



WINTER 2015

The Magazine

TRANSVERSE MYELITIS SOCIETY



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LETTER FROM THE EDITOR

This edition comes out just before Christmas, and Christmas is all about children, so we would like to celebrate TM children everywhere. They will say they are just normal, but the daily struggle with pain and bladder/ bowel problems etc. is not normal. No parent wants this for their child. To offer sympathy to these children, something they don't want or need, is easy. What they do have is far more precious, the support from their families. So we are saluting all those families by featuring a few of their amazing children and their achievements (we would love to mention them all but the magazine would be 100 pages long). On Page 2 we have Connor's story, one of real courage and achievement, written by his very proud Dad, Barrie Evans. I defy anyone not to shed a tear at the end when you read about his battle with the mountain (he won). As you will know, we love to acknowledge our fundraisers, so thank you to seven year old Katie for completing a 5K run, and raising £240. Of course we mustn't forget our 'TM kids', Penny and George, who, if they're not running, they're fishing, hill walking, swimming, playing golf...

When my friend, and fellow TMer, Graham Belchamber first approached me with the idea of an article on the psychological impact of TM, I replied immediately, yes please! Little did I expect 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 developed TM, as did Graham, in 2006. He readily admits that his experience of TM has had a profound influence on his practice as a psychologist. The third author is clinical psychologist Katherine Wright, who has an interest in Mindfulness. As the whole article runs to more than 3000 words, and nothing we wanted to edit out, I hope you don't mind waiting for the second part, which will be in our next edition.

The TMS is to be commended for using some of its funds by organising the first TM Family Weekend in the UK this year. It was an opportunity for families to come together, to share, support one another, learn, and develop friendships. It was such a worthwhile event, and by all accounts it was a great success. If it is to be repeated next year (and personally I think it should), we will need to start raising money to help pay for it. On Page 12 you can read what some of the participants had to say about it, and clearly they all had a ball.

Canine Partners train assistance dogs to transform the lives of people with disabilities by carrying out tasks such as opening and closing doors, undressing, pressing buttons, retrieving items, unloading the washing machines, and fetching help in an emergency. And as everyone knows 'a dog isn't just for Christmas', Susan Jones would agree with that, because a lovely dog called Buster is her lifeline 365 days a year.

Penny, George, Connor, Katie, Oliwia, Bret, and Calum, who are featured on the front cover, are just a few of our TM Warriors we would like to salute.

Zelda, Heather and I would also like to thank all the children and their families who have contributed to this magazine. We wish them all, and you, our readers, a wonderful Christmas and a fantastic 2016.

Annie



CONNOR'S STORY

AS TOLD BY HIS DAD, BARRIE EVANS



Connor was diagnosed with Transverse Myelitis (TM) on the 7th January 2003 at only seven months old. He woke up that morning seemingly paralysed from the waist down and by that evening he was in the Intensive Care Unit (ICU) at the University Hospital of Wales in Cardiff paralysed from the neck down

and on a ventilator to help him breathe. Luckily the diagnosis was made quickly by a consultant who had experienced a case of TM eight years previously. An MRI confirmed that the lesion extended from the base of his brain down to T4.

As a professional coach I know all about the effect that a “significant life event” can have on a person’s view of the world but “knowing” and “experiencing” are two totally different things! Nothing can prepare you for the effect that finding out your perfect little seven month old baby boy could become paralysed from the neck down overnight. Everything changes.

Over six weeks, Connor started to regain some movement in his limbs. Slowly, the movements improved until he fully regained the movement and strength in his arms and was able to sit up unaided. Connor’s legs started to recover during this time and eventually they became strong enough for him to stand. He now wears splints (AFOs) on both feet and uses crutches to get around for short distances and a wheelchair for longer distances. Connor has attended main stream school since the age of three and has a great network of friends who support him.

At 13 years of age, Connor is a typical teenage boy – loving nothing more than spending hours on computer games but he also likes to challenge himself physically. I have always been a keen runner and wanted to encourage Connor and his older sister Katie (16) to get involved in exercise so I started taking them to the weekly Saturday morning Parkrun (www.parkrun.com), a 5km timed run held at many locations all over the world. The event in Cardiff is popular and draws over 700 participants but I have only ever seen one

CONNOR'S STORY

AS TOLD BY HIS DAD, BARRIE EVANS

wheelchair athlete there – you guessed it – Connor. Starting out with his regular wheelchair at the back of the group he would work really hard at propelling himself around the 5,000m course. The finishing times were not record breaking at around 45 minutes but he did it and each week that we attended he required less assistance from me or Katie. Eventually he was getting around the course entirely on his own in around 40 minutes at which point it was becoming clear that the wheelchair was now starting to become the limiting factor for him. Amazingly, early in 2014 Connor was offered a FREE entry-level racing wheelchair from Motivation (<http://sports.motivation.org.uk/>).

Using his new chair, Connor completed the course in under 30 minutes – the effect it had on Connor was fantastic, you could see how proud he was of himself. Connor continued to race regularly and his time continued to improve down to 26 minutes. Unfortunately circumstances have conspired against him recently with operations resulting in fewer opportunities to attend. He can hopefully get back to it and maybe even achieve his dream of beating me around the course (I honestly don't think it will be that long before he does either – and I will be a very proud Dad the day that happens).

Connor is also a regular member of the local Disability Sports Group where he has been playing wheelchair basketball amongst other sports and helps out as a volunteer with the setting up and clearing away of the equipment for each session.

Earlier this summer, Connor attempted to climb Pen-y-Fan Mountain, which at 886m is the highest mountain in the Southern half of the UK. This was the first time that Connor had made it all the way to the top via the

peak next to it (Corn Ddu) and then all the way back down again completely unaided (other than using his crutches). Previously, I have ended up carrying Connor down, due to his fatigue. It took Connor about 4.5 hours to complete but the time didn't matter, getting to the top of the mountain on such a beautiful day was all that mattered. The commitment that Connor made to get to the top of that mountain was incredible. Regardless of how tired he was getting you could see that he was not going to give up. I had to practically force him to take rest breaks to allow his body a chance to recover a little but it was not until he reached the summit that he would allow himself a decent recovery break (before the walk back down). Unfortunately the descent was not easy as the pressure on his hands from walking down a steep slope for an extended period of time was excruciating. It was so painful that the only way to get any kind of relief was to pour freezing cold water from the fresh mountain streams over his hands to literally numb the pain. But Connor was on a quest and there was no way the mountain was going to beat him that day.

I am sure he felt very proud of himself when he reached the summit. The feeling was indescribable and I am not ashamed to admit that it brought a tear to my eye. He received lots of compliments from passers-by on the way up and on the way back down.

Who knows what the next challenge will be for Connor, all I know for sure is that there will be one because I know he will just keep on pushing himself. I don't tell you this enough Connor, but you are an inspiration to me and it is through seeing you achieve the things you achieve in life that makes me want to push myself further. I am extremely proud of you, son.

Barrie Evans

MIND OVER MATTER

ROBERT WHITTAKER, KATHERINE WRIGHT, GRAHAM BELCHAMBER

MINDFULNESS, PACING, FLARE UP STRATEGIES...

This article is a 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, with 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. 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 which all stopped working. This was 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 flare up's, 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, sorted out new experiences and new friends, enjoyed raucous debates, the unknown, unplanned and the unexpected, 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 railed 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 has since been reinforced.

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

MIND OVER MATTER

ROBERT WHITTAKER, KATHERINE WRIGHT, GRAHAM BELCHAMBER

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 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 to helping me put my experience into words. They were respectful of my reality and acknowledged rather than trying to change my feelings.

Therapists are often very enthusiastic about particular therapeutic approaches and techniques which has a lot 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 and 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, 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

MIND OVER MATTER

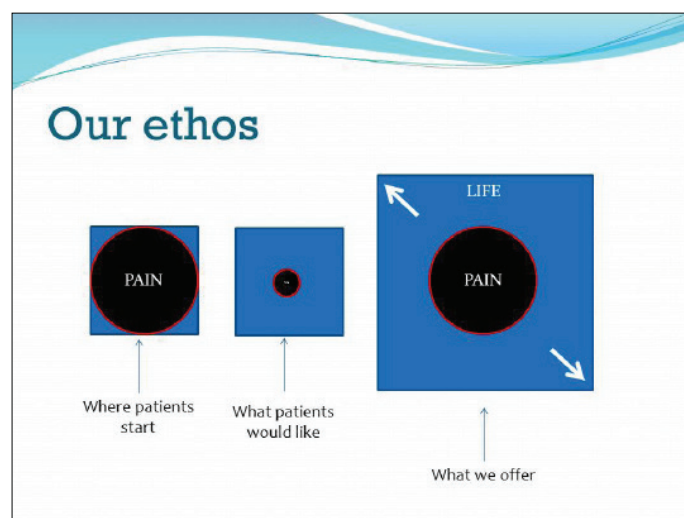
ROBERT WHITTAKER, KATHERINE WRIGHT, GRAHAM BELCHAMBER

emotional states - in no consistent order: shock, denial, rage, sadness and some kind of emotional reconnection. Difficulties in 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 five-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: I thought it might be helpful to say a bit about the **Bradford Living with Pain Service**. 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. For example, 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%.

I've included some slides from a presentation we did recently, as pictures speak louder than words sometimes. The slide below sums up our philosophy. That is, 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 in part 2 of this article, to be published in Spring 2016, 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, assertiveness and communication skills. All are inextricably linked, as I'll try to explore.

IT'S THAT TIME AGAIN

A SEASONAL OFFERING FROM RUTH WOOD



So it's THAT time of year again - the season of jollity, parties and giving of presents that nobody really wants and that will clutter up spare rooms and attics across the land until they get dusted off and either presented to the local charity shop or given to someone other than the one who gave them to you - you hope.

Now don't get me wrong - I don't hate Christmas - it's all the stuff that seems to automatically go with it that get me down. Shops full of Christmas cards in September, (have you tried to find birthday cards for anyone unfortunate enough to have been born in the last quarter of the year?) car parks brimming with grim-faced parents trying to find the ideal treat for their little angels whilst said cherubs are out of the way at school, pubs advertising Christmas dinners at special rates available from October 1st - well you get the picture!!

Since having TM I've discovered what a pain shopping can be. I used to enjoy using my lunchtimes from work trotting round the large stores matching items to people I loved and who I wanted to please with the ideal present. I can't do that now. I've got the time of course - I always wanted more time (and you know what they say about being careful what you wish for!). Two things I don't have any more though - the money to buy that ideal present and the mobility to nip around the retail park in the first place.

I've been cured of my desire to shop online - which once seemed the ideal solution. At the moment I'm trying to find how get rid of the "ideal shopper" rubbish that cascades down my computer screen at every web opportunity and when I do find an item that seems ideal I forget to check the size (this is how I ended up with a silver candelabra that was in reality only six inches high and wouldn't dominate the dining table in a dolls house).

So - what to do? One of the useful things about getting older (there are some!) is that my friends are feeling pretty much the same way I do - so we agreed between ourselves two years ago that we would use the money we'd saved for presents for each other to enrich worthy causes - so we all now support donkeys and help people in remote parts of Africa to access fresh water, which feels a pretty good thing to do.

Many of my relatives are now of an age where they don't expect presents at Christmas (though most of them still like birthday gifts!) so that cuts down the list.

This year I have decided to go away over the happy season - so many of those close to me now do the same that my area of friendship and relatives is empty, as far as access is concerned, anyway. I don't want another year of hanging around waiting for some nebulous invitation to share the annual poultry and ending up in my own house thankful for the dishwasher. Even settling down in front of Christmas "Strictly" doesn't do it.

So it's West Wales for me and my faithful spouse - watching wild water and listening to the scream of the cold wind whilst sitting in a friendly pub with comfortable friends.

Now that's what I call a Christmas!

SECONDARY SCHOOL

I have been really enjoying senior school. All the teachers are very nice and understandable. I'm now allowed to take my medication to school by myself. I'm also allowed to go to the bathroom in the middle of any lessons if I need to. For the S1 residential we went to Coylumbridge in Aviemore. We were there for 3 days and 2 nights. 100 children went on the first week and another 100 children went the next week. While we were there we went on a walk in the Cairngorms, made carts, played games and loads of other team building activities. The teacher in my group helped me with any of my worries. I also had my 'wobble watch' which told me when to go to the bathroom. In the mornings, because I was sharing a room with other people, I went to the nurse's room to do my Peristeen before everyone woke up.



INDIA

I'm just back from October holidays in India. What an adventure! It's amazing where you can catheterise when you set your mind to it! Interesting toilets in India!! We visited lots of cool places, Ranthambhore National Park and we spotted a tiger! Jaipur, Taj Mahal in Agra, we took a train to Rishikesh and rafted down the Ganga River! Rickshaws and an elephant ride in Delhi! What an experience! Great to visit friends and see new places.

ORTHOTICS

Recently I've been having a lot of big toe pain. It started in March when I was bashed on my right big toe by a hockey stick. We went up to the hospital and they said to rest it. So I did. 3 months later it was still bruised, swollen and very sore so Mum took me back to the hospital and they said this time that I would have to wear a cast for 3-4 weeks to rest my foot completely. The doctor thinks that I am constantly bashing my big toe and tripping up because my foot drags on the floor a little bit.

I was referred to orthotics and was fitted for new orthotic insoles and given a device called a 'Foot up'. 'Foot up' is easy to use. When you walk it lifts your foot up so, you don't drag it. I've found this very useful and I have really enjoyed walking with it. It makes a huge difference to people with foot drop issues.



HILLWALKING

I have joined the hillwalking club at school, it was great fun walking with all your friends. I was a bit worried about whether I would manage to keep up with the group and toilet issues, but I spoke to my teacher and he was really nice. I took it steady and completed the green hill in Glen Clova. I was exhausted when we finished, my foot was really sore but it was worth it!

Penny



MY SUMMER

*Hi it's me again, **George**.* This summer has been really busy for me and I've had a lot of new experiences. About two weeks before I got TM, me, my Mum and Dad and two sisters climbed up Bennachie (Mither Tap) together, and ever since I've wanted to do it again, and I finally decided I was ready this summer holidays. We asked some friends to come with us and put it on the calendar but when the day came my legs weren't working very well but I didn't want to be disappointed so I decided to do it with my crutches. It took all day as we went really slowly, so lucky we took a pack up with us and stopped for lunch on the way up. It felt great finally getting to the top even if I did have blisters on my hands; in fact, blisters on my blisters, but I was happy I finally did it. The view was amazing!!

Then in July I went to Tigh Mor in the Trossachs with my family and also my Nana, Grandad, Auntie Kate, Uncle Jim and my three cousins Paddy, Alice and Ted. We decided to climb Ben A'an and it was on a day when my legs were good so off we went. Me and Paddy and Ted were the first to get to the top, and Nana fell in the

mud but we were all really happy at the top. Auntie Kate brought chocolate to eat and boy did we need it! We also went fly-fishing while we were there and I caught my first fish, a rainbow trout. My sisters also caught one each. My Uncle Jim helped us to get it ready to cook and we had it for tea, and it tasted great. Me and my sister Tabitha ate one of its eyeballs each!!

I also started using catheters for the first time as my bladder is hard to empty now. It's not going too great but I think I might need to try a few different types before I find the one that's right for me so hopefully by the time I write again it will be going a bit better. It will be good to be the boss of my bladder rather than it being the boss of me!!!!

BUSTER & ME

HOW CANINE PARTNERS HELPED TURN SUSAN JONES' LIFE AROUND



I was working as a beauty therapist, had just started up my own business, and enjoying “normal” life. Then in 2011, aged 31, I had a rapid onset of TM, possibly triggered by flu, which left me paralysed from the chest down and my life changed overnight. It was devastating.

After 7 weeks in hospital I went into neuro rehab for three months. I went home for a few months, but life was incredibly hard and I still felt very unwell. I went into Stanmore Spinal Injury Hospital for more rehab which did help a lot, although I still couldn't come to terms with what had happened.

“Before getting Buster I had not been out on my own for two years so it was a great feeling the first time I walked him, just the two of us”

It was my sister Paula, whilst looking on the Internet for ways to help me, who came across Canine Partners, and was amazed at how the dogs can help people. She was sure this could be something that would benefit me so I applied. On the application form I had to give a medical report from my doctor and explain the difficulties that I have in daily life. Later I was visited by an occupational therapist to check my suitability and where I live. I then had to wait for the right dog to come along. I was soon contacted by Canine Partners with a possible match and visited by the trainer with Buster so they could see how he would get along with my cat, which seemed to go well. Once everyone was happy that Buster was the right dog for me, I attended a two-week training course in Heyshott which took me completely out of my comfort zone! Paula stayed with me for the first week and then my mum joined me for the second week. It turned out to be a great two weeks. The staff were amazing, as were the other two ladies doing the course at the same time as me. I stay in contact with some

BUSTER & ME

HOW CANINE PARTNERS HELPED TURN SUSAN JONES' LIFE AROUND

great friends I made there. I learnt how to work with Buster, what he could do for me, and how best to look after him. He was already trained to do a lot of tasks but they can then learn new tasks tailored to your needs.

Then it was time to take Buster home, which was very exciting. I couldn't believe that they were actually going to let me have this clever boy. Before getting Buster I had not been out on my own for two years so it was a great feeling the first time I walked him, just the two of us. Buster is amazing and very clever. He opens and closes doors, picks up anything I drop on the floor and gives it to me. He opens the washing machine and takes out the washing, can help remove clothes and shoes, and fetches the post. In the supermarket he can take things off the shelves and even take my debit card out of the card machine at the checkout.

“He has done a huge amount for my confidence. People love to stop and talk to us when we are out so I don't feel so self-conscious about being in a wheelchair as people aren't looking at me, they are too busy admiring Buster”

He has done a huge amount for my confidence. People love to stop and talk to us when we are out so I don't feel so self-conscious about being in a wheelchair as people aren't looking at me, they are too busy admiring Buster and want to know all about him. We have also met lots of new people and dogs when we are out on our regular walks.

I love his company at home. I feel safer and if I fall out of my wheelchair he gets the phone for me. We love having a cuddle whilst watching TV. Buster has become a huge part of my life and is loved by all my family. I would recommend anyone who's interested in getting an assistance dog to apply. You need to have a physical disability, like dogs of course, be over 18, and you must be able to exercise the dog regularly. There is no charge for the dog but you need to pay for its food, vet bills and insurance.

Getting Buster is the best thing I have ever done. They really are life changing dogs.



Canine Partners trains dogs to assist with practical tasks, enabling owners to regain independence. If you're over 18, living in the UK, and you have a physical disability that affects your mobility, then you could be eligible for a canine partner. If your application is successful you will be matched with a dog and invited to attend and complete a two-week residential course before taking them home, with ongoing support. For more information about the Charity call 08456 580480, or to enquire about applying call 01730 716043, or email info@caninepartners.org.uk for an initial enquiry form. More information can also be found at caninepartners.org.uk.



TM FAMILY WEEKEND



The TM Society Family Weekend took place on 10-13 July 2015 at the Calvert Trust in the Lake District National Park. It was a first for children and young people living with TM, ADEM and NMO and their families, bringing them together to share, support one another, learn, and develop friendships.

Thirty-nine people representing nine families participated. Eight paediatric medical professionals attended, including two neurologists, one consultant in neuro-disability, two nurses, one occupational therapist, one neuro-physiotherapist, and one urologist. Amy Rachel Curtis got TM aged 13 and now, as an adult, came with her family to speak to the children and their parents about her TM journey and what she is doing now. A representative from the Backup Trust also attended.

There were ice-breaker activities after dinner on Friday

evening. Over the three days, outdoor activities included orienteering, bushcraft, canoeing, zip-wire, rock and rope (swinging, climbing, abseiling), riding horses, trap driving, archery, and cycling. For the first time since the onset of their TM, one child made a full rotation when cycling and another rode a hand powered bike. Wheelchair abseiling was a popular activity. Evening activities included playing pool, chatting and having a disco in the games room.

Medical professionals gained insights following discussions, for example, around bladder issues. Further research/work may be done in this area using data from the PUDDLES study. The paediatric urologist advised children should avoid blackcurrant, fizzy drinks, and caffeine if they have an overactive bladder. The medical professionals also learned that temperature regulation is an on-going issue for children with TM and ADEM. Children experiencing behavioural issues after ADEM's onset is not uncommon and could be mistaken for autism, ADHD or Asperger's.

The full report on the weekend can be found by going to the TMS website. (**copy and paste link**) http://www.myelitis.org.uk/uploads/1/5/8/2/15824690/tms_family_weekend_2015_-_summary_for_website_v3.pdf

Penny

My favourite activity was kayaking because as well as paddling around the lake. We played games, had a water fight and jumped off the pier at the end!! The parents had the chance to hear presentations from nurses and doctors while we did activities. I loved meeting lots of TMers and learning new things that can help me on a daily basis. The whole weekend was planned very well, the food was delicious and the staff were very nice. I thoroughly enjoyed going to the TM camp and can't wait for the next one!!

TM FAMILY WEEKEND

Oliwia, Ela and Krzysztof

Oliwia was diagnosed with TM when she was 10, and was paralysed from the waist down. We were delighted to attend the TM Family Weekend. Our daughter is very shy and did not want to go, but we did because we wanted to get more information, talk to other parents, specialists and physiotherapists. We especially wanted to show our child that there are many children with disabilities who know to never give up, to fight and win! Oliwia was so happy when we arrived, going horse riding, cycling and canoeing. The activities were very motivational and Oliwia is now very daring, and independent. People told us even though TM is rare we are not alone, that we're all in a huge TM family. We thank the camp for getting us stronger.

Hi, I'm Oliwia and was diagnosed with TM when I was 10 years old. It really affected my life because I grew apart from some of my friends when I was in hospital and it really depressed me. My hobbies are singing, swimming, drawing, reading and writing (supposedly) great poems. I'm sometimes the leader of singing groups or I get solo songs in plays. I have two sisters of 4 and 21. They support me a lot. When I was at camp last year I met lots of new friends, but I mostly hung out with Penny, Emily and Katie.

Caren Bowyer

We were thrilled to bits this year to be able to attend the first UK Transverse Myelitis Family Camp. The staff were super friendly and knew just how to engage with the children, whilst supporting and encouraging them through the various activities. The weekend was completely inclusive, with every child being able to participate in all of the activities, regardless of their level of disability. The mornings were spent in our family groups participating in activities together, and in the afternoons the parents were able to meet experts in various different disciplines. After presentations from several guest speakers, parents were able to ask questions and give feedback. Especially helpful was the talk given by Amy, a TM warrior, who was able to answer questions that medical professionals could not. George especially enjoyed talking to her, and was pleased with the advice she gave him. The children, in the meantime, were in the expert care of specialist childminders having the time of their lives!!

During the evening we were able to relax and swim in the amazing swimming pool, complete with music, lights and waterfall, which the children loved. A disco on the final evening was a perfect end to the weekend.

It was wonderful to meet other TM parents, to compare notes and experiences, and to just talk to other Mums and Dads that 'get it', but especially to gather tips and advice from some of the parents that have been dealing with TM for a number of years. For the children it was an amazing opportunity for them to spend time chatting and playing with other children that understand their experiences, as well as just having lots of fun.

On the first day we all sat in our family groups to eat, but by day two the children had pushed a few of the tables together and decided to eat together, no adults allowed. The highlight of the weekend for me was seeing the children all sitting together having dinner, chatting and laughing like they'd known each other for years. A truly fantastic weekend.

THANK YOU

FOR YOUR SUPPORT



Katie Simpson, aged 7, who has had TM since she was 15 months old, **ran the 5K Big Fun Run Milton Keynes**. She was apprehensive going into the run because it was a longer distance than she had done before. The family had come to an agreement that big sister Sam would run around with Katie, but, not only did she beat her, she completed the race in 45 minutes and raised £240 for the TMS. Afterwards Katie said **'it was really hard but I am so pleased to have raised all this money for Transverse Myelitis.'**

Ann Hollywood opened her lovely home in Surrey to 74 ladies for a **Pamper Evening raising £1790 for Neuro Physiotherapy for children with TM**. It was not only a fundraising evening but also a 'fun raising' evening with a great time had by everyone in addition to the mini- treatments ranging from facials to reflexology. **Last year Ann raised almost £5,000 hosting a Race Night.**

Six months ago I approached **Marks and Spencer (M&S)** and asked them to help lots of mums, dads and carers who look after children with Special Needs. I have been liaising with M&S whilst they have been designing a new children's clothing range. All high street shops and online retailers stop making vests and bodysuits for children when they reach 3. Not all children are out of nappies and not all children are able to eat solid food. Children like my grandson Caleb need clothing which enables a nappy to be changed without having to fully undress him and also to be fed by a peg in his tummy, without undressing him. The specialist catalogues mean that you would have to spend £12 - £15 per item and lots of people do. Up to 3 years old

you can get around 5-7 vests/bodysuits for about £10. That is why I got in touch with M&S. The clothes will be available in the new year, around springtime and will be colourful, affordable and with the great quality M&S is renowned for. There will be sleep suits, vests, and bodysuits, all with poppers for easy accessibility and they will be made for children up to 8yrs. **Please, please share. We need to get the word out!!**

Rita Kutt from Leeds

Editor: Thank you M&S – other stores take the hint!

NEWS FROM THE COMMITTEE

Thank you to Support Groups!

The committee would like to extend a very big thank you to the following Support Group Leaders for stepping forth to lead a support group or their work over the years in leading them.

Southeast Support Group - Annie Schofield has stepped down as Support Group Leader and we would like to thank her for all her hard work to organise meetings, find informative speakers, and answer the questions of members in the Southeast. We would also like to thank Carol Preece and Peggy Hughes for assisting Annie with the running of the group. Annie, thankfully, will continue to edit The Magazine. Jane Paine and her daughter Lucy have stepped forward to lead the Southeast group now meeting at the University of Sussex Sports Centre in the Brighton area. Their first meeting is on 12th December.

Bournemouth/Poole - Lance Harris is standing down as chair at the end of this year and we would like to thank him for his contribution. We haven't seen the last of Lance! He will continue to provide support at meetings. The Bournemouth/Poole group is looking for a new chair and committee members. If you are interested, please contact Lance at lv.harris@hotmail.com.

Cumbria - A Support Group has been set up in the northwest of the Lake District in Eaglesfield near Cockermouth by Eileen Palmer. The first meeting was on 7th November. Sadly no one came however Eileen is not deterred and found the experience of preparing for it a useful dry run. A meeting will be organised in the new year.

Remember the bursary schemes available to you!

The TM Society offers the following schemes to help you. Money is still available in this year's budget and it would be great to see it fully utilised.

• ***Neuro-physiotherapy Bursary Scheme*** – If you have had no or little neuro-physiotherapy to help with pain, mobility, gait, balance, or spasticity issues, this scheme gives you two free sessions of neuro-physiotherapy. You will get helpful advice and learn what exercises you can be doing at home to maintain the benefits of these two sessions over the longer term.

• ***Coaching Bursary Scheme*** - This service is a form of emotional/psychological support for members who have an issue to resolve, really want to achieve something new, would welcome help adjusting to living with TM, ADEM,

NMO, or want to move forward in a positive way in their lives.

• ***Equipment Grant Scheme*** – You can obtain a grant up to 50% (up to a maximum of £1,000) of the cost of equipment not offered by statutory services, which can help in your rehabilitation, quality of life and independence.

• ***Travel Bursary Scheme*** – If you would like to attend a support group meeting but the cost of travel is not making that easy or possible, this scheme is for you. Contact the support group leader of the group whose meeting you wish to attend in the first instance.

For more information on any of these schemes, go to <http://www.myelitis.org.uk/our-services.html>

NEWS FROM THE COMMITTEE

Update on TMS's activities on educating healthcare professionals about TM and related conditions

In the 2014 member survey, 47% of respondents said the TMS could be providing information and learning sessions for healthcare professionals (HCPs). Throughout 2015, the TMS has been working with the Spinal Injuries Association to help deliver its new study day for healthcare professionals, The Non-Trauma Perspective. It covered the physical and psychological impact of non-traumatic spinal cord injuries (those incurred through illness like TM), the importance of timely diagnosis, the care pathway, TM and the TM Society's work.

The TMS has delivered this presentation in Birmingham, London and Manchester. Across these three study days:

- 187 HCPs attended
- 85 HCPs subsequently became members of the TM Society
- 57 HCPs from 52 hospitals have requested a presentation about TM and the TM Society in their hospitals
- 38 HCPs from 30 hospitals have expressed interest in a TM Special Interest Group for their professional development

The healthcare professionals received posters to put up in their hospitals, a copy of The Magazine and TMS leaflet. We are hoping this will go some ways towards newly diagnosed people finding the TM Society more quickly.

A big thank you goes to Danielle Pomerance and Eileen Palmer who helped Barbara Babcock to deliver the presentations in London and Manchester respectively.

Campaigning and advocating for your needs

In the 2014 member survey, 56% of you said the TM Society could be campaigning for better treatment and care with the NHS and government. The majority of the

TM Society's campaigning and advocacy efforts with the government and NHS occur through the Neurological Alliance and National Voices, charities whose sole purpose is to campaign with these bodies. Given the size of the TM Society and limited resources, the TM Society draws on the skills and resources available via these charities and so campaign and advocate through them. In addition, Barbara Babcock will also attend special events organised by these charities but also take part in special initiatives outside of them. Here are two such examples.

Spinal Cord Injury Charities Away Day

This meeting in November brought together charities which support people with spinal cord injuries and was an opportunity to identify where charities can work together on initiatives that benefit both and additional sources of support for members. As such, Barbara will be following up potential opportunities with the Spinal Injuries Association and Aspire so watch this space!

NICE guidelines on assessment, diagnosis and referral of neurological problems in England -

The TM Society registered to take part in this initiative which enables us to attend meetings as part of the development process and members to comment on the draft guidelines. Barbara attended the first scoping meeting on 11th November and raised a variety of issues people living with TM and related conditions face in the earliest of stages at onset through to referral to a neurologist. At present, the guidelines are not focusing on the rehabilitation and longer-term stages of living with a neurological condition, however the point was made that this is needed. Please keep your eye out for more information on how you can get involved in the consultation process in 2016.

NEWS FROM THE U.K. SUPPORT GROUPS

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

New Venue: University of Sussex, the sports hall, University Way, Falmer, BN1 9RH Brighton

Date: 12 December 2015 from 14:00 to 16:00 (GMT)

Parking is plentiful and free, and access will be around the back of the hall which will be sign posted - a flat path into the back entrance of the hall. There is a cafe and bar 2 minutes away on campus - a flat walk - should you need to buy a hot drink. Disabled toilets are next to the hall with no stairs.

To allow me to make sure we have enough space please email me at jane.paine@myelitis.org.uk to let me know you are attending. Please book a space for every person coming including a friend or carer coming with you. On the day if you get lost please call - **07940 110551** or the sports centre direct on **01273 678228**.

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

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

NEWS FROM THE U.K. SUPPORT GROUPS

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

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 Support Group

Venue: Evenley Village Hall (<http://evenley.info/villageLife/location.php>). This venue is 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

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

Norwich (East Anglia Support Group

Venue: The Therapy Centre, Units I & J Iceni 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**

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

UK SUPPORT GROUP 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@thewaltoncentre.nhs.uk

_John Radcliffe Hospital, Oxford Service Coordinator

01865 231 900

nmo.advice@orh.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

Contact Barbara Babcock

(chair) barbara.babcock@myelitis.org.uk

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Email: lew.gray@myelitis.org.uk

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