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Hello,

Welcome to the March/April issue of New Pathways. I really hope that you are keeping well. The current climate is quite a scary one, and not like anything any of us have ever experienced before.

In the following pages, we have heaps of positive stories to help you feel upbeat. On page 24, we hear from Laura Goodall who thought her showjumping career was over when she was diagnosed with MS. Fast forward a couple of years and she’s now a para showjumper for Great Britain! She tells her how she found inner strength and went above and beyond to realise her dream.

We’ve also got all your usual favourites, including tasty recipes, Ian Cook’s adventures, plus a simple guide to meditation and mindfulness—something we can all use in these anxious times.

Enjoy reading!

Allison

New Pathways
March/April 2020

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In the News
All the latest must-read MS research and stories

What we know about COVID-19 and MS

The MS Society's medical advisors, a group that includes some of the leading neurologists in the UK, have agreed the following joint statement on the COVID-19 coronavirus and MS:

“We have been closely following developments around the COVID-19 coronavirus. This is a rapidly evolving situation with a lot of uncertainty. We have set out below our initial advice based on what we know currently, but we will keep this under continual review as events progress and our knowledge of the virus improves.

“In line with general public health advice, people with MS should ensure that they wash their hands frequently and where possible avoid being within one metre of people who are coughing and sneezing. Those with other health conditions in addition to MS (such as cardiovascular disease or diabetes) should be especially careful to observe these recommendations.

DMTs

“As of today (6 March 2020) our assessment is that people with MS would not normally need to stop taking a disease-modifying treatment (DMT) as a result of the threat of the virus. As with many features of MS care, risks can vary widely from person to person and will depend on a range of factors including the clinical features of your MS, your general health, and any other long-term health conditions you have. We have set out below an assessment of specific risks regarding different DMTs, as general guidelines to helpful people make an initial assessment of their own risk and decide when to contact healthcare professionals for more detailed advice.”

Safe medication

“Glatiramer acetate (brand name: Copaxone), teriflunomide (brand name: Aubagio), dimethyl fumarate (brand name: Tecfidera) and beta-interferons (various brand names) are generally likely to be safer than the other DMTs as they are not considered to be generalised immunosuppressive therapies. We likewise recommend that people with MS who are taking natalizumab (Tysabri) continue as normal, noting that we will be closely monitoring the developing situation.

“If you are taking a course of alemtuzumab (brand name: Lemtrada), cladribine (brand name: Mavenclad), or ocrelizumab (brand name: Ocrevus) you and your neurologist should consider delaying this as these treatments can hamper your immune system. The case for waiting could be particularly strong if you are scheduled for a second or third course of treatment of one of these DMTs, where a delay of a few months is relatively unlikely to affect the clinical progression of your MS. Before cancelling a course of treatment it is important to first discuss this with a neurologist or other healthcare professional – it may be that having understood the risks you feel it is best to continue, or there may be an alternative DMT that would be more suitable for the time being.”

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More than a million people are using cannabis illegally to self-medicate in the UK, according to a new YouGov poll. The survey found that there are 1.4 million users, half of which take the drug every day. The total spend on black market cannabis is an estimated £2.6 billion every year.

Cannabis usage was found across all demographics of society, with many people reporting that they take it for a range of illnesses. The poll found one fifth of people with MS self-medicate with the drug, so do 40 percent of people with Huntington's disease. Almost a quarter of a million people with arthritis buy cannabis, 100,000 cancer patients, and well as people suffering from depression, anxiety and epilepsy.

The results are published in a report called ‘Left Behind - The Scale of Illegal Cannabis Use for Medicinal Intent’, by the Centre of Medicinal Cannabis. It states that the use of cannabis ‘unnecessarily exposes’ users to significant personal risk, and calls on the government to review policies that block suffers from accessing cannabis medicines legally.

Blood fats associated with increased artery size in people with MS

The amount of blood fats a person with MS has could be linked to changes in size of the arteries around their neck and skull, according to a new study.

Researchers wanted to investigate the link found in previous studies which showed cardiovascular health is a factor that affects MS occurrence and progression.

The team at the Jacobs School of Medicine and Biomedical Sciences, University of Buffalo, New York, recruited 104 people with MS and 41 healthy participants.

Magnetic resonance imaging (MRI) was used to take cross-section imagery of the carotid artery and vertebral artery, the two main arteries supplying blood to the neck and skull.

The scientists found that lipoprotein, which is a combination of protein and fat that sticks easily to blood vessel walls, had a strong association with artery size in people with MS. Those with higher levels of lipoprotein had larger arteries. There was also a moderate association with age and people with MS and artery size. These associations were not observed in the healthy group.

The researchers concluded that high blood fat levels are associated with problems in the arteries of the head and neck in people with MS. They said that while the clinical and pathological significance of this is unknown as yet, it indicates another mechanism of action by which blood fats may interact with MS pathophysiology and paves the way for further research.

www.ms-uk.org
Cognitive decline in MS may not be progressive or inevitable

Progressive cognitive decline for people with MS may not be as inevitable as once thought, a new 10-year study has found.

The study even found that for some patients, a ‘bouncing back’ effect took place and they improved in certain areas of cognition.

Researchers in Greece reviewed data from 59 patients. Of these, 14 had clinically isolated syndrome and 45 had relapsing remitting MS. At the start of the study, the Brief Repeatable Battery of Neuropsychological Tests was used to assess participants’ cognitive impairment, and again 10 years later.

The scientists found there was around a 10 per cent increase in cognitive impairment. But when looking at the data on a case-by-case basis, researchers said some people had failed at different areas of cognition to which their original decline was noted in. Overall, people with normal memory-related scores 10 years ago were more likely to be impaired in these areas after the 10-year follow-up.

Those with normal information processing speed scores rarely showed a decline when tested a decade later.

Some with baseline impairments in working memory and/or verbal fluency also experienced significant improvements in cognitive abilities 10 years on, often to the point of no longer being considered impaired.

The researchers said that this means cognitive impairment at baseline assessment does not necessarily lead to a progressive decline, and while the overall amount of individuals with cognitive impairment does increase, some people had improved in specific areas, and not declined in others. They said the improvements, or ‘bouncing-back’ effect seen in some areas of cognition may reflect the damage compensation capabilities of the brain in people with MS.

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Comorbidities do not raise risk of MS-related hospitalisation

Having comorbidities, or other health conditions, alongside MS does not increase the risk of hospitalisation for MS symptoms, a new study has found, but it does raise the risk for any-cause admission to hospital.

Researchers at the University of Saskatchewan in Canada wanted to discover if there was a link between comorbidities relevant to people with MS, specifically high blood pressure, hyperlipidemia (too much blood fat), diabetes, ischemic heart disease, chronic lung disease, epilepsy, migraines and mood and anxiety disorders, and hospitalisation.

With the exception of hyperlipidemia, all of the listed comorbidities raised a person’s risk for hospitalisation for any cause. The more comorbidities present, the higher the risk. But these other conditions did not raise the risk for hospitalisation for MS-specific reasons. Interestingly, the study found a link between having two or more comorbidities and a lower rate of MS-related hospitalisation.

The scientists said the reason for this may be due to people being on medications to treat these other conditions, which may have had ‘pleiotropic effects’, which means effects other than the originally intended ones. They gave examples of two medications, statins and metformin, used to treat high cholesterol and type 2 diabetes respectively, both of which have been suggested by previous studies to have beneficial effects on MS.

Medicinal cannabis users may develop tolerance to drug’s sleep-inducing effects

A new study has found that medicinal cannabis taken by people to help ease chronic pain may cause sleep problems.

Researchers found that when people first began using the drug, they were less likely to wake up during the night than those who did not take cannabis. But the scientists found that with continued use, people built up a tolerance and the effects on sleep were reversed, with users waking up more often during the night than non-users.

People taking the drug also ended up reporting more problems falling asleep than those who didn’t take it. Many people with MS self-medicate with cannabis, and medicinal cannabis is allowed to be prescribed on the NHS for people with MS, but only for muscle stiffness and spasticity, not chronic pain. The drug remains illegal in the UK.

The authors said that the study, which was published in the British Medical Journal’s Supportive and Palliative Care Journal, may ‘signal development of tolerance’ of the drug.

www.ms-uk.org
Eating less meat and eggs may slow onset and progression of MS

Reducing dietary intake of the amino acid methionine might delay the onset and progression of inflammatory and autoimmune disorders like MS, according to a new study.

In MS, the immune system’s T-cells attack myelin, the protective sheath surrounding the brain and spinal cord’s cells. Methionine serves as a building block of protein but also gets processed within cells to make a molecule called S-adenosyl-L-methionine (SAM).

T-cells don’t produce their own methionine and must instead absorb it from the person’s dietary intake. Methionine is particularly abundant in meat and eggs. Researchers found that during an immune response, T-cells absorbed methionine and converted it to SAM. A steady level of SAM increased the proliferation of a T-cell subtype, Th17 cells, linked to inflammation.

The scientists then fed mice a diet greatly reduced in methionine. They were found to have decreased proliferation of Th17 cells, which lead to a delay in disease onset and its progression.

“Methionine is critical for a healthy immune system,” says Russell Jones PhD, the study’s author. “Our results suggest, for people predisposed to inflammatory and autoimmune disorders like multiple sclerosis, reducing methionine intake can actually dampen the immune cells that cause disease, leading to better outcomes.”

The researchers did state that this study took place in a mouse model, so more research with human subjects was needed.

Feeding tube before 50 can extend life

People with dysphagia, which is a difficulty in swallowing, may live up to two years longer if they have a feeding tube before the age of 50, a new study has found.

It’s estimated around 30 per cent of people with MS have dysphagia. Problems with swallowing are known to significantly lower life quality, affect mental health and raise the risk of dehydration, malnutrition, and a spiration of food particles that can cause lung infections and pneumonia.

Treatment includes inserting a feeding tube through the abdominal wall to give nutrition and hydration, and reduce the risk of lung infections.

Researchers studied the medical records of MS patients who had a feeding tube inserted in Sheffield hospitals between 2005 and 2017. They found that after a year, 81 per cent of people were still alive, and more than half were still alive after two years.

People who had had the tube procedure before they were 50 survived longer, an average of more than two years, than with those who had it at later ages, who survived on average for another year and a half.

The researchers say that although more studies are needed, these findings “Will help inform clinicians and patients with MS making decisions regarding gastrostomy tube placement.”
85 per cent of people with MS experience insomnia

Insomnia is playing an unwelcome part in the lives of people living with MS, with 85 per cent of MSers experiencing sleeplessness, according to research from social network and charity for people with MS, Shift.ms.

A survey also found that a staggering 79 per cent of MSers experience sleeplessness every week, and this in turn is having a substantial impact on their health and wellbeing, as well as exacerbating their MS symptoms.

Three quarters of survey respondents told Shift.ms that sleeplessness is having an impact on their mental health and wellbeing, while 84 per cent believe it impacts their day-to-day life.

Following this survey and based on recurring conversations between members on the Shift.ms social network, the charity has created ‘Awake’, a storytelling film that explores the perspective of those experiencing both insomnia and a neurological condition.

The film was created using real-life phone calls from people living with MS and experiencing insomnia. Shift.ms set up a phone line that could be called throughout the night, with filmmaker Matan Rochlitz on hand to answer each phone call personally. The calls resulted in some emotional, authentic and surprising stories being shared.

“A diagnosis of MS can leave people to live a life full of uncertainty about their condition and future,” explains George Pepper, CEO and founder of Shift.ms. “This uncertainty can lead to lack of sleep that can have a serious impact on MSers, often going unrecognised by health professionals, heightening symptoms and having a negative impact on MSers’ quality of life.”

Learning second language boosts brain volume in people with MS

Have you ever considered trying to learn a second language? According to a new study, it could help expand areas of the brain that have been damaged by MS and boost mental wellbeing.

The research, which was published in the journal PlosOne and took place at Medical University of Innsbruck in Austria, enrolled 11 people with relapsing remitting MS (RRMS) and 12 healthy controls. The median average age of the participants was 37, the average time since diagnosis was 3.3 years, and they had an average score of 1.5 on the expanded disability status.

The study focused on teaching people English, which was none of the participants’ first language. They attended classes for three hours each week, and had homework. The training programme lasted for eight weeks.

The researchers took magnetic resonance imaging (MRI) scans of participants’ brains before the language training began. There was significant loss of grey matter volume in various regions of the brains of the people in the study who had MS.

Some studies in healthy adults have found that short-term language learning courses led to an increase in grey matter volume in certain brain regions, including areas involved in language and cognitive processing. After taking the course, scans revealed that grey matter increased in areas responsible for short-term memory (the hippocampus), learning (the putamen) and environment recognition (parahippocampus).

Despite having reduced grey matter, participants with MS were as successful in learning the language as their healthy counterparts in terms of listening comprehension, fluency and vocabulary scores.

These findings also indicate neuroplasticity (the brain’s ability to rewire after damage) is present in the brains of people with MS.

www.ms-uk.org
One in six MS carers working 90 hour weeks

As many as one in six carers for people with MS are working for more than 90 hours a week, a survey by the MS Society has found.
Out of 549 respondents to the survey, all of whom were family and friends who support a loved one who had MS, one in three said they had to give up paid work to care for them.
Forty one per cent of people were providing more than 35 hours of unpaid care each week, and 16 per cent were giving more than 90 hours.

A huge 90 per cent of people said their health and wellbeing had been negatively impacted because of their caring role, and only one in six people of working age had been given enough support to stay employed.

Cognitive impairment worsens during relapse

A new study has found that people who experience a relapse from MS tend to see a decline in cognitive test scores, and sometimes don’t experience a full recovery.
A team of scientists from the University of Buffalo looked at 50 patients diagnosed with relapsing remitting multiple sclerosis (RRMS). They were aged between 18 and 65 years and had an expanded disability status scale (EDSS) score of less than seven.
Patients also had to have experienced a decline in symbol digit modalities test (SDMT) of at least three points to show cognitive decline.
Each participant was evaluated at baseline, at point of relapse, and during a three-month follow-up.
Patients were evaluated on changes in cognitive processing speed, as measured by the SDMT, plus measures of memory, ambulation, and manual dexterity. The investigators sought to identify any correlations between these changes and EDSS scores, magnetic resonance imaging (MRI), and cognitive reserve.
At time of relapse, patients saw an SDMT decline from 55.2 to 44.6, recovering to 51.7 at the three-month post-relapse point, all of which were significantly different compared with the stable controls.
People also experienced a slowing in the timed 25-foot walk test.
The researchers say these findings contribute to a growing body of evidence about the long-term impact of relapses.

Living near busy roads linked to MS risk

A new study has found that living close to major roads or motorways increases the risk of MS.
Researchers at The University of British Columbia analysed data from around 678,000 people between the ages of 45 and 84 who lived in Metro Vancouver between January 1994 and December 1998. They investigated whether environmental factors during this period contributed to the development of neurological diseases including non-Alzheimer’s dementia, Parkinson’s disease, Alzheimer’s disease and MS.
The researchers found that living within 50 meters or less distance to a major road, or less than 150 meters from a motorway, was linked to higher incidence of all of the neurological conditions included in the study.
Researchers said that the presence of fine particulate matter, which is produced by combustion, might contribute to the risk of MS.

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Taking the next step

MSer Lucy Traynor tells New Pathways how she went from being ‘not at all sporty’ to preparing to run the Virgin Money London Marathon

One night in 2014, I was walking home from dinner with friends when all of a sudden I looked at the traffic to the side of me and realised that I couldn’t see properly. My vision had gone double. In the days that followed I was in denial, brushing it off as tiredness, trying to carry on going to work with horrific headaches and one eye closed, to finally going to an optician, my GP and then a neurologist. I will never forget seeing the results of my very first MRI scan. The neurologist tilted his computer screen to show the inside of my brain, only with big white blobs of scar tissue scattered seemingly everywhere. I went white as a sheet!

Anxiety and panic
The weeks following that first brain scan were a definite low point. My vision slowly came back to normal, and the headaches subsided, but I was left with an overwhelming sense of anxiety and panic. What was going on in my brain? Would it happen again? Was it multiple sclerosis (MS), or something else? Although I went back to work, I struggled to sleep and had barely any energy, only getting through the days with coffee after coffee. I had panic attacks most days and couldn’t take control of the worries filling my mind.

Four months later, the neurologist called me back for a follow up MRI scan. I was hoping for good news, but instead he told me he could see more damage to my brain which meant it was more likely to be MS, although he still couldn’t be certain.

Holistic approach
He gave me the option of beginning medication, but I wasn’t ready. There is no cure for MS and I wasn’t ready to start on medication that I might take for the rest of my life, especially without a definite diagnosis. Instead, I was determined to take control of my health, and so I made some huge changes to my lifestyle. I researched MS lifestyle factors and I quit gluten, dairy, alcohol and caffeine overnight.
I decided to quit gluten, dairy, alcohol and caffeine overnight. In a matter of days I began to feel better, and most importantly I felt a sense of control. A friend encouraged me to go on a mindfulness course with her, which helped me to take control of my thought patterns and to reduce my anxiety. The same friend told me about MS-UK and their helpline (funnily enough her mum had worked for the charity when we were at school together). At that point, I was curious to understand more about MS but Google was too overwhelming (there seemed to be so many bad news stories!) but the kind lady at MS-UK was a trusted source of information that I really valued.

A new blessing

The changes to my diet and lifestyle left me feeling healthy, energised, and happier. I consciously focused on all the good things I had – my friends and family who had been so wonderfully supportive, and my vision and physical strength which had thankfully restored following the relapses I had suffered.

In a way, the uncertainty of my future with MS made me keen to make the most of every moment, and be grateful for every day. In 2016, Nick and I had the most amazing blessing - our twin daughters were born! Thankfully, I avoided a post-natal relapse (which can be caused by hormone changes) and broadly felt really well, apart from the lack of sleep that came with baby twins!

Diagnosis at last

When I was finally diagnosed with MS in 2017, I agreed with the neurologist that it was time to begin medication. There were so many options available, each with different levels of effectiveness and a unique set of possible side effects. I struggled with my decision and turned to information offered by various MS charities for help and advice.

Fast forward to 2020 and I am training to run the Virgin Money London Marathon for the first time. I never believed previously that I was capable of a marathon. In fact, when my husband Nick asked me if I wanted to do a half marathon in summer 2019, I told him there was no way I could do it! Thankfully he persuaded me to give it a go, and once I had managed a half marathon, I felt I could do anything.

Nick and I decided that we wanted to raise money for MS-UK because we knew how fantastic they were in supporting me and we wanted to raise money to enable them to help others, too.

Inspiration

The last few months of marathon training have genuinely been fantastic. I’ve found that I love training for a goal that I always felt was unachievable, noticing myself get stronger with each run, and enjoying the mindful experience of running in the countryside and taking in the views, whatever the weather! Meeting the MS-UK team and the other runners has been brilliant too - a reminder of how many people there are out there who care, and hearing the stories that have inspired others to pick up their running shoes to raise money for this fantastic charity.

I am grateful to MS-UK for the opportunity to take on this massive challenge, and for helping me shift my mind-set from someone who isn’t at all sporty into a marathon runner! And I am forever grateful for my friends and family who have supported me in my own MS journey, and who are now helping me raise money for MS-UK. Thank you!
Getting on with MS

MSer and Feature Writer Ian Cook discusses ageing and multiple sclerosis

As you know, lots of people live very long and fulfilling lives with multiple sclerosis (MS). But when it comes to public discussions of life, death and MS, there is often talk in the media of euthanasia, even though this is a choice actually made by a tiny minority of MSers. Sadly, you see little discussion of the decades of great life the vast majority of us live with MS. Unfortunately, as with most news coverage, everyone focuses on the negative.

Looking forward to my 62nd birthday in a few months’ time, it’s reassuring, therefore, to read research published recently by the US National Multiple Sclerosis Society (NMSS), that the majority of us MSers can look forward to an almost normal lifespan – well, a lifespan just a few years shorter than the general population.

Life expectancy

The exact figure is seven years shorter but this isn’t so bad when you consider people with type 2 diabetes, on average, have a shorter life expectancy of about 10 years and people with type 1 diabetes, on average, have a shorter life expectancy of about 20 years. MS is very little in comparison to these relatively common conditions. Although that doesn’t exactly sound cheery, my point is that MS isn’t always a factor. Apart from cases of severe MS, which are relatively rare, the prognosis is generally good.

Keeping it real

That is not to say MS doesn’t bring additional problems as we grow older. Those of us getting on with MS are realists. We know we may also have to contend with issues like self-catheterisation and health problems that others don’t, and we are aware that our MS-related...
Most people with MS have a close to normal life expectancy

Lifestyle

unpredictability. Everyone is different when it comes to the condition, and it’s hard to predict with accuracy how MS will progress in individual cases. Most of us will have witnessed how the severity of the condition varies widely from person to person. What you can say with greater certainty is that most MSers will undergo a certain amount of disease progression during the course of the illness. To help determine our personal risk of progression, it helps to understand the risk factors at work here.

Risk factors

According to the US Mayo Clinic, certain factors indicate a higher risk of more severe symptoms, including the following – being over 40 at the initial onset of symptoms; initial symptoms affecting many parts of your body or initial symptoms affecting mental functioning, urinary control, or motor control. Looking at my own case, my first symptoms included motor control and urinary function (a bad sign) but as I was under 40 (a good sign) you could say it’s a mixed picture for me.

And when it comes to looking forward (prognosis) and complications that may arise, it is interesting that these are affected by the type of MS you have. Primary progressive MS (PPMS) is characterised by a steady decline in function without relapses or remissions. Life expectancy here is the lowest of all the types of MS. For relapsing remitting MS and secondary progressive MS (my type), there are several guidelines that help predict prognosis. People with RR and SPMS tend to do better if they have experienced few attacks in the initial years post-diagnosis and a longer amount of time between attacks, as well as a complete recovery from attacks. They also do better if symptoms relate to sensory problems, such as tingling, vision loss, or numbness and have neurological examinations that are almost normal five years after diagnosis. While most people with MS have a close to normal life expectancy, it can be difficult to predict whether the condition will worsen and by how much. However, MS isn’t a fatal condition.

My future hopes

So, as an individual MSer, I am bound to ask exactly what lies ahead for me. What can I expect as a 61-year-old man with SPMS diagnosed nearly 30 years ago? Research shows MS generally affects quality of life more than quantity of years lived. While certain rare types of MS can greatly affect lifespan, these are the exception rather than the rule. Those of us getting on with MS must contend with many difficult symptoms that will affect our lifestyle, but we can rest assured that our life expectancy essentially mirrors that of people who don’t have the condition.

Interestingly, Professor Gavin Giovannoni of Barts Hospital in London says he thinks ageing and MS is going to become a ‘hot topic’ this year. I hope this is the case and that we remain focused on the fact that although MS may mean living a life a little shorter than we would like, it’s certainly not a death sentence nor a reason to be preoccupied with euthanasia, despite what you might believe if you read certain sections of the tabloid press.

www.ms-uk.org
I experienced my first symptoms of multiple sclerosis (MS) in 1990 when I was 20 years old. Back then I was told that I had a virus that was similar to MS, but that it could not be MS because I was too young.

I was treated with steroids for three days and went into remission. In the summer I would feel fatigued and in winter like nothing could stop me. I kept as fit and active as I could. But increasingly, I noticed that my right leg was weaker than my left, and I would trip up on uneven pavement or if I was rushing.

After the birth of my daughter in 2004, I didn’t feel great and noticed I would limp when I was very tired and found it difficult to run. In late 2009, I saw a neurological consultant and after I had an MRI scan, I was unfortunately diagnosed with secondary progressive multiple sclerosis (SPMS).

I soon fell pregnant and had a son and was told I could not start medication until I had stopped breast feeding.

My faith
My faith was really important to me after my diagnosis. Muslims are taught that life on earth is temporary, that this life is a test, and you must live it being as good a person as possible. It is human to be kind and respectful to all living things, and to all faiths. This is not to say that I don’t feel frustrated that I can’t be the person I was when I was fit and healthy at 19 years old. However, especially after the age of 40, I have accepted my MS and make the necessary adjustments to my life far more than I used to.

The same cannot be said about some of my family members and friends, who do not see me live with MS, but to me that’s OK. My faith gives me hope that things will get better for people diagnosed with MS and in the meantime, I am grateful for what I have and will keep going as much as I am able to. I desperately don’t want to be dependent on others, but sometimes you have to, and I am thankful that they let me.

The holy month
Ramadan is the Islamic holy month where Muslims fast for a period of 29 or 30 days, depending on the sighting of the new moon. We consume no

My faith and my MS

Talat Ahmed explains how Islam helped her cope with her diagnosis, and the struggle to fast during the holy month of Ramadan.
food or drink between dawn and sunset. This year it runs from 23rd April to 23rd May.

The purpose of doing this is because as Muslims, we believe that it is the time to feel closer to God. It is a deeply spiritual time when we as a community become more focused on prayer and instilling a discipline to carry on the day without any food or even a drop of water. Instead, we focus on being thankful for what we do have, give to charity, reflect and correct our behaviours as human beings and not waste our time here on earth. We are not eating food and drink and we do this because we want to please Him.

In winter months, fasting during Ramadan was fine – not too hot. I got plenty of sleep because there were less daylight hours, and it felt great to be taking part with all the family. It felt really fulfilling. However, every year after Ramadan I felt my condition slightly worsen. But I persevered. It was important to observe fast, because it was what I was brought up to believe. The atmosphere in the household changes. Family feels more unified. We know we are going to have extra special food to look forward to – not the healthiest I hasten to add! But especially when you’re a kid, although it’s not obligatory to fast until puberty, there’s a change of routine to follow that felt special and came with a sense of togetherness, which is difficult to capture in words.

**Summertime sadness**

The Islamic calendar follows the lunar calendar which is shorter by roughly 10 days a year. Therefore, when Ramadan fell in the summer months, it was torture! I couldn’t wait for my respite (women who are on their period do not keep fast, but they have to make it up within the year). However, to my horror, my period never came, and annoyingly it was like that for five years!

People who are ill or have chronic health conditions, or mothers who are pregnant or breastfeeding are not required to fast during Ramadan. Therefore, last year was the first year I did not keep fast and I really felt like I was missing out. The weather was unbearable and so, with guilt, I felt relieved that I was not taking part. To make up for not fasting, I gave money to charity, so a poor person would keep fast on my behalf, which is equivalent to paying a person £5 per day. But, just because I do not keep fast this does not mean I cannot take part in all the other activities, so that has not changed much, and I do as much as I can.

**The hardest part**

The biggest challenge of Ramadan has to be lack of sleep. I need sleep. I love sleep. There’s a saying in Islam – ‘Prayer is better than sleep.’ I couldn’t quite follow that mantra. Tea and coffee withdrawal is hard, and I would normally give up tea and coffee and definitely eat a lot less chocolate during Ramadan. As soon as it ended, though, alas so did those good habits!

**My advice**

There are so many forums now and so much information out there on how to receive help. People live much better lifestyles nowadays by changing their diet and going onto disease-modifying treatments much sooner than when I was first diagnosed. Finally, we are so lucky to have the NHS in the UK and there is now a far greater investment into MS globally, which gives me hope that someday there will be a cure.

www.ms-uk.org
“SpeediCath® Compact Eve has given me a **freedom** that **grows every day**”

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**SpeediCath® Compact Eve**
“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 fiancéé. 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.

My catheter size is ..................CH

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How mindfulness can help

Awareness of your breath and body can transport you to a place of calm, says expert author Danny Penman

Studies have shown that practising mindfulness can improve quality of life and help people with multiple sclerosis (MS) cope better with the condition. Some studies have shown it can have a positive effect on pain, stress and anxiety. Here, we look at what it is and how to get started.

Unconscious awareness
Mindfulness is unconscious awareness. It is paying full conscious attention to whatever thoughts, feelings and emotions are flowing through your mind, body and breath, without judging or criticising them in anyway.

It is being fully aware of whatever is happening in the present moment without being trapped in the past or worrying about the future.

It is living in the moment, not for the moment.

Mindfulness is not a religion. Nor is it ‘opting out’ or detaching yourself from the world.

It’s about connecting and embracing life in all of its chaotic beauty, with all of your faults and foibles.

The aim of mindfulness
It is to understand how the mind works. To see how it unwittingly ties itself in knots to create anxiety, stress, unhappiness and exhaustion.

It teaches you to observe how your thoughts, feelings and emotions rise and fall like waves on the sea.

And in the calm spaces in between lie moments of piercing insight.

You are not your thoughts.
You are the observer of your thoughts. It’s a subtle distinction and difference that’s only perceived with practice.

Your thoughts are a running commentary on the world; a ‘best guess’ of what’s truly happening. Often, your thoughts will reflect the powerful emotional currents swirling through your mind, body and breath.

Sometimes they are true, sometimes they are a frantic work in progress, sometimes they are wrong.

Mindfulness teaches you to take the long view, to put your thoughts, feelings and emotions into a broader context.

And when you do so, your most frantic and distressing thoughts simply melt away of their own accord, leaving behind a calm, clear, insightful mind.

Awareness of your breath and body can transport you to a place of calm, says expert author Danny Penman
How did you do?
A person whose mind isn’t wandering, isn’t meditating.
Did you feel restless and uncomfortable? Discover a few aches and pains? Perhaps there was a long list of things that needed doing right now, this minute.
Maybe you had wild swings of energy. One moment you were bubbling with enthusiasm, then suddenly... exhausted.
And the powerful emotions that swept you along - the frustrations and disappointments, the feelings of inadequacy followed by the bitter taste of defeat as yet again you realised that your mind had wandered away from your breath.

Your mind may eventually become calm for a little while, or filled with thoughts or feelings such as anger, stress, or love. These may be fleeting. See them as clouds in the sky (simply watch them drift past). Try not to change anything. Gently return your awareness back to the sensations of breathing again and again.

After five minutes (or longer if you can manage) gently open your eyes and take in what you can see, hear, feel and smell.

Repeat twice a day.

You probably felt that your mind was so chaotic you will never be able to focus for more than a few seconds at a time. What a mess... This is normal. It’s your first lesson. This leads to the central guiding principle of mindfulness - you cannot fail. Realising that your mind has wandered away from the breath is the meditation. It is a moment of mindfulness.

Adapted from The Art of Breathing by Dr Danny Penman (Harper Collins), amazon.co.uk

www.ms-uk.org
Why leave a gift?  
By putting people affected by MS at the heart of our work, we can make sure that every person who leaves a legacy is honoured in the right way. We are an independent charity so we never accept funding that may jeopardise our ability to act in the best interests of people affected by MS. By leaving a gift in a Will to MS-UK, people hand down their legacy to the next generation. We could not be here for people affected by MS without this support.

Legal advice  
The first step is to seek support from a qualified solicitor or a member of the Institute of Professional Willwriters to help you get started. You can always take a family member or friend with you to appointments. A simple Will can cost between £144 and £240. If you have a more complex Will or require specialist services, the cost can go up to about £600. It really does depend on your individual circumstances, but you can compare quotes from a few solicitors before going ahead with anything.

Making a Will  
We know that it can be difficult to know where to begin when writing or updating a Will, so here’s some information about getting started which we hope you find useful. It’s important to remember you do not need to face this alone and by speaking to a legal professional you can be supported through this process. By having a Will you will provide security for your loved ones. A Will is a legally binding document, so you can have peace of mind that your wishes will be carried out.

Leaving a legacy  
Have you ever thought about leaving a gift for the next generation in your Will?

We know that thinking about your Will can be daunting. You want the peace of mind of knowing your loved ones will be looked after and your wishes will be honoured. It can feel like a big task, but by creating a Will you can be reassured that everything will be taken care of.

For the past 25 years, MS-UK has been supporting people affected by multiple sclerosis (MS). MS is a life-long condition that requires long-term support. There is currently no cure, so for the thousands of people affected across the UK we need to be here, not just today but in the future. In 2018, more than 20 per cent of our income came from legacies.

The MS community informs all that we do, so every penny donated to us is spent with care and consideration.

Call 01206 226500
"I was diagnosed with MS just over 20 years ago. I consider myself fortunate because my symptoms are fairly mild, which enabled me to work full time until I retired last year. The reason I am leaving a legacy in my Will to MS-UK is influenced by my nephew Philip who had primary progressive MS and has now passed away. Philip lived in his own property with the support of carers until he died in 2017. I like the fact that MS-UK give information and support to people diagnosed with MS to help them live as independent a life as possible.

Christine has decided to leave a legacy in her will

“I was diagnosed with MS just over 20 years ago. I consider myself fortunate because my symptoms are fairly mild, which enabled me to work full time until I retired last year. The reason I am leaving a legacy in my Will to MS-UK is influenced by my nephew Philip who had primary progressive MS and has now passed away. Philip lived in his own property with the support of carers until he died in 2017. I like the fact that MS-UK give information and support to people diagnosed with MS to help them live as independent a life as possible.”

Sarah was diagnosed with multiple sclerosis in 2007

Before connecting with MS-UK, she had not met anyone else affected by MS...

“I’ve strived all my adult life to be independent – financial independence and being mentally independent have always been very important to me. And I feel as independent now as I always did, although there have been some shaky moments over the years, particularly when I was first taken ill with MS, when I was diagnosed and when I’ve had relapses.

“I think fear of the unknown and of the future made me very scared, and my feelings of independence were badly shaken for a while. I’ve come to learn that knowledge about MS is a powerful tool for helping me come to terms with my condition. So I’m finding out about things that can help me achieve better independence now and for the future. Being able to think for myself and decide for myself is so important.”

Our supporters make it possible for MS-UK to be here for people like you when you need us.

What our clients say...

Our mission is to improve understanding of multiple sclerosis and provide support where it is needed most. Every gift that is left means we can offer our services to more people.

“For over 18 years (since being diagnosed with MS) of this journey, New Pathways has been like a friend by my side.”

Our counselling service gave hundreds of telephone sessions to people across the UK and we ended the year with over 2,000 subscribers to our magazine, New Pathways.

“You just understand how I’m feeling.”

Every legacy we receive helps make this work possible.

“You have got me through some dark times. I hope you will be around for many more years.”

Last year we answered hundreds of enquiries through our helpline. Every time we picked up the phone, we were able to be here for someone affected by MS.

Get in touch

MS-UK
Unsworth House
Hythe Quay
Colchester
Essex CO2 8J F

Call 01206 226500
Email jill@ms-uk.org
Visit www.ms-uk.org/
Gifts-and-Legacies

www.ms-uk.org
I was diagnosed with multiple sclerosis (MS) in 2015. I would lose the ability to feel temperatures and scald myself when I got in the bath. My skin would hurt and tingle, I was exhausted all the time, I’d fall over and I’d drop things. When I was competing on my horse, my muscles would collapse on me as soon as I got warm, my vision would blur and I’d fall off. I’d then struggle to walk for days after.

I had to stop competing as I kept having panic attacks on the horse while waiting for the symptoms to come. The more stressed I got, the worse the symptoms were.

Early days
At first, I was relieved to have a diagnosis and to know what was wrong with me. Then reality hit home. I got very depressed and felt like life as I knew it was over and I’d never be able to do anything with my horses again. I felt like I was going down a black hole. Everything I’ve worked for in my life was for my horses and I got to a stage where I couldn’t even look after them never mind ride them.

Taking the reins
Eventually, I decided I wasn’t going to let MS rule my life. I’m quite a determined person and felt I needed to do more and not just give up on my dreams. So I visited the doctors, was prescribed anti-depressants, and started to gradually get my fitness back up in baby steps. I began going out for
a walk on the horses until I built myself up. Exercising definitely lifted my mood. The more I did, the better I got, and it actually made my symptoms less severe, along with my treatments.

**Competing for Britain**

Around 18 months ago, I was classified as a para equestrian. Last year was my first proper year back into showjumping and, within my first four months, I was fortunate enough to be selected to represent Great Britain in para showjumping at Pferd International Munich in Germany at the end of May.

I had a tough two months prior preparing for the event, with different treatments, exercises and training every single day. It all paid off, though, and I came home with an individual silver and gold for my country!

Having MS can make competing difficult as you don’t know what each day may bring for your body. I never know when my muscles are going to have enough and pack in – I get next to no warning. Fatigue is also a difficult problem, especially when you are competing consecutively each day or twice a day. I have to really push myself to do it, but once I have, I will usually pay for it for a few days afterwards whilst my body recovers.

Competitions can be nerve rattling enough, especially when you are relying on an animal as your team mate, but the unpredictability of MS symptoms always makes it that little bit worse. I’ve had times when my legs have given up on me before I’ve even started, but I’ve just brushed myself off and tried again another day.

I also have to have my stirrups tied down as my legs have a mind of their own and can float off anywhere when I’m riding! My mum is an incredible help – I really physically couldn’t do it all, and she is always there on hand to assist when needed, or take over when my body gives up for the day.

To keep on top of things, I take a high dose of vitamin D, and have regular weekly visits to my chiropractors, Shrewsbury Family Chiropractic. I have a personal trainer twice a week to keep all of my muscles working – my motto is use it or lose it!

I used to have Copaxone injections, but my MS is too active and I was still relapsing five or six times a year, for around six weeks at a time. Now I’ve been having Tysabri injections once every four weeks for the last 18 months. I’ve only had one relapse since I’ve been on it and that was in the first six months.

**New opportunities**

Since my diagnosis and becoming a para show jumper, I have had so many opportunities come my way which I couldn’t have had had as an able-bodied rider. I have met so many incredibly inspiring people who have also got difficult battles to fight. And to have inspired others to pursue their dreams gives me such a buzz. I was shortlisted down to the top four in the country for the Horse & Hounds ‘Inspiration of the Year’ Awards in 2019. For my actions to have had that effect on people is an incredible feeling and encourages me to keep fighting even on the toughest of days.

To anyone newly diagnosed, I’d say things may be tough now, but it won’t last forever. There is light at the end of the tunnel. You may not be able to do what you did prior to diagnosis, but you’ll be able to find new ways to adapt and still lead the life you dreamt of as long as you keep a positive attitude.

To have inspired others to pursue their dreams gives me such a buzz.
We are travelling through uncharted waters right now and firstly I want you to know that we wish you well in this challenging time.

It goes without saying that everyone must do everything they can to avoid getting ill, but I’m aware that in difficult times it can be all too easy to neglect our mental health. Please rest assured that no matter what measures need to be put in place, at MS-UK our priority is to be here to help the MS community. While our offices are closed to ensure the safety of our staff and our clients, colleagues will be working remotely and our Helpline will remain open should you need information or emotional support. Please call for free on 0800 783 0518.

Staying at home and keeping safe in the current climate can present its own challenges. Sitting around watching TV all day is tempting, but the fact is, it’s important to keep active even if you aren’t able to get out and about in the fresh air. That’s why MS-UK’s physical activity specialists have put together a series of five videos to help you exercise safely in your own home whatever your level of ability. You’ll find these on our YouTube channel, plus all of our other social media.

We are sorry for any delays and inconvenience caused by the current situation. Please keep checking our website (www.ms-uk.org) and social media pages for updates and we aim to return to the normal running of all our services as soon as it is safe to do so.

Our services are all still available to you. To register for MS-UK Counselling, visit www.ms-uk.org/counselling. If you have a query regarding New Pathways magazine, please email newpathways@ms-uk.org.

For all other enquiries, please email info@ms-uk.org or call 01206 226500.

Due to the high volume of enquiries we are getting at this time, we aim to respond within three working days but this may not always be possible at the moment.

I wish you and your families all the best during the current health scare. Hopefully we will be back on track and up and running again as soon as possible.

Amy

Call
01206 226500

Email
newpathways@ms-uk.org
Low mood, depression and MS

MS-UK Counsellor Annabel Nicklin discusses the difference between low mood and depression, and how to spot if you have a problem.

The mental health charity, MIND, estimate that one in four people living in the UK will experience a mental health problem each year. As counsellors, we are often asked what the difference is between low mood and depression.

Low mood symptoms
Symptoms of a low mood can include worry, feeling anxious or a sense of panic, sadness, tiredness, anger, frustration and low self-esteem.

When does low mood turn into depression, though? The most important sign to recognise is if we notice that our low mood is starting to interfere drastically in our daily life and is lasting longer than a couple of weeks. This may be a sign of depression.

Depression
How we might feel and think
- A sense of hopelessness
- Feeling tired, lethargic or lacking in energy
- No self-esteem or confidence
- Isolated and unable to relate to other people
- Feeling guilt and worthlessness
- Being critical towards yourself
- Feeling empty or numb
- Have little pleasure in life or having stopped enjoying the things you used to enjoy

How we might behave
- Feeling tired all of the time, so not doing as much in our daily life
- Loss of appetite which leads to weight loss, or comfort eating leading to weight gain
- Physical aches and pains that don’t correlate to physical activity
- Loss of interest in sex
- Avoiding social activities or events that you would usually enjoy
- Neglecting ourselves – not washing frequently, for example

I think I might be depressed
If you think you may be depressed, be honest with yourself and know that it is nothing to be ashamed of. You should always seek help as there is no need to suffer alone in silence.

Below are a few suggestions that you may find helpful
- Talk to somebody you trust about how you’re feeling
- Book an appointment with your GP
- Contact the MS-UK Counselling service. This is confidential and is open to people living with MS, and is the only service of its kind available in the UK. Visit www.ms-uk.org/counselling
How to get your 8 hours

Nutritionist and author Rob Hobson shares his top tips for getting a decent night’s kip

Lights out!

In 1981, a Harvard Medical School professor, Dr Charles Czeisler, discovered that it is daylight that keeps our circadian rhythm, or body clock, aligned with our surroundings. Any light can suppress the secretion of melatonin, so try and keep your bedroom dark by using dark blackout blinds or investing in a sleep mask.

If you wake up during the night, then any light creeping through gaps in curtains and blinds can be a distraction preventing you from getting back to sleep. While any light can suppress the secretion of melatonin – the hormone that promotes sleepiness – it is blue light that has the greatest negative effect. This light is omitted from electrical equipment such as computers, mobile phones, notebooks and TVs.

If you do need a light on, then research has shown how red light has the least impact on melatonin production making this wavelength of light the most conducive to sleep.

You can buy red or pink bulbs to use in your bedroom and even strings of novelty lights, but these may not be to everyone’s taste. The next best thing is to use incandescent bulbs that give out diffused, warm light and can be controlled with a dimmer switch on side lamps. During the day, make sure you expose yourself to plenty of natural light as this can help to boost mood and make you feel more energised. This in turn can have a positive effect on your ability to sleep at night. But remember, when it’s time to sleep, it’s lights out!

Chill out

If you want to prepare your body for a good night’s sleep, you need to chill out. When we think
Epsom salts are a good choice for putting in the bath water

about the effect of temperature on our body it’s easy to assume that heat can help us to sleep. Sitting outside in the midday sun or inside a hot study can leave you feeling dozy, but the tiredness you feel from high external temperatures during the day is just a side-effect. In contrast, your circadian rhythm is very attuned to body temperature – it’s one of the functions it controls to help you fall asleep or stay awake. During the day, your body temperature rises naturally until late afternoon, at which point it then starts to fall. As you start to fall asleep your body temperature begins to lower by one to two degrees, which helps the body to conserve energy. This drop in temperature signals the release of melatonin to help induce relaxation and sleep by slowing the heart rate, breathing and digestion. If your sleep environment is too hot or cold, this can make it more difficult for your body to reach the optimal temperature required for a good quality of sleep.

Take a bath
While it may seem counter intuitive to what we’ve just discussed, many studies have shown that warming your body by bathing can help to promote sleep, but to harness these effects, timing is key. The best time to take a bath is at least one hour before you hit the hay, as this gives your body enough time to cool down to its optimum sleep temperature. Similar effects have been shown when showering or even soaking your feet in warm water to increase your skin and body temperature. Bathing has also been shown to help relieve anxiety and muscle stress, which can help with relaxation and sleep. Epsom salts are a good choice for putting in the bath water, as they are rich in magnesium which helps to promote muscle relaxation.

Oils traditionally used for relaxation include lavender, bergamot and ylang ylang. You can make bath time even more relaxing by burning candles and turning out the bathroom light. Listening to calming music or using a meditative app on your phone can also make bath time even more relaxing and offer an opportunity to calm a busy mind.

Brain download
Restlessness and a busy mind can easily make falling asleep difficult. As you lie awake your mind can go into overdrive while you focus on the issues and worries impacting on your life, many of which you will unconsciously ruminate on all night. People who write down their thoughts, activities and tasks that need to be completed before they go to bed fall asleep much quicker than those who don’t. Keep a pad of paper and a pen next to your bed so you can jot down your thoughts before you go to sleep each night. As well as writing down your worries and stresses, include any unfinished tasks that need to be completed the following day, or make a to do list. If you wake up during the night and your mind starts to wander, read through your diary and to-do list, adding to it if you need to. Sometimes the best ideas can occur in the middle of the night, so be sure to keep plenty of space to jot these down. Don’t spend hours lying in bed trying to fall asleep. Instead, get up and sit somewhere quiet, keeping the lights down low. Use this time to help organise your thoughts by writing them down rather than letting them buzz around on repeat in your head.

Get comfortable
The position you choose to sleep in could be a factor in your ability to sleep through the night. The most common sleep position – and the one recommended by many sleep experts – is fetal. If you choose to sleep this way you should favour the opposite side to the one of your dominance (in other words, if you’re right-handed, choose your left side). Not all experts agree on this though, with many suggesting that sleeping on your back is better for your health, even though this is the least popular position to sleep in. Establishing the best position for sleep ultimately comes down to comfort, and you can figure this out through trial and error.

Extracted from The Art of Sleeping by Rob Hobson (£9.99, amazon.co.uk)
Kedgeree with dark leafy greens

This is the ultimate comfort food - creamy, warming and filling, just what's called for on a cold day. It's a great option for entertaining because you can cook the rice, sauce and eggs in advance, meaning you won't have to spend long away from your guests while you're assembling it.

**Ingredients**

- 2.5cm piece of ginger, peeled and finely chopped
- ½ tsp ground cumin
- ¼ tsp ground turmeric
- ½ tsp garam masala
- 150g basmati rice, rinsed
- 2 large brown onions, chopped
- 200ml double cream
- 70g unsalted butter
- 1 medium red chilli, deseeded and finely chopped
- Salt and black pepper to season
- 250g fresh spinach, washed
- ½ lemon
- 4 large eggs, hard-boiled and peeled

**Method**

1. Cook the rice in a large pan of boiling water until tender. Drain and set aside.
2. Melt the butter in a very large saucepan over a medium heat, then add the onions, chilli and ginger and sauté until softened a little. Add the spices, cook for a further minute, then add the spinach. Cover the pan and cook for a few minutes, shaking the pan from time to time, until the spinach has wilted. Add the cream, bring to the boil, then reduce the heat and simmer gently for 5 minutes. Season with salt and black pepper, then squeeze the juice from the half lemon into the sauce. Stir the cooked rice into the sauce and check the seasoning.
3. Spoon the rice onto four plates, placing two halves of a boiled egg on top of each portion.

**To serve**

Hot buttered toast

Call 01206 226500
Harissa Falafel

Ingredients

For the wraps
- 4 soft tortilla wraps
- 2 baby gem lettuces, washed and chopped
- 1 avocado, halved, stoned, peeled and sliced

For the quick-pickled cabbage
- 125ml apple cider vinegar
- 1 tbsp caster sugar
- 1 tsp salt
- 1 tsp yellow mustard seeds
- ½ tsp black peppercorns
- 1 shallot, thinly sliced
- 200g red cabbage, thickly sliced

For the falafels
- 50g quinoa (dry weight)
- 240g tinned chickpeas, drained
- 1 tbsp harissa paste
- 2 garlic cloves, roughly chopped
- ½ tsp ground coriander
- ½ tsp ground cumin
- 1½ tbsp plain flour

plus extra for coating
- ½ tsp baking powder
- 1 small onion, roughly chopped
- a handful of flat-leaf parsley, stems removed
- a handful of coriander, stems removed
- 5 tbsp vegetable oil for frying salt and black pepper to season

For the tahini dressing
- 2 tbsp tahini
- 2 tsp lemon juice
- ½ tsp white wine vinegar

Method

1. To make the pickling liquor for the cabbage, combine the apple cider vinegar, sugar, salt, mustard seeds and peppercorns in a small saucepan with 125ml water and bring to the boil. Remove from the heat as soon as it boils. Put the shallot and cabbage into a clean, heatproof jar, then pour the hot pickling liquor over it and press the cabbage down to ensure it’s all submerged. Leave it to cool, then seal with a lid and refrigerate it for at least a few hours, ideally overnight.

2. To make the falafels, cook the quinoa in a large pan of boiling water for 10 minutes or until the quinoa is tender. Drain and allow it to cool.

3. Put the chickpeas, harissa paste, garlic, spices, flour, baking powder, onion and herbs in a food processor and blitz until smooth, adding a tablespoon of warm water if it is dry and crumbly. Keep adding warm water, a tablespoon at a time, blitzing between additions, until you have a paste that will hold together (you may need up to 6 tablespoons).

4. Transfer the mixture to a bowl, then stir in the quinoa, season to taste with salt and black pepper, and chill in the fridge for at least 1 hour.

5. To make the tahini dressing, combine all the ingredients with 3 tablespoons of warm water in a small bowl and whisk until smooth. Season to taste.

6. Using clean hands, take egg-sized lumps of the falafel mixture into your hands and shape them into patties (the mixture should make around twelve). Press them together, then roll them gently in flour – they will be fragile, so handle them with care.

7. Heat the vegetable oil in a heavy-based non-stick frying pan over a medium high heat, then fry the falafels in batches, carefully flipping them over halfway through cooking, until they are golden brown on both sides. Transfer to a plate lined with kitchen paper to soak up any excess oil.

8. To assemble the wraps, spread a generous spoonful of the tahini dressing on each wrap, then divide the lettuce, avocado and falafels between them. Add some pickled cabbage to each, then drizzle over a little extra tahini dressing. Wrap them up tightly and serve immediately.

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as featured in Pathways magazine late 2019

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HSCT one year on

MSer and Feature Writer Ian Cook catches up with two HSCT patients one year on from the launch of new MS charity AIMS

Just over one year ago, I attended a black tie fundraising ball at Villa Park, Birmingham, launching a new charity promoting haematopoietic stem cell therapy (HSCT) for MS.

The new charity, Auto Immune & Multiple Sclerosis (AIMS), was set up to help people with auto-immune illnesses, particularly MS, to access HSCT treatment. HSCT is where an MS patient’s immune system is replaced or ‘re-booted’, and as a result the myelin coating of nerves in the brain and spinal cord no longer suffer the auto-immune attacks that characterise MS.

HSCT uses high-dose chemotherapy which wipes out the body’s existing immune system. The immune system is then rebuilt using stem cells which have been ‘harvested’ from the patient’s blood before chemotherapy and are then re-introduced afterwards. The newly rebooted immune system suffers no further auto-immune attacks, preventing further damage.

At the AIMS launch I met a number of MS patients who had received HSCT. So how are they doing one year on? One of the people I met was Damien Scott, who was diagnosed with relapsing remitting MS in 2004. Damien travelled to Moscow in 2017 for treatment at the A.A. Maximov Haematology and Cell Therapy Department of the National Pirogov Medical Surgical Centre. At the Villa Park event Damien gave me some background information about his trip to Moscow.

“My decision was made easily. Whilst my disease has been very stable, I felt it was worth the risk as MS can turn progressive at any given time. My treatment experience was nothing short of amazing and life changing. The hospital care was second to none.” Last year Damien said he had noticed a real improvement in his MS symptoms, so have those improvements been sustained over the past year? I asked him. He said: “I’m doing well, I have had no disease progression or relapses. I have zero regrets about going to Russia for HSCT treatment and would repeat it without a second’s thought.”

Another person who is doing well following HSCT treatment is Becky White who was treated with HSCT for her MS at Hammersmith hospital in 2018. She said “Since having HSCT I have experienced a number of improvements in my MS symptoms. The burning in my thighs, fatigue, weakness in my legs and Lhermitte’s sign have gone. Other difficulties have reduced, like the optic neuritis. I have had two MRI scans since I had HSCT and both scans not only show no new lesions, they show that existing lesions have reduced in size and some have disappeared. Although since 2018 I have been diagnosed with Graves’ disease (overactive thyroid), but am really not finding this difficult to manage. Overall, the HSCT patient reports one year after the Villa Park event are highly positive and the AIMS charity which organised the event goes from strength to strength. All looks well for HSCT as a new MS treatment. All credit to AIMS.

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WASHABLE INCONTINENCE UNDERWEAR
Fatigue is one of the most common things we have to deal with when we have multiple sclerosis (MS). It is often the most challenging to explain to someone who has not experienced it. It’s easy for someone who doesn’t have MS to mistake being fatigued for being tired, but we all know this is very far from the truth.

There is no legal requirement to disclose you have MS to your employer however, if you need any support, you may find that you need to share your diagnosis. If you have relapsing remitting MS it is often helpful to share that you will have good periods and challenging periods, so your employer knows you may need different things at different times.

Run out of juice

For me, fatigue is the one constant of my diagnosis. I have found it helpful to be clear that it is not simply being tired and a good sleep won’t necessarily make it better. I find using the analogy of a mobile phone battery helpful. We all find ourselves getting tired over the day. Like a mobile phone, our battery runs down and there comes a point we need to charge it back up, with sleep. With fatigue, it’s more like the battery is faulty. Even when you plug in the charger it doesn’t go back to full power, it’s more like the battery has been removed and the phone is off.

Sharing information like this is key to accessing the support you need from your employer. Under the Equality Act 2010, you are entitled to reasonable adjustments by law and in my experience there are lots of things that can be done to help with fatigue.

Consider the location of your desk to the places you need to access regularly such as toilets, filing cabinets, photocopiers and the kitchen. Removing the need to walk across an office regularly can make a huge difference

- If you are located on the top floor, use the lift. If there is no lift available ask to be located on the ground floor if this is suitable. Think about parking – could you request a space closer to the building?
- Consider temperature. I find that the hotter I get, the more my fatigue affects me. Perhaps being located next to an open window or the air conditioning would be helpful, or having a desk fan
- Think about travel. Often if we have to travel in rush hour, it can affect us more. We are less likely to be seated on public transport, or find ourselves stuck in traffic. Ask to move your hours so you arrive at work earlier or later and therefore leave earlier or later
- If you travel longer distances for work, like me, diary management is critical. If I have to travel to London for the day then I know the following day I am going to be wiped out and therefore I can manage my diary so I have a day off, or some less-demanding work the day after.

The most important thing is to ask for help. Battling on can lead to feeling even worse or a relapse.
Get ready for Tri in July

Do it your way for MS-UK!

• Set your own pace, in your own place
• Whether you roll, stroll or ride, everyone can take part with pride

This year MS-UK is launching a fully accessible event that everyone can get involved with, wherever you are based in the country.

During the month of July, we are asking people to be part of ‘Tri in July’, either individually or as part of a team.

Pick three challenges from a list that incorporate the elements of a regular triathlon which is a combination of running, swimming and cycling. An alternative to running could be walking, instead of swimming you could sail and you could also be unique and roller skate instead of cycling! You can certainly do it your way for MS-UK.

Choose a distance of 1k, 5k or 10k, or set your own distance - the challenge is up to you!

Our Fundraising team will be there to support you all the way.

If you raise over £100 you will then receive an exclusive MS-UK medal.

Contact Jenny to find out more information jenny@ms-uk.org
Fundraising

MS-UK update

Enlli Parri and Aled Burd tell us what they love so much about street collecting

We are running the Virgin Money London Marathon as part of MS-UK’s team purple. Having family members living with multiple sclerosis (MS), we know how challenging life can be and realise the importance of having the right support and guidance, and this is why we’ve chosen to run for MS-UK. The support they provide really is second to none and we couldn’t be prouder to wear the #TeamPurple vest to run the London Marathon again this year.

Raising awareness

Street collections are a great way of fundraising and a wonderful way to get out into the community and to speak to so many different people. It always amazes us when we are out collecting the amount of people who have connections to MS, be it through a family member, friend or colleague. By being out in the community, we have the opportunity to share the great work of MS-UK with so many. Street collecting is also an opportunity to raise awareness of MS and the sometimes silent and invisible daily struggles some people have to deal with.

The most important aspects of a successful street collection are to be positive, enthusiastic and happy. Whatever the weather, we always feel that it’s an honour to be out on those streets sharing the amazing support MS-UK provide with the wider community.

Dress to impress

Dressing up in fancy dress is a great way of standing out! As you can see from the pictures, Aled enjoys this part far too much! It’s very important to obtain a street collection permit from the council – it is illegal to do a street collection without one.

We love our days of street collecting, from the interesting and deep conversations to the funny characters we’ve met over the years! Street collections are a great way to get out into the community, to spread the word about MS and to speak with so many different and interesting people.

Dressing up in fancy dress is a great way of standing out

If you are interested in taking part in fundraising, email jenny@ms-uk.org or call 01206 226500.

www.ms-uk.org
Letters

Your letters

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

Learning from scratch

Suddenly it is becoming easier. I have had to step up recently to help my wife cope with her MS and I have come to the conclusion that the reason men are crap at it is they genuinely do not know what is behind every door except the fridge and loo.

So after 48 years of marriage I am in the lime light rushing around at first, then getting into the swing of it, picking up things when I have a spare hand as I go by saves another trip. I’ve learned that while waiting for the kettle to boil, emptying the dishwasher that is bleeping beside you is a good plan. The washing machine can be tackled next. Not a big deal if you look properly and quickly learn not to mix whites and coloureds. You can only get away with it once!

The tumble drier is easier – we have a minimum iron setting so that gets my vote, and things are folded promptly while still warm and popped in drawers straight away (I now have intimate knowledge of my wife’s knickers draw). I have also developed a rare talent for a man – I can now put a bra on.

Cooking is becoming easier and you soon learn that one extra for the pot can ruin a good meal so follow the recipe exactly if unsure. That’s why it’s in black and white. I am still learning that caring for someone you love with MS is a challenge for both of us, but with a little thought and some more insight from my wife we will get there. After all, she has had her whole life to love, nurture and guide our family’s progress – as for me it’s only been a couple of years so I’m still in the learning phase.

Regards from a man in training,
Joe

Tooth solution

Recently my wife Rosemary has found opening and squeezing toothpaste on her brush increasingly difficult so Mr Gadget (me) swung into action and, after giving the web a few prods, ended up on eBay where I found the answer to our problems.

All you have to do is push your brush into the portal on the front and it deposits toothpaste on the brush head. It will take all makes of toothpaste and is pleasing to the eye. I was so chuffed I thought I would share it with you. If it helps one other person, my job is done. The Ecoco Automatic Toothpaste Dispenser costs £9.99 from amazon.co.uk

Best Regards,
Joe
In response to Mrs Ventom’s letter, page 39, issue 119 of New Pathways, which struck a chord with me. My wife Kathryn has PPMS, and she too rarely says please or thank you! Perhaps she also has forgotten? One thing she does like to do is adult colouring. This really is a cost effective pastime, and the results can be so effective they deserve to be framed.

An adult colouring book and pack of felt tips are all that’s needed. She sits at the dining table happily colouring for hours.

Kind regards,
Andy

Adult colouring

In defence of Amazon

For disabled people, electronic media and the freedom to buy online are huge assets. The demise of the high street is sad, however, there are many of us who are not able to ‘go to the shops’. Through online sites such as Amazon as well as individual companies it is possible to select, purchase and have delivered most of the items that are needed. I offer a vote of appreciation for this!

Best Regards,
Shirley

Drawing inspiration

In response to the lady requiring inspiration on subjects to draw, I would like to suggest the following.

I am a wheelchair user now and love to draw/paint watercolours – a table easel can be useful but I sit at my dining table and a bowl of fruit or vase of flowers is a readily available subject. I also find pictures in magazines often inspire and I am a member of an art group in my local village so I also benefit from the social aspect of being amongst like-minded folk. I am sure there will be a group near to your correspondent where she would be warmly welcomed no matter what level of ability – everyone has to start somewhere!

Best wishes
Kath

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Best wishes
Kath
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I have always loved walking through wooded areas. As a child, I found forests exciting and a bit scary – rather like Narnia in the book *The Lion, The Witch and The Wardrobe*. As I got older, they became a place to escape to, where I could unwind from the pressures of everyday life. Being surrounded by trees always made me feel at peace with the world, and raised my spirits if I was feeling down.

When multiple sclerosis (MS) began to limit my ability to walk long distances, or travel safely on uneven surfaces, I began to fear that I would never again enjoy relaxing walks through woodland areas. Then I discovered that just a short way from my home, snaking its way through our town from the medieval Prittlewell Priory in the east to Belfairs Woods in the west, is an ancient track called the Prittle Path. Running alongside a small stream, it is shaded by overhanging trees for much of the way, and the well-maintained surface of the track makes it ideal for wheelchairs and mobility scooters as well as dog walkers and cyclists.

**Feeling recharged**

In summer, the banks of the stream are covered in wild flowers, while the ancient woodland at the end of the path is full of majestic old trees, some of which are many hundreds of years old. I go there whenever I need to recharge my batteries, and I always come away feeling better for the experience.

It turns out that I am not imagining the positive effects that a walk in the woods can bring. ‘Forest bathing’ as this practice is called, has now been scientifically proven to enhance our health in all sorts of ways.

**The science**

In the 1980s, Japanese scientists began to research the possible physical and psychological benefits of ‘Shinrin-Yoku’ or ‘taking in the forest atmosphere.’ What they discovered is fascinating. A two-hour forest bathing session can reduce blood pressure and heart rate, lower cortisol levels (which in turn reduces stress), and improve concentration and memory. Furthermore, it seems that chemicals released by the trees, called phytoncides, can have an anti-microbial effect on our bodies, boosting our immune systems, something that could be particularly beneficial for people with MS.

**Meditative experience**

But the benefits are not just physical. Research suggests that spending time among trees can produce the same effect as meditation or mindfulness, quietening the mind, decreasing depression, and bringing a feeling of inner peace. So, whenever you feel in need of a spiritual or physical ‘lift’, remember that something as simple as sitting on a seat under a canopy of trees in your local park may have all sorts of benefits, both mental and physical.
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.
The joy of movement

Columnist and MSer Charlie Gee dedicates this month’s instalment to his trusty exercise bike

In my pre-MS existence I used to be an enthusiastic long-distance runner, so when the condition came along it was rather sad for me and I missed the exhilaration of scooting along with the wind whistling in my ears.

Fast forward to my MS days. When my mother had moved on to her next existence I was left a small legacy, some of which I spent on a Medimotion machine, which I saw advertised in one of the early New Pathways. I think I started to get involved about issue 12, so there’s a good chance that they’ve been advertising in the magazine since its inception. The guy I bought it from was based in mid Wales and he had a wonderful line in patter – a real salesman. He was selling the machine through a German company and I thought at the time it’s a bit pricey, but boy have I got so much pleasure from it over the last 15 years or so. Those Germans know what they are doing when it comes to things like this!

My workout

At first I had no trouble getting onto the bike on my own, fastening my feet to the pedals and pressing all the buttons myself to regulate the speed and all that stuff, but, as the condition progressed, I now have had to let the carers put me on the bike and then I cycle for about an hour, after which one carer comes back and gets me off it. The wonderful design enables me to put in as much or as little effort as I want for my morning workout. I say the morning because I have found that to be the best time for me to do it.

All in the arms

My previous carers were good because I would do the first four days of the week exercising my legs and on the Friday and Saturday I would do 30 minutes on my arms. Sunday was my day of rest. The arms are much trickier than the legs and one person with that care company could do it really wonderfully. My left arm is my weaker one and I noticed it was beginning to drift up into the classic MS position. I have to have a special glove which my daughter Jackie has put together so that I am able to hold on to the handlebars.

Teamwork

I do my exercise to music and my playlist for my arm exercises is up-tempo, and the carer had to hold my hand onto the handlebars, which meant he had to move along with me. We did manage to get it up to 40 revolutions per minute, but that was a one-off seeing how fast we could go, and I eventually settled on 34 per minute. So we were both getting a workout. In fact, he was getting more of a workout than me as he had to keep hold of my left hand while I enjoyed the exquisite pleasure of feeling my shoulder blades’ rotation.

I am thinking of employing him privately so he can show his technique to the present carers because I feel doing arm exercises is very important. I have noticed that people with MS let their arms start to bend up over their chests and I could feel the same thing happening to me during my period of inactivity.

By contrast, the work on the legs part of the machine is a much more sedate affair. I go along at 15 revolutions per minute and I can drift off and experience the feeling of running again. Unfortunately that company went out of business and the present caring company dawdled in getting me on the bike again. I was inactive for nearly a year and had to threaten them with leaving before they were prodded into action.

Health and safety

I feel the world has gone health and safety mad. When I was a child it was so different – we could actually go out and play. We could do things that had an element of danger. When I explained to the carers that I do not have to leave the chair in the machine procedure, they understood that there is no danger. All I have to do now is get somebody to learn how to use the arm section of it. It should be interesting to see if I could carry on doing it to the age of 100 years and beyond!

www.ms-uk.org
Q I was in my local independent health food store and was told that lion’s mane mushrooms can be a good supplement to take. Can you tell me more?

A Lion’s mane mushrooms (also known yamabushitake) are large white mushrooms. They get their name as when they grow they have a flowing appearance and look like a lion’s mane.

In her book ‘Managing multiple sclerosis naturally’ Judy Graham says that lion’s mane can help with fatigue, immune modulation and also have anti-inflammatory action. Recent studies have shown that lion’s mane mushrooms contain two compounds that can stimulate the growth of brain cells.

In studies on mice, lion’s mane mushroom and its extracts have been found to reduce symptoms of memory loss, as well as prevent neuronal damage caused by amyloid-beta plaques (the lesions that are found in the brain in Alzheimer’s disease). There are no studies which have looked at whether lion’s mane mushroom is beneficial for Alzheimer’s disease in humans, however as far as we know, however it seems as it is a mushroom and some people have allergic responses to them, caution is always suggested.

Q Do you have any information about insuring electric wheelchairs? I have just found out I am not insured via wheelchair services.

A There is no overall obligation to have insurance for wheelchairs (or mobility scooters). Nevertheless it is a good idea to make sure you are covered.

It is worth checking with your home insurance provider to see if you are already insured. Some home contents policies cover mobility products. However, even if you are covered, it is worth exploring whether the cover is really right for you. Your home insurance may pay for a replacement if your wheelchair is stolen or damaged, but does it cover you for public liability and personal injury, should you accidentally cause any damage with your mobility product, or have an accident whilst using it?

As with all policies, there are many things to consider when thinking about insurance cover for your wheelchair including public liability, breakdown recovery, accidental damage, theft, and travelling abroad.

It is also worth speaking with your local mobility specialist and asking who they recommend for insurance. They may get favoured rates, or at least have a known company that they recommend. If you use the Motability scheme to purchase a powered wheelchair from www.motability.co.uk they will provide insurance cover on all their products.

As with other insurance, get a few quotes to enable you to compare the level of cover and the price.

There are a few insurance companies who provide dedicated policies for mobility products. Below are the web addresses of some that insure powered wheelchairs and mobility scooters.

www.bluebadgemobilityinsurance.co.uk/electric-wheelchair-insurance

www.fishinsurance.co.uk/products/powered-wheelchair-insurance

www.surewise.com/wheelchair-insurance

www.chartwellinsurance.co.uk/electric-wheelchair.php
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Hello everyone, I am Scott McCormick. You might remember me from Channel 4’s Gogglebox if you watched it – I was on it with my wife Georgia, son Isaac, St Bernard John and Labrador Lola.

I have been asked to write a column for you guys in New Pathways magazine, and I hope I can do this justice for you all.

I was extremely excited when the charity asked me, because I find them to be totally unbiased and supportive of people’s journeys, no matter what choices you decide to make in your treatment for multiple sclerosis (MS).

If you follow MS-UK on social media, you might have seen some of the vlogs I made on YouTube about my Haemoglobin Stem Cell Treatment (HSCT) journey, and so I felt continuing on in the form of this column was a no-brainer for me. For those who are unfamiliar with HSCT, I shall write about this a lot more in time. Many of you on Twitter have followed my journey, and now I have been given space to talk to those who may not have known me from social media (find me on Twitter @goggle_beard).

With my background of 22 years serving in the Royal Air Force as an aircraft engineer, I do tend to look at things very differently to the rest of the civilian populace, as I hope you will see, enjoy, and laugh about with me. My humour is extremely dry and I can be very blunt, but that drive has been what’s seen me through an extensive career and illness. I will be sharing my experiences both good and bad with you, as well as the ludicrous and sometimes downright spiritually crushing experiences as a man and a father.

The one thing I never wanted my boys to see was a man that was a quitter, and I can only hope that they draw from the betterside of how I conducted myself. Being the only breadwinner in the house, having to pay the mortgage and the bills, plus my wife’s extensive wine consumption (shhh!), did weigh greatly on my mind, and became quite consuming at times, but I will be sharing my thoughts with yourselves as time goes on, and I hope it helps.

You will hopefully see that no subject is taboo, and that everything can be laughed at in time. There is always a silver lining to every cloud, but sometimes you have to look very hard for that tiny prick of light. It can be difficult to find but is always there. Some of these I can already see in my mind, and write about them in the future, but my approach is anything but normal. Possibly my biggest concern at the moment is how on earth I’m expected to condense my usual 10 minute rants on YouTube into a tiny, meagre, minuscule, 600 word article. I know, right? How the hell am I supposed to do that? My wife tells me she is going to drop me off at an old people’s home for the weekend so I can get my word count in for the day. Let’s just say I can talk the hind legs off a donkey, and then some.

My first experience with MS was when I was on the Harriers at RAF Cottesmore in 2001, and my right eye began playing up. The colour washed out in my vision, and I missed something on a highly detailed inspection on the jet. Thankfully, this was picked up before the aircraft flew, but due to the worry this caused I went to the doctors on base and was diagnosed with optic neuritis. I’ll elaborate more on this next time.

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