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Hello,

Welcome to the July/August issue of New Pathways. I hope you are keeping well.

This issue we’ve got lots that I hope will inspire you. On page 22 Katie Ruane, a qualified naturopath, shares her natural tips to boost your wellbeing. We’ve got another series of exercises from our wellness coaches to keep you active while you are at home – you’ll find those starting on page 24. There’s also advice from our HR guru Rebecca Armstrong on your rights if you are having to return to work after months of shielding, plus lots of real-life stories from other MSers, the usual delicious healthy recipes and lots more.

And please, if you have time, fill out our reader survey on page 41 – it really will help us shape the content of New Pathways in the issues to come.

Enjoy!

Allison

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Study finds air pollution and MS link

Air pollution increases the risk of developing multiple sclerosis (MS), a study from Italy has found.

Researchers discovered that people who live in urban, polluted areas have a 16 per cent greater risk of developing the condition compared to those living in rural areas. Fine particle pollutants (2.5 micrometers or less in diameter) were particularly linked to the increased risk.

The research was announced at the 2020 European Academy of Neurology (EAN) Congress, which was held virtually due to the global pandemic.

Previous research has identified a number of environmental factors as triggers for MS, including cigarette smoking, vitamin D levels and diet. Pollution has also been suggested as a factor.

Researchers took a group of 927 people with MS in northern Italy and examined their exposure to air pollutants, in particular fine particulate matter smaller than 2.5 micrometers in diameter (known as PM2.5).

These particles come from industrial activities, heating, vehicles and agricultural activity. They are a mixture of solid and liquid matter suspended in the air.

People living in urban areas were 16 per cent more likely to develop MS compared with people in rural areas.

The area of Italy studied, Pavia, was divided into three pollution bands from north to south, with the southern area being the least polluted. Researchers noted that cases of MS seemed to be less common in this region.

They adjusted for other factors which may contribute, including age, education levels and housing density, and researchers found using statistical analysis that people living where there were very low levels of PM2.5 had a low MS risk. People living in urban regions were 16 per cent more likely to develop MS compared with people in rural areas.

The study also noted that there were 169 cases of MS per 100,000 inhabitants, which is ten times higher than the figure 50 years ago, which was 16 cases per 100,000. The researchers said that rising pollution across the decades could be a factor in this.
People with radiologically isolated syndrome have 50% chance of developing MS

Half of people with radiologically isolated syndrome (RIS) will go on to develop MS, according to a new study.

RIS is a phenomenon where MS-like damage shows up on an MRI but the person has had no symptoms.

Researchers conducted a 10-year follow-up of 451 people who had been described as having RIS, and found that 51.2 per cent of them went on to develop MS.

The study identified factors which increased the likelihood that a person would develop MS. These included having signs of spinal fluid proteins called oligoclonal bands, being of a younger age, having MRI lesions in the spinal cord or lower back part of the brain, and newly active lesions on follow-up MRI scans.

Trials are now being conducted to determine if treating people who have RIS with disease-modifying drugs will delay or prevent the onset of MS.

Some MS disability may build progressively and not be tied to relapses

A new study has found that disability seems to accumulate in people with relapsing remitting MS in a progressive way, rather than because of relapses.

To get these findings, researchers analysed data from people taking part in two ocrelizumab clinical trials. They said they found that in a typical population with relapsing remitting MS, as much as 80 to 90 per cent of overall disability was accumulated independently of relapses.

Progressive MS and relapsing MS are regarded as separate clinical forms of the condition, with people accumulating disability in different ways.

But increasing evidence supports relapsing MS patients also worsening over time, even when relapses are well under control with disease-modifying drugs.

Researchers say that their findings support the theory that “MS may be a single disease continuum with an underlying progressive disease course and a highly variable superimposed accumulation of disability resulting from relapses with incomplete recovery.”

www.ms-uk.org

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DMT does not increase risk of severe COVID-19

Data from France has shown that for people with MS, high scores on the expanded disability severity scale (EDSS), age, and obesity were linked as risk factors to more severe COVID-19 infections, but use of disease-modifying therapy (DMT) was not. The study involved 347 patients who had an average age of 45 and who had either confirmed or suspected COVID-19. Of these, 73 were hospitalised and 12 died. Researchers found that the main risk factors for severe COVID-19 were neurological disability measured on the EDSS scale, followed by age and obesity – the latter two are already known to be risk factors for the healthy general population.

“Our data does not support an increased risk of severe outcome associated with DMTs, which should reinforce the recommendation of not stopping current DMTs and not delaying treatment initiation in patients who have higher disease inflammatory activity, risk for relapses, or subsequent disability,” investigators wrote.

Switching from Tysabri increases risk of relapse

A new study has found that the risk of a relapse for someone with relapsing remitting MS switching from Tysabri (also called natalizumab) to another injectable or oral after two or more years on the therapy is two to three times higher than if they continued on Tysabri.

The drug is an antibody-based injection therapy that prevents immune cells from entering the brain. Studies show it is very effective at treating MS, but it increases the risk of progressive multifocal leukoencephalopathy (PML), which is a rare brain infection caused by the John Cunningham virus. Doctors will often look to switch patients to another drug as long-term use (more than two years) of Tysabri is linked to an increased risk of PML.

The researchers say the study highlights how important it is to assess the risk of PML and the risk of a return of disease activity before making any decisions about switching.

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Higher teenage BMI raises MS risk for men

Men who have a higher body mass index (BMI) between the ages of 16 and 20 have a bigger risk of being diagnosed with MS later in life, regardless of fitness level, a new Swedish study has found.

Previous research has suggested body weight could be an environmental factor which increases MS risk, in particular obesity before adulthood. A recent review found mixed evidence for this claim, and so researchers investigated more closely. They found a linear relationship between earlier-life BMI and the likelihood of MS being diagnosed in later life. For every additional point on a man’s BMI, which ranged in the study from 15 to 35, their risk of an MS diagnosis rose by 3.4 percent.

Higher levels of blood protein linked to faster MS progression

A new study has identified a possible biomarker in the blood that may help predict the severity and progression of MS. High levels of neurofilament light chain (NfL) was linked to higher disability and faster disease progression by researchers at the University of Ottawa in Canada. NfL is a protein released by nerve cells when they are injured, and it is commonly used as a marker of nerve cell degeneration in neurodegenerative disorders. At the moment, there aren’t any established biomarkers doctors can use to ascertain the severity of a person’s MS. Measuring for NfL could potentially be a way for physicians to choose the best course of treatment for each individual patient, say researchers, as if they were able to identify people with more aggressive MS early on, they may be able to alter the path of its course, and delay or even prevent disability.

“One day, multimodal prognostic indices including clinical, MRI and serological data such as NfL may assist in the identification of high-risk patients who may benefit the most from early aggressive therapies. Conversely, patients identified as having a very good prognosis may not require treatment at all, or will choose the safest and more modestly effective treatments,” said the researchers.
Just four weeks of mindfulness meditation could help to improve emotional balance and thinking ability in people with MS, and even more so than cognitive training, new research has found.

The study split 61 patients randomly into three groups. One was given four weeks of mindfulness-based training (MBT), another had four weeks of adaptive computerised cognitive training (aCT), and the last group served as a control.

The mindfulness training given featured in-person sessions every week of two hours, and at-home self-practice for 40 minutes. The patients learnt to do body scanning, to be aware of their breath, and seated meditation. They were told to focus on their thoughts, emotions and bodily sensations.

The aCT group also had two hours of weekly in-person sessions and 40 minutes of work at home. They had to read and take part in video game exercises which were focused on brain processing speed, working memory, attention, and executive function.

Cognitive impairment was evaluated using the Brief Repeatable Battery of Neuropsychological Test (BRB-N), Symbol Digit Modalities Test (SDMT), and the Paced Auditory Serial Addition Test (PASAT), both before and after patients had the training.

Brain processing speed was significantly improved in the mindfulness group, compared with the aCT and control groups. Working memory was also boosted, which researchers say was linked to changes in awareness the mindfulness training provided.

Emotional control was evaluated using self-reported and behavioural measures. Compared to the other two groups, the mindfulness group demonstrated a better ability to regulate emotion. They also had less feelings of worry, acts of rumination and repeatedly thinking about problems to an extreme extent than the others.

If you’d like to have a go at mindfulness, try MS-UK’s ten-minute guided meditation at www.youtube.com/channel/UCMK3P_VOufDtfKU-JWkoeArg or search YouTube for ‘mindfulness meditation’.
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**Weight added to argument Epstein-Barr virus triggers MS**

Further evidence that the Epstein-Barr virus (EBV) may cause MS comes in the form of a new study from Germany in which all 901 early disease patients were carrying antibodies against the virus. This means that everyone in the study was currently, or had been, exposed to it.

Published in the Journal of Neurology, Neurosurgery, and Psychiatry, the study looked at 901 people with early MS included in the German National MS cohort and tested them for EBV. The group were aged between 27 and 41 and 42.2 per cent had clinically isolated syndrome and 57.8 per cent had early relapsing remitting MS.

The researchers used data from 16,163 people who had routine EBV tests as a control group. As controls, the team used data from 16,163 individuals tested for EBV for routine diagnostic purposes.

Using various testing methods, it was established that all patients were or had been infected with EBV.

Some experts have said they think EBV infections could be the root cause of MS, with the virus somehow tricking the immune system into attacking the myelin sheath. If this were true, it would mean every MS patient would have had to have been infected with the virus in their lives, but some studies have demonstrated people can have MS without being previously infected. However, researchers have questioned whether this was true because people had been misdiagnosed or the tests for EBV were not accurate enough.

The researchers said that the viral infection is unlikely to be the only cause of MS, however, and there was a high prevalence of EBV infection throughout the control group also.
As I am writing this we are still in the grip of this lockdown, but the announcement for pubs and restaurants to reopen has just been made. Hopefully by the time you are reading this it will have relaxed somewhat. The weather has been very hot – stifling in fact.

I usually get up in the morning at 7am. My dinner time is 11:30am and on this particular day, Veronica my carer had prepared my usual salad which we would eat on the grass outside my window. She daubed me with sun cream to protect my palest of pale skin. We were just about to go outside when my friend Vicky (pictured with me) came through the front door and asked me if I fancied going to the opera. “Is the opera going on right now?” I asked. When she answered “Yes!” I could not refuse an offer like that, so we put the salad into a bag and set off in the wheelchair. We got to the venue just as it was starting. There was one lady and some music playing through a speaker. It took place in a churchyard, and on entering we were greeted by the most powerful of voices singing songs from The Sound of Music. Then she did some operatic songs, Oh My Dear Papa and the Pavarotti number Nessun dorma. She sang a very moving version of Imagine by John Lennon. She finished up with a jolly song and got a standing ovation.

Her name is Nicola Mills and she was born close to Oldham which is about five miles from me. She made it big in New York but she had never forgotten her humble roots. During this lockdown she is actually going round to people’s houses and singing for their weddings. She said there is no obligation but I have some CDs in the car which you can have for whatever you can afford. I bought one for £10 and I am so glad I did. I apologised to her for not giving her a standing ovation – I gave her a sitting ovation instead. She didn’t seem to mind. Her CD was called Songs for the People. The BBC were there filming and it was shown on Look North, and can also be found on YouTube. She is a very special lady!
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My symptoms started off with slight numbness and difficulty walking. The only way to explain this is that I just started to be very conscious of my walking and thinking about almost every step.

I was on my uni year abroad working in Paris when this all started. It was a Friday and I was going on a weekend away with a friend. The whole break I was complaining of this strange feeling in my legs but just ignored it. The trip was great and we travelled back ready for work on Monday. But, that day I really noticed my walking and my left leg felt heavy. I got to work and thought that if it doesn’t get any better I will go to a doctor. Things continued to get worse.

My boss recommended her doctor in Paris and I got an appointment for the next day. I asked the doctor if it could be multiple sclerosis (MS) and he said there is no reason to suggest that as I am so young and have no family history of it. A few weeks later, I went for
my MRI scan. I was petrified but for anyone reading this who is due to have one – it really isn’t as bad as everyone makes out and the main thing is just to stay calm. I was handed a book full of pictures of my brain and a CD with 3D views – it was very cool. I was told that I had some areas of inflammation on my brain but they were not growths (so a brain tumour was ruled out, phew). They advised me to see a neurologist as soon as possible. I then decided to fly home to the UK and to pay to see a neurologist so they could look at my results quickly. So, that takes me to diagnosis day. My neurologist took a quick look at my pictures and asked me a few questions and that was it, I was diagnosed with relapsing remitting MS on 19th April 2018.

In denial
The early days were difficult and I think I was in denial for a lot of that time. I told my closest friends and family about my diagnosis but I did really struggle to find the words. I didn’t know how to tell the rest of the people in my life. Then, I found a skydive on the MS Society website and saw that it was going to be held in September. I thought it would give me something to focus on but also give me enough time to process everything.

I shared my JustGiving page with everyone, on all forms of social media, and I received an enormous amount of support. This was such a good distraction for me during a very dark time. It gave me something to focus on and I received so many lovely messages and donations. The skydive was something totally out of my comfort zone and something that I never thought I would do. But for my first charity event for MS, I wanted to push myself and do something that, without the MS diagnosis, I would never have done before. It was one of the best experiences of my life and I would recommend it to anyone. The early days were hard but you just have to keep going. You have to find some sort of positive in it all.

I take Tecfidera and although the side effects were awful at first, now all I really experience is flushing. Plus, two years on, I’ve developed no new lesions! It’s all trial and error, you have to keep going until you find something that works for you.

Writing therapy
I started my blog at www.butyoudontlookill.com just over a year ago and I love it. I talk about anything and everything and it’s like a therapy to me. Hopefully, at the same time, it’s helping others.

The main thing that has changed in my life is my perspective. I have an urge to do everything that I wouldn’t have done before my diagnosis. I want to make a difference in this world and to help others. I appreciate life way more now than I did before my diagnosis and I think that is what’s helped me find peace with MS. Sure, some days I hate that I have MS and no control over my body but, most days, I am happy that I feel like I have a purpose in this world.
If you suffer from heat sensitivity you will know it can be a big summer holiday spoiler and although other multiple sclerosis (MS) symptoms often get talked about, heat sensitivity doesn’t get the coverage it deserves.

As a sufferer I find this fact surprising because the link between heat and MS has been known about for 130 years. Back in 1890 Wilhelm Uhthoff, a German neuro-ophthalmologist, noticed that some of his MS patients’ visual problems got worse after exercising and getting hot. This later became known as Uhthoff’s phenomenon.

The first thing looked at was the fact that MSers overheat because we lose our ability to sweat as MS progresses. Normally adults can sweat between two and four litres per hour or 10–14 litres per day and sweat cools the skin as it vaporises in a process known as ‘evaporative cooling’. But in MS things don’t work so well.

Research carried out in 2009 at Oulu University Hospital in Finland looked at sweating in 29 MS patients and compared these patients to 15 people unaffected by MS.

The research found that MS patients sweated markedly less than people without the condition. After just 10 minutes of heating, sweating was significantly lower in the forehead, feet and legs of MS patients than in those who didn’t have MS, meaning MSers were overheating as they were unable to benefit from evaporative cooling.

Sweating in simple terms is a two-way process. Temperature receptors in the skin send messages through the nervous system to a part of the brain known as the hypothalamus where heat-sensitive nerve cells are located. These cells in turn send messages to millions of sweat glands in the skin to release sweat causing evaporative cooling. For a message to travel between the hypothalamus and the sweat...
glands the nervous system must carry these messages efficiently.
One of the key chemical elements involved in this process of efficient communication is sodium. As axons in the central nervous system heat up, the amount of sodium moving into the nerve increases in a process known as sodium loading. However in MS this process goes into overdrive and excessive sodium makes it harder for messages to be sent efficiently up and down nerves to and from the sweat glands. This results in less sweating and overheating.

**Sodium loading**

Dr Mark Baker of Queen Mary, University of London is currently researching ‘sodium loading’ in axons. Dr Baker is looking for a drug or drugs that could target MS heat sensitivity by reducing the amount of sodium entering nerve cells when the temperature increases, allowing messages to muscles to be sent more securely and therefore better communication with the sweat glands and more sweating.

**Drug hope**

One drug that is believed could have this effect is bumetanide. This drug is already used to reduce extra fluid in the body (oedema) caused by conditions such as heart failure, liver disease, and kidney disease so we know it’s safe to use. It is thought bumetanide might be effective in tackling heat sensitivity because it reduces the amount of sodium entering cells. Dr Baker has been leading research into this area but says that bumetanide comes with major problems. It is poor at getting into the brain and nervous system and thus poor for accessing damaged axons. A side effect of bumetanide is increased urination – something that would be unwelcome by many of us MSers. Dr Baker says these facts are leading him to look for other drugs.

“We need to investigate other compounds that have much better brain penetration and we have plans to do this. We also think there may be another molecular mechanism causing sodium loading that is not affected by bumetanide and this is one of the things we are working on.

“Exploring this avenue may allow better pharmacological control of temperature-dependent symptoms, and in the longer term could provide a route to neuroprotection. So right far down the line neuroprotection is a massively exciting idea that means we may be able to protect axons and neurons from the worst effects of neuro-inflammatory disease and slow progression by reducing the energy expenditure in axons as well.”

It is hoped that continuing work on heat sensitivity could lead to other drugs which would not have the side effects of bumetanide and may even have a neuroprotective role too.

I, for one, will be hoping that it’s not too hot this summer, and I will of course also be using a fan, a spray and possibly other cooling aids in case, like last year, we have another long hot summer. Meanwhile the heat is on in the search for a new cooling drug.

Patients were lowered into a hot bath to see if their condition worsened. If it did, they were diagnosed with MS.
I had been experiencing numbness in my left hand for a while and checked in once with our GP. Looking back, I also had weird tingling numb episodes in my legs which I ignored. That September weekend, my legs went very weak indeed and I couldn’t stand. Multiple sclerosis (MS) was diagnosed and I was put onto mega doses of intravenous corticosteroids.

During those long nights, I heard the next patient coughing horribly. I didn’t want to be that poor soul. That patient had throat cancer. I knew I was lucky. There is always someone worse off.

I went back to work and lasted another six years, on medications, but it was tough. I ended my clinical career with ill health retirement in 2010 and was very down for a while, contemplating a bleak future.

My family were very supportive, and I still managed to attend some veterinary conferences to keep in touch with colleagues and friends. I used sticks, then a rollator and now use a power chair and sticks.

I wanted to be part of society and still contribute something. Being good at Black Ops 2 on the PlayStation was great, but it didn’t cut it as a way to spend the rest of my life.

I looked for a way to volunteer and managed a few hours each week at Glasgow Stobhill’s Patient Information Centre, and I met super people there. A stand-up comedy course for people with chronic ill health was suggested. That was brilliant, especially as I couldn’t really stand! The people were wonderful, funny and great for building confidence.

Then one day, a text changed my life forever. Lissann Wolfe, a veterinary nurse I used to work with, now leads the clinical skills team at Glasgow Vet School. Did I want to present a wee teaching day? My family were from Glasgow’s East End and I went to a large comprehensive school in one of the city’s new towns.

Dad was a firefighter who retrained to become a teacher before sadly dying young. I finished my studies at Glasgow vet school just before my 22nd birthday. I was in mixed practice in Fife for 2 years before joining the People’s Dispensary for Sick Animals (PDSA) in London. I enjoyed a hectic, rewarding 25 years with PDSA, becoming senior veterinary surgeon at East Glasgow PetAid Hospital. I am married to Colette and we have three children, who grew up to make us proud. Life was good and very busy.

Life is precious
Colette and the children were in a bad car crash one September Bank Holiday weekend 25 years ago. They miraculously survived and, as a result, we don’t take our lives for granted. September weekend is memorable for us and in 2003, it became memorable again.

When MS derailed Niall Connell’s beloved career as a vet, he had no idea the huge opportunities that lay further along the track.

I travel the three miles from Euston station to Belgravia House through the streets in my power chair.
session to some first year students on professionalism? I really enjoyed the morning talking to the students and afterwards, found myself doing ad hoc work for the vet school, assessing practical exams and online portfolios. It is tiring, hard work, but I cannot emphasise how incredible and rewarding I found this. I am part of something special.

In 2012, I attended an RCVS ‘Question Time’ just outside Glasgow. The Royal College of Veterinary Surgeons, based in Westminster, is our Regulator and Royal College, being responsible for some 30,000 veterinary surgeons and 16,000 Registered Veterinary Nurses. We are a self-regulating profession and the majority of Council is elected by our two professions. The then CEO spoke of changes happening and I was impressed. I thought I might throw my hat in and try to be elected. I had no veterinary political involvement in my career. It’s not an easy thing to do and tough to get on… but I managed it! I couldn’t believe this. I was an elected member of RCVS Council, going up and down from Glasgow to London on the train, with the amazing Passenger Assistance folk supporting me. I travel the three miles from Euston station to Belgravia House through the streets in my power chair. It is exhausting, rewarding and the most humbling experience of my life. Imposter syndrome has a go at me every day but it’s worth it. Meeting our wonderful vets and nurses and working with some of the best, hardest working people I’ve ever known is an experience beyond measure. And things got even better…

**Biggest achievement**

Since last July, I have the incredible honour of being the 148th President of the Royal College of Veterinary Surgeons. The ceremony was held in One Great George Street, off Whitehall on a hot day, and I celebrated with my family, friends and colleagues. The year has been an absolute rollercoaster of graduations, events, meetings and decision making. As things would have it, I have become the RCVS President with Brexit and of course, the COVID-19 pandemic. The latter is one of the greatest challenges our society has ever seen but I am very privileged indeed to work with a fantastic RCVS team.

Although the MS symptoms do their best to intrude, I regard myself as very fortunate. I cannot hate my MS, because ironically, it took me to the highlight of my career 10 years after I thought it was over. I am married to Colette, we have three children and now three grandchildren. For me, life has been very kind. I realised a long time ago that if you spend time listening to the banging of doors closing behind you, you may miss the ones opening quietly ahead.
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"It’s discreet. I can just be myself."

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

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

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

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

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Dear readers,

I would like to update you on what has been happening at MS-UK this past couple of months and how you can find out more about the services we offer.

Here at MS-UK we are adjusting and adapting to the current situation as rapidly as possible in the hope that our services can continue uninterrupted. All of our staff are working from home and I am proud of the work my team are doing to support people affected by multiple sclerosis (MS). Our helpline saw a dramatic increase in contacts as lockdown began, and whilst the calls are a little less as people settle into this new phase, the team have done very well in juggling childcare and working to answer all contacts that have been made. Whether it has been MS-related information or for emotional support required, my team continue to deliver excellent service through this challenging time.

**Video counselling!**

I am also pleased to let you know that we are now able to offer video counselling using Zoom, a platform many more of us have become aware of since the pandemic. We have already begun to deliver counselling sessions face to face through this medium and, so far, the feedback has been positive. If you think you would benefit from counselling, whether through video or the phone, please make a referral for yourself online by visiting [www.ms-uk.org/counselling](http://www.ms-uk.org/counselling) or calling 01206 226500.

**Loneliness and isolation**

We had hoped to launch our Loneliness and Isolation report during MS Awareness Week but the pandemic got in our way. Instead, the report was launched during Loneliness Awareness Week. For the report, we travelled the country, held focus groups and did extensive research. We hope to use our findings to not only to look closely at what we can do to support people but also to influence other organisations and the public to be aware and make positive changes.

**Mindfulness**

As I write, we are also in the middle of running our first virtual mindfulness course from Phil Starin, one of our trustees, a primary progressive MSer and qualified practitioner. We plan to run the course again in September, so if this is something that interests you, simply email [JosephsCourt@ms-uk.org](mailto:JosephsCourt@ms-uk.org) or call 01206 226500.
Similarly, we are looking at taking some of what we do at our wellness centre on to the national stage. We are beginning with live streaming accessible exercise classes for people living with MS on Facebook, so if you would like to tune in head on over to our Facebook page where we will post dates and times of upcoming sessions. Visit www.facebook.com/MultipleSclerosisUK

We are planning to run our information sessions online in future, so please do sign up to our email newsletter by visiting www.ms-uk.org/ms-uk-newsletters and you will be the first to know what is running, when and how to sign up. We have covered various subjects from mental health to carers’ support.

Finally, if you just need someone to talk to please don’t forget that our helpline is always there for you for both information and emotional support, for anyone affected by MS. You can call 0800 783 0518, Monday to Friday, and if no one is available, leave a message and someone will get back to you.

Stay safe and keep well.

Amy

Call 01206 226500
Email newpathways@ms-uk.org

Our report’s key findings

We know that to re-engage with society, a person needs the right mental space, not just practical opportunities to socialise. People need to feel that they are valued as individuals, not seen as problems to be solved. We know that loneliness is normal, and even healthy. It only becomes a problem if people become isolated through circumstances beyond their control. As a charity we are now looking at what we can do to help people feel more connected and more independent. You can read the full report by visiting www.ms-uk.org/loneliness-and-isolation-report

Donate by text

To give: £5 text URGENT5 to 70456

£10 text URGENT10 to 70456

£20 text URGENT20 to 70456

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

To give without receiving further contact by phone and SMS, add the word ‘NO’ e.g. ‘URGENT10 NO’ to 70456
Lifestyle

The natural approach

Katie Ruane is a science degree-qualified naturopath. Here she shares some easy naturopathic tips to boost your wellbeing.

As with any health condition, a holistic approach can make a big difference to your wellbeing. Here are some of my recommendations for boosting your health naturally.

**Nutrition**
Try to buy the highest quality produce you can, and organic wherever possible. This ensures your food is high in nutrients, and helps you avoid unnecessary chemicals.

Eat the rainbow! It’s so important to have at least three different colours of vegetables on each plate, and I’m afraid white potatoes don’t really count, sorry. But, if you leave the skin on, there are more health benefits than eating them without as there is vitamin C that sits just beneath the skin. Eating it will also help increase your fibre intake. If you peel it off, though, you remove much of the goodness and you are basically just eating sugar.

- The reason why three different colours of vegetables is important is because the colours are made up of different nutrients. A really good example of this is carrots, which have high levels of orange beta carotene which is really nourishing for the eyes. This is why we are told when we are little that if we eat carrots we will be able to see in the dark. Aim for half of your plate to be filled with vegetables, and then eating three different colours is easy to do. Consuming this much veg should also help keep your bowel moving and help reduce constipation. If constipation is a hindrance it may be worth looking into getting some plain psyllium husk capsules to help get things moving – make sure you drink lots of water with it though. Ask your doctor first if psyllium husk is safe for you to take if you have ever had stomach pain, nausea or vomiting, trouble swallowing or a sudden change in bowel habits lasting longer than two weeks.

Vitamin D, as we became very aware of during the COVID-19 lockdown, is so important for the immune system. We get vitamin D from the sun, but many of us do not get enough and it can be wise to supplement. But, because some medications for multiple sclerosis (MS) work on controlling the immune system, it’s best not to buy supplements unless you have had a blood test or spoken to
your clinical team about it first. Food sources of vitamin D include butter, oily fish (salmon, mackerel, herrings, sardines, anchovies, trout), liver and eggs, although it isn’t possible to get enough from dietary intake alone.

Vitamin C is also important and once again you can increase levels safely in the body by eating more leafy green vegetables like broccoli, kale and spinach, and by adding lemon juice to water.

Magnesium is also crucial and is found in nuts, seeds, avocado, and dark chocolate – just make sure it has 75 per cent cocoa solids.

### Hydrotherapy – the magic of water

If you struggle with the heat and it makes your MS symptoms worse, having a cool footbath can help reduce these, and if you are able to get into the bath, having a neutral bath can help calm the nervous system. A neutral bath is 33.3-36.1 degrees celsius. If you are struggling to switch off at night and you can tolerate heat, then have a warm bath. It throws us back to being happy in the womb and helps switch off the fight-flight stress response and turns on the rest and digest one.

You can check with your clinician to see if you are OK to have an Epsom salt bath, tepid if the heat aggravates your body, or a tepid foot bath with the salts in, which may help you sleep.

### Essential oils

People are blown away by how effective essential oils are, so they can be a really fab thing to have in a cupboard or the fridge. They can be put on a tissue to breathe in, added to a footbath or bath, or mixed up in an oil like sunflower and rubbed into the skin. Never drink them though.

If you are feeling very overwhelmed, stressed, and can’t sleep, then one drop of highland lavender (Lavandula angustifolia) on a tissue underneath the pillow can really help. You can also put one drop on a tissue to breathe in during the day. It might make you feel sleepy though, so do be careful.

If you are feeling a bit low and want to be energised, then mandarin (citrus reticulata) can be a great oil to have. Just put a drop on a tissue and breathe it in.

www.ms-uk.org
24 Exercise

Keep active at home

These basic seated upper body exercises are designed to achieve sustained movements and get your heart rate up.

There are two groups of exercises here
1. Engagement
2. Mobilisation

Neural engagement and stretches

Start session
Use a pillow support to help your seated posture if you have weak trunk control. It will allow for better range of motion. Concentrate on your breathing rhythm with four seconds in through the nose and four seconds out through the mouth. Before you begin, think whether you’ve had any new symptoms, for example any joint issues that are affected by exercise, or high blood pressure. If you feel dizzy or sick, stop exercising.

Head push back
Put hands or hand on back of your head, push back on hand. Do 5 seconds on, 5 seconds off and complete 6-8 reps.
Keep your hands below shoulder height if you have high blood pressure.

Walk like an Egyptian
Arms out to side with one palm up and one palm down, look at up-faced palm. Using our breathing rhythm then move head towards opposite palm, moving head left and right.

Neck stretch
Look towards your armpit and place right or left hand gently on top of your head to give slight tension to the stretch, with the other hand reach down towards the floor. Hold for 6-8 seconds and repeat on other side 6-8 times.

Headphone stretch
Hands on sides of your head like you are putting on headphones, thumbs on jaw line, tuck elbows to together to feel the stretch in upper mid back. Hold for 6-8 seconds, relax, then repeat 4-6 times.
Exercise 25

Mobilisation

**Shoulder rolls**
Make individual circles with each shoulder, with your hands on your thighs.
Repeat 10 times each side, and do 2-3 sets.

**Pelvic rolls**
With your hands on thighs, roll your pelvis back, drawing in your tummy, then roll your pelvis forward and sit up onto your sitting bones. Use your breathing as your tempo.
Do 10 reps and 2-3 sets.

**Seated Cobras**
Thumbs together, centre line of your body, then move hands outward so thumbs point upwards and palms face to the front.
Do 10 reps and 2-3 sets.

**Arm swings**
Double or single arm, use the other hand for support if necessary.
Do 20-30 swings and 2-3 sets.

**Hugs**
Cross arms over your body, touching the backs of your shoulders, then open up your arms to the side with palms open and thumbs uppermost.
Do 10 reps and 2-3 sets.
26 Exercise

**Trunk rotations/torso twists**
With a good seated position, place fist and hand together to the front and rotate torso to left and right with control. Make sure that your head is facing forward throughout movement.
Do 20-30 reps and 2-3 sets.

**Side bends**
2 versions, one with your hand sliding up the side of body as you reach towards the floor, the second with your hand on the side of your head, then come back to centre position to finish the movement.
Do 10 each side and 2-3 sets.

**Arm abduction**
Palms up above thighs, then lift out to the sides so palms are facing down, elbows bent at 90 degrees.
Do 10-20 reps each side and 2-3 sets.

**Shoulder presses**
Individual or alternating, with palms facing towards your body at shoulder height, individually push hand upwards, rotating hand so palm is facing forward as you go through the movement.
Do 10-20 reps and 2-3 sets.

Call 01206 226500
An easy solution

MSer and Feature Writer Ian Cook trialled a simple plastic device for the bathroom which helped wonders with his bowel problems.

Last year, after years of constipation, I decided that I needed to take matters into my own hands, metaphorically speaking.

My bowel movements, which for decades had been regular, with a bowel movement once a day usually after breakfast, were becoming less and less frequent. Constipation and ‘faecal urgency’ were now real problems for me.

Common problem

I decided to see if there was anything I could do about my constipation and occasional faecal incontinence. I quickly came across an innovation called the Squatty Potty. This really is one of those devices that does exactly what is says on the tin. The Squatty Potty is basically a small plastic box you push under the toilet and which you place your feet on when you poo. You are then in a squat position. The thinking behind the box is the simple observation that our ancestors squatted for centuries before the invention of the modern-day toilet. In fact, the majority of the world’s population still squats rather than sits.

Nothing to loo

The Squatty Potty sounded worth investigating. There was just one problem. It was rather expensive, retailing at £27 at squattypotty.co.uk.

However, I soon discovered cheaper alternatives were available online for less than half the price. So after a while I spent £8.98 on a ‘squatting folding toilet stool’ on Amazon.

From the moment I put the squatting folding toilet stool under the toilet, and placed my feet on it, adopting the squatting rather than the sitting posture, everything seemed more natural. The bowel movement was swift and easy. My bowel felt totally empty afterwards and it was a good feeling.

My verdict

I have been using my squatting toilet stool daily for more than a year and have even taken it away with me when I have travelled from home. Looking back, I can confidently say the squatting folding toilet stool has been my best MS-related buy of the past 12 months, and although I am wary of saying that it is the end of my toilet troubles, I can say that for the past year something that was very troublesome is now well under control. If only everything in progressive MS was so simple.
As someone who has had multiple sclerosis (MS) for just over nine years now, the process of acceptance took me what feels like a very long time.

What is acceptance?

Unlike the general understanding of acceptance, psychological acceptance refers to the process of fully embracing one’s feelings and emotions without avoiding or pushing them away. The former understanding may imply that acceptance is related to a process of giving in and resigning to the consequences of the situation taking a rather passive role. The latter understanding refers to a process where the person themselves is an active participant in the psychological management of the situation and its consequences.

For people with MS like me, we have several additional factors to contend with. There is no known cause, there is no cure, the symptoms are so varied and can affect any part of the body and that symptoms, whether mild or severe, can come on in an instant, so I find a level of uncertainty is always present.

But to accept a diagnosis of MS isn’t to just resign to a potential possibility of severe deterioration and loss of function in the near or distant future. In fact, it is quite the opposite. Acceptance of MS is to adapt to life with a chronic illness, and to be an active participant in the process.

Why is it so important?

Through my research, I’ve learned that acceptance is recognised by psychologists as a core component of successful coping and as part of the process of adjustment to a diagnosis of MS. A 2011 study published in the journal Psychology & Health found acceptance to be consistently linked with increased psychological wellbeing in terms of less symptoms of anxiety and depression, increased health-related quality of life, improved marital relationships and increased positive feelings.

In fact, psychological variables such as acceptance are noted to be even better predictors of psychological wellbeing than clinical variables such as disease severity. Having been through the...
process myself and the various twists and turns that accompany the journey I’ve lived the benefits of acceptance. It’s almost like when I hit a certain level of acceptance it became a lot easier to manage any symptoms that MS throws my way.

**There are a number of reasons why I think this may be**

- Acceptance can have positive consequences in empowering and allowing people to take an active role in managing their illness, asking questions and seeking help when needed. This is further reflected in a general positive attitude towards MS
- Acceptance has been linked to seeking social support which is known to be beneficial to wellbeing
- Acceptance in the moment helps to prevent you from catastrophising and dwelling on negative thoughts which can lead to pathological responses such as stress, anxiety and depression
- Acceptance frees you from the psychological battle against avoidance therefore leading to less negative feelings of frustration and psychological fatigue

Like for many others with MS, it’s not been an easy journey, but it was that moment when I realised that it is OK to feel these kind of emotions that I suddenly felt that ‘aha’ moment in accepting that I am a Hannah, and I have MS. It was a moment where the weighted blanket that had been holding me back had been removed. I felt lighter. I felt free. That’s not to say that over nine years on I don’t ever have these negative feelings, because I do, but I’ve now managed to develop the skills to manage them much more effectively.

**Work towards acceptance**

If you are struggling with acceptance, here are some tips to accept and embrace your ‘new normal’

- Make full contact with your emotional experience without trying to change, escape or control events. You can’t alter the fact that you have MS, or escape it when the symptoms are ever-present. Likewise with your thoughts – they are just thoughts so don’t fight to change them or push them away
- It’s normal to go through negative emotions of grief and even denial and this OK. Allow yourself to feel these rather than fighting them
- Practice with other non-MS related thoughts and feelings so that the process of acceptance becomes easier and something you can integrate into all areas of your life
- It’s not an easy process. It doesn’t always just happen in an instant
- Adjust your expectations and do what you can within reason. Work with your MS and adjust your expectations to be within what you can do as you establish a ‘new normal’

This is my favourite one. I’ve learnt to live with and accept my MS by finding alternative ways to attain my goals instead of resigning to not being able to achieve them ever. For example, I’d dreamt of doing a PhD but for a long while and didn’t think it possible due to MS-related obstacles that would potentially make it difficult. After a lot of head scratching and searching, I finally came across the perfect opportunity to complete my PhD by distance. It has allowed a great amount of flexibility that lets me work with my symptoms, rather than fighting against them.

- Ask for support if necessary
- Support others by helping them in the process of acceptance and it will help to reinforce your own skills in it too

www.ms-uk.org
Khayan thee hnat
Stuffed aubergine curry

Ingredients
- 2 tbsp dried shrimps
- 5 tbsp oil (vegetable, sunflower or peanut)
- 2 medium onions, finely chopped
- 5 garlic cloves, finely chopped
- 1 tsp chilli flakes
- 1 tsp turmeric powder
- 1 tsp paprika
- 1 tsp shrimp paste
- 8 long baby aubergines (about 500g)

To serve
- Handful of crispy fried shallots
- Handful of coriander leaves (optional)

Method
1. Pound the dried shrimps to a powder using a pestle and mortar, or use a food processor. Heat 4 tablespoons of the oil in a large lidded frying pan over a low-medium heat and cook the onion and garlic for about 10 minutes until soft and golden-coloured. Add the chilli flakes, turmeric and paprika to the pan and stir for a minute or 2, until fragrant. Stir in the shrimp paste, so it melts into the mixture, add the shrimp powder and mix well, then empty the contents of the pan into a separate bowl.

2. Cut the aubergines in half along their length, but not all the way through, keeping the stem intact. Then make another cut along the length, again preserving the stem, so the aubergine is in quarters but still connected by the stem. Carefully ‘fill’ each aubergine with the mixture with your hands. This may get a bit messy and some of the filling may fall out, but that is fine. You should be left with a small amount of filling to add to the cooking sauce.

3. Give the used frying pan a bit of a wipe with kitchen paper, then heat the remaining oil in it over a high heat. Carefully add the aubergines. Try to turn them over carefully so that all sides are charred. This should take a couple of minutes. Add 150ml of water to the pan with the remaining filling and bring to the boil. Leave to simmer with a lid on. After 15 minutes the aubergines should be soft and ready to serve. Garnish with the fried shallots and coriander.
Mohinga
Aromatic fish noodle soup

Ingredients
- 2 tbsp rice flour
- 6 garlic cloves, peeled
- thumb-sized piece of ginger, peeled
- 3 lemongrass stalks
- 6 tbsp oil
- 3 medium onions, thinly sliced
- 1 tbsp paprika
- 2 tsp turmeric powder
- 1-2 tsp chilli powder
- 1 tsp shrimp paste (optional)
- 2-3 tbsp fish sauce, plus extra to season
- 400g tin of pilchards in brine (if you can’t find pilchards use tinned sardines)
- 300g shallots, peeled
- Black pepper

To serve
- 400g dried rice vermicelli (0.8-1mm size), cooked, rinsed and left in cold water
- 3 limes, cut into wedges
- Garlic oil
- Chilli flakes or chilli flakes in oil
- 6 hard-boiled eggs, cut in half
- Coriander leaves
- 1 batch of crispy chana dal crackers broken up

Method
1. First prepare the rice flour. Toast it in a dry frying pan over a medium heat for 3-5 minutes, stirring occasionally. Tip the flour out onto a plate and set aside.
2. Crush the garlic and ginger to a paste using a pestle and mortar or blitz in a food processor. Cut off and discard the first 5cm of the thin end of the lemongrass stalks and remove the tough outer layer, then bash what remains with a pestle or rolling pin to release the flavours.
3. Heat the oil in a large casserole dish over a medium heat. Add the sliced onions and cook until soft, stirring occasionally, for 5 minutes. Add the crushed garlic and ginger mix and stir for 1 minute, then add the lemongrass stalks. Add the spices, shrimp paste, if using, and fish sauce and stir well. Then add the contents of the pilchards tin, including the brine. Mash the fish then add the toasted rice flour and mix well to prevent it sticking to the bottom of the pan.
4. Top up with 1.2 litres of water and add the whole peeled shallots. Bring to the boil and simmer gently for 1 hour, uncovered, stirring occasionally. Once cooked, remove the lemongrass, add a good grinding of black pepper and adjust the seasoning with a little fish sauce.
5. Put some drained rice noodles into each individual serving bowl, ladle over the soup, add a squeeze of lime, a drizzle of garlic oil, some chilli, as desired, and top with boiled eggs, coriander leaves and your broken up crackers. Serve immediately.

Serves 4-6

Extracted from The Rangoon Sisters by Amy and Emily Chung (Ebury Press, £20)
Photography by Martin Poole

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In February 2013, my first symptoms were tingling in my fingertips, progressing to what I thought was a kidney infection as my left kidney area was really tight. My stomach area seemed itchy but when I scratched it, it was like sunburn which progressed down my left side. I then got optic neuritis in my left eye. I also was struggling at times to speak as my jaw felt really tight. I was super tired.

My GP referred me to neurology. I had an MRI in 2013. Two lesions were found on my spinal cord and a small number of lesions on my brain. This is when I was told it was benign multiple sclerosis (MS) and that effectively, I had an attack of the nervous system. They said I could go back to living a normal life. As you can imagine, I was elated with this news, and soon after I got an excellent job – it was a career changer and I loved it. However, within a year I had obvious balance issues. When I went to the GP, they told me I had labyrinthitis. Three times I was told this over three years.

The third time was March 2017, when one GP had the bright idea to read my records and see my history and the benign MS. During this time, I had been made redundant three times in the space of seven months. The third redundancy probably came at the right time. I had ongoing balance issues and I got foot drop. My co-ordination was bad, as well as my balance. So I was sent back to neurology for another MRI and was officially diagnosed 20 February 2018 with relapsing remitting MS.

Relief
I was relieved as it had taken six years to officially confirm that I had MS. I more or less knew I had it, but it needed confirming. The same day, I agreed on a disease-modifying drug (DMD), Tecfidera. When I got home, and over the weeks that followed, I had a mix of feelings, a bit like a grieving process. I felt extremely isolated as I didn’t know much about MS. I was worried I was going to lose my independence. I started looking for support groups online and I found a couple that I liked, but I was still looking for something a bit more. I wanted to be a part of a group that I related to. Where I could be honest and true and at the same time laugh. Then I went online and started an MS Facebook group, MS Troopers UK, which has so far been remarkable to be part of.

Medication
I stayed on Tecfidera until May 2019. It was a fairly good DMD, although if you don’t follow the guidelines, the gastro issues are horrible. I had to stop this DMD as my lymphocytes had gone down.
too far, and hence my immune system would begin to be compromised. I started on my next DMD in January this year, and I had no relapses during the break. I am now on Plegridy, again a non-invasive DMD. I self-inject once a fortnight. The side effects can be flu-like, but I don’t seem to be getting too many, thankfully.

I’ve looked into dietary strategies for MS and make an effort to eat healthily. I tend to steer clear of processed foods, avoid gluten and follow a higher protein and lower carb way of eating, loosely based on the paleo diet. I avoid foods like bread, pasta and potatoes. I also take vitamin D as advised by my neurologist.

Life now
I am fortunate as I run my own business which I’ve been doing for three years now, and so I can work from home and don’t have set hours. In my old job, I was struggling with all the travelling I was doing due to pain and fatigue and digestive issues (which is a polite way to put it!).

I have two border collies (pictured) so they get me out of the house every day. I can’t walk far and only on flat ground, so I drive to the beach where the dogs can run about off the lead and I can sit and throw the ball for them. They are my lifeline. So life has slowed down considerably, but I am enjoying what I do and people in the industry I work in totally respect my MS.

My advice
To anyone recently diagnosed, I’d say don’t be afraid, you are stronger than you think. This is not a life sentence. There are lots of DMDs to choose from. Find an online group – this came to my rescue because there are so many like-minded people out there going through the same, and they will listen and empathise.

Your family may initially not understand, and you will find out who your real friends are, and that is difficult, but required because there are many more sincere true friendships to be made within this global community.

Take time with your family members – if they care they will listen, and they will eventually understand. Most importantly don’t stop having fun and laughing. It’s the best medicine.

To join Briony’s group, search Facebook for ‘MS Troopers UK’.
I have primary progressive multiple sclerosis (PPMS).

It affects my nerves and can cause pain, extreme fatigue, anxiety, depression, and affect vision, continence, speech, movement, strength, balance, ability to think, sensation, and more. Many symptoms aren’t visible.

My symptoms will increase over time. I may have times where they flare up temporarily in addition to the overall increase. Some medications may help slow the progression or manage symptoms, but there is no cure.

Living with this is my normal.

Sometimes I need to push myself to do more and other times I need to recharge.

Right now I need to recharge.

Don’t worry. I am looking after myself and will be ready to face the world again soon.

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Empowering individuals and promoting understanding and acceptance.

Products designed by disabled people, for disabled people. Enabling communication about disability with style, accuracy and humour.

(Products shown are not to scale)
Everyone with multiple sclerosis (MS) is classed as vulnerable under the COVID-19 government guidance; however, some people with MS have been considered extremely vulnerable and for the past three to four months have been shielding. The government has now decided that people should stop shielding from 31 July. For many people this is an extremely stressful time as the expectation shifts towards getting back to work. Firstly, we must remember that even though shielding is ending, the virus is still active and people with MS are vulnerable.

Employers have a duty of care for the wellbeing of their employees and are obligated under The Equality Act 2010 to make reasonable adjustments. Furthermore, the COVID-19 guidance requires that a full risk assessment is completed within every business. Consideration needs to be made regarding how all staff will be kept as safe as possible, including those who are vulnerable. Employers should be holding individual conversations with those returning from shielding to support this transition. This might include:

- Discussion on how you are feeling about returning
- Sharing with you the risk assessment to give you a clear picture of how risk is being managed within the business
- Discussion about what else can be done to support you, for example continuing to work from home where this is possible, temporarily adjusting your role so you can be in the safest job possible, and how they will support you to stringently maintain social distancing. This should be a conversation so you can ask questions, share your ideas and hear the company’s plans

- Building on the above point, what reasonable adjustments need to be agreed to optimise your safety? This could involve, for example, changing hours so you can be dropped off and picked up by a family member so you do not need to travel on public transport

This is a challenging time for everyone. Employers are also navigating new guidance and working through how to support people. Discussion is the key to making this work.

www.ms-uk.org
Overcoming this year’s difficulties

These are challenging times for charities, as Fundraising Manager Jill Purcell explains.

When COVID-19 hit, we saw much of our income dry up literally over night due to major fundraising events being cancelled all across the country. It was time to act quickly and think outside the box to find new ways for our supporters to continue fundraising for us and help us continue to provide our vital services for anyone affected by multiple sclerosis (MS).

With a bucket full of determination and a huge dose of passion, we launched our urgent appeal to raise general funds and our first ever virtual event, My MS Marathon, to raise money for our telephone counselling service.

I am really pleased to say that we have had an excellent response. At the time of writing we have received over £10,000 in donations. Thank you to all of our New Pathways readers for making very kind and generous contributions. It just goes to show how much people can pull together and care about our MS community. The appeal is still running, so if you would like to make a donation we’d be hugely grateful for your support.

My MS Marathon is going so well that we’ve decided to extend the event until September, so there is still time to take part! We’ve seen lots of interesting challenges being taken on, from walking and running to gaming. People love My MS Marathon because it is really accessible and you can take part at your own pace. It just needs to be focused around the number 26 – the amount of miles in a marathon. Everyone that raises over £100 receives an exclusive My MS Marathon medal, too.

“If I’m doing a lap a day!”
Catherine Wakefield, who lives with secondary progressive MS, was inspired to take part in My MS Marathon after a friend told her about it on Facebook. Catherine calculated that if she did a lap a day around her village green every day for a month using her “purple wheels of steel”, she could smash the marathon distance and so her challenge was born. Catherine said “If Captain Sir Tom could do it at 100, surely I could manage a few laps around the village green!”

If you would like to take part in My MS Marathon, all you need to do is dream up your challenge based around the number 26, pledge to raise £100 and sign up at https://www.ms-uk.org/my-ms-marathon. Thank you in advance for your support.

Whilst the appeal and My MS Marathon are working well, the road ahead is still very rocky. We are constantly working on new ideas to bring in much-needed funds so we can continue to help anyone affected by MS.
Could you volunteer to place collection pots in your local area for us?

Here at MS-UK, we have an amazing group of volunteers who we call our MS-UK Community Champions, and we are looking for more people to help.

It doesn’t matter where you are in the country, if you think you can help us to raise vital funds by placing collection pots in your local area, then please do get in touch with our Community Fundraiser Lucy today on 01206 226500 or email Lucy@ms-uk.org

Thank you again for all your support and stay safe and well.

Jill Purcell, Fundraising Manager

Donate by text

To give: £5 text URGENT5 to 70456

£10 text URGENT10 to 70456

£20 text URGENT20 to 70456

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

To give without receiving further contact by phone and SMS, add the word ‘NO’ e.g. ‘URGENT10 NO’ to 70456

Can you add gift aid?

If you would like us to add gift aid to your donation please complete the information on the tear off slip and return it with your cheque. Please post it to FREEPOST MS-UK (no stamp is required).

☐ I am a UK taxpayer and I would MS-UK to treat this donation and any donations I make in the future and have made in the past four years as Gift Aid donations, until I notify you otherwise.

I understand that if I pay less Income tax and/or capital gains tax than the amount of Gift Aid claimed on all my donations in that tax year it is my responsibility to pay any difference. I understand that MS-UK will reclaim 25p of tax on every £1 that I give. Gift Aid is reclaimed by MS-UK from the tax I pay for the current tax year. Please let us know if your tax circumstances or name and address details change so we can amend our records.

Your details

Title __________ First name ________________________ Last name ________________________

Email ________________________ Postcode ________________________

Can you add gift aid?
Over to you

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

Dear New Pathways,

As always, I read your magazine from cover to cover as soon as it arrives! A couple of issues back I was interested to read Charlie Gees’ article on the Medimotion exerciser, and in particular his endeavours to stop his arms from contracting. This has been one of my aims for many years as well. I also use a Medimotion and to stop my arms contracting in my sleep I wear wrist weights at night which help to keep my arms by my side. My theory is that when I do move my arms there is some resistance, thereby using my arm muscles as well. Could you pass this on to Charlie please and thank him for his continued interesting articles in the magazine.

Many thanks,

Angie
Waterlooville

Dear New Pathways

I have MS and just received my May/June issue of New Pathways and read the letter from Chris in Bodmin. He says his wife takes low-dose naltrexone (LDN), as do I, and goes on to suggest Dr Robert Lawrence would prescribe if you have no success with your own GP.

Unfortunately Dr Bob is no longer able to do this due to his health and age. I would like to inform you I now get my prescription from Clinic 158 – the telephone number is 01413 577357, and get my prescription filled at Dickson Chemist in Glasgow, as they put no fillers with the LDN.

Really LDN should be available from your local GP but due to it being off licence, many like myself have to go down a private route to obtain this.

Dr Bob has been taking it for many years and knew one of the pioneers of early research, Dr Bahari, a neurologist.

I myself have taken LDN for four or five years, but find it very unfortunate I cannot get a prescription from my local GP. I just wanted to inform New Pathways readers in the hope this helps some people.

Many thanks,

John, Eastbourne

Contact us
Write to “FREEPOST MS-UK”
(no stamp is required)
Call 01206 226500
Email newpathways@ms-uk.org

Call 01206 226500

Keep moving

Letters
Dear New Pathways,

After nearly 40 years, 21 of which I have had MS (now secondary progressive MS), my bowel problems are sorted! This is what’s worked for me.

Every morning I have a bowl with

3 dsp rolled oats
2 dsp ground flaxseed
2 dsp of mixed nuts or seeds
1 dsp desiccated coconut
Either milk (whatever type you prefer) or I just use bottled water from the fridge.

I have been choosing this rather boring breakfast but it definitely works on a daily basis.

No more medication! I would say it’s worth a try after 40 years of doctor visits and various medication. It works and what a difference it has made for my bladder and the rest of me.

Thanks for a great magazine.

Regards,

Shirley,
Northamptonshire

Dear New Pathways,

Like Chris from Bodmin’s wife on the letters page last issue, I too take low-dose naltrexone.

Getting it on the NHS is not straight forward. It must not be made with lactose as this cancels its effectiveness. You also have to spend time finding the best dose for you. Mine comes from IPS Specials whose website is www.ips-pharma.com.

It can also only be prescribed off-script. My MS nurse said my GP was putting his head on the block. Plus it’s not cheap because it’s a special order.

The best thing to do is to go online and look up Linda Elsegood’s website at ldnresearchtrust.org. She’s spent years of her life campaigning for it. I’ve found the dose that works for me and, yes, I sleep like a log most nights. It has also improved my cognitive ability. Please look up Linda’s website and convince your GP it’s worth a try.

Also, to the lady that wrote in last issue with smart phone issues – I think there may be a solution. I’ve had similar problems and my cousin who is blind advised me to get in touch with the Royal National Institute for the Blind. It didn’t matter that I’m not blind, and they had loads of good advice. It’s worth a try.

Kind regards,

Penny
Cornwall
Do you offer a service that helps people living with MS?

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You could advertise in the leading magazine for the MS community, contact us today:

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Call 01206 226500
Please fill out our reader survey to help us make New Pathways even better.

Your feedback is really important to us and we want to make sure we produce a magazine that meets your needs. Please take some time to let us know if we’re on the right track and where we can make improvements in our annual survey below. All contributions are anonymous, we won’t ask you for any identifying details.

Age
- Under 18
- 19–24
- 25–44
- 45–64
- 65–74
- 75+
- Prefer not to say

What is your sexuality?
- Heterosexual
- Gay
- Lesbian
- Bisexual
- Other
- Prefer not to say

What is your gender?
- Male
- Female
- Non binary
- Other (please specify)

What is your ethnic group?
- I would best describe my ethnic group or background as...
- White - English / Welsh / Scottish / Northern Irish / British
- White - Irish
- White - Gypsy or Irish traveller
- Any other white background
- Mixed / multiple ethnic groups - White and Black Caribbean
- Mixed / multiple ethnic groups - White and Black African
- Mixed / multiple ethnic groups - White and Asian
- Mixed / multiple ethnic groups - Any other mixed / multiple ethnic background
- Asian / Asian British - Indian
- Asian / Asian British - Pakistani
- Asian / Asian British - Bangladeshi
- Asian / Asian British - Chinese
- Any other Asian background
- Black / African /Caribbean / Black British – African
- Black / African /Caribbean / Black British – Caribbean
- Other ethnic group – Arab
- Other (please specify)

What is your education level?
- Degree or equivalent
- Higher education
- A level or equivalent

www.ms-uk.org
Reader survey

☐ GCSE or equivalent
☐ Other qualifications
☐ I have no formal qualifications
☐ Don’t know
☐ Prefer not to say

What is your marital status?
☐ Single
☐ Living with a partner
☐ Married
☐ Same-sex civil partnership or marriage
☐ Separated
☐ Divorced
☐ Widowed
☐ Prefer not to say

Are you a parent?
☐ Yes
☐ No
☐ Prefer not to say

How many people live in your household?
☐ Only me
☐ Two people
☐ Three people
☐ Four people or more
☐ Prefer not to say

Where do you live?
☐ Scotland
☐ Northern Ireland
☐ Wales
☐ North East
☐ North West

Yorkshire and the Humber
☐ West Midlands
☐ East Midlands
☐ South West
☐ South East
☐ East of England
☐ Greater London
☐ Overseas

A friend of mine has MS
☐ I am a professional working in this field
☐ I have no personal connection to MS
☐ Employ someone who has MS
☐ I prefer not to say
☐ Other (please specify)

What is your religion?
☐ No religion
☐ Christian including Church of England, Catholic, Protestant and all other Christian denominations)
☐ Buddhist
☐ Hindu
☐ Jewish
☐ Muslim
☐ Sikh
☐ Prefer not to say
☐ Any other religion (please state)

Which MS-UK services have you used?
Please select all that apply
☐ MS-UK Helpline
☐ New Pathways magazine
☐ My MS-UK app
☐ MS-UK Counselling
☐ Josephs Court, Wellness Centre
☐ MS-UK website
☐ Choices leaflets
☐ I have followed MS-UK on Twitter, Facebook or YouTube
☐ None

Do you consider yourself to have a disability?
☐ Yes
☐ No
☐ Don’t know

What is your employment status
☐ A homemaker
☐ A student
☐ Employed
☐ Medically retired
☐ Military
☐ Out of work and looking for work
☐ Out of work but not currently looking for work

How are you affected by multiple sclerosis?
☐ I have a diagnosis of MS
☐ I believe I may have MS
☐ I care for someone with MS
☐ A relative of mine has MS

Call 01206 226500

www.ms-uk.org
If you have MS, what type do you have?
- Benign MS
- Clinical isolated syndrome
- Primary progressive MS
- Relapsing remitting MS
- Secondary progressive MS
- Other (please state)

Which of these do you use to manage your MS?
- Counselling
- Diet
- Disease-modifying drugs
- Exercise
- Medical cannabis-based products
- Mindfulness
- Physiotherapy
- Vitamin supplements
- Other (please state)

How long have you been a New Pathways reader?
- Less than a year
- More than a year

Do you feel that New Pathways helps you make informed choices about how you live with MS? Please let us know the reasons behind your answer

Why do you read New Pathways?

What would you like to see more of in the magazine?

Do you like the way the magazine looks and the design of its pages? Please give reasons

Is there anything you would prefer not to see in the magazine?

Do you feel that New Pathways improves your understanding of MS? Please let us know the reasons behind your answer

MS-UK wants a world where people affected by MS live healthier and happier lives. Do you think New Pathways helps you do this? Please let us know the reasons behind your answer

We would like to cater for all MSers at any stage of their MS. Do you feel like we cater for your stage of MS enough? Please let us know the reasons behind your answer

Please return your completed survey to MS-UK by 31 August 2020. Send it to FREEPOST MS-UK (no stamp is required)
Multiple Sclerosis And Urinary Incontinence

Why does it happen?
Nerve damage to the myelin sheath caused by M.S. can affect how the body interprets the signals between the brain and the bladder and bowel affecting both the bladder and sphincter muscles and the co-ordination between them needed to urinate normally. This leads to incontinence problems. Someone with M.S. may experience urinary frequency, urge incontinence, overactive bladder, stress incontinence or overflow incontinence. There are many conservative methods which can help or it may be a case of adjusting medication to help alleviate your symptoms and using devices to manage.

Conservative Treatments
It is important to keep the bladder and bowel as healthy as possible by eating a healthy, balanced diet with plenty of fibre and consuming enough fluid (6-8 glasses a day). Bladder retraining involves establishing a regular routine for bladder activity and retraining your brain to hold on. It can help to go to the toilet after every meal or every few hours and make sure you are eating and drinking at regular times.

Pelvic Floor Muscle Exercises
The Pelvic Floor is a layer of muscles that stretch from the pubic bone to the coccyx and then from side to side. These muscles help to support the bladder and bowel plus the womb in women. These muscles can become weak through trauma such as childbirth or pelvic surgery, changing hormones, persistent coughing, chronic constipation or nerve damage from M.S. When these muscles become slack it can weaken the sphincter muscle to the rectum or bladder allowing the involuntary passing of stool or urine.

Vibrance Pelvic Trainer® is a medical grade vaginal probe that vibrates gently when you contract your pelvic floor muscles correctly. You can see results faster than struggling along with poor technique.

Self-Use Continence Products
There are many products available that can help you to feel more comfortable:

• Incontinence pads and pants – these are available in a variety of sizes and absorbencies and can help to draw fluid away from the skin
• Urethral Control Devices: Pacey Cuff is the newest version available that allows men to control accidental leakage. It can be worn for up to 60 minutes at a time and is suitable for swimming.

• Wearever® is a washable incontinence underwear: comfortable cotton material with modern styling options for men and ladies, and a built-in washable absorption pad (150ml / 300ml and 650ml) that can be washed up to 250 times – much better for the environment and incredibly discrete.

• Male incontinence sheath – these can be worn over the penis and attached to a leg bag. These are particularly useful at night.
• Urinal Devices such as Afix Core® can be the ideal solution for outdoor activities. Urine drains out from a double walled soft PVC receptacle that houses the penis, through a non-return flapper valve into variable sized thigh bags or leg bags depending on the severity and volume of leakage, and your mobility. The urine is contained within the waterproof bag, you stay dry and odour isn’t an issue – just empty when convenient. Available on NHS prescription.
• For greater confidence, the Uresta® bladder support is simply inserted it into the vagina until the bell shape presses gently against the vaginal wall to support the urethra instantly preventing leaks mechanically for 6 out of 10 women and reducing leaks for a further 2 out of 10.
• Bed pads and mattress protectors – these can help to keep the bed clean and dry. There are also covers and pads available for chairs.

Be confident again and choose life – not leaks.
Visit mypelvichealth.co.uk for more information
Q&A 45

Questions and Answers

Ryan and Laura want to hear from you

Q I have multiple sclerosis (MS) and want to know if it is safe for me to use a vibration plate?

A Vibration plate technology for MS has been looked at in some studies. A review in 2018 found improvements in muscle strength, functional capacity, coordination, resistance, balance, and spasticity, though these studies were limited. There is nothing about your MS specifically that should stop you from being able to use a vibration plate.

If you have any other health issues, talk with a health professional or your local physiotherapy team within the neurorehabilitation team (your MS nurse would give you the contact details). There is also often physiotherapy support within local MS therapy centres, many of which use vibration plate technology. Download our exercise Choices booklet or order a copy by visiting www.ms-uk.org/choicesleaflets.

Q I have registered with the ‘drug science’ website and project Twenty21. Can you explain more about it?

A Project Twenty21 aims to review cases where medical cannabis has been prescribed in the private sector, to gather data and build an evidence base to present to the NHS demonstrating the value of medicinal cannabis.

Patients will pay a subsidised fee for their prescription, capped at £150 a month (not including prescription costs and consultations). Medicinal cannabis comes with guarantees of safety and quality, will be grown under controlled conditions, have followed good manufacturing practice and be free from contaminants. It will also have laboratory reports which will tell the prescribing clinicians the range and amounts of the various cannabinoids the cannabis contains.

There are eligibility criteria for the project. To find out more about it, visit www.drugscience.org.uk/project-twenty21/

Give us your feedback

We are always trying to improve our services and we value the feedback of our clients. We would be grateful if you could take a few minutes to complete a short survey about your experiences of using the MS-UK Helpline. www.surveymonkey.co.uk/r/H8VTJ98

How to contact us

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

Call 0800 783 0518
Email info@ms-uk.org
Visit ms-uk.org/helpline
Scott’s final say

After I had gone blind in one eye in May 2006, I was signed off work for the next few months until the middle of August whilst I got used to having one functioning eye. Not long after, our second son had been born without a hitch. In fact we were at home by 4 o’clock in the afternoon straight after Georgia had given birth and waiting for the Chinese to open so we could order dinner.

I was finally diagnosed with multiple sclerosis (MS) in December 2006. Because I knew the Harrier jet like the back of my hand, once I’d got used to having one eye and a new sense of depth perception, I was allowed to stay working with the blessing of my management. This meant so very much to me as the standards we had to work at had to be perfection and nothing less. This went on swimmingly for the next six months before I was given beta interferon, my first disease-modifying drug (DMD). This was to be self-injection into the thigh on a weekly basis and I thought this would be a piece of cake – just stick a needle in your thigh and the job’s done! No, not that simple at all.

I would press the needle in so slowly I could feel it breaking muscle fibres.

On a Sunday night, it was a regular occurrence for Georgia to find me sweating, laying on the floor on the brink of fainting, having not even done it yet. I would get myself in such a tizz and press the needle in so slowly that I could feel it piercing my skin, and breaking every single muscle fibre as it slowly penetrated deeper before I finally got to the right depth and squeezed it. Some killer squaddie I was, eh? It didn’t even hurt, it was just all in my head. Please tell me someone is reading this with a smile on their face, knowing exactly what I’m talking about? I can’t be the only one that felt this was an unnatural act! I spent the next nine months feeling like I had the worst flu ever. I’d wear several layers of clothing just to try and stay warm, and generally feel like death from the Monday morning after having the injection on the Sunday night before, until the following Saturday, where I would feel all right for half a day. I told the doctors this, and I was told I’d get used to it. I never did, so I just stop taking them. I took no more meds until 2011 when I had another relapse, just after I had been promoted to sergeant. Next time, I’ll explain what that meant for my career.
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