

The Magazine

TRANSVERSE MYELITIS SOCIETY



Research Into Demyelination & Repair

DR. DENISE FITZGERALD



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Letter From The Editor

ANNIE SCHOFIELD

Being told you have an incurable condition is pretty devastating, and I suspect I'm not the only one to follow every news story on possible cures. Unfortunately, many of these are just that, 'stories', or they are a long way into the future. So it was with great excitement that I read earlier this year about a research team at Queen's University Belfast, led by Dr Denise Fitzgerald, and their new experimental discoveries on how the immune system helps to repair myelin in the spinal cord and brain. Particularly poignant was the fact that Denise Fitzgerald had herself contracted TM at the age of 21 (fortunately she made a good recovery). I was beyond excited when she agreed to take time out from her busy schedule to write an article for this magazine, explaining how it all happened. You may not have heard of T cells before, so turn to page 6 to learn more.

I have always had a keen interest in food and this has led me to reading everything I could about nutrition and how diet might help me have better quality of life post TM. By co-incidence my daughter's best friend, Luisa Carugati, was training to be a nutritionist and expressed a wish to use me as a study case. She started researching individual TM cases, and the word inflammation was at the forefront, so from there we started discussing what foods might help – and I am delighted to be sharing this with you on Page 12. It makes fascinating reading, and may be of help to you.

On Page 21 you will find our new contributor to our TM Kids, Katie Simpson. She replaces Penny Winton who has moved to Houston with her family. Katie clearly has the same zest for life and we're thrilled to have her on board.

It's always great when articles we have chosen for the magazine appear to reflect current thought, and this edition is no exception. Mental Health is a big topic at the moment, and most of us are aware that one of the many side effects of TM can be depression. However, if more people felt able to seek support when they are struggling, this could prevent issues growing into even bigger ones. Barbara Babcock's article on Page 22 on why your mental health is as important as your physical health goes a long way to remove the stigma.

Someone who spent 6 years fighting an energy sapping (mental and physical) unwinnable battle of attempting to

change his diagnosis, was Graham Belchamber. You can read his account of how he finally accepted he had TM on Page 26.

I believe it was Napoleon who referred to the British as 'a nation of shopkeepers'. If he were alive today he would probably change that to a 'nation of fundraisers'. We all know about the big TV jamborees, and the marathons where thousands of people are collecting for a huge range of charities. It seems the TMS is no exception and with each edition there are more and more fundraising events to celebrate. Not just the marathons, but walks, golf, cycling, bridge, painting, parties and much more.

Elsewhere, Solicitor Marsha Thompson tackles a thorny legal issue – discrimination in the workplace, Ruth Wood gives us an amusing slice of her life, Leonie Ashenden gives an update on PIPs and Lew Gray reports on TMS Member Services.

This magazine has been printed for the benefit of TMS members, however, by taking a copy along with you every time you visit a health professional you can spread the word further and educate others about TM. We still see new members join the society. People who have never met anyone else with this rare condition, despite having been diagnosed many years ago. Although we hope members will be happy to pay for their own copy, we positively plead with you to ask the TMS for as many extra FREE copies as you think you can hand out.

I would like to take this opportunity, along with my co-editors, **Zelda** and **Heather**, to wish you all a very happy and healthy 2018.

Annie

As ever, we need your stories, comments and suggestions for future magazines. Please email me at annie.schofield@myelitis.org.uk

What Exactly Is Transverse Myelitis

ZELDA CARR EXPLAINS

Literally translated Transverse Myelitis (TM) means ‘situated or extending across’ and ‘inflammation of the spinal cord’.

Transverse Myelitis is an inflammation of the spinal cord, where the immune system targets the myelin sheath (nerve insulation) causing spinal cord damage. The inflammation disrupts communication along the spinal cord, potentially causing paralysis, along with motor and sensory issues. TM is considered an autoimmune condition, where the body mistakenly attacks the spinal cord.

The medical profession don't know what causes TM but the inflammation is sometimes preceded by viral or bacterial infections. Patients have also reported attacks following a vaccination, which causes an immune response. Other cases appear to be idiopathic, which means the cause has not been identified. TM is normally monophasic i.e. once only occurrence; a small percentage of patients have recurrent TM.

Symptoms can appear suddenly, within hours or slowly over several weeks. Symptoms can be severe and include paraesthesia (strange sensations like burning, tingling and numbness), and paraparesis (partial paralysis of the legs). Dependent on the segment of the spinal cord affected, respiratory issues can also be experienced. TM can affect the autonomic nervous system, which controls involuntary body functions such as heart rate, digestion, urination and respiration. This may result in underlying health problems.

The location of the damage in the spinal cord determines which parts of the body are affected. Please refer to the diagram opposite.

In some people, TM may be the first presentation of other neurological conditions, including Multiple Sclerosis (MS), Acute Disseminated Encephalomyelitis (ADEM) or Neuromyelitis Optica (NMO). MS is normally characterised by short, partial lesions, whereas NMO is characterised by long lesions over a number of segments of the spinal cord - Longitudinally Extensive Transverse Myelitis (LETM).

TM is a very rare condition, (approx. 300 cases a year in the UK) and many practising physicians have neither heard nor seen a case of TM. When a patient presents

at the hospital, normally through A&E, the condition is rarely recognised. Doctors need to take a detailed medical history, perform blood tests and rule out other causes. Many patients are misdiagnosed initially. An MRI greatly assists in the diagnosis of TM, where lesions can normally be observed on the images. Unfortunately there is no 'cure' for TM but fast treatment is essential for patients who are significantly affected by the condition. First line treatment normally consists of high doses of anti-inflammatory corticosteroids, either intravenously or by mouth. The steroids reduce the inflammation thus reducing any further damage. Plasma exchange or other immunosuppressant treatment may be prescribed where steroid treatment doesn't work.

Recovery usually starts within weeks of diagnosis. After the initial treatment, rehabilitation is essential to get the affected limbs mobilised. Improvements often happen quickly within the first six months and up to two years or more. A neuro-physiotherapist will understand the condition better than a standard physiotherapist. The TMS offers bursaries for members to receive two free sessions with a neuro-physiotherapist. One third diagnosed with TM report a good recovery, one third have only a fair recovery (moderate degree of permanent disability), and one third have a poor recovery. Building core strength supports recovery. Many members have found Pilates, Yoga, Tai Chi, riding and swimming beneficial.

One of the biggest residual problems people encounter is pain so a careful pain management plan is essential. Some people manage pain through alternative therapies but others will need medication to cope with the pain. Fatigue is another challenge people face daily so managing the day's activities is important. The 'Spoon Theory' can help with managing fatigue by saving enough energy for the day.

Educating family members is important as many of us look 'normal' on the outside. Our suffering is not visible. If family members and friends have a good understanding of the condition, their support can help us enormously.

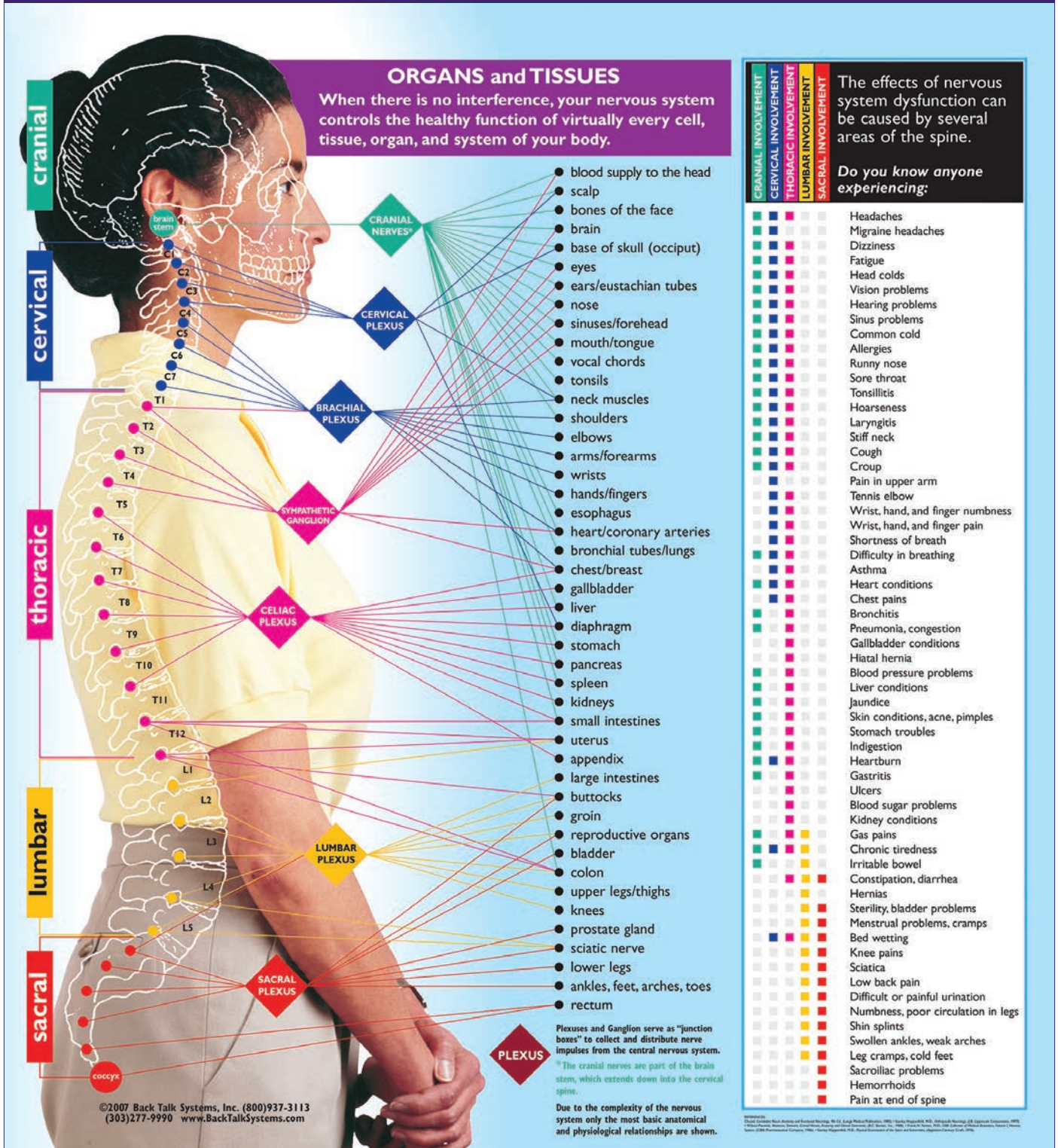
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What Exactly Is Transverse Myelitis

ZELDA CARR EXPLAINS

NERVE FUNCTION

Many things can impair your nervous system and interfere with its function.





Research Into Demyelination And Repair

DR. DENISE FITZGERALD

Dr Denise Fitzgerald undertook her BSc in Cell Biology and Molecular Genetics at University College Dublin (1996-2000) where she went on to pursue her PhD in Immunology under the mentorship of Professor Alan Baird (2000-2004). During this time Denise developed a keen interest in Central Nervous System demyelinating diseases and in 2004, she moved to Thomas Jefferson University, Philadelphia to pursue postdoctoral training in demyelination research. During that time, Denise was awarded a three-year postdoctoral fellowship from the National Multiple Sclerosis Society (USA) which supported her commitment to this area of research. In 2009, Denise moved to Queen's University Belfast to start her own independent neuroimmunology research group where she is currently Senior Lecturer in Immunology and leads a team of ten enthusiastic and dedicated researchers. Funding for her research is predominantly supported by the Wellcome Trust and the Biotechnology and Biological Science Council.

Earlier this year a research team at Queen's University Belfast (QUB) in Northern Ireland reported new experimental discoveries of how the immune system helps to repair myelin in the spinal cord and brain.

The leader of that team, Dr. Denise Fitzgerald, was starting a PhD studying inflammation at University College Dublin in Ireland when she was diagnosed with Transverse Myelitis (TM) in 2001. Her onset of TM was rapid; within two hours she was in A&E at St Vincent's Hospital, Dublin with complete paralysis from the chest down. She was very lucky – the neurologist who examined her, Professor Michael Hutchinson, was a world expert on Multiple Sclerosis and quickly diagnosed TM. She was also lucky to have an excellent recovery with only minor movement and sensation loss.

After 5 weeks in hospital and several months of intensive physiotherapy she returned to her PhD studies under the mentorship of her very supportive supervisor,

Professor Alan Baird. She completed her PhD studies on inflammation in 2004 and decided to do advanced research training (postdoctoral training) in inflammatory demyelination, which took her to Thomas Jefferson University in Philadelphia.

As a Post doctorate, Denise's research focused on how the immune system caused damage to myelin in the brain and spinal cord. She was awarded a three-year Postdoctoral Fellowship by the National MS Society (USA) and spent a total of five years in Philadelphia. In 2009, Denise was offered a position at Queen's University Belfast in Northern Ireland that would allow her to start her own research laboratory and team. A key decision point for her research was either she continues what she knew she could do well or change direction. She took a risk and decided to develop a research programme that would focus on how myelin is repaired. Her rationale for this change was based on the many drugs that were in the pipeline and being approved



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for reducing the frequency of myelin damage in MS. However, no drugs had been developed to help repair the damaged myelin after an attack. If successful, such a treatment could potentially benefit all types of MS as well as other demyelinating conditions like TM, NMO and even some childhood conditions in which myelin does not develop properly.

The early years of any laboratory research is critical. The key goals are to secure external funding to pay the research team, experimental costs and publish papers. This is not easy when you don't have a track record in a research area. For this reason, Denise enlisted the help of several myelin repair experts to help get her new research programme off the ground. A key collaborator was Professor Robin Franklin (Cambridge) who offered advice and guidance and even agreed for the senior scientist in his lab, Dr. Chao Zhao to fly to Belfast and spend a week in Denise's lab, training her team. These collaborative efforts grew, with support from myelin research teams in Edinburgh and San Francisco.

“Denise didn't leave her immunology background behind, she focused her studies on how the immune system, so often a culprit in myelin damage, can also be beneficial in repairing myelin.”

Denise didn't leave her immunology background behind. She focused her studies on how the immune system, so often a culprit in myelin damage, can also be beneficial in repairing myelin. To do this, her team designed experiments in which products from animal immune

cells, called T cells, could be added to oligodendrocytes (myelin producing cells). Immature versions of oligodendrocytes are unable to make myelin however combined with products from specialised T cells which had been switched on, the immature oligodendrocytes rapidly matured and started making myelin. This was an exciting discovery because immature cells are often found in areas where myelin repair has failed. This means that potential remyelinating drugs could resolve one of the key bottle-necks by boosting myelin repair.

For successful remyelination to occur, however, it's not enough for oligodendrocytes simply to mature. These cells need to reach out to nerve axons and wrap the myelin around these nerves so the team moved to the next phase by using brain tissue from laboratory animals to see if this could be done. First, they placed pieces of brain tissue in an incubator for two weeks to allow myelin wrapping around the nerves in the tissue to occur. Next, the team added a chemical to the brain tissue damaging the myelin around nerves and the oligodendrocytes. When this chemical is removed and the brain tissue is washed, the natural myelin repair programme within the brain tissue is activated. The team added products from activated specialised T cells and measured how quickly the myelin was repaired. The specialised T cell products accelerated the wrapping of myelin around nerves, showing that these T cells don't just coax the oligodendrocytes to mature, they help these cells to go on and repair the damaged myelin in these experimental models.

The next phase of the work was even more challenging. The research team wanted to know whether their discoveries would help repair myelin in living animals. To

Research Into Demyelination And Repair

DR. DENISE FITZGERALD

do this they created a small area of myelin damage in the spinal cord and monitored myelin repair. They saw that these specialised T cells arrived at the site of myelin damage quickly but when these T cells were removed, the repair of myelin slowed down considerably. When they studied the unrepaired lesions, there were far fewer mature oligodendrocytes present. When they reintroduced the specialised T cells by injection, numbers of mature oligodendrocytes were boosted in lesions, showing that these specialised T cells help to drive the myelin repair process. To find out if specialised T cells also helped to repair myelin in the brain, the researchers also studied damage to brain myelin. Again, removing specialised T cells impaired myelin regeneration in the brain, demonstrating that these T cells help repair myelin in both brain and spinal cord tissue.

Going back to experimental models of cells and tissues in dishes, their experiments lead to the discovery of a new substance that was not known to be produced by T cells before, called CCN3. This substance helps repair other types of tissue damage naturally, however, it is not suitable to use as a drug at this time as it can also play a role in diseases like cancer. This study was the first discovery that CCN3 has any role in myelin production and this has opened many new questions.

The team are now working to understand which part of CCN3 is helping to mature oligodendrocytes to determine if a drug could be made from it for future testing. They are also studying other types of specialised T cells to determine which may help or hinder the repair of myelin. Most importantly, they are also working on human T cells and oligodendrocytes to find out how much of their mouse cell discoveries translate to human cells. These new studies are being performed in collaboration with other research teams in Cambridge, Edinburgh, San Francisco, Swansea, Cardiff and Nice. In addition, three new research teams have joined Queen's University Belfast starting new programmes in myelin and neuroinflammation research.

These fundamental discoveries, while a long way off from clinical trials, help to steer future research efforts and potentially, drug development. The ultimate goal of the QUB research team is to help develop a new class of treatments for demyelinating conditions that will help repair myelin and restore at least some of the functions lost when myelin is damaged. They may have a long road ahead but with the help of leading researchers from around the world and a passion for figuring out how the immune system and nervous system interact, they are committed to this ambitious goal. **You can follow updates from the team at their Facebook group page www.facebook.com/TheFitzgeraldGroup1**

Glossary : A T cell, or T lymphocyte, is a type of lymphocyte (a subtype of white blood cell) that plays a central role in cell-mediated immunity.

An axon is a long, slender projection of a nerve cell, or neuron, that typically conducts electrical impulses away from the neuron's cell body. Axons are also known as nerve fibres. The function of the axon is to transmit information to different neurons, muscles, and glands.





How We Might Lower Inflammation With Diet

LUISA CARUGATI

Luisa Carugati's earliest memories are in the kitchen with her father (a chef), watching him prepare food, waiting for the moment he allowed her to try the creation of the day. This inherited passion for food has led Luisa to her studies of Naturopathic Nutrition and Complementary Medicine since 2006 at the college of Naturopathic Medicine in London. She is a member of The Association of Naturopathic Practitioner



When the possibility of contributing to the TMS magazine on nutrition was first mentioned to me, I must admit I was overwhelmed with how I could cover so many individual, important issues.

Naturopathic Nutrition is all about treating the whole person in such an individual way that I found it challenging to settle one area of nutrition to focus on.

However, the more I read about TM and individual cases, there is one word that is undeniably at the forefront of all cases - Inflammation.

So then my important question became "How can we lower inflammation with diet?". Everywhere you look on the internet there are anti-inflammatory diets, but no precise anti-inflammatory diet prescription one should follow exactly. There is no evidenced based medical research proving conclusively that any given expert's or doctor's diet protocol works. That being said, many can be effective by increasing fruit, vegetables, nuts, legumes and seeds, which are at the cornerstone of most of these diets.

Basically, it boils down to eating a rich variety of plant based foods, less animal proteins, processed foods, refined carbohydrates, sugar, salt and fried foods. On average plant foods contain 64 times more antioxidants than animal foods. Is this a diet or a sensible more natural way of eating?

There are so many foods that are individual to each person that could drive an inflammatory response. An extreme example is coeliac disease where an abnormal immune system reaction /chronic inflammation is caused by the protein gluten found in everyday bread, pasta, and cereals. Diets high in dairy products have been shown to promote extreme inflammation in some people. My point is that it is essential to listen to your body as we are all so unique. Even keeping a food diary to monitor if any foods perhaps trigger an unwanted reaction may be a helpful tool.



How We Might Lower Inflammation With Diet

LUISA CARUGATI

The more research I read, the more I have come to realise that healthy foods are not interchangeable. Some foods and food groups have nutrients not found in abundance elsewhere. In other words, not all fruit and vegetables are created equal.

High-antioxidant fruits and vegetables, such as berries and greens, have been found to douse systemic inflammation significantly better than the same number of servings of more common low-antioxidant fruits and vegetables, such as bananas and lettuce. So unfortunately, it is not as simple as your five-a-day government recommendation.

Research has shown that adipose tissue (fat) produces inflammatory mediators called adipocytokines. Carrying too much adipose tissue for your build can contribute to systemic inflammation.

Energy density (the amount of energy a food contains) is a relatively new concept that has been identified as an important factor in maintaining healthy body weight composition. Adding more vegetables and fruit, even alongside a standard western diet, has been shown to drop, not gain weight, even though you are eating more. Research has shown that gut bacteria can create anti-obesity compounds from the fibre. So just by adding three apples or pears on top of whatever else you may be eating, has been shown to increase weight loss.

Increasing any form of physical activity has also shown to decrease inflammatory mediators, although it is unclear if this effect is independent from weight loss.

Increasing your fibre from whole plant foods can stop the body from going on the inflammatory offensive. This is because the primary fuel that feeds the cells that line our colon is a short chain fatty acid called butyrate which our good bacteria makes from the fibre we eat. Butyrate suppresses our inflammatory reaction, telling our immune system to stand down. We can invest in probiotics but without a good balance of good bacteria initially created by fibre, we are literally flushing them away.

So what food can play a key role in helping to reduce inflammation? High fibre but what else? We also need to MAXIMIZE certain nutrients in our diet. More omega-3 rich foods (EPA/DHA), anti-oxidants, minerals, vitamin D3, water and so on.

Plants contain chemicals called phytochemicals that provide them with their colour, distinctive smell and protective qualities. There are four main categories of phytochemicals that have been shown to inhibit inflammation.

Carotenoids - found in sweet potatoes, apricots and leafy greens

Flavonoids - found in apples, soy, citrus and coffee

Polyphenols - found in green tea, grapes and berries

Sulforaphane - found in all cruciferous vegetables

Apart from boosting the antioxidant capacity of our cells, this compound has been shown to decrease autoimmune inflammation in T-cell driven disorders

How We Might Lower Inflammation With Diet

LUISA CARUGATI

such as multiple sclerosis. SFN (Sulforaphane) significantly inhibited the development and severity of MS in animals, mitigating inflammatory infiltration and demyelination in the spinal cord. Unfortunately, studies in humans are lagging.

Low levels of magnesium, vitamin C, vitamin B6, vitamin E, or vitamin D are all associated with inflammation and inflammatory diseases. All of these, apart from Vitamin D, are found in abundance in leafy greens, nuts, legumes and citrus. So all this just by increasing plant based foods in your diet.

Vitamin D is a whole subject on its own. Muscle weakness is a common presenting symptom of vitamin D deficiency. As we age our muscles lose Vitamin D receptors. Supplementation in randomized trials have found to boost global muscle strength and improve balance. Going into these darker months, it is strongly advised to have your levels checked.

Increasing monounsaturated fats, found in nuts, olive oil, avocados and omega-3 polyunsaturated fats found in flaxseeds, fish and walnuts are associated with decreased biomarkers of inflammation. Flaxseeds are a very rich source of omega-3 fatty acid and amongst many other things have demonstrated to prove very helpful in reducing inflammation.

Turmeric, along with cloves, ginger and rosemary was recently shown to significantly stifle the inflammatory response on a cellular level. The researchers chose something really inflammatory – oxidized cholesterol is what you end up with in your blood stream after eating fried chicken. They then measured how much Tumour Necrosis Factor was produced. TNF is a powerful inflammatory cytokine, infamous for its role in autoimmune attacks. Turmeric was the most effective and protective compared to ginger, cloves and rosemary from oxidative inflammatory injury. The dose was only 1/4 teaspoon.

A simple way to increase these foods on a daily basis in your diet could be something as easy as a check list in your kitchen. You can literally check them off when doing a meal. This also can help with grocery shopping too. It can be a good initial tool to create a routine. Of course,

there is no need to be obsessive as we all have hectic days but hopefully the feel-good factor should motivate us to eat better the next day if we have eaten poorly.

The list below has nine categories which mentions how many times you could aim to include these types of foods in your daily diet.

Food for thought ...

DAILY LIST

Beans/legumes – Black beans, butter beans, cannellini beans, peas, broad beans, edamame, kidney beans, haricot bean, pinto beans, split peas, chickpeas, tempeh and lentils

Serving Size

¼ cup of hummus

½ cooked beans

1 cup of fresh peas or sprouted lentils

Daily Recommendation

3 servings per day

Berries – Blackberries, blueberries, acai berries, cherries, grapes, cranberries, goji berries, mulberries, raspberries and strawberries

Serving Size

½ cup of fresh or frozen

¼ cup dried

Daily Recommendation

1 serving per day

Cruciferous vegetables – Broccoli, rocket, bok choy, kale, Brussels sprouts, cabbage, cauliflower, collard greens, horseradish, radishes, turnip greens and watercress

Serving Size

½ cup chopped

¼ cup Brussels sprouts or broccoli

1 tablespoon of horseradish

Daily Recommendation

1 serving per day

How We Might Lower Inflammation With Diet

LUISA CARUGATI

Additional greens – (yes as well) Beet greens, kale, sorrel, young salad greens, spinach, Swiss chard, mustard greens, all greens

Serving Size

1 cup raw

½ cup cooked

Daily Recommendation

2 servings per day

Other vegetables – Artichokes, asparagus, avocados, beets, bell peppers, carrots, corn, garlic, mushrooms, okra, onions, sweet potatoes, pumpkin, sea vegetables, yams, tomatoes etc

Serving Sizes

½ cup of raw or cooked non-leafy vegetables

½ cup vegetable juice

Daily Recommendation

2 servings per day

Flaxseeds – Brown or golden

Serving size

1 tablespoon ground, bought or grind with coffee grinder

Nuts and seeds – Almonds, brazil nuts, cashews, hemp seeds, chia seeds, macadamia, pecans, pumpkin seeds, sesame seeds, sunflower seeds, hazelnuts, pistachios, pine nuts and walnuts

Serving Size

¼ cup of nuts or seeds

2 tablespoons nut or seed butters

Daily Recommendation

1 serving per day



Herbs and spices – all spices especially cloves, ginger, rosemary and turmeric. Fresh or dried

Daily Recommendation

¼ teaspoon of turmeric as well as any salt free herb and spice you use regularly

Whole grains – Barley, brown/black/wild rice, buckwheat, millet, oats, popcorn, quinoa, rye, teff, amaranth, whole wheat pasta

Serving Sizes

½ cup hot cereal or cooked grains, pasta

1 cup of cold cereal

1 slice of whole meal/rye/spelt bread avoiding white processed baked goods on a daily basis

This all may look like a lot of food for thought, but this is not a diet, just a reminder of how many fantastic, healthy foods we can add to our menu everyday. If you whip up a salad of 2 cups of spinach, handful of water cress, a handful of walnuts, some hummus, half a bell pepper and a small tomato, you will have included seven servings off this daily list.

You should always speak to your doctor before making any major changes to your diet particularly if you have any other health condition which might affect your dietary requirements. I am not a medical practitioner and do not provide medical diagnoses or treatment.



TMS Family Weekend

This year marked the third time the TM Society's Family Weekend took place. This important event is starting to become a regular feature in the TM Society's event calendar and we are so pleased that our fundraisers are making this possible.

As in previous years, this year's Family Weekend was held at the Calvert Trust in July. The Calvert Trust is a residential outdoor centre in the Lake District National Park, whose main aim is to offer life changing

“ This year was the biggest weekend we have ever had! Over 60 people attended (we were full to the brim!!), all partaking in a range of activities such as orienteering, bush craft, canoeing, zip wire, riding horses, trap driving, archery, obstacle course, and cycling. ”

experiences through challenging outdoor activities, which provide positive results that last long after the stay at the centre. Their experienced instructors work with the families to ensure that everyone reaches their potential no matter what their level of ability, building confidence and developing a range of skills and leaves many people with long lasting memories. It is the perfect setting for the TM Society and certainly achieves all the aims of the weekend that we had for the children with TM, ADEM, and NMO and their families.

This year was the biggest weekend we have ever had! Over 60 people attended (we were full to the brim!!), all



TMS Family Weekend

partaking in a range of activities such as orienteering, bush craft, canoeing, zip wire, riding horses, trap driving, archery, obstacle course, and cycling.

These outdoor activities are incredibly important. Our children with TM, ADEM, NMO and AFM learn that they can do what everyone else does by finding their own way to do the activity. They often find they can do things they thought they could not do or were no longer possible. For example, a 10 year old member who has mobility issues completed a difficult obstacle course with the support of the instructor and her family.

When we're not busy in the outdoors navigating our way through the challenging activities, we relaxed in the indoor hydrotherapy pool, played in the games room, and hung out with new friends whilst watching movies or TV. There was a disco on the Sunday evening and Michael (one of our camp councillors) brought along his guitar and played and sang for everyone. Natasha Baker MBE also sent an inspirational video explaining how she became a Paralympic athlete and that anything is possible.

In addition to having fun, there is an educational element to the weekend. We had question and answer sessions with medical and healthcare professionals which was offered to both the parents and children/young people to give them the opportunity to learn

more about TM/ADEM/NMO. The professionals who attended included an occupational therapist, a dietitian, neuro-physiotherapist, a neurologist and a specialist in education and inclusion from the Backup Trust.

New families found the Q&A's especially beneficial. The children and young people, including the siblings, learned that others experience the same symptoms or issues as them. The Q&A for the children and young people provided an opportunity for them to learn they are not alone in their experience, a reassuring and powerful realisation.

We also had a neuro-physiotherapist attend who offered aqua therapy, physio and neuro-physiotherapy sessions which many of our families commented on how beneficial the service was. One beneficiary of the aqua-therapy said it helped ease their spasms enormously.

This is a special weekend which fosters individual and family wellbeing by helping families achieve their potential through the outdoor activities; providing educational opportunities to help the parents, children and young people learn more about their condition and how to best manage its impact; and most of all providing a community where it's ok to be you just as you are with others who are on the same journey.

The Family Weekend will take place again 6-9 July 2018 so make sure to put the dates in your diary now. If you



TMS Family Weekend



are member of the TM Society and have a child who will be in the eligible age range of 4-17 in 2018, you will receive an email about next year's family weekend around the new year. Registration will open in February 2018. We want to make sure we can keep offering this special weekend to families well into the future. This weekend is organised by volunteers, including parents and a former participant, so your fundraising monies will go 100% towards making this event happen. So, join us in making this weekend happen. Any donation you can make or fundraising activity you want to hold would be very much appreciated. Thank you.

By Owen Swift & Barbara Babcock

Barbara Babcock's full report can be found by going to www.myelitis.org.uk/uploads/1/5/8/2/15824690/tms_fw_2017_-_feedback_report_for_website.pdf



MOLLY AGED 16

I used to think that I was alone in my condition and now I know there are others just like me who I can talk and relate to. I was slightly apprehensive to take part and speak up at first because I was worried I wouldn't fit in. However, when I got there and introduced myself to the families, I realised we weren't so different after all. Having the same sort of conditions meant we could relate through them. Being older than a lot of the children was also nice for me because I felt like I could support them in their conditions and help them through some of what I have been through in the past. Everyone was able to take part in every activity no matter what issues they had, which really helped me personally as I struggle with a lot of physical activities. But the amount of support I had was fantastic, and therefore I was able to participate in everything offered to me.

GRACE AGED 9

The centre we stayed in was fantastic. I loved the games room and the swimming pool. We did lots of outdoor activities with other families. My favourite was archery. I was really good at it! I had lovely meals all weekend. My favourite meal was breakfast because I got to eat loads and loads. The other families and kids that I met have a lot in common with me. This was really helpful because we understood each other and knew what everyone was going through. My brother and sister got to meet other kids with Transverse Myelitis which made them think a lot about my life. We were very nervous when we arrived at the centre but by the time we left we'd made great friends and great memories. I love love loved it!!!!



Disability Discrimination In The Workplace

MARSHA THOMPSON

Marsha Thompson is an Employment Solicitor with Slater and Gordon, and has acted on a number of high profile cases, including bringing an Unfair Dismissal case against a member of foreign royalty and advising a senior employee on a serious Whistleblowing case concerning allegations of anti-Semitism. She also has experience of running a pro-bono legal advice surgery (advising employees with disabilities) for a charity in Redhill.

According to The Transverse Myelitis Society, sadly, there is still an increasing number of employees with Transverse Myelitis ("TM") that are facing disability discrimination in the workplace. Often employees do not know whether they are being discriminated against but in some cases the discriminatory treatment is fairly obvious. In all cases, it is important for employees to be aware of their rights and their employers' duties under the Equality Act 2010 ("the Act"). Employment Lawyer, Marsha Thompson answers some frequently asked questions below.

How does the law define a disability?

For the purposes of the Act, a disability is a mental or physical impairment which has a substantial and long-term adverse impact on a person's ability to carry out day-to-day activities. When assessing the adverse impact of any impairment, the effects of medication or physical aids should be disregarded.

It is likely that many TM sufferers will be classed as disabled under the Act. This will depend on a number of factors including the severity and duration of their symptoms. If in doubt, speak to your trade union representative or seek legal advice.

What are the different types of disability discrimination?

The Act offers protection from the following:

Direct discrimination – treating an individual less

favourably than someone in a similar situation because of their disability. For example, refusing to give a job to the best candidate because they have TM and the employer making stereotypical assumptions about the candidate's ability to do the job as a result of their condition.

Indirect discrimination – the employer's usual practice or policy is applied equally to everyone, but disadvantages disabled employees who share a particular disability. For example, an employer requires all employees to work full-time, but a disabled employee with TM struggles to work these hours due to the fatigue and chronic pain caused by TM.

Discrimination arising from disability – treating an employee unfavourably because of something arising from a disability. For example, refusing to promote an employee with TM due to mobility problems caused by his TM.

Harassment – Intimidating, degrading or offensive treatment relating to someone's disability, such as name-calling.

Victimisation – subjecting an employee to detrimental treatment for making a complaint about the way they have been treated or because they have chosen to bring proceedings for disability discrimination.

The Act also provides a duty on employers to make

reasonable adjustments to alleviate the disadvantages faced by disabled employees. This is a key protection for disabled people in the workplace.

Is my employer obliged to make any adjustments to my role/duties because of my TM?

Yes - The Act imposes a duty on employers to make reasonable adjustments to help disabled job applicants, employees and former employees in certain circumstances.

The duty can arise where a disabled person is placed at a substantial disadvantage by:

- An employer's provision, criterion or practice
- A physical feature of the employer's premises
- An employer's failure to provide an auxiliary aid

However, an employer will not be obliged to make reasonable adjustments unless it knows or ought reasonably to know that the individual in question is disabled and is likely to be placed at a substantial disadvantage because of their disability. Therefore, it is important to inform your employer as soon as you are diagnosed with TM so that they can make any reasonable adjustments necessary.

What should my employer do if my TM makes it difficult/impossible to carry out my job?

Your employer should first consider any reasonable adjustments that can be made to your existing job. If there are no reasonable adjustments that can be made, your employer should consider redeployment.

Does my carer have any rights under the Act?

Under the Act, carers have some of the same rights as the people they care for. Carers have the right not to suffer less favourable treatment or be harassed because of another's disability. However, there is no general duty to make reasonable adjustments for carers and nor do they have protection against indirect discrimination.

Under my employer's sickness absence policy, disciplinary action can be taken at various absence trigger points. Does my employer have to ignore absences caused by my TM and related illnesses?

Your employer must treat disability related absences with care. Your employer should consider what adjustments

can be made to the sickness absence policy, for example, extending the trigger points and allowing more absences before starting to take action.

Even if adjustments are made, it should be noted that if absences continue, your absence may ultimately reach the point where dismissal on the ground of capability is a reasonable course of action for your employer to take.

I work for a small business with only five members of staff. Does disability discrimination law still apply to my employer?

Yes – the Act applies to all employers whether they are large or small. There are no exemptions for small businesses. Therefore, your employer will have a duty not to discriminate under the Act.

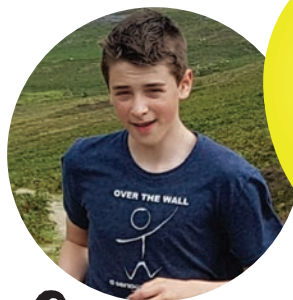
What can I do if I am being discriminated against because of my TM ?

1. Confide in a family member regarding your concerns.
2. Keep an accurate and clear record/diary of any incidents of discrimination.
3. Raise the matter informally with your line manager or another manager (if you feel able to).
4. Consider raising a formal grievance regarding the discriminatory conduct experienced.
5. Seek advice from your trade union and/or legal advice from a solicitor.
6. ACAS provide a free early conciliation service to assist with resolving employment disputes.
7. If the matter cannot be resolved internally, you may wish to bring an Employment Tribunal claim.
8. Exercise caution – there are strict time limits in the Employment Tribunal. Claims must be brought within three months minus one day from the discriminatory treatment.

Lastly, if you feel you may have been discriminated against because of your disability and would like advice regarding your legal rights, contact our expert employment lawyers on freephone **0800 916 9060** or **slatergordon.co.uk**

Slater and Gordon are a leading employment law firm with offices across the UK.





George



TM

Hi it's me again George. I am now a TM teenager, and in my second year at secondary school, which I am really enjoying. I am in all the top sets so my Mum is happy too. I am still DJ'ing and now I'm learning to play the drums too. There are lots of clubs at secondary school; I go to the drum club, the DJ club and the computer coding club.

This year has been a really busy one so far. Earlier in the year me and my family adopted a dog from Romania – he's called Les and is a real handful! He's so funny and makes us laugh so much. Sometimes he opens the tumble drier when it's on and Mum gets really cross as we'll find him sitting on a pile of hot towels or bedding – it's so funny!! Luckily he gets on really well with our other dog Tallulah and they've become really good friends. He's much younger than Tallulah and needs much more exercise so I've been walking much more than usual as it's mine and my sister's job to walk him. It was tough at first as it made me quite tired but I'm used to it now.

Every summer I like to challenge myself with a long walk or climb – this year we camped on the Isle of Skye, and whilst we did lots of walking we did one really, really long one, which was quite hard. We walked to an abandoned village called Boreraig; it was about 10km across moorland and hills. We walked past waterfalls and saw an eagle. When we got there it was amazing, so quiet and very eerie, but beautiful. The walk back was so hard but I was determined to get back without help (plus I didn't have much choice as we were in the middle of nowhere!!) It was such an achievement to get back to the car, and when we got back to the tent my legs went all wobbly!! Luckily they were fine by the next day as we went to the fairy pools at Glenbrittle. They are really beautiful pools and waterfalls in the Black Cuillin mountains. I think they're quite special because even though it's the coldest water I've ever felt (and usually I don't feel the cold) I felt amazing afterwards!! I felt energised and warm. I wish I could swim in there every



day. I also swam in the sea at Dunvegan, but it wasn't quite as special as the fairy pools!!

I'm not taking any of my bladder meds anymore. Sometimes if I have a growth spurt, or if I'm feeling poorly with a cold or something, my bladder starts not to work properly again and I'll take the Desmopressin for a bit again, but mostly I'm medication free which feels amazing and means that after nearly 6 years my body is still improving. I hope that makes other people feel optimistic about their recovery.

KIDS

FOR KIDS, BY OUR KIDS GEORGE & KATIE



Hello my name is Katie and I am 9 years old. I was diagnosed with Transverse Myelitis when I was 15 months old when all of a sudden, my legs didn't work. I went to Milton Keynes Hospital where the Doctors ran lots of tests and they then decided I needed to be transferred to John Radcliffe Hospital.

When I arrived at John Radcliffe Hospital they did an MRI scan and confirmed I had Transverse Myelitis. I was a patient there for 10 days. My legs had stopped working and my bowels and bladder had also stopped. My mum and dad had to learn how to catheterise me.

I have regular hospital appointments at John Radcliffe and Milton Keynes Hospitals. I attend physio and orthotic appointments. 8 years on and I can run with my friends even though I may not be as fast as them and I try every challenge that comes my way. I have run a 5k run to raise awareness of Transverse Myelitis and raised £220.

I love all physical activities. I attend swimming, dancing, violin, brownies, gymnastics and playing outside on my monkey bars. Since having TM, the things that have changed me is that I can't run as fast with my friends (I can't catch up) and I can't balance for that long. My favourite role models, are my PE teachers Mr Shirley, Mr O'Grady and Mrs Morrell because they're really sporty and they give me lots of encouragement. The problem with my body is when other people are hot I am cold and when people are cold I am hot. I also have constant pins and needles feelings in my hands and feet.

The really exciting thing is that my dance teachers have picked me to be in the Junior Strictly Come Dancing at the MK Dons stadium on the 19th November 2017. We are going to compete against other schools. I attended it last year and I was very nervous dancing in front of other people and being graded but this year I am confident and excited.

This summer I went camping in Cornwall with my family. When we arrived my mum, dad and my brother Michael set up the tent while me and my little brother Ewan went to the park. It had monkey bars, a slide and a rock wall. There was also a little park. We went to Tintagel castle where we met our cousins. There were hundreds of steps to climb to the top. I got tired very easily but

I wanted to reach the top so I kept having small stop breaks and I achieved my goal. The view from the top was amazing. After the castle we went to the beach at Perranporth. The waves were very strong so we stayed in the rock pools. I loved every part of our camping holiday especially the cooked breakfasts.

I also attended the Calvert Trust with the TM family weekend. I love this event as I get to meet all my original friends and make some new ones and learn from each other.

I'm looking forward to January because I'm going to Butlins with my Brownie group. We are staying over for the weekend and are going to ride some exciting rides on those days. I will also be attending the O2 with my school choir Harmonize. We sang at the O2 last year. This was an amazing opportunity for me and one I will remember forever.

I am planning on going skiing with my school in 2019. This will be the first time I will be abroad with none of my family. It will be scary but exciting as I may have Transverse Myelitis but it does not stop me from enjoying my life.





Wide Awake Again

Many of us have sleep issues since experiencing Transverse Myelitis (TM) and feel very isolated, especially in the middle of the night. There was a very active discussion about sleep on the TM Society Facebook page and we have selected a few posts to share with you.



Join us on Facebook

Facebook.com/Transverse-Myelitis-Society

Wide awake again...over a year now since I slept through the night. Do many of you suffer as well? My interrupted sleep is mostly to do with bladder issues but so difficult to relax and sleep again once I am awake. Makes the day ahead so challenging as I'm always so tired.

The same here...I may have had two decent sleeps since diagnosis two years ago. I have no issues with my bladder, it's all in my legs and feet. I usually fall asleep around four or five. Ugh!

My bladder bothers me to the point of four or five visits to the bathroom per night.

My feet hurt so bad when my feet first hit the floor.

My sleepless nights with bladder issues stopped when I started taking amitriptyline!

I always fall asleep as soon as my head hits the pillow then I usually wake after two hours, I drop off again but then wake up almost hourly but also need the loo once or twice.

I'm with you on this one, I really can't remember the last time I can sleep properly (sic).

I find it so difficult to fall asleep. Just can't get comfortable and relaxed. Restless legs syndrome in addition to neuropathic pain.

The pain is unbearable and then get the numb bits and burning bits, can't win!

Every day for four years... maybe only three hours and yes just to go to the loo...I gave up telling my family of what was going on as I think they got bored of listening...for the last two years I have slept in my own room...been married for 34 years...I am only 51...to be

honest a lot of people would think it would be the end of my marriage but if anything having separate bedrooms has saved it!

I fall asleep very easily but then wake up in the middle of the night with foot neuropathy, I have been trying to apply Mindfulness but when all is quiet in the middle of the night and the neuropathic pain is striking, it's so difficult. It's the urgency to go to the loo that wakes me and then it's the feeling that I need to go again almost immediately.

Snap, thought the past couple of months I have slept well, only getting up once I've started taking TURMERIC capsules twice daily.

I haven't slept for more than four to six hours for over two years.

A bit opposite, kind of wish my bladder would wake me up...

My life's mission is to spread the word about CBD. I take a sleep syrup. CBD has changed my life with TM!

I sleep with Sky news on low. If I wake up it always sends me back to sleep!

I get up and try and sleep in the chair but always put the news on the TV and have it turned down low, I always doze on and off.

Tingling like crazy this morning, the joy!

Not great to read of everyone else's struggles but don't feel so isolated about it now.



Why Your Mental Health Is So Important

BARBARA BABCOCK

Barbara Babcock holds a Master's in coaching psychology and works as a coach supporting people to rebuild and renew their lives after a serious health issue. She works with charities to help them develop and evaluate coaching and self-management educational initiatives, and is also working with neurologists to design a research study evaluating treatment and care and the psycho-social impact of TM. Previously she was a TM Society committee member from 2010-2013 and chair from 2013-2016. Barbara had TM in 2008 with lesions at C4/C5

When adjusting to living with a serious illness like TM, ADEM or NMO - whether this experience is more recent for you or you've been living with it for some time and things have changed - you can experience a period of mental upheaval.

You may experience anxiety, scared of what your future will be like, worrying about every twinge and odd feeling in your body, feeling unbalanced emotionally, and are quickly moved to tears, anger or both. The rollercoaster of emotions is never-ending. You want to feel a sense of calm and balance. You want to feel normal again but are not sure if that's achievable or how.

Firstly, it is possible to return to a sense of wellness and normality. I have helped clients successfully do this after they experienced the onset of a serious health issue. Just a heads up that 'the normality' often looks and feels differently from what it was like before.

Secondly, feeling the way you do because of the changes in your health is actually normal. These periods of adjustment are about transitioning from one way of doing and being to another. It's about change. And when we experience change, we can experience all sorts of

unfamiliar and unpleasant emotions, particularly when the change is not expected nor welcomed.

So you are not going crazy. You are experiencing another side to your mental health. Read on to learn why looking after your mental health is as important as your physical health when living with a serious or chronic illness. But first, let's review that definition of mental health because it can sometimes get in the way of people seeking out support.



Why Your Mental Health Is So Important

BARBARA BABCOCK

Debunking the myth of mental health

In our society, we have come to associate the words 'mental health' almost exclusively with issues such as anxiety, depression, panic attacks, phobias, eating disorders, obsessive compulsive disorder, bi-polar, suicide, schizophrenia, other personality disorders, etc.

It is also often assumed that help is only for these types of issues, and if you don't have them, you don't need help, and should not need help. But if you access help, then you must have something wrong with you, like a 'psychological problem' and be 'screwed up'.

That societal definition of mental health doesn't do much for empowering people who are experiencing high levels of stress, anxiety, and depression (maybe for the first time), to seek help and support.

The definition also discounts the whole human experience and all the good things we experience and feel. It has resulted in lack of recognition that people with mental health issues can and do experience good feelings, good times and periods of happiness.

Just as our physical health can experience good and bad periods, so does our mental health. At times our mental health is ill, other times it is in good shape.

'Mental health' is a neutral term like physical health. Just as we have physical health, we have mental health.



The #ihavementalhealth campaign

In August, the #ihavementalhealth campaign on Twitter reminded me of this and its importance to people like you and me who live with chronic illness or the ongoing after effects of a serious illness.

Dr. Ilan Ben-Zion (on Twitter @drilanbz), a clinical psychologist in the UK started that campaign when he was sharing his NHS stories via the @NHS Twitter account. The campaign's aim is to show how neutral the term 'mental health' is and that we all have it. In turn, this can reduce the stigma mental health has developed and normalise people seeking support when they feel they are struggling.

If more people feel able to seek support when they are struggling, then this can prevent issues growing into even bigger ones.

“When living with a chronic illness or the after effects of a serious health issue, your mental health is just as important as your physical health.”

Your mental health is just as important as your physical health

When living with a chronic illness or the after effects of a serious health issue, your mental health is just as important as your physical health. The reasons for this are several.

In my own and my clients' experiences, stress can exacerbate symptoms. Learning ways to effectively manage the impact of stress becomes very important to reduce its impact on your symptoms. I've had clients report feeling a reduction in symptoms due to addressing issues which caused them to feel stressed, and learning to manage the stress differently.

Also, stress and anxiety can become more prevalent due to the uncertainty which often accompanies a change in our health.

Why Your Mental Health Is So Important

BARBARA BABCOCK



Having support to adjust to any unwelcome and unwanted change with your health or any other part of your life can help you to work through the stress, anxiety, depression and emotional struggles more quickly and effectively so you can return to that sense of calm and balance you've been seeking, and experience quality of life and normality once again. Timely support can also prevent issues escalating, allow people to appreciate and feel their self-worth, and to continue being a part of society.

“ Stress can exacerbate symptoms. Learning ways to effectively manage the impact of stress becomes very important to reduce its impact on your symptoms. ”

Sometimes the physical health issue can cause changes in the brain which impact emotions, cognitive abilities and executive functioning. Side-effects of medications can also cause these issues. This is when it is important to have a suitably qualified healthcare professional involved who can formally assess the issue and recommend strategies and treatments.

These reasons show that mental health is ever-present, there is a complex relationship between our physical and

mental health, and it's super important and ok to look after it and seek support to enable us to do that.

To show your support for these ideas, get on social media, introduce yourself and use the hashtag **#ihavementalhealth**.

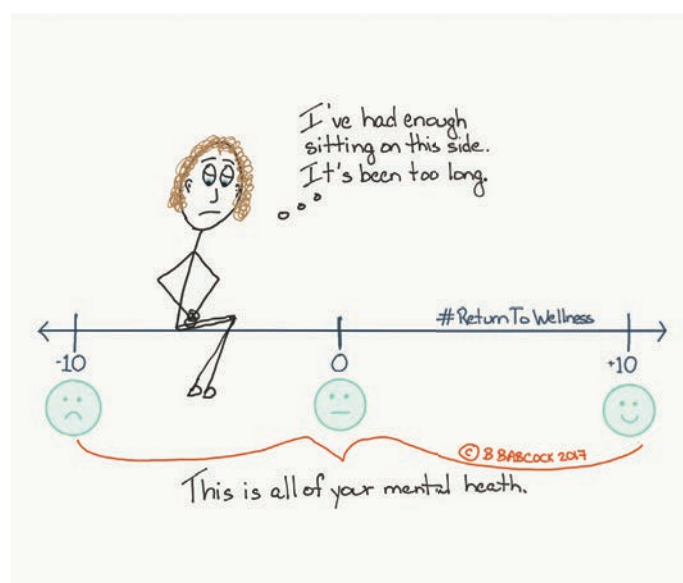
“ Having support to adjust to unwelcome and unwanted change with your health can help you to work through the stress, anxiety, depression and emotional struggles more quickly and effectively. ”

My name is Barbara and **#ihavementalhealth** (and TM) In fact, **#weallhavementalhealth**

This blog was first published on Barbara's blog on 23 August 2017 at www.returntowellness.co.uk/blog

If you would like support to find ways to improve your mental health, the TM Society offers members a Coaching Bursary to receive specialist support to do that. You can find more information here -

www.myelitis.org.uk/our-services.html - or contact Barbara Babcock at **barbara.babcock@myelitis.org.uk**.





Acceptance

GRAHAM BELCHAMBER

Graham Belchamber is from Hastings, East Sussex and had an attack of TM in 2006, retiring on medical grounds in 2011. He devotes his time to patient involvement activities with East Sussex Health Trust and Faculty of Clinical Health Psychology as a visiting speaker at psychology graduate courses and professional training courses, talking about the impact of TM. He recently authored a 'Practical Guide to Patient Involvement' that is being distributed to psychology staff throughout the country.

A quick internet search led me to this formal psychological definition of acceptance;

"Acceptance in human psychology is a person's assent to the reality of a situation recognising a process or condition (often a negative or uncomfortable situation) without attempting to change or protest it."

For me and Transverse Myelitis (TM) it took a good six years after the attack before I truly accepted I had this chronic condition. That acceptance came from joining a pain management programme at my local general hospital that included psychology as a key therapy.

Following that programme there was no eureka moment. It was a gradual mellowing of movement from telling the world I was fighting TM, or protesting it as the definition above says, to explaining to people what TM is, its effects on me, alongside the various pills and potions I take and their impact.

From then on I stopped fighting an energy sapping (mental and physical) unwinnable battle of attempting to change my diagnosis, and found myself comfortably telling people and myself that I had TM. I had accepted it.

So, what had I learned that moved me from fighting to acceptance?

It's quite a tough message to take in but essentially, in my own words, it goes something like this.

If you have had all the medical examinations, tests, prodding and poking, conversations with doctors and specialists and been told that there is no cure for TM, then you must begin to accept that this is it.

Yes, there may be ways of managing and diluting the various effects and disabilities it has caused and there may be some recovery, but TM is here to stay with whatever the pain, fatigue, physical and mental nasties it has left you with.

That is not an easy message to take in and if you are reading this and not reached that point then I have no doubt that you are not the only one.

So, if you are in that position then what to do? In my experience you cannot force acceptance of your condition on yourself or on others such as partners, family, friends and work colleagues who are in their own different ways, in this with you.

TM has left me with nerve pain from chest to waist, my legs feeling sunburnt, a very tight belt like pull across my waist, bowel and bladder dysfunctions, fatigue and jerky/jelly legs on occasions. Whilst not fighting TM, equally don't give in to it and simply laze away the days feeling sorry for yourself, or go at full pelt pretending it is not there (as I did), or live in the hope of a cure at the end of the rainbow. For me the transition to acceptance

Acceptance

GRAHAM BELCHAMBER

began from the psychological technique of splitting your life activities into three; what I must do, what I can do and what I know is beyond me.

There are three very practical examples from my own experience.

Chores around the home, like mowing the lawn, caused my nerve pain to hit the roof. Equally, simply weeding, bending at different angles, pushing and pulling my body, however gentle, is very painful whereas vacuuming the house across carpets with an upright cleaner does not exacerbate my pain.

The acceptance lesson is that while there are chores you may have done as a matter of course and are no longer possible, there may be others that are.

Travelling, especially in the car, with the constant vibration of the wheels on even a flat surface, the lumps and bumps of pot holed roads, the stopping and starting, and the jerking and pulling of a seatbelt is painful for me. Car journeys may be unavoidable but if not then trains and most buses are a far less painful option for me.

The acceptance lesson is don't pretend the pain is not there or become marooned at home. Instead look at transport options such as a shorter drive to the nearest station and a rail journey for example, rather than a lengthy painful road trip. So, accept what is not possible, plan and focus on what is.

Arriving early is not a crime. For me, rushing or arriving just in time for the start of something is bad news as my nerve pain increases, and it always takes me a while to settle my body.

The acceptance lesson is pacing and planning your activity to take your TM into account. It is essential to build in that bit of extra time, whether it is walking, using your mobility aids or using transport to get somewhere, and have time to get comfortable when you arrive. This also helps avoid fatigue.

With or without TM, a key part of acceptance is completing activities that are crucial to your well-being, the things you must do such as taking your medication, personal hygiene, exercise (however limited that may

be due to your personal situation), resting and a healthy diet. By accepting you have TM, it does not excuse you from not taking care of yourself as much as is possible.

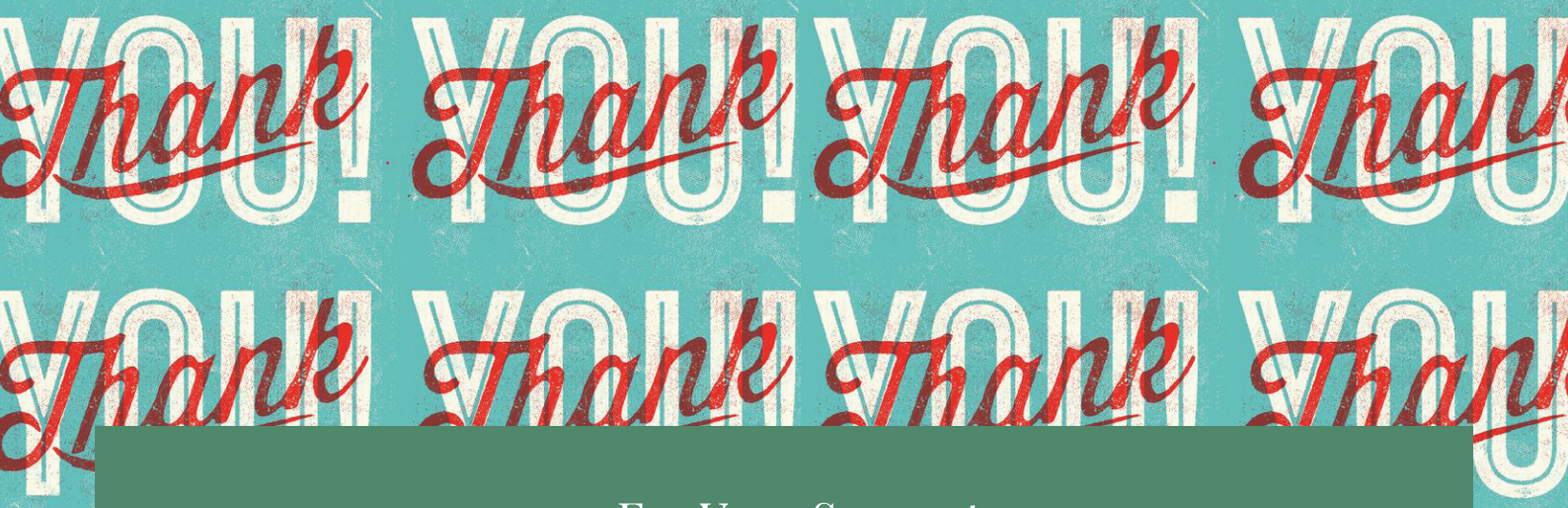
Finally, however difficult or limited it may be, build into those can do's the things that you enjoy. Have your fun whether it's reading a book, listening to music, going along a seafront, or meeting up with friends for a coffee to simply socialise.

Without the psychological lessons, I might still be fighting rather than accepting my TM and not in such a good mental health position. If you are struggling, speak to your GP and ask for help.

I started with a formal description of acceptance and I will end with a more lyrical one that sums it up for me;

"You've got to learn to live with what you can't rise above" (Bruce Springsteen from "Tunnel of Love")





For Your Support

On behalf of TMS we want to thank each and every TMer, their family and friends who organised the events below, and many more, too numerous to mention. Of course the money raised is vital to our mission of providing information and support, and enables us to continue services like TM Family Weekend, equipment grants, neuro-physio and coaching bursaries. But even more important in the long run is the opportunity for us to raise awareness of TM. Every time someone sees a TMS leaflet, poster, wristband, T-shirt or JustGiving webpage, their first reaction is "Transverse Myelitis – what's that?" which always leads to great conversations. People with TM are always telling us they wish there was greater awareness of TM. The best people to raise awareness are US! Well done all. [Lew Gray, Secretary TMS](#)

12TH MARCH 2017

MICHAEL WILLIAMS

Congratulations to Michael Williams who ran the Bath Half Marathon on 12th March 2017 with a finishing time of 2:02:41. Michael decided to support the TM Society after his Dad's diagnosis of TM in 2015.

HE RAISED MORE THAN £600

22ND JULY 2017

ANNE HURT AND KATH CRAWFORD

Thanks to Anne Hurt and Kath Crawford who raised £400 for the TM Society with their stand at the Tibshelf Carnival in Derbyshire on Saturday 22nd July 2017.

SHE RAISED £400

KAREN PEARSON

Karen Pearson raised £1265 from 2 exhibitions and an art teaching day at Worthing Artists Open House and Paint and Picnic Day.

SHE RAISED OVER £1265

ANN CURTIS

Ann Curtis (Katie Simpson's grandmother) raised £1000 fundraising from Swaffham Golf Club Ladies (Norfolk).

SHE RAISED £1000



ALLY PALMER

Ally Palmer organised a Big Breakfast for teachers and staff at Smallwood Primary School, Wandsworth, London and raised £342.

SHE RAISED OVER £342

30TH SEPTEMBER 2017

ANTHONY MCTAGGART & MICHAEL JONES

On 30th September Anthony McTaggart and Michael Jones completed the 'Ay Up Yorkshire Sportive', a 93-mile bike ride, in 8 hours and 3 minutes to raise money for the TMS. 'The weather was quite nice (not too hot) until the last hour where the heavens opened and we got soaked.'

THEY RAISED OVER £1000



THE POMERANCE FAMILY

The Pomerance family organised a TMS Charity Golf Day at Dyrham Park Golf Club and invited around 60 golfers to join them. Danielle's brother and husband Scott ran the par 3 contest out on the course, while others collected donations, sold raffle tickets and served refreshments out on the course.

The Day started with cooked breakfast at 7:30 and finished with an excellent lunch in the beautiful listed Georgian clubhouse. The Day concluded with a full range of golf competition prizes and raffle winners, raising a net of £4210.

THEY RAISED A NET OF £4210

27TH JULY 2017

RAVI AND RICCI HANNAH, PLUS FRIENDS

Ravi and Ricci Hannah, plus friends, cycled from Marble Arch to the Arc de Triomphe on 27th July 2017 raising over £3500 for the TM Society. Their mother Carol, who has had TM since 2011, was at the Paris finish line to welcome them.

THEY RAISED OVER £3500



BECKY, JENNY, SOPHIE, CHARLOTTE, RACHAEL AND LUCIE

Becky, Jenny, Sophie, Charlotte, Rachael and Lucie took part in the Summer Wolf 2017 run.

THEY RAISED OVER £800



KAI ADAMS

Kai Adams held a TM birthday fundraising event which raised over £2000. 'We did this by having a face painter, an auction, a raffle, and my friend Anthony had his legs waxed for a fiver a strip!! We also had a food van and a bar, who both made contributions.'

HE RAISED OVER £2000



ZEUS KNIGHT

As if this wasn't enough, her cousin Zeus Knight, aged 14, who lives in Cyprus, has also been busy! His school raised €400 euros by selling merchandise, cakes and bringing a euro in for non-uniform day! On a visit Kai gave a talk in his school assembly to raise awareness of TM.

HE RAISED €400



TMS Member Services

The fundamental purpose of the TM Society is to provide information and to support people with TM (or ADEM or NMO or AFM), their carers, families and supporters. Since our start in 2004 we have done this in a variety of ways. Initially we concentrated on support groups and conferences to foster face-to-face contact. Later we developed our own website, TMS Magazine and Facebook groups.

Now we have grown from 400 to over 2000 members. We rely on an ever-expanding number of unpaid volunteers who have allowed us to gradually expand services (including this magazine!).

We get about 200 new members every year, which we think is the majority of people getting TM, ADEM, NMO in UK. So a large part of our services is providing initial information, advice and support to newly diagnosed TMers and their families. (I include ADEM, NMO, AFM etc in 'TMers' for brevity.) Of course we can't provide medical advice, but we do a lot of 'signposting'!

The NHS normally provides some limited rehabilitation for most TMers if they are in major neurological hospitals. But as we all know, the outcomes are highly variable. After discharge (when we are neurologically 'stable', regardless of how much recovery has occurred), some TMers get help from NHS community services but most do not. In addition, it is characteristic of TM that more subtle issues (pain, clinical depression) can arise long after the discharge from acute care.

So what to do? Support groups, where we can advise and help each other, are often very effective. Asking for advice (or venting for sympathy) works well on Facebook, where other TMers are always generous and keen to help. The goal, everyone agrees, is to find a 'positive mental attitude' which of course is a highly individual process, yet there are many common elements.

Neuro-physiotherapy bursary for TMS members

Most TMers need lifelong neuro-physiotherapy, but the NHS does not provide this, and the TM Society cannot afford to either. But the longer a TMer goes without neuro-physio the more useful it is to have a review (something like an MOT test), preferably from a specialist neuro-physio with experience of TM, so they know what to look for.

Most TMers are discharged from rehabilitation with a more-or-less serviceable gait, usually with a walking aid or alternatively confined to a wheelchair. In almost every case over the following years, it leads to what physios call 'compensatory movement', which is a sensible adaptation but can be very complex and individual. Compensatory movement then creates its own problems and imbalances, often leading to pain and 'balance problems'. These 'knock-on' problems further limit our activity and can lead into a vicious spiral of reduced mobility, fitness and chronic pain. This is not good for mental health either!

The primary aim of a good neuro-physio assessment is to unpick the original TM-caused weakness and sensory derangement, from the later compensatory movement which can often be improved, once we are aware of it. In many cases TMers find that we are capable of more than we expected, since the original TM damage has improved over years. But the improvement can be masked by compensatory movement. And of course we usually don't try to exercise muscles which we 'know' don't work!

This was the rationale for the TMS neuro-physio bursary which is available for all members. We have found several of the best neuro-physios in the UK to work with – unfortunately they have mostly left the NHS now and 'gone private'. 229 TMers have had neuro-physio

TMS Member Services

bursaries since we started in 2014 and the feedback we get is 95% positive. Some members have even said the physio helped with their pain and they were able to reduce their medication.

It's not so much what you DO at the neuro-physio assessment. it's what you LEARN, developing your own strategies going forward to maximise your movement efficiency. This is why it's a good idea to take someone with you to observe – one member's daughter videoed the entire assessment on her smartphone.

"This far down the line, I had just about given up on myself but I am already seeing an improvement and hope to continue to build up my strength and improve my balance problems."

Leigh-on-Sea Essex

"I am really motivated now, and have been shown that my right leg is not just the dead and useless lump I thought it was and has some potential for improvement in function."

Newport south wales

"We found our visit to the clinic very useful, we learnt more in the 2 hours than we had in the previous 5 years."

Mother of 7-year-old TMer, Leicester

More detail can be found on TMS website: click on About TM and then TM and Physiotherapy.

Coaching bursary for TMS members

Life coaching is another intervention which helps TMers achieve that positive mental attitude we all know is vital for rehabilitation and health. Coaching is not for depression or low mood – this is better treated by NHS with counselling or CBT. Coaching (done by phone or Skype) is for members who have an issue to resolve, really

want to achieve something new, or would welcome help adjusting to living with TM, ADEM or NMO.

TMS is very lucky as we have an expert TMer with an advanced qualification, Barbara Babcock. If you are interested in coaching, Barbara will discuss with you what life coaching can do and make sure it is right for you before you start.,

Here is what a couple of members said after using the coaching bursary:

"The coaching has really helped me come to my own conclusions of what I need to be doing next in various areas of my life (managing symptoms, work, relationships)."

"I have found coaching so helpful and informative. It has given me such a different perspective on where I am and where I may need to go. It has also really boosted my self-confidence and has made me excited about what may come next, not worried about it like I was before!"

You can read more about the Coaching Bursary scheme on the website at www.myelitis.org.uk/our-services.html and if you are interested in taking part, contact **Barbara** at barbara.babcock@myelitis.org.uk

Equipment grants for TMS members

The TM Society Equipment Grant Scheme enables members to access funding for equipment which aids in their rehabilitation, ability to self-care, and/or ability to maintain or increase their independence and/or quality of life.

Since the Scheme started in 2014, we have provided grants for items ranging from electronic front door access system to power wheelchair adaptation for a TMer lacking arm strength to sports wheelchair, standing frame etc. Because we all live with TM ourselves, we pride ourselves on making quick and flexible decisions. All you have to do is fill in the EGS application form which can be downloaded from our website.



In My Dreams I'm Dancing

RUTH WOOD

Ruth Wood was a singing teacher and actress before she contracted TM in September 2006. Apart from creative writing, she is back teaching again part time and runs singing groups for people with neurological conditions. She is also about to become a presenter on local radio.

I feel as if my life has gone down the wrong end of a telescope. One minute every day is full of exciting things, a job, travel, a good social life and a shiny new husband, then suddenly it's zoomed down to total dependence on other people, inability to even tie a shoelace (I haven't got any but if I did I couldn't do it) and being pushed where I may not necessarily want to go. I'm used to towering over people (I'm 5 foot 10), helping get cans down from shelves in supermarkets for tiny little old ladies, and suddenly here I am at everyone's crotch level and eye to eye with small children in pushchairs. And I'm crowd phobic (an extension of my claustrophobia – note the panic attack when they tried to give me an MRI scan)

So here I am, sitting in the middle of the tools section in B&Q. This is not my preferred place. In fact on a scale of 1 to 10 I would give it about minus 90. But I don't have much choice. Since I have been in a wheelchair, I have discovered just how very differently men shop as opposed to women. When my carer/chauffeur spots a well-stocked tools section, he virtually salivates. In fact, he has all the appearance of a woman in a designer dress shop with the word SALE emblazoned across every rack. I have looked at the drills/screwdrivers/whatever that he is handling with a slightly glazed expression and in the past I have said things like "Haven't you got two of those already?" and he has said, with a look of incredulity that I could so misunderstand what is going

on, "Not like this one, no" and I would give up and go and look at the lighting section (I never buy any, I just like to look).

“It's not so much a question of women come from Venus and men come from Mars, more a sort of men hunt and gather and buy tools, and women do their own thing.”

Well, that was the past. There's no point saying anything now, partly because he is well over 6 feet tall and I am reduced to the level of a pushchair, but also because he has parked me out of the way and wandered off, so he wouldn't hear me anyway. Now don't get me wrong, this man has a virtual halo around his lovely head for the way he has been looking after me since I came out of hospital. But I am realising more and more that it's not so much a question of women come from Venus and men come from Mars, more a sort of men hunt and gather and buy tools and women do their own thing.

Just before we came in here, we went to a shopping centre – all on the ground floor, disabled toilets (or toilets for the disabled – but it was locked anyway) and

In My Dreams I'm Dancing

RUTH WOOD

every shop only disabled friendly because they can move all the displays that are on wheels. Now I am fairly shy – especially with people I don't know – and even shyer about "making a scene" (very "English"). My preferred method when shopping in a new store is to have a quick gander through the window, decide if they've got the kind of thing I want, suss out how the shop's arranged, then quietly walk in and look around. I never make a fuss and I rarely ask a shop assistant for – well – assistance.

was looking for anyway – something I would have quickly realised if I'd had time to look through the window. Eventually I made my feelings known (by shouting "they haven't got what I want") and we left.

“What I do not want to do is to be pushed straight into the shop, knocking aside display racks, catching small children on the ankles and forcing the shop assistant to rush over and move all the fittings.”



What I do not want to do – other than in my worst nightmare – is to be pushed straight into the shop, knocking aside display racks, catching small children on the ankles and forcing the shop assistant to rush over and move all the fittings – even the ones people are looking at. If I had ever wanted this amount of attention I would have found a job jumping out of birthday cakes half naked at all-male parties. But this is what happened in the bag shop. And I can't communicate with my driver because he's way above my head and behind me – and anyway he's deaf and won't wear his hearing aid. The worst bit about all this is that the shop didn't sell what I

Of course, another thing about a wheelchair – even the nice one I'm in – is that your feet stick out of the front. My feet are not huge – a narrow size six and a half and quite dainty – but they still jut forward of the footrests, as I found out in Boots when I was pushed straight up to the counter. I know I've not got much feeling in my feet anyway, but it's the principle of the thing. Having educated my carer/chauffeur in this delicate point, in the next shop he parked me sideways on to the displays. Which is why I'm sitting in B&Q with a cricked neck.

PIPs An Update

LEONIE ASHENDEN

In June 2013, the way people claim Disability Benefit changed. Initially the Government set a date when everybody on Disability Living Allowance (DLA) (within the age limits applied) should have been asked to apply to transfer onto Personal Independence Payment (PIP). The change should have been completely finished by May 2018. The Government released an update on 19 July 2017 to say that all invitation letters would be sent by late 2018 with the process to be completed by mid 2019.

When PIP was first rolled out, the Department for Work and Pensions (DWP) set a 16-week timeline from applying for PIP to the decision being made. However, in reality you can wait anything from four to five months for a face-to-face (F2F) assessment and the decision will come around four to five weeks after that. The DWP have written a list of conditions that should be assessed by the doctor (this has been added to the files on the TMS Facebook page). When you have your F2F you can request a copy of the assessor's report. You do this by phoning PIP on 0345 850 3322. This will help if you must write a Mandatory Reconsideration (MR) as you will need information from the report.

MRs are done by writing to the DWP (address on the award letter) about why you disagree with their decision. Be aware that 80% of MR's are refused but almost 70% are overturned at appeal. It may be worth going to appeal, although stressful, to get the desired outcome. If you end up with zero points after your decision and MR, it is still worth appealing since over 25% of people who win at appeal start off with no points. These are Statistics provided by the Minister of State for Disabled People on 02 May 2017. You must do an MR in order to go to appeal, as the MR letter must be sent in with your SSCS1 (appeal) form. If you do end up at appeal, whilst waiting for the appeal date, if you haven't already done so, consider writing a diary of how your daily living tasks and mobility are affected by your condition.

Some people who have moved onto PIP when the benefit first came out are now facing their renewal. About a year before your renewal is due you should receive an AR1 form which differs from the original PIP2 form completed when you first applied. The AR1 form

will ask for healthcare information, medication and your conditions. From there the form asks by tick box whether each daily living and mobility task has got worse, better or stayed the same. There is space underneath, as per the PIP2 form, to explain your answer. Even if tasks have stayed the same this does not necessarily mean you will avoid a F2F. The DWP look at the complete form including changes in medication or which medical professionals you see – you should explain any changes in the extra information section.

After recently speaking with my local MP, she said the Government do realise there is a problem with the PIP process, particularly the way F2F are being conducted and the way reports are being written up. We also discussed the fact that people with long term conditions who aren't going to get better, are being given an award of three to five years which is not cost effective.

From 21 June 2017, ATOS was rebranded as Independent Assessment Services (IAS). This is something to be aware of if you are to be assessed by them as you will now receive letters from the new company.

If you would like to read previous information about PIP and the application process, see issues 6 and 10 of the magazine.

If anyone has any other questions or needs any help with their PIP my email is leonie.ashenden@myelitis.org.uk.

FAQ

Can I claim PIP if I work?

Yes, PIP is not a means tested benefit.

I still have one year left on my award. Why have I been sent a review form?

They will send your review form a year before your end date because of the length of time it takes to go through an assessment and a decision being made.

I am still on DLA indefinite award will I remain on this?

PIPs An Update

LEONIE ASHENDEN

No, the DWP have extended the date that everyone aged 16-64 will have to apply by. This now stands at late 2018 with the process being completely finished by mid 2019. You can however apply before the DWP write to you. You do this by phoning them.

I am going to appeal the decision and have sent off all the paperwork I have. What else can I include?

Consider writing a diary and include any difficulties you have, what help you get and what you can and can't do. If you didn't include this in your initial application, it can be expanded on. You could ask your carer/family member to write about what they have to do for you, and the difficulties they see you have. Also include a copy of the condition insight report (found in the files on the TMS Facebook page).



JOIN US ON
facebook

The Transverse Myelitis Society Facebook page now has well over 2000 members! Here members are able to ask personal questions, without judgment. The answers may give a level of assurance that the symptoms they are experiencing are not uncommon and offer some help from their own experiences. The page is actively used and carefully moderated by the administrators so comments are completely confidential. Although the TMS page was established for people in the UK, people from all over the world are welcome to join.

Follow us on Twitter

The Transverse Myelitis Society Twitter page now has well over 700 followers!
Keep up with our tweets over at @T_M_Society



UK Support Group Information

Support Groups are a great way for people with TM and their carers/family members to interact with others facing the same problems. Attending a local support group can give you an insight into local facilities such as physio-hydrotherapy or neurologists that you may not necessarily know about. It also allows you to talk to people in the same position as you - and hopefully point you in the direction of some useful advice. The support groups also allow carers to offload and discuss strategies and best practice.

LONDON SUPPORT GROUP

Venue: Arcadis House 34 York Way London N1 9AB. The venue is wheelchair friendly and car parking free of charge from 1.30pm on Saturdays in York Way. There is no London Congestion Charge on Saturdays. We are a short walk, 3-4 minutes, from King's Cross Station.

For further details please contact Danielle Pomerance, danielle.pomerance@myelitis.org.uk

BRISTOL SUPPORT GROUP

Venue: We hold our meetings in the main reception area of the HOLIDAY INN, Filton and they are very informal; any friend or family members are more than welcome. Look out for Jean's blue balloon.

For further details please contact Steve Collins, stev.collins@blueyonder.co.uk

POOLE/BOURNEMOUTH SUPPORT GROUP

Venue: The MS Society Bournemouth Branch, The Osborne Centre, Church Lane, West Parley, Ferndown, Dorset, BH22 8TS.

For further details please contact Lance Harris, 01202 515216 or email, lv.harris@hotmail.com

NORTHEAST SUPPORT GROUP

Venue: Bede Room at Cornerstones, Chester-le-Street Methodist Church, North Burns, Chester-le-Street DH3 3TF.

For more information please contact Nikki Macleod, nikki.macleod@myelitis.org.uk

TELFORD/WEST MIDLANDS SUPPORT GROUP

Venue: The White Lion Inn, Holyhead Road, Ketley, Telford, TF1 5DJ

For further details contact Anna Paulsson-Habegger, aph71@hotmail.co.uk

TAUNTON/EXETER SUPPORT GROUP

Venue: Holiday Inn Taunton. M5Jct 25, Deane Gate Avenue, TA1 2UA. Held in main reception.

For more information contact Rob Reeves, reeves@myelitis.org.uk

EAST MIDLANDS SUPPORT GROUP

Venue: The Village Hall, Lullington, Near Swadlincote, DE12 8EG.

For further details please contact Janet Ashenden. Janet.ashenden@myelitis.org.uk or Leonie Ashenden, leonie.ashenden@myelitis.org.uk

TRANSVERSE MYELITIS SCOTLAND

For more information please contact Linda Cornwall, linda.cornwall@btinternet.com

Useful Contact Information

Bladder & Bowel Foundation

0845 345 0165

www.bladderandbowelfoundation.org

Brain & Spine Foundation

0808 808 1000

www.brainandspine.org.uk

Carers Direct

0808 802 0202

www.nhs.uk/carersdirect

Carers: The Princess Royal Trust

England 0844 800 4361

Scotland 0300 123 2008

Wales 0292 009 0087

info@carers.org | www.carers.org

Continence Foundation

www.continence-foundation.org.uk

info@continence-foundation.org.uk

Depression Alliance

0845 123 2320

www.depressionalliance.org

Scope

0808 800 3333

www.scope.org.uk

Disabled Living Foundation

0300 999 0004

www.dlf.org.uk

Disability Now Magazine

0207 619 7323

www.disabilitynow.org.uk

Driving: Disabled Motoring UK

01508 489 449

www.disabledmotoring.org

Driving Licences:

DVLA Drivers Medical Unit

0870 600 0301

Gardening

www.gardeningfordisabledtrust.co.uk

Mobility aids: Just Mobility

01923 265 577

www.justmobility.co.uk

Motability Car Scheme

0300 456 4566

www.motability.co.uk

Neuromyelitis Optical

www.nmouk.nhs.uk

The Walton Centre, Liverpool Service Coordinator

0151 529 8131

nmo.advice@waltoncentre.nhs.uk

John Radcliffe Hospital, Oxford Service Coordinator

01865 231 900

nmo.advice@ouh.nhs.uk

Pain Concern

0300 123 0789

www.painconcern.org

Pain: British Pain society

0207 269 7840

www.britishpainsociety.org

Prescription Prepayment Certificates

Nhsbsa.nhs.uk/1127.aspx

RADAR (The Royal Association for Disability and Rehabilitation)

[https://crm.disabilityrightsuk.org/](https://crm.disabilityrightsuk.org/radar-nks-key)

radar-nks-key

The National Key Scheme (NKS)

offers disabled people independent access to locked public toilets around the country.

Riding for the Disabled Association (RDA)

www.rda.org.uk

info@rda.org.uk

Welfare & Disability Benefits

(Dept. of Work and Pensions)

0800 882 200

www.dwp.gov.uk

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