



Join us on Facebook
www.facebook.com/Transverse-Myelitis-Society



Follow us on Twitter
[@T_M_Society](https://twitter.com/T_M_Society)

Spring 2016 || £2

The Magazine

TRANSVERSE MYELITIS SOCIETY



PHOTO IS COURTESY OF THE TENNIS FOUNDATION



Gordon Reid
Wheelchair Tennis Champion



TM Awareness Day
9th June 2016

CONTENTS

3	LETTER FROM THE EDITOR
04-05	WHAT EXACTLY IS TRANSVERSE MYELITIS ZELDA CARR EXPLAINS
06-08	GORDON REID – WHEELCHAIR TENNIS CHAMPION HIS STORY
10-11	RETURNING TO WORK – YOUR RIGHTS MARSHA THOMPSON, EMPLOYMENT SOLICITOR
12-13	OCCUPATIONAL HEALTH – YOUR RIGHTS JOANNA ROBBINS
14-16	MIND OVER MATTER PT. 1 ROBERT WHITTAKER, KATHERINE WRIGHT, GRAHAM BELCHAMBER
17	TM SILVER LININGS
18-20	PHYSIOTHERAPY IN THE MANAGEMENT OF TRANSVERSE MYELITIS ELISSA BENSON, NEUROPHYSIOTHERAPIST
21	TM FAMILY WEEKEND
22-23	TM KIDS FOR KIDS, BY OUR KIDS, PENNY AND GEORGE
24-25	MIND OVER MATTER PT. 2
26	SINGING IS THE WAY FORWARD RUTH WOOD
27-28	ALL-TERRAIN WHEELCHAIRS TRIALLED BY JONATHAN GREEN
30-31	TM AWARENESS DAY UK HOW YOU CAN HELP
32-33	A YEAR IN MY NMO LIFE NIAMH TELLS HER STORY
34-35	NEWS FROM THE COMMITTEE
36	TMS PRIORITIES FOR 2016
37-38	UK SUPPORT GROUP INFORMATION
39	USEFUL CONTACT INFORMATION

LETTER FROM THE EDITOR

I think I speak for most when I say that the onset of TM, or one of its associated conditions, is a pretty life shattering experience, but since we started this magazine I never cease to be amazed at the sheer bloody mindedness of people to rebuild their lives.

So, we are very proud to showcase another TM star, Gordon Reid. Earlier this year Gordon won the men's singles wheelchair tennis at the Australian Open, defeating the world No.1. Since his win there has been quite a bit of media coverage, but we were more interested in how his journey from a 12 year old, lying in a hospital bed, paralysed from the waist down, to where he is today. And who better to tell his story than his mother! Alison Reid has written a wonderful moving account of his life since that fateful day, but, being very modest, she has left out the sacrifices she made. Gordon needed someone with him every time he travelled until the age of 18, and that person was Alison.

A subject that is constantly discussed amongst our members is the problem of going back to work post TM, so we do hope our 2 complimentary articles are helpful. The first, on Page 10, is around your legal rights, by Employment Solicitor Marsha Thompson, and the second by Joanna Robbins, a Specialist Practitioner in Occupational Health.

On Page 14 we have one of the best 'self-help' guides I've ever read. What makes it so relevant is that one of the authors, Rob Whittaker, is not just a Clinical Psychologist, but also has TM. He readily admits that his experience of TM has had a profound influence on his practice as a psychologist. Katherine Wright is also a clinical psychologist with an interest in Mindfulness, which has become very popular recently.

I'm delighted that Elissa Benson agreed to write such an in-depth article on Neuro Physio for us. TM can result in life changing consequences, and physiotherapy can help

at all stages, from the acute onset through to the long-term management. We hear all too often how seldom people get access to it, so let's use this magazine to show health professionals how vital it is.

As usual, just reading about what our TM Kids have been doing lately leaves me exhausted. Penny had an amazing trip to India with her family, then she was off ski-ing for her school. George has been surfing, and taken up DJ-ing. But we are also reminded of the side effects of TM that they are constantly dealing with, and this time it's 'foot drop' and problems with gait. Niamh provides us with a candid review of her life during 2015, the difficulties with juggling her school work with managing her symptoms and disabilities from NMO. Niamh's paintings are quite abstract and colourful, due to her sight deficiencies.

Elsewhere, for all of you for whom fancy a bit of off-roading with a difference, Jonathan Green has been trialling a few all-terrain wheelchairs (real boy's toys). In contrast, Ruth Wood tells us why we should all take up singing.

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, who have never met anyone else with this rare condition, despite being diagnosed many years ago. Although we are hoping 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.

As ever, we need your stories, comments and suggestions for future magazines. Please email me at

annie.schofield@myelitis.org.uk

Annie



Annie Schofield



Zelda Carr



Heather Coltman

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.

Thanks to Back Talk Systems, Inc. for the image.

www.backtalksystems.com

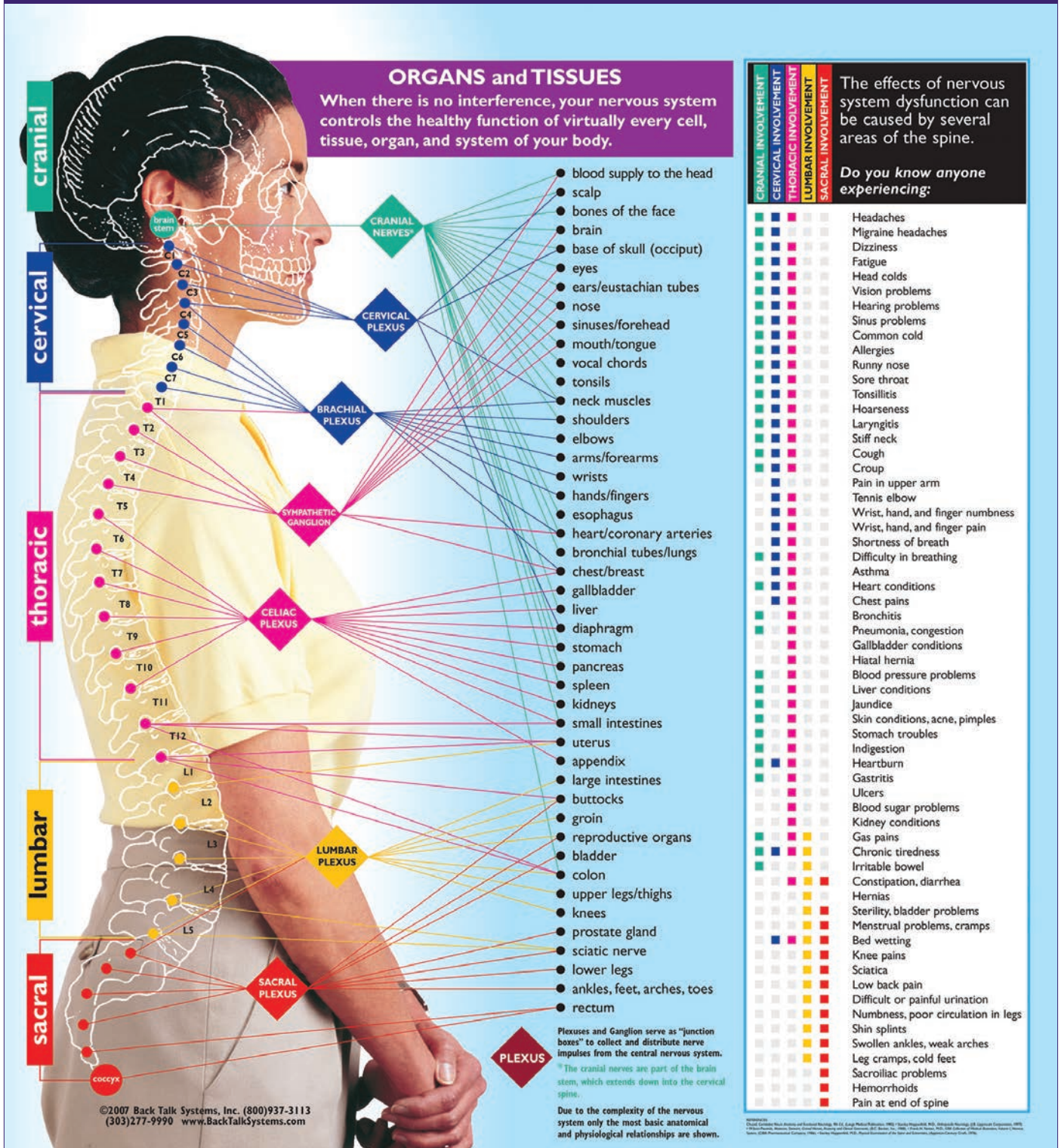
www.backtalkeurope.com

WHAT EXACTLY IS TRANSVERSE MYELITIS

ZELDA CARR EXPLAINS

NERVE FUNCTION

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



GORDON REID – WHEELCHAIR TENNIS CHAMPION

HIS STORY

When **Gordon** first took up the sport of wheelchair tennis 11 years ago, it was purely for exercise and to regain some fitness after being struck by Transverse Myelitis. At the time he had no idea that he could rise so far in the sport, nor of the opportunities and friendships it would bring.

Friday 24th September 2004, a week before his 13th birthday, Gordon and a group of his friends had spent most of the day playing football in the park opposite our house. One of his friends came to find me telling me that Gordon couldn't stand up properly. I found him at home sitting on the edge of the bath, unable to stand, with pain in the back of both legs. He thought he might just have cramp from playing so much football.

The advice from the GP was to apply hot and cold compresses to the backs of his legs for an hour. As there was no improvement, we took him to the surgery. He was still thought to be suffering from leg cramps and sent home. We were reassured by the doctor and to call should Gordon's condition worsen over the weekend.

Gordon felt better the next morning but the leg cramps soon returned, worse than the previous day, accompanied by severe pain in his lower back. Gordon was prescribed pain killers and a muscle relaxant. Around teatime Gordon told me he had "pins and needles" in his legs and couldn't feel his feet. Our GP called an ambulance and Gordon was taken to Yorkhill Children's Hospital in Glasgow.

By the time we reached the hospital he was totally paralysed from his waist down and suffering with severe back pain. The following day, Gordon was transferred to the Neurology ward at Southern General Hospital where he underwent a series of tests including a lumbar puncture and MRI scan. Gordon was transferred back to Yorkhill, his home for the next several months. After a few weeks, following a process of elimination, a diagnosis of Idiopathic Transverse Myelitis was given.



LONDON PARALYMPICS 2012 / PHOTOS COURTESY OF THE TENNIS FOUNDATION

Offers of help and support from family and friends enabled either me or Gordon's dad to stay with him. His friends organised a rota to ensure he was never without visitors. The hospital staff were wonderful, cheery, caring and understanding.

Gordon had been warned that he might never walk again, but his goal was to get back on his feet. His dream was to play football again. He never complained, remarking that compared to the other children on the ward, he was the best off. He used his wicked sense of humour to deal with difficult situations. Despite his pain he would always ask to do a little bit more at his physiotherapy sessions, understanding the importance to his recovery process. He first learnt to sit up and then transfer to a wheelchair, the freedom causing great excitement. Over the next few months sensation and movement gradually returned. Gordon was fitted with orthotics and able to get onto his feet in a standing frame. He began a phased return to home and school, which fortunately was equipped with ramps and lifts. His wheelchair proved to be a great attraction. On his first day back the headmaster found Gordon propped up against a wall while his pals took it in turns to do "wheelies" in his chair!

We heard of a wheelchair tennis group at a leisure centre close to the hospital, and suggested to Gordon to give it a

GORDON REID – WHEELCHAIR TENNIS CHAMPION

HIS STORY

try. He loved it from the first session and was welcomed and encouraged by the other players. Knowing how to play tennis, his challenge was to master the movement of the wheelchair.

Six weeks after being discharged from hospital Gordon entered and won his first wheelchair tennis tournament. Encouraged to enter the British National Championships, members of the Tennis Foundation watched him play. They invited him to a European junior camp taking place in Rotterdam during the summer holidays. He never looked back.

To come to terms with his disability Gordon preferred to concentrate on what he could do, rather than what he couldn't. He loved the speed of his wheelchair and the powerful game.

I think he also enjoyed being part of a group where he wasn't different to the others. He commented recently that he sometimes feels like he leads a double life, one at home with family and friends, the other on tour with his tennis circle.

With the support of the Tennis Foundation he began entering international tournaments and earned his first senior ranking. Friends, local schools and businesses fundraised to provide his first made-to-measure tennis chair. Gordon had to find a balance between education and tennis. He always had full support from the school staff who allowed him time off encouraging him to take advantage of the opportunity.

As his chair skills improved, Gordon started winning more tournaments and his rankings rose. He became National Men's Champion at the age of 15 and the following year won the Cruyff Foundation Junior Masters in Tarbes, France. He qualified and was selected to be part of Team GB at the 2008 Beijing and 2012 London Paralympics.

Gordon is now a full time athlete, balancing training and competition. Tournaments have taken him all over the world meeting some remarkable people. He enjoys visiting schools and businesses, showcasing his sport. He loves to encourage children

and adults to try wheelchair sport, not only for the physical benefits, but also for the fun and social opportunities it brings.

Last year Gordon led the GB men's team to victory for the first time at World Team Cup, the wheelchair equivalent of the Davis Cup and followed this with his first Grand Slam doubles wins at Roland Garros and the US Open. A win at the Doubles Masters in California meant Gordon ended the year ranked No 1 men's doubles.



His success has continued into 2016 with a first Grand Slam singles title, won in Melbourne at the Australian Open. This year at Wimbledon wheelchair singles competition is being introduced. September will bring the Rio Paralympics where once again our Team GB athletes will have the opportunity to display their talent.

We are all right behind you Gordon, proud of all that you have overcome and achieved, and the inspirational way in which you have done it. Can't wait to see what you do next.

Alison Reid

GORDON REID – WHEELCHAIR TENNIS CHAMPION

HIS STORY

Gordon kindly offered to answer questions from TMS Members.

Q You contracted TM aged just 12, how did it impact on your life as a teenager?

A It completely changed my entire life. Every little thing in daily life was different somehow. I was constantly active as a kid and it was difficult when I was forced into a position where I couldn't stay active. I think it made me grow up and mature a lot earlier than most teenagers, as well as making me appreciate all the great things in life more.

Q I am in awe of your ability to be an athlete with TM. You are an inspiration to all disabled people. Chronic fatigue is a common side effect of TM. Do you suffer from it, and, if so, bearing in mind your work schedule, how do you manage it?

A I think when I was younger I used to struggle a lot with fatigue. I would often come home from days at school and feel like I had no energy at all. These days I think I have improved my fitness to a level where I don't struggle with it as much. There will still be times where I'll feel tired but now I think that's more down to my full time intense training schedule. I think the best thing to do to try and combat it is to try not to focus on the feeling of being tired and try anything to take your mind off it.

Q Wimbledon is to hold wheelchair singles competitions for the first time this year. How difficult is it to make the transition to playing on grass – bearing in mind just pushing a wheelchair is difficult enough?

A For sure Wimbledon is physically the toughest event in our calendar. It's a lot harder to move on the grass courts and we fatigue a lot quicker than when on hard courts. The good thing though is that we start our competition during the end of the 2nd week at Wimbledon so most of the grass is quite worn down and the ground is harder so easier to roll on.

Q We know you visit schools in order to encourage children to take up sport. What advice would you have for children disabled by Transverse Myelitis?

A The main point I would like to say to any child going through the same experience as me is that I understand how it feels to be in the horrible position they are in, but having a disability isn't



the end of the world. It can be difficult and challenging physically and mentally at times but it is still possible to live an incredible life. My best piece of advice would be to take every challenge they face head on and try to stay positive as much as possible.

Q The London Paralympics did a huge amount to raise the profile of disability sport. What do you think we can do to help maintain that interest?

A The interest from the general public during London 2012 was incredible. For all of disability sport and definitely for wheelchair tennis. We need to keep the momentum going by keeping disability sport in the public eye and making it as accessible as possible to everybody. I also think the work being done in schools to educate children at a young age about disability sport is very important and needs to continue and grow.

Q Which of your many achievements are you most proud of and why?

A Although winning the singles at the Australian Open in January is probably my biggest achievement on paper, my most treasured moment in my career so far and the one I'm most proud of is the London 2012 Paralympics. It was an incredible experience to play on the centre court packed out with 5000 people and to share some unforgettable moments with all my closest friends and family.

Tailored neuro-physiotherapy for children and young adults

The Birkdale Clinic specialises in working with children and young adults to support them with neurological conditions such as:

- Cerebral Palsy
- Transverse Myelitis
- Downs Syndrome
- ADEM
- Genetic Disorders
- Developmental delay

Our innovative approach uses the body's sensory motor and language systems. In our custom-built clinic, we work to gently engage the patient's mind and body to achieve positive change. Part of our ethos is to empower the entire family and make sure that all care supports the individual in their journey towards improvement. Many of our patients show long term results that exceed all expectations.



"The staff are very friendly, helpful, extremely thoughtful & attentive to my needs" Nando Provin



Please contact us for further information

RETURNING TO WORK – YOUR RIGHTS

MARSHA THOMPSON, EMPLOYMENT SOLICITOR



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.

The thought of returning to work after several weeks or months away from work can often invoke feelings of worry and anxiety for many employees. Some employers discriminate against those with long term mental, neurological or physical conditions which in turn perpetuates the stigma that surrounds these types of illnesses.

According to The Transverse Myelitis Society, many employees with Transverse Myelitis (“TM”) and their families have faced such stigma and discrimination at one point or another. The issue is that far too often, employees do not know their rights on returning to work, having no one to turn to for advice and the issue gets overlooked.

What Does The Law Say?

The Equality Act 2010 (“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.

Who is Protected?

Disabled job applicants, employees and former employees are protected under the Act.

Under the Act, a person is disabled if they have a physical or mental impairment, and the impairment has a substantial and long-term adverse impact on their ability to carry out normal day-to-day activities.

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.

What Adjustments Can be Made?

The Equality and Human Rights Commission Statutory Code of Practice (“the EHRC Code”), contains a non-exhaustive list of potential reasonable adjustments that employers might be required to make. These include:

Making adjustments to premises. For example, widening a doorway, providing a ramp or moving furniture for a wheelchair user

Providing information in accessible formats. This could include producing instructions and manuals in Braille or on audio tape

RETURNING TO WORK – YOUR RIGHTS

MARSHA THOMPSON, EMPLOYMENT SOLICITOR

Allocating some of a disabled person's duties to another person. For example, a job involves occasionally going onto the open roof of a building, but the employer transfers this work away from an employee whose disability involves severe vertigo

Transferring a disabled person to fill an existing vacancy. An employer should consider whether a suitable alternative post is available for an employee who becomes disabled (or whose disability worsens) where no reasonable adjustment would enable the employee to continue doing their current job

Altering a disabled person's hours of working or training. This could include allowing a disabled person to work flexible hours to enable them to have additional breaks to overcome fatigue arising from their disability, or permitting part-time working or different working hours to avoid the need to travel in the rush hour

Assigning a disabled person to a different place of work or training. For example, relocating an employee's work station to an accessible place

Dealing with the return to work

1. Talk to Your Manager About Your Illness

It is important to be frank, open and honest with your manager/ employer about your TM, how it affects you and how they can assist in your return to work.

There is a lack of knowledge around lesser known illnesses such as TM which means employers may be scared to raise the issue for fear of saying "the wrong thing". As a result, the issue does not get discussed and can be overlooked completely. This can in turn make you feel excluded and isolated so do keep the lines of communication open.

Whilst on sick leave, it is also a good idea to keep in touch with your manager and colleagues at work by email or telephone. This will help you to stay connected and facilitate your eventual return to work.

2. Inform Yourself

Arm yourself with as much information regarding your illness as you can. You can then share this with colleagues in the hope of educating those you work with.

You should also look into whether any support is offered by your local NHS Trust. Check your local NHS Trust website for details.

3. Know Your Rights

Not all employers will know what their obligations are under equality legislation, whether you would be classed as disabled under the Act and whether or how to implement reasonable adjustments.

You should talk to your union representative if you are a member of a union. Your union representative can assist you in meetings with your employer and check that you are being treated fairly.

4. Build up a Support Network

Being off work due to long term illness can make you feel isolated and vulnerable, so getting emotional and practical support helps with recovery. Various charities offer a range of support and advice. In addition, social networks are a great way to connect with others in the same situation and online blogs can also provide useful information and support.

You can also contact one of your local TM support groups.

5. Go Easy on Yourself

Those with TM know all too well that the condition can leave you feeling drained with very little energy. Be sure to return to work slowly and gradually build up to a level you feel comfortable with and within your capabilities.

For more information see: www.myelitis.org.uk

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.

OCCUPATIONAL HEALTH – YOUR RIGHTS

JOANNA ROBBINS



Joanna Robbins is a qualified nurse with 30 years experience in a wide variety of specialities, the last 10 years working in Occupational Health, where she has gained the Specialist practitioner qualification. Joanna manages and is a director of an independent occupational health company that provides complete occupational health provision to companies ranging from high performance engineering companies and councils.

Returning to work after an absence due to illness is often followed by a phased return to work. Time on sick leave can vary, but often a period of four weeks will trigger a company's long term sickness absence policy, usually involving a referral to Occupational Health. In 2011, the sickness absence system was reviewed and recommendations for improvement

were made. The government accepted a number of recommendations, including the introduction of an Occupational Health assessment and advice service to help those off sick for four weeks to get back to work (Gov.uk 2011).

“Once a person is back at work, a workstation assessment may be required. Office chairs are highly variable and it's important to source an adequate chair which provides the required support ”

The majority of large companies do have Occupational Health Departments staffed by qualified Occupational Health Professionals. They will be able to give guidance on a phased return to work, which can be included as an option on the employee's fit note. This allows employees, who may not yet be fully fit, the chance to return to work earlier in their recovery by allowing them to do less hours and duties that are amended/adjusted, based on a return to work plan, specifically designed for them by the Occupational Health Adviser. This allows the employee to return to work sooner and get used to being back in the workplace; this is beneficial for the employee's mental health and has been shown to improve overall well-being.

The process of developing a successful phased return to work plan will depend largely on the reason for the employee's sickness absence. It is important that the employee has not returned too soon, or too quickly to their role following a significant period of absence. Whilst they may be deemed medically fit to resume duties, a swift return may prove to be detrimental in the long term. Different people recover at different times from similar illnesses and an inability to cope could be demoralising for the employee if being introduced back into the workplace too quickly. Poor concentration or difficulty in making decisions could be misconstrued by managers as poor levels of performance. It is, therefore, imperative that the employer understands about the employee's condition and has realistic expectations about recovery and rehabilitation rates.

OCCUPATIONAL HEALTH – YOUR RIGHTS

JOANNA ROBBINS

For smaller companies there is also the Government's new scheme which is called Fit for Work, which is a telephone based service and is available to anybody who has been on a period of sickness absence of four weeks or more. The person can be referred by their GP or by their employer. This system allows an assessment by telephone and then a written return to work plan.

Residential rehabilitation is very successful following a diagnosis of TM. The multidisciplinary team associated with the care can help towards a successful integration back into work. The intensive nature of the rehabilitation does increase the recovery of any loss of sensation or functional ability.

A diagnosis of Transverse Myelitis will usually be considered as fulfilling the criteria required for protection under the Equality Act 2010. The Equality Act allows for people with disabilities to be protected within the work place. A phased return to work is considered to be a reasonable adjustment within the guidance, the reasoning being that after a period of sick leave, a return to possibly fulltime hours will cause significant fatigue. A gradual return to full time hours will allow rest periods to manage the fatigue gradually. A phased return over four weeks allows for the adjustment required to manage the fatigue.

“A diagnosis of Transverse Myelitis will usually be considered as fulfilling the criteria required for protection under the Equality Act 2010 which allows for people with disabilities to be protected within the work place.”

Half time hours are usually the starting point for a phased return. This could be half time over three or four days per week, increasing on the second week to five half days per week. The following third week could be two full days and three half days, then the fourth week of the phased return could be three full days and two half days. In the majority of cases it would be expected that the employee would return to fulltime work at this point. The employer should set targets and monitor the employee when work is increased throughout the return to work

period. The employer will need to consider the impact of the reduced hours on the employee's pay.

If the diagnosis and prognosis is poor, there is a Government scheme called Access to Work, a scheme offered by the Government to all people who have a disability. This is accessed by the employee initially and then often an assessment will take place at the workplace to assess whether significant adjustments are required; this could be provision of a wheelchair or provision of automated doors. Access to Work is really used for larger requirements. For small businesses they do have to provide a portion of the money required for the adjustments, but Access to Work will also fund significant parts. Access to Work will also fund taxis to work if required.

Once a person is back at work, a workstation assessment may be required. Office chairs are highly variable and it's important to source an adequate chair which provides the required support. Voice recognition software is very useful if you are experiencing pain and fatigue in your arms, shoulders and neck. Voice recognition software is excellent in providing access to all of the Microsoft Office applications. There is a certain amount of training required for the voice recognition software, but it is a very useful way of resting shoulders and arms. There are certain types of mouse that also are very useful.

A regular follow up with Occupational Health is advisable if possible. Smaller companies who possibly may not have an Occupational Health department would benefit from an Occupational Health Assessment, engaging an independent Occupational Health Advisor or Physician who would come into the workplace to advise on any alterations required. They will also advise on a number of other aids that could be utilised already discussed within this article.

COHPA is a 'Not for Profit' Non-regulatory Membership Association for Occupational Health and Wellbeing providers and was founded in 2004. It is the Commercial Occupational Health Providers Association and will provide details of independent Occupational Health providers across the country.

MIND OVER MATTER PT. 1

ROBERT WHITTAKER, KATHERINE WRIGHT, GRAHAM BELCHAMBER

MINDFULNESS, PACING, FLAREUP STRATEGIES...

This article is collaboration between *Graham Belchamber*, patient's representative on the British Psychological Society Faculty for Clinical Health Psychology, *Rob Whittaker* and *Katherine Wright*, Clinical Psychologists at Bradford Teaching Hospitals NHS Foundation Trust.

Our aim is to explain how psychology can offer assistance to people with TM and other chronic life changing conditions from Graham's experience as a patient and Rob's as a psychologist who himself has TM, and Katherine's as a psychologist specialising in chronic pain.

Graham: My attack of TM was in 2006, following a yellow fever jab for a holiday and as I was recovering from a nasty bout of tonsillitis. So tickets to see Bruce Springsteen and the holiday went south, along with my legs, bowels and bladder that all stopped working, combined with a pneumatic drilling in my head, intense back pain and three stone weight loss. Those few days changed my life completely.

Five years on with severe nerve pain all over, spaghetti legs, fatigue, memory problems, dysfunctional bladder and bowels and increasingly severe flareups, I was strongly advised to take medical retirement by my GP, Neurologist and employer's Personnel and Occupational Health teams. So at the tender age of 49 I received a pension and a bus pass.

Rob: Uncannily my attack of TM was also in 2006, also following injections for a holiday in Asia. My first symptom was what I thought was a splinter in my back from crashing into the boards around the pitch while playing five-a-side football. Over time the sharp, prickly feeling spread around my whole torso. I can best describe it as bad sunburn combined with a load of holly leaves stuck up my t-shirt. For me though the fatigue was

the most debilitating symptom. Thankfully I was spared any motor or continence problems – my experience very much at the mild end of the TM spectrum compared to Graham's. It was around 18 months before I was properly functioning again.

Graham: Soon after retiring I joined the Pain Management Programme at the Hastings Conquest Hospital and I was at quite a low ebb. I had always been positive, open minded, sought out new experiences and new friends, enjoyed raucous debates, the unknown, unplanned and unexpected and avoided pessimists, cynics, small mindedness and negativity as much as I could.

But five years of TM and a lifetime of this incurable painful condition ahead, I was starting to fear, rather than enjoy the unknown of what's next and felt in danger of TM turning my personality into the very cynic I had always rallied against. I was starting to feel uncomfortable with myself. Yet here I am in 2015 writing this as a positive story and that's thanks to the psychological techniques I learnt on the PMP and reinforced since.

Rob: I was (and still am) working as a clinical psychologist with people with physical health problems in the hospitals in Bradford. My experiences of TM have had a profound influence on my practice as a psychologist. Many of the conditions affecting the people I have worked with have caused great fatigue for example. I know first-hand how quickly fatigue can erode a person's sense of humour and their sense of hope. At the lowest ebb of my TM I felt quite down, feeling both incapable of contributing to the world and fearful that others would judge me negatively for my lack of contribution – think me a malingerer. Additionally, throughout my illness was the fear that this would never resolve – particularly that it would morph into the degenerative trajectory of MS. I was quietly terrified. Low mood, anxiety and uncertainty are such common experiences of the patients I work with – at times the resonance with my own experiences has been quite powerful. I learnt some important lessons in how I might try and be helpful to the patients who consult me from the varying responses of my

MIND OVER MATTER PT. 1

ROBERT WHITTAKER, KATHERINE WRIGHT, GRAHAM BELCHAMBER

colleagues at the time. Some expressed a very compassionate, kind, gentle attention and concern. They allowed me to voice my concerns, to work out how I felt about what was happening through helping me put my experience into words. They were respectful of my reality and acknowledged rather than tried to change my feelings.

Therapists are often very enthusiastic about particular therapeutic approaches and techniques which has lots of advantages, though it can lead to an overconfidence in the truthfulness or value of these ideas and practices. Some of my colleagues offered, surely with the best of intentions, some thoughts and ideas that I found far from helpful. One set up a meeting for me with an MS professional on the assumption that many of my anxieties were about a condition I knew very little about and thought that a bit of reality testing would help. It didn't – it made me more anxious. Another called me a "typical over-pacing bloke". Another wondered with me whether I had any unconscious conflicts which were causing my medically unexplained symptoms. I felt not listened to, insulted and angry.

Over time I have come to appreciate the importance of the fit between therapist and client – it matters less what the "content" of the therapy is – as long as it makes sense to both parties and it feels as though they have a productive working relationship it is likely to be helpful. For some people therefore, the more "educational" approaches such as those described by Graham absolutely fit the bill. Learning new skills, whether mindfulness, relaxation, positive self-talk, self-compassion, assertiveness skills etc – can be hugely helpful. For some people it will be the "therapeutic frame" that is important – regular contact in a safe, undisturbed setting with an empathic, attentive listener who will neither push you to confront pain you cannot tolerate nor simply allow you to wallow with no sense of forward trajectory (though I absolutely believe in the value of "wallowing" for a while) can be of enormous comfort. Therapy is in essence a relationship and by definition therefore there is no one-size-fits-all solution – it is highly idiosyncratic.

A crucial difference between my and Graham's experience is that I required sensitive support through a time-limited trauma;

Graham has had to adapt to a probably permanent set of changes to so much of his life. One of the key tasks Graham has had to tackle has been acceptance of the chronicity of his condition. Many patients living with chronic pain have told me over the years how vital this acceptance is – simultaneously crushing and strangely liberating. Many of the psychological approaches to chronic pain involve shepherding patients towards a consideration of how they might rebuild a life of value given their physical and perhaps other constraints. There is grief in this and I feel that allowing for "normal" bereavement processes to occur is an important step along the way. More helpful then to frame "depression" as a bereavement reaction. Bereaved people often find themselves in a range of emotional states - in no consistent order: shock, denial, rage, sadness and some kind of emotional reconnection. Difficulties pacing can I think be construed as denial or perhaps expression of rage against loss. For me to go from working full-time and playing 5-a-side to unable to walk the 200 yards to the newsagent at the bottom of my street constituted an unbearable transition I was not prepared to make. Effective pacing and acceptance are surely key to living with a condition such as TM, but we should not underestimate their substantial emotional costs.

Graham: There were four particular psychological techniques that I learnt from the PMP and in refresher sessions since; Mindfulness, pacing, splitting my life/activities into three and acceptance of my condition.

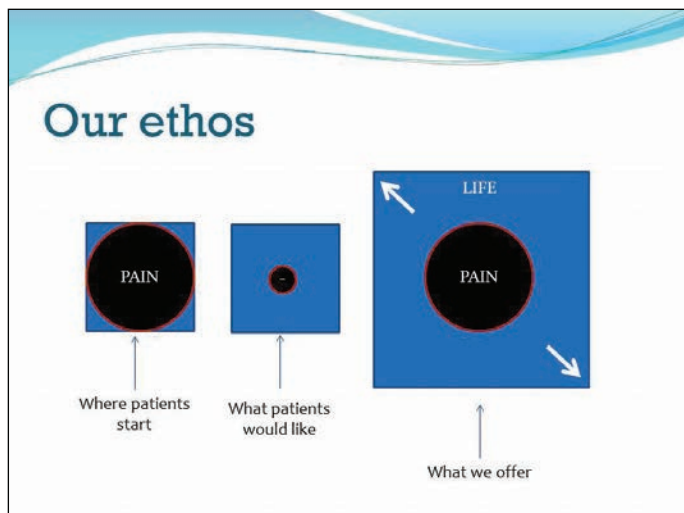
Katherine: So I thought it might be helpful to say a bit about the Bradford Living with Pain Service here. We are a team of Clinical Psychologists, Pain Specialist Physiotherapists, an Occupational therapist and a GP with a special interest in pain. We facilitate a group programme of eight 3.5 hour sessions for people living with long term pain. And just to offer some hope to all the people who may read this article, we do get measurable results that people's lives improve by going on the programme. Eg, 60% show a significant improvement in mood and 38% a complete recovery from depression. Pain self- efficacy, a measure of how confident people are in managing their pain, increases by 75%.

MIND OVER MATTER PT. 1

ROBERT WHITTAKER, KATHERINE WRIGHT, GRAHAM BELCHAMBER

I've included some slides from a presentation we did recently, as pictures speak louder than words sometimes.

Our philosophy is that we don't aim or claim to get rid of people's pain, but we do try to shrink the impact it has on people's lives.



Another principle is that there is no one answer: we offer a toolkit of ideas and different things work for different people.



I won't have room to describe all the tools listed above, so I'll concentrate on the four that Graham identified and add two more that people in our groups seem to find particularly helpful – developing self-compassion, and developing assertiveness and communication skills. But they're all inextricably linked as I'll try to explore.

Graham: Mindfulness really assists when I can feel the nerve pain gathering, when I am having trouble sleeping or feeling down in the dumps because of my health. And importantly, rather than reaching for the medication box for an extra dosage, I find that mindfulness really helps combat the pain.

Katherine: The principles of Mindfulness are summed up in the slide below.

The 'mind full' cloud shows that we humans have minds that are always busy-busy- busy, darting about all over the place, full of plans, and often worries for the future, and memories and often anxieties and regrets about the past. But if we think about it:

'The past is history, the future's a mystery, all we have is the present, and it is a gift.'

Meaning that we often miss the richness of all the present moments in our lives because we're so busy living in the past and the future. The idea is to set aside time to practice Mindfulness meditation, where we try to bring the attention back to the present, whatever it brings, the good, the bad and the pain. It's important not to feel we've 'failed at Mindfulness' when the mind spins off again and again, but simply to notice, and bring it back to the present moment. And to try, as we go about our lives, to notice and inhabit the present moment a bit more. There is lots of evidence that practising Mindfulness can reduce stress, anxiety and depression and improve the lives of people living with pain. People in our groups have reported increased well-being, less worry, and that pain is less troublesome.

... *continued pages 24 - 25*

The TMS Facebook page is the modern day equivalent of the magazine 'Agony Aunt' column, with the advantage of hundreds of people willing to give advice. But Redi Dora's question threw up some very interesting answers.

How about we each share at least one positive thing about TM. I'm sure if we give it some thought we'll be able to come up with at least one.

My Contribution

TM has taught me to appreciate the simple things every day. A nice shower, hanging out with friends, a meal...

TM taught me to fall in love with exercise. I was overweight and unhealthy. After TM struck I couldn't walk properly for a long while, then I started to walk more and more, then I started to swim.... Then I started to run. Next thing I'm running 5ks/10ks and two half marathons. If I didn't have TM I would have carried on taking my body for granted, but now I run for fun, as an anti-depressant - and for awesome weight loss.

I have started a psychology degree with the Open University. As I can't walk exercise is hard, I get to exercise my mind and find the subject fascinating.

It's given me a chance to retire early on medical grounds, so I haven't lost out on my pension and I have a disability bus pass so I can go where I want on local buses! Freedom.

TM made me totally re-evaluate my life and everyone in it. Now I know my own worth, never again will I settle for anything other than the very best, equally I only give the very best and I believe I'm a better person for it. All those little things that seemed so important before really do mean nothing to me now.

For me it's helped me to sort good friends from casual acquaintances.

I appreciate every day I am here. Even though I have always been a sympathetic person, I am now totally empathic to people with disabilities. I love life even though there are struggles.

TM has made me a more positive person.

My son lost the use of his legs and bladder in October last year and is now back at school walking to and from school twice daily.

Started a degree in Law, given my mind another focus and loving it.

I can't walk but I have learned to knit, crochet and make birthday cards. I wouldn't have done this if I was able as I was too busy working and looking after my home... I never sat long enough to knit.

Learning to say no and not feel guilty is a lesson in progress but it feels good to be straight.

On good days, I can walk my dogs again.

Makes me put everything into perspective, when colleagues get stressed I tell them - there are two boxes in life, the life box & the death box. If something is heading towards the death box, then we worry! And it never is heading that way. I hear them saying it themselves now!

I discovered just how deeply and truly my husband loves me. We both went through a traumatic year and came out the other side as stronger people.

Appreciation of simple things in life, as well as being able to do more reading and research in areas of science that I enjoy.

It taught me to appreciate the things I took for granted and instead of dwelling on things I can no longer do, focus on what I can do.

TM has taught me to celebrate the days when I am pain free.

As for me, I get to be Editor of this magazine - how else would I have been able to let loose my inner journalist?
Annie

PHYSIOTHERAPY IN THE MANAGEMENT OF TM

ELISSA BENSON, NEUROPHYSIOTHERAPIST



Elissa Benson is one of the partners at Neuro Rehabilitation Kent, a private practice providing specialist neurological physiotherapy services based in the community around West Kent and the bordering areas. She has over twenty years' experience in the management of acute and long term neurological conditions.

PHYSIOTHERAPY CAN HELP AT ALL STAGES OF TM TO

- Manage symptoms
- Reduce secondary consequences
- Reduce impairment
- Increase activity
- Maximise functional ability
- Increase participation

TM is a rare neurological condition involving inflammation of the central nervous system, specifically the spinal cord. It can be idiopathic or can arise as part of the overall picture in a variety of other conditions. The presence of an inflammatory process means that the acute symptoms can arise gradually over several hours and continue for several weeks. Dependant on the level of the spinal cord affected symptoms can include pain, muscle weakness, loss of sensation, paralysis and loss of bladder and bowel control. Some patients may experience respiratory difficulty due to paralysis of the respiratory muscles. The majority of people will only have one episode of acute TM, some may have a recurrence. It's estimated one third of people will make a full recovery; one third will have some residual issues and one third will develop a significant level of disability hence at least two thirds of sufferers will need some level of on-going rehabilitation. Physiotherapy can help at all stages, from acute through to the long-term management.

In the acute stage, when the diagnosis and prognosis may be unclear, physiotherapy would focus on the management of symptoms, including positioning in the bed or chair, help manage pain, maximise function and most importantly prevent secondary problems due to the development of shortened muscles or a mal-aligned posture. If breathing muscles are affected, a function of physiotherapy may be part of the overall management especially if assistive ventilation is required. Those who may still have a level of mobility, physiotherapy would focus on selecting appropriate walking aids and ensuring their correct use.

As acute inflammation begins to settle symptoms may start to resolve and impairments reduce. The rate and extent to which this happens can again be very variable. As therapists we understand the ability of the central nervous system to adapt. The aim of therapy intervention is to optimize all remaining functional ability whilst directing recovery through the reorganisation of the central nervous system, both from a sensory and motor (movement control) perspective.

Physiotherapy at this stage will often focus on regaining postural control as part of directing increasing functional ability

PHYSIOTHERAPY IN THE MANAGEMENT OF TM

ELISSA BENSON, NEUROPHYSIOTHERAPIST

and recruiting appropriate muscle activity to avoid problems of abnormal tone and muscle imbalance. Specific management of soft tissue shortening and joint stiffness through positioning, stretching and exercise may be required. Intervention may focus on regaining the ability to properly align your body segments in sitting and standing as a precursor to moving and walking. This may involve assisting you to come into an upright position against gravity and regain your balance. Following an acute episode of this sort there may be a level of de-conditioning (lowered level of fitness) which would reduce your strength and stamina. Rebuilding both of these would be part of an overall physiotherapy programme.

“Most people will only have one episode of acute TM. It’s estimated one third will make a full recovery; one third will have some residual issues and one third will develop a significant level of disability. ”

Some individuals may experience persistent loss of sensation or abnormal sensation like numbness or pins and needles due to the damage to the nervous system. Pain can also be an issue. Alongside medication, physiotherapy input can be helpful in managing these symptoms using a variety of techniques and modalities. These may include using a TENS (transcutaneous electrical nerve stimulation) machine or sensory re-education techniques.

In some cases the assessment, provision and education of correct use of equipment such as wheelchairs, walking aids, foot and hand splints are indicated. An assessment of adaption to the home may be done by an Occupational Therapist, working in conjunction with a Physiotherapist. Interventions are likely to take place in an acute hospital setting. Discharge from here may be to a rehabilitation facility or to home depending on the level of recovery and individual circumstances. Medical input will now be minimal, on-going physiotherapy still has a big part to play. For those people going home, they will either go

along to a physiotherapy department for treatment or someone would go to their home.

The focus would very much depend on the individual issues but may include, treatment of problems with your joints or muscles; pain control; managing seating and postural control issues. If you are walking, it may involve re-educating normal movement patterns and optimising your balance with or without the use of walking aids. If bladder control is an issue your physiotherapist may be involved in a bladder retraining programme under the guidance of whoever is managing your continence overall. The need for strength and stamina training is often on-going as your activity levels increase, as is the management of fatigue through learning to pace activity if this forms part of the overall picture.

As the central nervous system retains its ability to reorganise in response to experience, recovery from TM or any other neurological condition can continue for a long time. Physiotherapy can contribute to that recovery process too. It may be in the form of continued treatment to direct the regaining of normal movement or in the prevention of secondary problems from postural mal-alignment or altered muscle tone; provision or review of equipment as needs change; or in the development of an on-going management plan with periodic review. Sometimes physiotherapy and/or occupational therapy intervention will be indicated in a return to work or school assessment. Physiotherapy may help reintegration into the community via practising getting on/off a bus or learning to use the facilities at the local gym.

For most people a robust maintenance programme, targeted to the individual, based around their desired goals, will replace regular physiotherapy. Using everyday functional activities to maintain and gain ability is recognised to be very effective. Physiotherapy has a continuing role in long term management and access to therapy can make a significant difference to an individual's quality of life. Intervention may be in the form of the treatment of an acute injury, reviewing of equipment needs, or revising the maintenance programme. It may also include education of family members and carers around how best to support an individual's on-going recovery and

PHYSIOTHERAPY IN THE MANAGEMENT OF TM

ELISSA BENSON, NEUROPHYSIOTHERAPIST

possible signposting to other relevant agencies. Whatever the intervention, it is the timely access to appropriately skilled and experienced input that prevents a loss of activity leading to a loss of participation and a reduced quality of life.

As a private practitioner working in the community, people living with a long term neurological condition who have developed a new problem or whose ability has deteriorated often contact me. In these circumstances my response would be to suggest a thorough assessment involving a complete history and leading to the identification of specific issues. Subsequent discussion would then establish what that individual wanted to achieve and what was feasible based on the assessment. Intervention may vary, but the aim would always be to maximise individual potential towards improving quality of life.

TM presents as an acute condition but its effects, for many, are life changing and long term. Neurophysiotherapists recognise this and support the availability of intervention on a long term basis, using an individual person centred approach. The TMS offers support to members in finding a suitably qualified neurophysiotherapist in their area and a bursary scheme for members who may need assistance in accessing input. Details of this can be found on the TMS website.

Elissa is registered with the Chartered Society of Physiotherapists (CSP) and the Health and Care Professions Council HCPC and is a member of The Association of Chartered Physiotherapists Interested in Neurology (ACPIN). She can be contacted via

www.neurorehabkent.co.uk

Soft tissues connect, support, or surround other tissues. Examples include your muscles, tendons, fat, and blood vessels.

Functional Activities are tasks or acts that allow one to meet the demands of the environment and daily life e.g. washing, dressing, eating.

Postural control is defined as the act of maintaining, achieving or restoring a state of balance during any posture or activity.



AN IMPAIRMENT IS A PROBLEM IN BODY FUNCTION OR STRUCTURE

AN ACTIVITY LIMITATION IS A DIFFICULTY ENCOUNTERED BY AN INDIVIDUAL IN EXECUTING A TASK OR ACTION

A PARTICIPATION RESTRICTION IS A PROBLEM EXPERIENCED BY AN INDIVIDUAL IN INVOLVEMENT IN LIFE SITUATIONS

A PHYSIOTHERAPIST CAN INTERVENE AT ANY LEVEL

- By treating an impairment
- By reducing an activity restriction
- By problem solving a participation restriction

TM FAMILY WEEKEND

8 – 11 JULY 2016

Who is the weekend for?

The Family Weekend is for children aged 4-17 who have Transverse Myelitis (TM), Acute Disseminated Encephalomyelitis (ADEM), Neuromyelitis Optica (NMO), Optic Neuritis (ON) or Acute Flaccid Myelitis (AFM), their siblings and parents (immediate family).

Why attend?

The purpose of the weekend is to bring families together to share, support one another, learn, and develop friendships. The ethos of the Calvert Trust is to learn and achieve through challenging and adventurous outdoor activities. There will be a range of activities such as sailing, horse riding, trap driving, archery and more that you and your children can take part in. Medical and healthcare professionals will also offer educational sessions for parents.

Who can apply?

The weekend is open to members of the TM Society in the UK, but members do not need to be UK residents. If you are not a member, you can easily become one by completing the online membership form www.membership.myelitis.org.uk (there is no fee to join).

Costs

The weekend is free for families to attend (subject to returnable deposit) - accommodation, meals and the activities are included. Families pay for travel costs to and from the venue and for travel insurance.

Places available

All 60 spaces have been registered, but until deposits have been paid we won't know for definite how many places are available. In the meantime, families will be placed on a waiting list.

The weekend is open only to the immediate family, i.e. the child who has TM, ADEM, NMO, ON or AFM, their siblings and parents. Up to four children per family can attend.



“Our mission is to enable people with disabilities to achieve their potential through the challenge of adventurous activities in the countryside in order for them to develop, change perceptions and make positive and lasting changes to their lives.”

The event will take place at the Calvert Trust in the Lake District.

This venue is a residential outdoor centre with over 35 years' experience delivering challenging outdoor adventure holidays for people with disabilities. On the shores of Bassenthwaite Lake, in the heart of the Lake District National Park, the centre offers a warm welcome, and an accessible venue and accommodation.

The Calvert Trust endeavours to offer life changing experiences which provide positive results that last long after the stay at the centre. Their experienced staff will work with you to ensure that everyone reaches their potential no matter what their level of ability, building confidence and developing a range of skills, which enables visitors to take up new daily challenges back at home.

TM KIDS FOR KIDS, BY OUR KIDS, PENNY AND GEORGE

FUNCTIONAL ELECTRICAL STIMULATION (FES)

Last year I was having lots of problems with my foot. My big toe was really sore all the time. The hospital found it was inflamed and they popped my leg into a cast in the summer holidays. After summer the hospital gave me a device called a 'foot up' to help me lift my foot up! After a couple of weeks using the 'foot up' my walking had slightly improved and my shoes weren't as worn down. We did some research on other devices that did the same job but worked a little better. That is when we found FES.

FES "is a technique used to produce contractions in paralysed/weakened muscles by the application of small pulses of electrical stimulation to nerves that supply the muscle. The stimulation is controlled in such a way that the movement produced provides useful function. FES is used as an aid to assist walking and also as a means of practicing functional movements for therapeutic benefit." (Odstock Medical Website)



MY TRIP TO INDIA

I went on a trip of a lifetime in October last year to India to visit friends. We flew into Jaipur, then onto the Ranthambore National Park. We went on two safaris and spotted lots of wildlife. My favourite was a big bear and a tiger!

In Jaipur, we visited the Pink Palace, then onto Agra to see the Taj Mahal. What a magical place. It brought tingles up my spine and it wasn't TM!!

Travelling to Delhi we stayed with friends, then onto Rishikesh. We went white water rafting down the holy river Ganges. It was great fun! Back to Delhi to visit all the sights and experience our first rickshaw and elephant ride. Food was good and thankfully no tummy problems!

My best moments were white water rafting and camping in the national park.

SKI RACING

This year I joined the Robert Gordon's College (RGC) ski race team. We train at Garthdee snow sport on a Monday after school. I was asked if I wanted to race at the Lecht Ski Centre, Strathdon

in the SSSA 2016 Alpine Series. I was a little worried as I had never competed in a ski race before!

I left early in the morning to catch a bus up to the Lecht Ski Centre. Mine was a novice race which was for students who have no experience of racing. It started at 11am so we had plenty of time to do some training beforehand.

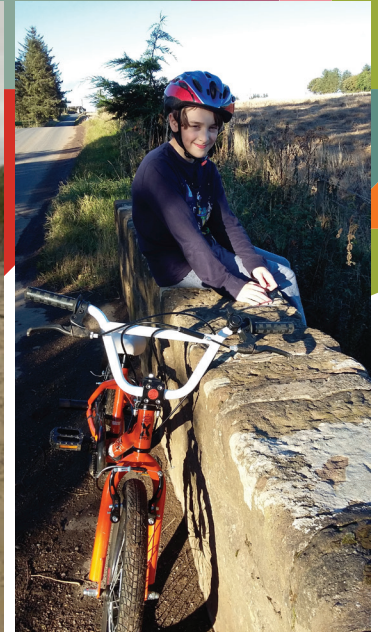
We had our team talk and allowed to have a course inspection. I was number 55 and when my turn came, I was really nervous. It was a slalom course and we were allowed two timed races. My first race went really well. Unfortunately my second race was abandoned as the skier ahead of me was injured after a fall so my race was stopped. I had a really good start but unfortunately stumbled on a turn and lost some time. The mix of excitement and nervousness is amazing. I just loved my first experience of racing!

At the end of my race we went for a hot chocolate.

Our team did really well. Our school (RGC) took home 4 medals and we all had a great time. I really enjoyed the race and the social side of the day out, I can't wait for the next one!

Penny x

TM KIDS FOR KIDS, BY OUR KIDS, PENNY AND GEORGE



Hello everyone, it's me again, *George*. I have been really busy since my last letter. I have taken up DJ'ing (you can follow me on Soundcloud), computer coding and surfing with my friends Robert and Elliott. The surfing is quite hard on my arms, and it's difficult to move them the next day, but I really enjoy it. I do have some exciting news! It started when I was at TM camp last summer, and I met a lady that was a physiotherapist that is an expert in conditions like TM, in fact some of the children already knew her. She was really nice and she looked at my back and legs and noticed that I stood and walked a little bit funny. She said that some neuro-physiotherapy could help me and that if I wanted to I could go and see her. Well, we live in Scotland and she lives in London, which is a long way!

So the TMS paid for me to see a lady much closer to us in Aberdeen. Her name is Donna and she's really nice. I saw her once before Christmas and then again a couple of weeks ago. The first time I went to see her she had a really good look at how I walked, sat and stood and I did a few exercises with her. She asked me loads of questions about how active I am and how often I get tired and which bits hurt me. I told her about my bladder not working too well and she said she might be able to help. I thought that I was quite fit, as I'm quite active, and I do ballet, but when Donna had finished assessing me she said that my trunk was weak, especially on one side. I think I had

concentrated on getting my arms and legs fit and then forgot about the middle!! She showed me an exercise which my Mum calls happy cat-sad cat, where you arch your back and then dip your back, and I just couldn't do it properly. Me and Mum were really surprised. My back did it in lots of little stages instead of one movement. So Donna gave me a few exercises to do over Christmas, to try and build up my core strength.

I went back a couple of weeks ago for a follow up session and Donna was really surprised how much stronger my middle was. The exercises had really helped. She spent a long time showing me more exercises, and it was really hard work. Afterwards I was so tired I slept in the car on the way home! She showed my Mum how to tell if the muscles were working or not, and when to stop doing certain exercises if the muscles were doing too much. Donna is going to put all of the different exercises she showed me into an exercise programme for me to look at every day. She's going to send it to my Mum but we haven't got it yet so I'm just practising the ones I can remember for now, but I'm definitely feeling much stronger. My bladder is still a pain, but hopefully this will eventually get better too. I'm still learning to use catheters but I'm finding it really difficult....but that's another story!!!

MIND OVER MATTER PT. 2

Graham: So the next key technique I learnt on the PMP, that I implemented immediately, was splitting my life into three;

- the things you have to do for example taking your medication, eating and drinking, personal hygiene, resting and whatever exercise you can manage.
- cutting out completely everything you would like to do or think you should do but that are simply beyond you or exacerbate your pain.
- maximise what you enjoy doing within the limits of your pain and TM.
- The third lesson, which I admit to finding the hardest to implement is pacing.

Before TM I had a very active lifestyle, full time employment and plenty of sport and exercise. Now at times I keep on as if I do not have TM and then crash. The result is fatigue and I find myself both completely physically and mentally exhausted like a cloud coming over me and I have to stop whatever I am doing immediately.

Katherine: I'm going to take prioritising and pacing together as they are so closely linked. Nearly everyone struggles with these, probably nearly every human being on the planet.

It's often helpful to think about humans in terms of how we got here via evolution. We've survived on the planet by having a strong drive to achieve things – in the early days, to find food, shelter and sexual partners. We get a hit of feel good chemicals in the brain (dopamine) when we achieve things. And achieving things brings other rewards, such as respect, admiration, status... and a clean house. So it's really understandable that people find it hard to wind that down a bit. Also, staying in 'doing mode' can be a way of fending off difficult feelings that creep up when we're quieter, such as worry and sadness. But research shows that when people manage to pace, they achieve MORE over time than if they do the boom and bust thing. A tip we recommend is to evaluate activities on a 1-10 scale for effort, and try to go along at a five all the time. As I said, these ideas are all interlinked, and a Mindfulness approach to life can help with acceptance of not being able to achieve everything

we used to, and also with managing tricky emotions that may descend in moments of inactivity.

Another way of looking at pacing and prioritising that some people find helpful is to imagine you have six spoonfuls of energy to last you through each day. What do you want to use them on? Anger, anxiety, conflict can take up quite a few of your spoonfuls. Deciding what you want to spend your spoons on each day can help with prioritising activity, and managing emotions as well. And they're both closely linked with Graham's fourth hurdle, acceptance.

Graham: The fourth lesson was acceptance of my condition. Before I attended the PMP I was in the mind set of fighting TM and telling people that's what I was doing. I was ignoring the reality of having a serious illness, attempting and increasingly failing to carry on as normal at home and at work and suffering the consequences of increasingly severe flare ups.

One of the key lessons I took from the PMP was accepting I had TM, there is no cure for it and I became increasingly more confident telling people that. That was a significant change in my mind set and from then on I started to focus on what I can do with my TM life rather than missing and regretting what I am not able to do.

Katherine: It's probably most helpful to think about acceptance as a journey, rather than a one-off step. As Rob says, it involves the painful acknowledgement of loss, and grieving for those losses - and grieving takes time, and it progresses through stages such as denial and anger. Acceptance is closely linked to Mindfulness, as that involves accepting whatever is happening in the moment, without judgement.

Metaphors can be helpful in thinking about acceptance. We suggest people think about holding a party...it's going to be perfect, but an unwanted guest, Joe, turns up, and spoils it by being rude to all your best friends. You try to hide him in the kitchen, but he won't stay there, and in the end you tell

everyone to go home and the party is ruined. But Joe is still there in your kitchen, and tells you he will always be in your life. What do you do? Get drunk to try to forget him, try to push him out the door, keep so busy that you don't have to think about him, shout at him...?? Or, just get on with life as best you can? Yes, Joe is the pain.

This can lead onto thinking about your life as a bus. Has pain been driving your bus? If you were driving, where would pain sit? Where is your bus going? This can lead to thinking about values that can guide our lives. Can the same values guide my life as before the pain, even if the journey is different, and there are many things I can't do anymore? Eg, can I still be a loving parent by spending time reading to my child, even if I can't play football with him?

Thinking about how hard it is to pace things, leads the fifth tool I want to talk about, which is self-compassion.

Life can be hard at times for all people, as well as squirrels. We've evolved to survive, not to be happy. We all have 'old brains', which respond with lightning speed, and a 'better safe than sorry' vehemence to threat – it's how our ancestors in caves survived. So we are as a species prone to be hyper-alert to danger. But because we also have 'new brains' that allow us to reflect on dangers, we can magnify them even more, and get into vicious cycles of worry.... and then we worry about worrying. And because we are a social species, we worry about not being liked, about being not good enough and letting people down.

It's helpful to be kind to ourselves and remember we are only human and can only do our best! And to learn to take good care of ourselves, and soothe and comfort ourselves, as well as other people.

There is growing evidence that people who have developed self-compassion suffer less anxiety and depression.

This brings me to the last tool, assertiveness and communication skills. Because, in order to make sure our own needs are met along with everyone else's, we need to be able to express those needs assertively, and to distinguish between assertiveness, aggressiveness, passivity and passive

aggression. A good guide to this is in the Northumberland NHS guide to assertiveness.

Self-compassion

1. Noticing the pain, distress or difficulty you are experiencing
2. Recognising that pain and suffering are things we all struggle with
3. Asking yourself how can I comfort and care for myself in this moment?

Resources

- Exercises and guided meditations to help build self-compassion:
<http://self-compassion.org/category/exercises/#exercises>



Conclusion

Graham: The pain and physical difficulties will always remain and fatigue engulfs me like a blackout curtain when I, by my own limited standards now, I overdo things. So while I rest considerably more, religiously take my medication and fully appreciate that a working life is completely beyond me, what I can do now thanks to psychology is in my own and a different way, enjoy my life.

Rob: Complex, variable chronic conditions such as TM can usefully be addressed using a range of psychological approaches: from supportive counselling to specialist multidisciplinary pain management. Different approaches and different therapists will suit different people – you may need to shop around. Speak to your GP about the options in your area.

Thanks to Graham for giving me this opportunity to reflect on my experiences and offer my thoughts. My very best wishes to you all.

SINGING IS THE WAY FORWARD

RUTH WOOD



I'm a singing teacher, and for six years, during my first four separate and confirmed attacks of TM, I was unable to fulfill my chosen role. Although I re-trained in Neuro Linguistic Programming (which is very useful) and wrote my book about my first year of disablement, in my heart I felt diminished because I could no longer work with my passion for teaching singing, acting and all things associated! Strangely, being unable to perform didn't hit me with the same intensity, so when I saw singers in shows and concerts I didn't feel frustration that I couldn't be up there doing it as well.

Over the years, before TM, I've had some amazing experiences and travelled all over the world. Being a singer was very fulfilling in some ways, in that I met people and saw places that otherwise I wouldn't, and that's given me the satisfaction of having good memories.

But teaching is an ongoing process - the longer I worked the more I appreciated how much there was still to learn! I missed the students - their eagerness, their differences and similarities, the satisfaction of seeing someone alight with joy when they found their own unique voice. I missed the training courses, keeping up with the new scientific discoveries and exchanging knowledge with other teachers.

Just over two years ago I decided to get back into teaching again, albeit very part time, and I contacted a local music school who were short of one singing teacher. Within three weeks I was up and active again. There are many wonderful things about singing, not least the posture and the breathing. As a teacher, I find demonstration to be invaluable, so gradually, bit by bit, my own posture improved and I was able to begin to win the battle against the banding constricting my diaphragm.

Although my own voice had suffered badly, it was only as a result of the damage my body had suffered, and it was enough to be able to sing with students when necessary.

The job with the school finished, but I continued and built up the practice a couple of hours here, a couple there.

Last week I went on a training course to learn to become a group leader to set up singing groups for people with Dementia and Alzheimer's. It was a very interactive two-day course in Suffolk. On the second morning, as we broke for coffee, one of my new friends said, "Ruth, you're walking so much better today". I was. There's a lot of research being done on the health benefits of singing. It's not just about the physical benefits - though those are considerable - but what is happening to the brain.

“Using singing, together with rhythmical movement, we can help our bodies to begin to heal. Even just learning to breath properly can measurably improve our immune systems. ”

When you sing regularly - and that can be just once a week, especially with other people - not only does your brain set up millions of new neuro pathways, but it alters physically, gaining mass and plasticity.

For those of us with neuro diseases and conditions, this gives new hope. Using singing, together with rhythmical movement, we can help our bodies to begin to heal. Even just learning to breath properly can, amongst other benefits, measurably improve our immune systems.

The research is relatively new and on-going, but the results are already speaking for themselves. I see great hope and am very excited about being a part of this initiative, as well as appreciating the differences it is making to me physically, mentally and emotionally.

Humans evolved to sing - we were doing it for millions of years before language developed - and it makes sense to keep singing. We all have a voice, unique and truly ours, which comes from a very deep and old part.

So think about it - then find a singing group and try it. Don't worry about what you think you sound like, or the fact you have to sit down! Then let me know how you're doing!!!

ALL TERRAIN WHEELCHAIRS TRIALLED BY JONATHAN GREEN



For many years one of my passions has been hiking and walking over mountains and hills, here, in the UK, but also Europe, USA and New Zealand.

I took it all too much for granted – until later in 2011, when I was struck with Transverse Myelitis. The inflammatory condition was relatively slow onset, starting with some slight numbness at the soles of both feet, which didn't seem very surprising as I had just successfully finished the Three Peaks Challenge!

Now paralysed by LETM from T6, with the usual bladder and bowel dysfunction, chronic pain and fatigue etc., I'm confined to a wheelchair – but making the best of it. But none of this has dampened my desire to get 'out and about' again in the countryside. So, how about considering a powered "All-Terrain" wheelchair?

The first one tested was the "**Extreme X8**" by 'All Terrain Wheelchairs'. As stated on their web-site "This is not your standard power wheelchair!" "The Extreme X8 will be your partner to just about any destination; through sand or snow and up or down kerbs. If the great outdoors is where you want to be, the Extreme X8 is waiting to take you there."

The trouble is Cambridgeshire, where we live, is flat! However, it went up and down some 6-inch kerbs with no trouble at all, likewise across a slightly undulating rough grassed area. So I needed to test it on some hills, and that's what we did – on the Long Mynd, in Shropshire!

The "four independent, high speed, high torque & high efficiency motors" coped with the steep incline easily, at varying speeds too, up to 10km/h. Battery life seemed excellent, and even after 4 hours use the battery strength indicator was still just over half-full.

The Extreme X8 is undoubtedly a very robust, well-made machine with lots of potential for additional features, such as a seat rising, tilting and reclining system. It 'feels' safe and secure while sitting in it, with good quality harnessing – and the seat seems comfortable and suitably pressure relieving. With a base width of 710mm, I was just about able to drive it into our house. But realistically, it's not an indoor toy! It's not cheap either, the basic model is around 12K.

The second machine I trialled was an "**Overlander 4**" supplied by "TerrainHopper", an all-terrain machine of an altogether different kind! A serious off-roader!

I only tried this Overlander locally, over some rough, sloping ground adjacent to a ditch, but it handled it with ease. I'm yet to try it further afield and up some serious hills – but alas I've already fairly well discounted this one, due to some serious disadvantages over the other all-terrain wheelchairs; for instance, it would have to 'live' in the garage, and might only be used a few times per year – insufficient to justify the 12K price-tag. From the website, "Overlander 4 is the full blown go-anywhere Wheelchair and a dream come true for those who wish to go to previously inaccessible places; thanks to the unique patented independent suspension system, you are not thrown all over the place!"

Due to the 'extreme' nature of this particular machine, it is perhaps unfair to try and directly compare it with the other machines that I trialled. It's therefore important to really know what you're wanting to 'achieve' as an end result.

The third machine trialled, was the "**DL Stand Up**" by Mybility. From their website "The Mybility All Terrain Stand Support System Wheelchair truly liberates the user with unprecedented

ALL TERRAIN WHEELCHAIRS

TRIALLED BY JONATHAN GREEN



flexibility and is the only stand up all-terrain wheelchair on the market.”

As with the previous models ‘on test’ the machine appeared to be very robust and well-engineered throughout, although I was a bit ‘put off’ by its appearance, due to the rather large battery compartment mounted behind the main frame of the chair!

One immediate advantage was that it was easier to enter and manoeuvre within our house. It’s narrower than the ‘Extreme X8’ by about 25mm, which makes a considerable difference through doorways! One big difference was its ability to rotate both sets of wheels to create a tighter turning circle, plus the ability to allow the user to ‘stand’ whilst also safely strapped in and still able to move around in that position. This machine also has the potential to allow the chair to recline into a horizontal position (as if on an elevated sun bed!).

Externally, it performed really well – up and down large kerbs, across rough grassed areas and gravel. In that respect, it was able to perform comparably with the X8.

It was the most expensive to buy when configured for multi-purpose usage – around 18K! Although the basic model was around 14K.

The fourth machine was the **Levo C3** from Gerald Simonds, a very elegant machine compared to the more ‘rugged’ look of the others.

Due to the weather, a thorough-going outdoor trial was not possible, but it was fairly robust at handling the varying terrain. However, it was limited to kerbs that are no more than 100mm.

As a powered wheelchair around the house, it’s probably as good as it gets – with its ability to get you elevated into a standing position whilst still being able to manoeuvre about the house. With a tight turning circle of 1.075m, this power-chair is well suited to handling the internal environment, without destroying your carpets. The physical benefits of ‘standing’ are well known, and therefore the DL Stand Up and Levo C3 offer considerable benefits.

In many ways, the DL Stand Up offered the widest scope of compromises for all-terrain capability and day-to-day functionality, but the downsides were manoeuvrability around the home and the overall cost when priced up for what I would require (about 18K)!

By the way, each machine is probably equally transportable. Any one of these machines could be ‘life changing’ in their characteristic ability to propel you into the ‘great outdoors’. If you’re more inclined to the more ‘extreme’ mode of transportation, then the ‘Overlander 4’ has got to be your vehicle of choice! It’s awesome! However, for me, on balance, I’m going to have another go with the ‘Levo C3’ and see just how much of a game changer that could be!

N.B. Prices are approximate at time of going to press

www.allterrainwheelchairs.co.uk

www.terrainhopper.com

www.mybility.co.uk

www.levousa.com

From Childhood To Adulthood
GO BEYOND THE BOUNDARIES



Sand, snow, mud.

Trekkinetic manual & power chairs will cope with almost all terrain.

Considerably lighter than most other chairs and can fit into most cars without adaptations.

From childhood to adulthood with a removeable hyperforma child insert seat.



WWW.BEYONDTHEBOUNDARYWHEELCHAIRS.COM

CALL

0203 643 5943 / 07885 059990

OR EMAIL

BEYONDTHEBOUNDARYS@GMAIL.COM

TM AWARENESS DAY UK

9TH JUNE: HOW YOU CAN HELP



LYNN POWELL, TM SOCIETY VOLUNTEER
AWARENESS DAY COORDINATOR

TM Awareness Day UK: 9 June “Let’s make a difference together.”

I was appointed in 2015 to grow the existing TM Awareness Day online community, produce a set of awareness-raising resources, and provide support to members via the awareness@myelitis.org.uk email address and TM Awareness Day UK Facebook page.

As this year’s Awareness Day approaches, I wanted to share a few successes from last year to encourage people to start thinking about what they can do to support TM Awareness Day UK in 2016. A full run-down of TM Awareness Day UK 2015 was emailed to all members on 9 February.



2015 Highlights

Facebook ‘BIG CONVERSATION’ reached over 10,000 people

We asked people to show their support for TM Awareness Day by liking the Facebook page, and sharing posts and awareness-raising ideas with friends. The number of likes grew to 500 - that’s 376 new people in the TM Awareness Day Facebook community! Thanks to your activity on the Facebook page on 9 June as part of our TM Awareness Day ‘BIG CONVERSATION’, our posts reached 10,619 - up from a previous daily high of 428!

Potential Twitter audience grew to 33,000

The number of people visiting the Twitter page grew from 273 to over 1300, and our potential audience grew from 2,255 to 33,000! Thanks to people tweeting, re-tweeting, tagging, and using the TM Awareness Day hashtags, we reached a much wider public audience than we could have done alone.



New TM Awareness Day Pack helped 41 people run events and raise funds

A 7-page TM Awareness Day section was added to the TM Society website, including a range of free-to-download resources, awareness-raising ideas, and new TM Society promotional merchandise. TM Awareness Day Packs were also posted out to people on request.

41 PEOPLE ORDERED AWARENESS DAY PACKS TO HELP PROMOTE AND RUN THEIR TM AWARENESS DAY EVENT. THE NEW TM SOCIETY MERCHANDISE ALSO PROVED A POPULAR WAY OF RAISING FUNDS.

TM AWARENESS DAY UK

9TH JUNE: HOW YOU CAN HELP

How you can support TM Awareness Day UK 2016

There are lots of ways you can help: big and small, as an individual member, a support group, on your own, or working together with others. Think about what you enjoy doing, and who you think needs to know more about TM, and plan an activity around that. Here are some ideas and more are listed in the Awareness Day Guide. Do one or more, or combine a few together. And of course you are free to think up your own ideas and design your own publicity using the TM Society logos, which can be downloaded from the website.

Join us on Facebook



Like our **TM Awareness Day UK Facebook page** and share your awareness-raising ideas, tips, questions, event information and photos. Also share our posts with your friends, and the public. On TM Awareness Day update your profile picture to the TM Society awareness ribbon.

www.facebook.com/tm.awareness.day.uk

Follow us on Twitter



Retweet our tweets to your followers, tweet about your Awareness Day plans, and tag @TM_awareness_UK Use hashtags such as **#TransverseMyelitis #ADEM #TMAwarenessDay #NMO #Let'sMakeADifferenceTogether**.

www.twitter.com/TM_awareness_UK

Wear something TM-related on the day

Buy a TM Society ribbon pin, wristband, trolley coin key ring or t-shirt. Or get some blue ribbon and make something yourself. If you're a bit more adventurous, dress in blue or dye your hair blue. Make sure you have some TM Society information to hand out to explain why you look the way you do! And don't forget to take photos.

Hand out TM Society leaflets, magazines and posters

Hand out copies of the TM Society leaflet and magazine at your local GP surgery, physiotherapy and neurological clinics, hospital, A&E department or wherever you feel there are

healthcare professionals who need to be made aware of TM and the TM Society. Use the Distribution Record to record who you give information to. If you prefer to send information by post, use the Introductory Letter to Healthcare Professionals to introduce yourself. Ask if you can put up a TM Society poster.

Get sponsored

Run a marathon, or turn a personal goal into a fundraising challenge. Tell people about TM and why you are raising money for the TM Society, and ask them to sponsor you. Set up a fundraising page on JustGiving, or order a collection tin from the TM Society. Tell us what you're doing so we can help with promotion.

Run a raffle

Ask family, friends, colleagues and local business for donations of prizes. Or ask people to guess how many sweets in the jar, weight of the cake, etc., and offer a prize for the closest.

Contact your local radio, TV, newspaper or healthcare publication

Download the Awareness Day Press Release Template, and tell local media about your TM Awareness Day UK event. Have someone on hand to talk to reporters, and use the Photo Permission Form to make sure you have people's permission to share photos. The media love a good photo opportunity and personal story.

Attend a healthcare professional's meeting

GP surgeries and clinics usually have regular staff meetings and training sessions. Ask if you can come and talk to them about TM and the TM Society, and leave information they can share with colleagues. Personal stories help engage medical staff in a way that written information alone can't.

Everything you do for TM Awareness Day UK 2016 - big or small - will help raise awareness, reduce isolation and - in time - lead to people being diagnosed quicker and getting better treatment and support.

We may be a small charity, but by working together we really can make a difference!

Email: awareness@myelitis.org.uk

Website: www.myelitis.org.uk/tm-awareness-day.html

Twitter: @TM_awareness_UK

Facebook: www.facebook.com/tm.awareness.day.uk

A YEAR IN MY NMO LIFE

NIAMH TELLS HER STORY



My name is Niamh, I am 14 and I have Neuromyelitis Optica (NMO), a condition that has affected many parts of my body, mainly my optic nerve and spinal cord. I have had several attacks which began when I was four and I was diagnosed at the age of five. I never fully regained my sight and I have mobility issues, pain, sleep issues and fatigue all of the time. I miss a lot of school but I remain determined to do what I can.

January 2015

My NMO pain is really bad. My back feels as though someone is sending electric shocks through my spine. When I have pain like this I can barely do anything. It takes all the strength I have to go anywhere and I miss school. The steroids I started this month are already making my cheeks puffy!

February 2015

I travelled to Oxford to see the NMO specialists. The steroids are creating a lot of discomfort and I'm gaining weight. My gabapentin has been increased to 1800mg a day. It's still not working. I'm on 15 tablets a day now. It's a rainbow every time I take them. It doesn't bother me the number of medicines because I know they help, despite the horrific side effects.

March 2015

21 tablets a day. I've started taking them in a shot glass to make it a bit exciting. My pain is awful. It's everywhere, all through my spine and my legs. I just get random shooting pains everywhere. I'm getting frustrated with myself because I'm missing so much school. I understand that my health is important but my education is important too. It makes me feel sad because I know I'm not reaching my full potential. But I am proud of myself when I still get good marks even when I'm doing work at home.

April 2015

I'm losing my mind. I'm in so much pain. I don't understand why they've given me a tablet which has intensified everything. I hate steroids! My joints have started clicking constantly and they are getting stiff, which makes it hard to move with my crutches. I attend my blood test. They test EVERYTHING to ensure I'm okay. My best friend and I call them the 'vampires'. We love to joke about my illness just to lighten the mood. She's the only one who finds my NMO jokes funny, other people are not so sure.

May 2015

Exam month. I use Braille, large print, modified papers and my teaching assistant is able to scribe and read some of it, which is helpful. School is difficult when your attendance is below 50%. I continue to keep on top of the work because I need to learn. My steroids aren't working. I'm saying goodbye to prednisone and hello to hydrocortisone.

A YEAR IN MY NMO LIFE

NIAMH TELLS HER STORY

June 2015

I am currently facing the vicious cycle of pain. I met the guide dog trainers at school and they let me walk one around a little. It was awesome. I really think a guide dog would help me. One problem. I can't use a crutch and walk a dog! My life is a constant battle of trial and error with medication. Each week there's more colours to add to the rainbow pot of pills! I wish it was a pot of gold!

July 2015

I'm away on holiday for a few days but need to be back for hospital appointments. The pain in my back is quite bad and we're restricted to what we can do on holiday. I'm all puffy from my steroids but I'm trying to stay distracted and enjoy my time.

August 2015

My feet are swollen and I sleep with them on pillows which is beneficial. I've been for another meeting with the guide dog trainers which went really well. I'd love to have a guide dog to help me and for a sense of partnership but I'm just not well enough to do everything that is required.

My dad has hired me a wheelchair. I'm not too happy but it helps me get around on our holiday. I think of it as being pushed around like a princess haha. I've had such a lovely summer having short breaks and being with family. I'm worried about my school attendance this year. I hope it will be more than 50%.

September 2015

A nice birthday present for me. The doctors are decreasing my steroids by 5mg every 4 days until I reach 15mg. It's making me feel quite ill. I feel like I'm on a boat. I think that the taper is happening a little too quickly.

October 2015

I'm starting physiotherapy to help regain strength in my legs. Fingers crossed it will work! The doctors have replaced the immunosuppressant I've been on since the age of 5. My new wheelchair has arrived. It helps me to save my energy for important things like school. My grandparents help me a lot with day time care whilst my parents work. I get work sent to my iPad from the school and I try to do as much of it as I can.

November 2015

I went for a synacten test to see if I can come off my steroids as they're causing lots of damage. The results from my synacten tests show that my adrenal gland still isn't working so I'm staying on my steroids. I'm not feeling good and I have not been to school this month.

December 2015

I've been to see the specialists in Oxford again and they want to change my medication. I'm a bit worried it'll make me ill over Christmas. I'm trying really hard to enjoy myself but it makes me so tired! I want to cuddle up in bed. I'm looking back at 2015 and the things I've achieved during the year and I'm shocked that I've managed to leave my bed.

I am so determined. I know I can get through this, I just need to slow down and take one day at a time. My health is worse than it was when I started the steroids in January, which is a little frustrating.

I try not to get my hopes up about anything health related because my body will work when it wants to. My best friend is so supportive. We laugh, cry, disagree, support and help each other through so much. My teaching assistant is amazing, she does everything she possibly can. During art, she is always there to help when I can't see the colours. Whilst painting I go mad and use every colour in the pallet. I'm proud of myself for fighting through each day, and for the support I have given to others in the chronic illness community and thankful for their support.



NEWS FROM THE COMMITTEE

Dear Members,

For the past 6 years I have been a Committee Member of the TMS with the last 3 years as its Chair. My term as Chair comes to an end in April and I would like to let you know that I will not seek another term and will also step down from the Committee. To close off my term, I would like to share with you what has been achieved and my thoughts regarding the future and to thank you.

The guiding light for me in the Chair role have been:

- We are a member organisation, so you influence what we do
- Our charitable objectives in the constitution: to provide information, support and advice, and raise awareness of TM, ADEM and NMO among the public and medical professionals
- Much has been done during the past three years to ensure the TMS's activities align with that, which I share here so we can celebrate them together.

How the TMS works

- For the first time in 2013, the TMS Committee set priorities to focus its work for the year ahead and continues to do this.
- Launched a website and took on member registration from our sister organisation in the USA resulting in people finding the TMS more quickly and an increase in membership.
- Separated management of the London Support Group from the TMS Committee.
- Conducted a survey to obtain members views on what the TMS should be doing.
- In 2015, held the AGM alongside the member conference to widen member participation for the first time.
- Obtained insurance for the charity.
- Attempted to update operational and governance practices where needed including how member information is stored and handled, volunteers are recruited, safeguarding, and finances.

How the TMS works

- Participated in the Spinal Cord Injury Priority Setting Partnership to set research priorities.
- Developed relationships with pharmaceutical companies who are conducting research into NMO.
- Member of Steering Group for the STRIVE clinical trial to represent the patient voice.
- Representing the TMS on an international working group that is revisiting the diagnostic criteria for TM.

Services, activities and support for members

- Launched the Neuro-physiotherapy Bursary Scheme. Added an ongoing neuro-physiotherapy scheme for children and a top-up scheme to give previous participants an opportunity to have an annual re-assessment. Held a neuro-physiotherapy workshop for members.
- Launched the Equipment Grant and Coaching Bursary Schemes.
- Held member conferences in Liverpool and Oxford in 2014, Birmingham in 2015, outside London in 2016.
- Strengthened relationships with other neurological and spinal cord injury charities, which provide services relevant to our members' needs.
- New Support Groups were established, and others closed or moved location.
- Developed 'How to Start a Support Group' handouts to help volunteers establish support groups.
- Established a Support Group Sub-Committee to deal with matters relevant to Support Groups.
- Held the first TMS Family Weekend.
- Created the TM Condition Insight Report for use when applying for benefits.
- Printed The Magazine for the first time.
- Creating a Frequently Asked Question document to be published in 2016.
- Piloting a non-medicinal Pain Management Bursary.
- Conducting a feasibility study on establishing a helpline.

NEWS FROM THE COMMITTEE

Campaigning & Advocacy

- Regularly represent members' needs in the campaigning activities of the Neurological Alliance and National Voices, charities that campaign with the government and NHS for better health and social care.
- Raised awareness of TM, the TMS and members' needs with Andrew Burnham in 2014 (when he was Shadow Secretary for Health), and in 2015 Jeremy Hunt, Secretary for Health.
- Became a member of the Primary Care Neurology Society, the professional organisation for GPs with an interest in neurology, and information about TM, related conditions and the TMS is available to its members.
- Stakeholder for the NICE consultation on the development of guidelines for assessment and referral of potential neurological issues.

Fundraising & Awareness

- Developed fundraising resources and practices to support fundraisers.
- Developed a fundraising/awareness pack of promotional items to support members' fundraising and awareness raising activities.
- Applied for a Children In Need grant to help cover the Family Weekend costs, however we were not successful.
- Proactively supported the TMS's 2015 London Marathon runner; obtained a place in the charity ballot for the 2016 London Marathon.
- Recruited a volunteer to coordinate activities and engage members for TM Awareness Day (9th June) in 2015 and 2016.
- Delivered educational presentations on TM, ADEM and NMO to 187 healthcare professionals via the Spinal Injuries Association study days.

During this time, income increased from £28,085 in 2013 to £77,300 in 2015.

I would like to thank a variety of people. Firstly, thank you members for your participation, in whatever form it takes, in the activities of the TMS. As we are a member organisation, your participation and feedback is vital.

Thank you to the Support Group Leaders, their committees and spouses, partners and friends for providing valuable support to our members.

Thank you to the spouses, partners, family and friends. You too have been impacted by TM, ADEM or NMO and I deeply appreciate how you support your loved ones who have the condition. You are our hidden heroes.

Thank you to all of our fundraisers whose efforts enable us to continue what we do.

Thank you to all the healthcare and medical professionals who treat our members, have spoken at and attended our events, raise awareness, and are reading this magazine. We appreciate your desire to learn and share your knowledge. Please keep up your valuable work.

Finally, thank you to those individuals who provided an alternative view, appropriate challenge, and insight which I found very supportive: Cindy Morelli, Jean Anthony, Annie Schofield and Lynn Powell.

Regarding the future, it is vital the TMS builds on its accomplishments and relationships to create more informational resources for members, proactively promote a research agenda, build on the awareness raising and fundraising work, continue to educate healthcare professionals, campaign with the NHS and government on issues relevant to members' needs, and update operational practices particularly around governance to ensure the future viability of the charity. I call on all of us to do what we can to contribute to that future.

Rest assured this is not a final goodbye. I will continue as a volunteer running the Coaching Bursary Scheme, supporting organisation of the 2016 TMS Family Weekend, finalising the Frequently Asked Question document, designing and running a 'manage your TM' course, educating healthcare professionals, and representing your voice on three external initiatives focusing on research and treatment.

When I took on this role 3 years ago, I said I saw it as being a steward of the TMS. It has been my absolute pleasure being your steward.

Thank you, **Barbara Babcock**

TMS PRIORITIES FOR 2016

The TMS Committee sets priorities annually to focus its work and the 2016 priorities and their budgets are outlined here.

Support & Support Groups

To provide various forms of support and information for members. This priority started in 2015.

Talking Matters Groups - £500

Members consistently say they wish to meet others living with TM, ADEM and NMO in their local area and when they do they remark on how beneficial it is. Pilot 2-3 Talking Matters Groups, which are one-off meetings in locations where there are a lot of members but no support groups.

New & Existing Support Groups - £1,000

- Use the Spring member conference to generate interest in starting a support group and raise awareness of how to run one effectively.
- Determine and implement strategy for support groups that have not met for at least one year.

Membership lists – No costs are foreseen

- Identify how membership lists can be easily accessed, understood and used by Support Group Leaders and Committee Members.
- Identify how members can identify and self-maintain their preferences on the type of information they receive from the TM Society.

Telephone Support Line - £25,000

- Carry out an in depth feasibility study to determine actual costs and work required to establish and maintain a telephone helpline. Sufficient budget has been set in case this is feasible to do.

Produce Information

Produce information which meets members' needs and can also be used by Support Groups – self-management course, publish frequently asked questions documents, redesign resources page on website - £500

TM Society Family Weekend - 8-11 July 2016 at the Calvert Trust in the Lake District - £25,000

This event provides children with TM and related conditions, their siblings and parents the opportunity to learn about and achieve their potential through challenging and adventurous outdoor activities. Educational sessions for the parents with medical and healthcare experts will also be provided.

2016 Member Event & AGM - £25,000

Hold a weekend member event, which is educational and provides an opportunity for people to meet others living with TM/ADEM/NMO.

TM Awareness Day on 9th June 2016 & Fundraising - £1,100

Continue previous year's activities of offering awareness packs, engaging with members and the public on social media (Facebook and Twitter).

Campaigning/Advocacy - £2,000

These initiatives started in 2015 and will continue through 2016. Represent the TM Society at:

- TM International Working Group regarding the diagnostic criteria for TM.
- Meetings to develop NICE Guidelines for Assessment, Diagnosis and Referral for Neurological Conditions (NHS England). These meetings take place in London and NICE reimburses travel costs

Non-medicinal Pain Management Bursary NEW - £2,000

Offer a non-medicinal pain management bursary scheme to members who have received little treatment for their pain or have exhausted all available conventional treatment routes.

Neuro-psychology Assessment for Children NEW - £3,000

Offer to those children whose behaviour and/or development has been impacted by their condition.

Educating health care professionals (HCPs) NEW - £8,000

To provide healthcare professionals, including those who are supporter members of the TM Society, access to courses to expand their skillset in treating people living with TM and related conditions.

Governance - £2,500

Obtain advice re appropriate safeguarding practices appropriate for the size of the TM Society, ensure relevant policies are in place, and training is provided to relevant committee members and volunteers. This will include understanding if any roles require to be DBS checked.

Budget for other services and activities:

Neuro-physiotherapy Bursary Schemes

for adults and children - £10,000

Equipment Grant Scheme - £8,000

Coaching Bursary Scheme - £3,000

Travel Bursary Scheme - £1,500

Donation to research - £5,000

Publish **The Magazine** three times per year including printing one issue - £3,000

Operations/Overheads - £2,500

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 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 allow carers to offload and discuss strategies and best practice.

London Support Group

Venue: ECHQ, 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

South East Support Group

Venue: University of Sussex, the Sports Hall, University Way, Falmer BN1 9RH, Brighton. Parking is plentiful and free. Access around the back of the hall which is sign posted. Flat walk. Disabled toilets next to hall. For further details contact **jane.paine@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.

Directions: Leave the M4 at junction 19. Take the M32 towards Bristol and leave at junction 1. Take the third exit on the roundabout (A4174) heading towards Filton and Parkway Train Station. The hotel can be accessed via a slip road approximately 800 yards up on the left. For further details please contact **stevecollins@blueyonder.co.uk**

Cumbria Support Group

Venue: Eaglesfield Village Hall, Barkers Meadow, Eaglesfield, Near Cockermouth CA130RN. For further details please contact **Eileen Palmer**, Eileen.palmer@myelitis.org.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

UK SUPPORT GROUP INFORMATION

Exeter / Taunton Support Group

Venue: NOTE Holiday Inn not HOLIDAY INN EXPRESS Taunton. M5 Jct 25, Deane Gate Avenue, TA1 2UA. Future meetings in a private room. For directions go to <http://supportgroups.myelitis.org.uk/exeter>. For further details please contact **Rob Reeves**, rreeves@myelitis.org.uk

Norwich East Anglia Support Group

Venue: The Therapy Centre, Units I & J Icenti Court, Delft Way, Norwich, NR6 6BB. There are plenty of car parking spaces. For further details contact **Gill Rice**, gillian.rice@myelitis.org.uk, Tel: **07867 781096** or **07867 781096**

East Midlands Support Group

Venue: The Village Hall, Lullington, Nr Swadlincote, DE12 8EG. For further details please contact **Janet Ashenden**. Janet.ashenden@myelitis.org.uk **01827 373997** or **0753 551661**

Oxford/Northamptonshire Support Group

Venue: Meetings are held either at Evenley Village Hall (www.evenley.info/villageLife/location.php) or the John Radcliffe Hospital in Oxford. These venues are suitable for members from Northamptonshire, Oxfordshire, North Buckinghamshire, South Warwickshire and is easy to travel to. For further details please contact **Zelda Carr** Zelda@cqc-ltd.com or **07795 155205**

Telford Support Group

Venue: The Horseshoe Inn, Holyhead Road, Ketley, Telford, Telford and Wrekin, TF1 5AE. For further details please contact **Anna Paulsson-Habegger** on **07581 708597** annaph@blueyonder.co.uk

Sheffield Support Group

Venue: St Mary's Church Hall, South Road, Walkley, Sheffield, S6 3TE. For further details contact **John Peckett**, johnpeckett@hotmail.co.uk

Transverse Myelitis Scotland

Venue: Dates of our meetings are posted on our webpage www.myelitis.org/scotland where travel directions can be found by clicking on the Events link. For any further information please contact **Margaret Shearer** on **01292 476758** or email margaretshearer@myelitis.org

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 Optica

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/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

_Transverse Myelitis Society

35 Avenue Road Brentford TW8 9NS

www.myelitis.org.uk

U.K. registered charity 1108179

Lew Gray (Secr) 020 8568 0350

Email: lew.gray@myelitis.org.uk

Editorial Team

Annie Schofield, Zelda Carr, Heather Coltman

Design by **Nakia** at www.summermoonandco.com

nakia@summermoonandco.com

Articles signed by the authors represent their views rather than those of the TM Society. Mention or advertisement by the TM Society of products or services is not an endorsement by the TM Society.



35 Avenue Road Brentford TW8 9NS

www.myelitis.org.uk

U.K. registered charity 1108179

Contact Lew Gray (Secretary)

Email: lew.gray@myelitis.org.uk