accumulation of any disability or disabling symptoms is likely to be minimal. Studies have shown that a very small minority of people living with MS in the UK will genuinely

have a benign form of MS.

A person with benign MS can still experience relapses, and their MS may change as they grow older. After a relapse, with benign MS, there is complete recovery. People with this form will have little or no disability after 10-15 years of being initially diagnosed as RRMS.

There are some MS researchers that won't use the term 'benign' as they say it is RRMS with very long periods of remission.

For a good, clear and well-written (with cited sources) article on benign MS, please see the website below from Very Well Health. It is American, but has been written by a medical professional and is peer-reviewed. Visit www.verywellhealth.com/benign-multiple-sclerosis-2440516

Our
helpline
team



Ryan



Laura

How to contact us

If you have any questions, worries or need some help, get in touch for free

Call 0800 783 0518

Email info@ms-uk.org

Visit ms-uk.org/helpline

Give us your feedback

We are always trying to improve our services and we value the feedback of our clients. We would be grateful if you could take a few minutes to complete a short survey about your experiences of using the MS-UK Helpline.

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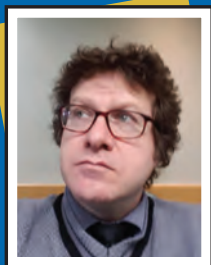
jack@centuryonepublishing.uk



01727 739 196

Scott's final say

In his second installment, our columnist discusses his dramatic diagnosis



After having been diagnosed with optic neuritis in the right eye, I

thought it was nothing more than tonsillitis, but in the eye!

My vision came back to normal again after a few weeks, and I would be back working on the aircraft like nothing had ever happened. No matter how much I rack my brains, I can never recall anybody mentioning multiple sclerosis (MS) at this time, and in typical Scott style I didn't dwell, or look deep into it.

This was all back in 2001 and I was working as an aircraft engineer in the RAF. Fast forward in time and the next five years saw me operate from the aircraft carriers, for the Kosovo no-fly zones supporting ground troops, being posted to a new

section for deep aircraft maintenance, and in the end, being sent to Kabul and Kandahar in Afghanistan. Here, I operated a whole section on my own as the lead corporal, attached to number four Squadron, a sister Harrier squadron of mine I knew well. All this was done to the letter, by the book and I came home in the summer of 2005.

In May 2006, my left eye started aching for no

with the instruction not to open it and to give it to the doctor on the RAF base. This drove Georgia crazy! I spent the remainder of the weekend keeping her away from the envelope. When I got to my doctor on base on Monday, he read the letter and called the local civilian hospital, telling me to go there straight away. The letter from the optician said he suspected brain cancer.

When I got to the hospital,

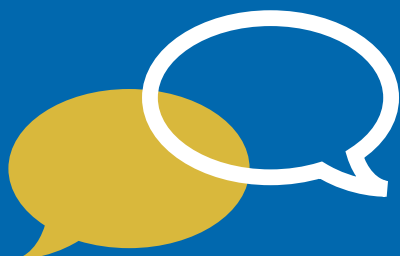


My doctor read the letter and called the local civilian hospital, telling me to go there straight away

apparent reason. By the weekend, it had gone completely and utterly blind. It was quite a huge thing for me in my job because I need all of my senses about me all the time due to the potential for my work to be very dangerous.

My wife Georgia urged me to go to see the local optician to find out what was going on. They were very thorough. They gave me a brown envelope

I was in to see the doctor within minutes, so I think they were taking this seriously. By the end of this appointment it was confirmed it wasn't brain cancer but might be something else. The doctors were reluctant to say what it might be without confirmation, so an MRI was booked. MS had been mentioned, but no one was going to say this with any conviction at this stage.



medimotion

GET MOVING EVERYDAY...

Enjoy safe exercise at home with MOTomed

Passive/Active Movement Therapy Devices

Regular MOTomed training can build endurance and strength, improve circulation and increase range of movement.

**Popular
Interest free
hire/buyer plan
available.**

**Delivery,
setup and
training
included.**

Widely used in UK hospitals, rehab centres, stroke clubs, MS therapy centres, leisure centres, schools and colleges.



MUVI



LOOP



Gracile

Discover how MOTomed can work for you:

tel: 01559 384097

sales@medimotion.co.uk www.medimotion.co.uk

THERA-Trainer EXERCISE BIKES

ACTIVE / PASSIVE



WHY THERA-Trainer?

Regular exercise at home is encouraged to help maintain and improve muscle tone, circulation and flexibility, decrease fluid retention and increase stamina levels - all vital for anyone with limited mobility.

CHOOSE
THE RIGHT EXERCISE
bike to suit both your
need and budget from
our range of THERA
trainers.

HIRE
PLAN
AVAILABLE



MOBI
540



TIGO
530



TIGO
558



TIGO
510

FOR A FREE NO-OBLIGATION DEMONSTRATION
IN YOUR HOME OR REQUEST A BROCHURE
CALL US ON 01908 564100
or email info@medicotech.co.uk

 **01908 564100**
 **info@medicotech.co.uk**
 **www.medicotech.co.uk**
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