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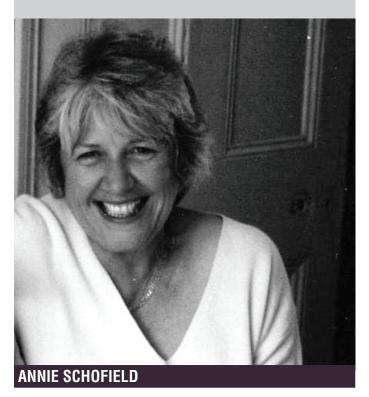
Transverse Myelitis S O C I E T Y



CONTENTS

01	LETTER FROM THE EDITOR
02	GO WITH THE FLOW ANNIE SCHOFIELD OVERCOMES HER SCEPTICISM TO TRY CRANIOSACRAL THERAPY
03	AND RELAX STEVE HOLDEN GETS POSITIVE RESULTS WITH HYPNOTHERAPY
04	A MESSAGE FROM OUR CHAIRMAN
\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\	TO P OR NOT TO P RUTH WOOD BEMOANS THE SHORTCOMINGS OF DISABLED FACILITIES WHEN NATURE CALLS
(1)(1)(1)(1)(1)(1)(1)(1)(1)(1)(1)(1)(1)(LEARNING TO MOVE AGAIN HUW GALLAGHER AND HIS MUM TELL US ABOUT FELDENKRAIS
///////////////////////////////////////	MAKING THE CONNECTION ZELDA CARR REDUCES HER PAIN USING SHIATSU
(1) (1) (1) (1) (1) (1) (1) (1) (1) (1)	NEWSBITES NEWS IN BITE-SIZED CHUNKS
10\	RIDE LIKE THE WIND CLARE ROWNTREE REDISCOVERS CYCLING WITH THE HELP OF HER E-BIKE
11-12	LET NOTHING GET IN THE WAY MOLTEN ROCK TELL US ABOUT THEIR LATEST OFF-ROAD WHEELCHAIR
13-14	TALK TO YOUR DOCTOR BARBARA BABCOCK ADVISES HOW TO GIVE FEEDBACK TO YOUR HEALTHCARE PROFESSIONALS
15	PAIN, PAIN GO AWAY KATIE HAMILTON ENLISTS IN THE PAIN MANAGEMENT PROGRAMME IN LIVERPOOL
16-17	THE GREAT DEPRESSION CONSULTANT NEUROPSYCHIATRIST DR MAYUR BODANI TALKS ABOUT THE RELATIONSHIP BETWEEN DEPRESSION AND TM
181	MY STORY HEATHER COLTMAN SHARES HER TM JOURNEY
19	NEWS FROM THE UK SUPPORT GROUPS FIND OUT WHAT'S HAPPENING AT A SUPPORT GROUP NEAR YOU
20	USEFUL CONTACT INFORMATION

LETTER FROM THE EDITOR



Dear Readers.

Welcome back to edition 3 of our TM magazine. What a fabulous summer of sport we have seen! Now that the fireworks have faded and the inspiring Olympians and Paralympians have returned to their day-jobs, I've been reflecting on Lord Coe's message of the lasting "legacy" that the Games will leave.

From my own perspective, I suddenly feel cool to be in a wheelchair. I hope London 2012 will help change what the word "disabled" conjures up. I can quite understand why my daughters don't tend to tell their colleagues that their mother is disabled. The automatic response is "I'm so sorry", as if I was on the verge of dying. And yet, post-Paralympics, I was proud to learn that one of them posted on facebook "Particularly pleased to hear Natasha Baker won Paralympic gold as she has transverse myelitis, the same rare condition as my Mum'.

It seems this 're-educational legacy' is not only for the grown ups. I heard a story the other day of a 5 year old girl who had been transfixed by not just the Olympics, but the Paralympics

more so, and was very curious to know what the matter was with the athletes. One day she said to her mother 'I'm very lucky at the moment, aren't I, because something like that could happen to me one day'. Yes, one day you can be doing your usual 40-minute swim, the next you can be lying in a hospital bed, paralysed from the waist down. Stuff happens.

But, as our wonderful Paralympians have shown, that does not have to mean the end. They refused to be let their disabilities define them, and did not believe that recovery must stop once the rehab stops.

We all know that traditional medicine offers limited help for TMers so in this edition we have focussed on some complementary therapies. I am a well known sceptic of anything 'alternative', but I have to admit I was completely won over after several sessions of craniosacral therapy and I'm delighted to say our readers were more than happy to share their experiences with Hypnotherapy, Shiatsu and something called Feldenkrais which Ros will introduce you to.

As we discussed in our last issue, exercise is very important so we hope you will enjoy reading about Clare's rather special bike. On the other hand, if you are looking for something a little more 'exhilarating' how about an 'off road' wheelchair? These bikes have been up Snowdon, on the beach – and even used to herd sheep!

Dr Mayur Bodani spoke at one of our South East Support Group meetings on the connection between Depression and TM. It was so interesting I asked him to write an article for the magazine. Please let me know if you have more questions for him.

We also have a very candid account of living with pain from Katie Hamilton, a useful guide to dealing with the medical profession from Barbara Babcock, Heather Coltman's TM 'story', and another amusing slice of life from Ruth Wood.

We hope there is something for everyone but as ever, please send any stories, letters, or suggestions for future issues to

annie.schofield@myelitis.org.uk

GO WITH THE FLOW

ANNIE SCHOFIELD OVERCOMES HER SCEPTICISM TO TRY CRANIOSACRAL THERAPY

Before TM, Annie would never have considered the likes of acupuncture, reflexology or craniosacral therapy, but now that she is partly paralysed and in constant pain she is willing to try anything which might help. She had already tried the first two, to no effect, and probably would not have thought of trying craniosacral therapy if it had not been that her best friend, Frances, was training to be a Therapist and asked if Annie would be one of her case studies. Here's how they got on.

Frances: It's fair to say that Annie had zero expectations of the treatment. She was extremely sceptical of any therapy she considered "airy-fairy" and not scientifically proven. At the time she was having acute pain radiating down one leg as a consequence of a fall plus she felt she ticked all the boxes for clinical depression.

Annie: Frances would turn up with her mobile couch - hard but surprisingly comfy - and I would be covered with my snuggly rug. First of all she would sit behind me and gently cup my head in her hands. The thing I always noticed was that her hands seemed very hot. After 10-15 minutes, she would quietly move to one side and place her hands on my hip (of the leg that was causing me the pain), then later I would be aware of her gently holding my ankles. After this I couldn't tell you very much because I would drift off, not always to sleep, (although sometimes I would almost be aware that I was snoring), but just to another place.

Frances: Craniosacral therapy is a whole person approach to healing which acknowledges the inter-connectedness of mind, body and spirit. The theory underpinning it is that the body has an inherent, natural wisdom and ability to change. The changes could be physiological or psycho-emotional.

The therapist listens through her hands for the body's own priorities for change and encourages that priority to arise. This priority may well not be what the receiver has in mind as the cause for treatment. The art is to connect with the underlying forces of health and to facilitate a process of natural reorganisation. These forces express as subtle motion of tissues and fluids that can be felt by sensitive hands. Various motions can often be felt by the receiver too, often much to their surprise!

Annie: When Frances first started working with me, I was rather tense and emotional. I was very unhappy with where I was living, not enjoying work and had recently had a bad fall. However, after the first few sessions I noticed that on getting down from



the couch I felt much more relaxed, and could move much more freely, pain free, for a while.

Frances: The most noticeable change was in her mood and her attitude towards her condition.

Annie: I'll never forget my fourth session. As usual, at the end I would sit up and Frances would ask me questions for her case notes. This time all I could tell her was that I had seen a white, fluorescent band encircling my body from my head down to my feet and back again. 'Oh yes' she said calmly 'I was unblocking the flow of blood in your hip where you had had your fall'. I just couldn't argue with that!

Frances: There are a range of complementary therapies for those that choose to explore those options and craniosacral therapy is one of them. It can be a matter of personal choice. I think Annie is pleased she tried it.

Annie: I agree. I was completely unprepared for the feeling of complete relaxation at the end of each session. Because I can only walk with crutches, and only have one leg functioning anywhere near normal, I suffer from a lot of tension in my shoulders, as well as pain in the hip of my 'good' leg. It was almost like the after effects of a really good massage, yet this was totally non-invasive.

For more information, visit www.ccst.co.uk

TRANSVERSE MYELITIS SOCIETY

STEVE HOLDEN GETS POSITIVE RESULTS WITH HYPNOTHERAPY

AND RELAX

Steve Holden's battle with TM started in July 2007 when he collapsed with severe weakness and found himself in intensive care. Although he has made a degree of recovery since then, he suffers with ongoing, severe neuro-pain and has struggled with depression. When the pain meds failed to help, Steve tried a range of complementary therapies and surprised himself when he found that hypnotherapy really did help. He and his therapist, Sharon Downes, tell us what's involved.

Sharon: Everybody's experience of hypnosis is different. The best way to describe it is being in a deeply relaxed state yet aware of your surroundings at the same time. Some people experience the relaxed state as feeling weightless while others experience it as if they are sinking down into the chair.

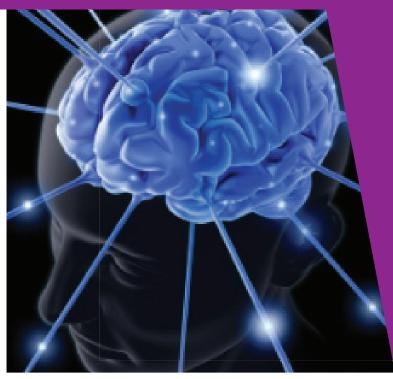
Steve: There are no swinging pendulums. I just feel myself switching off from the outside world as I tune into what Sharon is saying or asking me to visualise.

"I've learned that being in a relaxed state of mind, makes the pain much more manageable."

Sharon: Most people find the experience to be very calming and relaxing. Moreover they feel a sense of peace and comfort. It is not unusual for a client to feel rejuvenated and refreshed after a session; as if they have had a couple of hours of really good sleep!!"

Steve: I certainly leave my sessions feeling much more relaxed. The treatment has taught me how to listen to my body, and to understand what my body is telling me. A relaxed state of mind makes my pain much more manageable.

Sharon: The deep relaxation helped Steve to release the tension he was feeling in his body, particularly around the neck and shoulders. Those with physical disabilities, or who suffer pain, can experience high levels of worry, stress, anxiety and fear. This can produce extra acid in the stomach or additional physical tension and pain in the body. Regular hypnosis allows the body to relax for prolonged periods of time, not just when the person is asleep, and this can bring about more permanent changes.



Steve: My friends and family have noticed a huge change in my attitude. My depression has lifted. I felt much more positive about life from the very first session.

Sharon: I think this is because Steve has a better connection with his intuition, so he is more readily aware of positive changes that he needed to make for his own healing.

Steve: I've also been taught some self-relaxation techniques to use at home, which have helped me a lot. Sharon has made me a CD to treat my symptoms of Seasonal Affective Disorder, which usually plagues me over the winter months. Last year, I did not suffer from SAD at all which I believe is due to the hypnotherapy. I have also used hypnotherapy to aid my very successful weight loss programme so I'm a true convert.

Sharon: Hypnotherapy is very much a partnership – your client absolutely has to want to make positive changes in order for hypnosis to work – but it is an incredibly powerful tool to help you make the changes you wish to make, seemingly without willpower or stress!!

Sharon Downes is a professional hypnotherapist with Blue Owl Spirit in Hampshire.

For more information, visit www.blueowlspirit.co.uk

A MESSAGE FROM OUR CHAIRMAN



Dear Members.

What a summer it has been! There can be no doubt that our nation delivered the most superb Olympics and Paralympics to the world. Team GB did spectacularly well and exceeded medal expectations in both sets of Games.

We were lucky enough to be at the Olympic Park to watch some of the athletics and at Greenwich for the Dressage. On the wonderfully easy journey to and from the venues we had the time of our lives chatting to people from all over the world so thrilled to be a part of this huge event. The bonhomie was palpable with everyone having fun and simply enjoying being in our great Capital.

You will have read of the huge success of our very own Natasha Baker who has overcome enormous difficulties to be a double Gold Medal winner at the 2012 Paralympics and I for one stood with tears in my eyes as she proudly took her place on the rostrum, trembly-mouthed and singing the National Anthem. What an inspiration she has been for us all!

I don't envy the IOC having to set the categories for all the Paralympians. It must be the most difficult of tasks, judging one person's disabilities against others. One only has to come to a TM support group meeting to see a vast spread of differing

abilities. From my own very low key symptoms to those of you who haven't managed to walk in years. And we all have the same weird neurological condition. Extend that across all of the Paralympians and you can see why it can be so baffling for athletes and organisers alike.

I followed the case of the poor American swimmer with TM. Having taken part in the heats for her race, she still needed official recognition from the organisers whether her ability was to be downgraded or in fact recognised at all. How simply frightful when you have trained every day for years to get to the stage where you travel across the world and then may be disqualified because your disability doesn't fall into a recognised category. Let's hope that by 2016 in Rio things will have been ironed out a little more.

As to other matters, we have recently had designed TM Society tee-shirts which would be ideal to wear when you are fund raising or indeed anytime you feel able to spread awareness. They can be bought from Barbara Babcock and sent to you for £15 each (including P&P). All Support Group Leaders should have theirs soon so please ask them for more details.

"How simply frightful when you have trained every day for years to get to the stage where you travel across the world and then may be disqualified because your disability doesn't fall into a recognised category"

Committee member, Nick Heal, and I will be visiting the Spinal Injuries Association in a couple of weeks so I'll report back in the next Magazine. We are hoping to be able to glean more about the work they do and see if TMS will be able to join with them on projects.

It seems a little early to be wishing a happy festive period but as this will be the last Magazine of the year, I'd like to wish you all a gentle glide in to what is always a very busy time of the year and hope that you enjoy the Magazine. As ever, our thanks are due to our editorial and production team and the feature writers without whom there would be no Magazine.

Yvonne

TO P OR NOT TO P

RUTH WOOD BEMOANS THE SHORTCOMINGS OF DISABLED FACILITIES WHEN NATURE CALLS

Recently I was asked to provide my opinion on the newly opened toilet for the disabled in our local church. If I'm honest, the refurb was disappointing. The location was difficult to access when coffee was being served as everyone got in the way; the door was incredibly heavy and swung both ways; there was no mirror... At least the colour scheme was fairly pleasing.

This got me thinking more generally about toilets for the disabled (let's face it, disabled toilets are just ones that don't work!).

"Another bug bear I have – why does it seem to be felt by designers that the disabled don't want a mirror in the loo?"

Problems can vary from place to place. They are hidden under stairways (at least one service station on the M6 employs this); located beyond "ordinary" toilets with difficult access; or at the other extreme, trumpeted in such a way that it is obvious to all and sundry where you're going. (I particularly dislike the latter type). Of course, that's only the outside.

Once you've got in (using the Radar Key that I only found out about two years into my disablement) you're confronted by gleaming white porcelain and shiny chrome which looks very nice until you realise that once you've sat down you can't reach the loo paper without having to perform some form of contortionism worthy of an Olympic Gold Medallist. Having performed your task, you then find that if you're what they call "ambulatory disabled" the sink is too low and the hand dryer back breaking.

Another bug bear I have – why does it seem to be felt by designers that the disabled don't want a mirror in the loo? Do they think

we're all so disgusted with our bodies that we don't want to see them? I hasten to disagree! I'm a woman. I don't only go to the loo to pee – I also want to wash and dry my hands in comfort without having to crick my back to do so, and I need to replenish my make up and comb my hair without using guess work!

When I started using public toilets (disabled, for the use of), I was in a wheelchair – and I found very quickly that it doesn't seem to have occurred to many designers that the toilet cubicle should be big enough not just for a wheelchair of standard design, filled with a person of large(ish!) frame, but also another person. The unfortunate fact is that some of us are unable to use the facilities on our own, and need a carer to be there with us to – well – care! Not something talked about in the Corridors of Power, I'm sure, but it should be on somebody's agenda.

So... if anyone out there knows any designers, perhaps a gentle hint should be given that if you're going to design toilets for disabled people, would you not think that a disabled person or two on the team would be a good idea? Either that or we tie up a couple of architects, shove them in wheelchairs and see how they get on?!



LEARNING TO MOVE AGAIN

HUW GALLAGHER AND HIS MUM TELL US ABOUT FELDENKRAIS



At 15 months' old, Huw ran joyfully with friends in the playground. But after 3 weeks with a burning fever, he couldn't sit, crawl, stand or walk. He didn't speak for 6 months. He was later diagnosed with ADEM. Huw (now aged 6) follows a very holistic programme of ongoing, daily rehab. One of the components over the past year has been Feldenkrais.

Huw had little spontaneous recovery after his illness. Every gain has come through his hard work and determination. He has - very gradually - repaired the neurological feed throughout his body. He can now voluntarily move almost all of his muscles.

Putting it all together in a controlled and coordinated way remains the hard bit and so he continues to have severe difficulty with standing and walking.

Most days, he copes with his condition with an amazing level of maturity. But there is no denying it frustrates him. He tearfully explains "I know I'm clever and I have a good imagination and I'm good at lessons and all those other things you tell me. But I really, really wish I could walk like everyone else."

When he will deign to go slowly, with focus and concentration, Huw

can make a pretty good stab at a natural gait over short distances. But add his 6 year old's need for speed, then he's an unbalanced and ungainly toe walker, creating havoc with 2 sticks. Huw's mum Ros says that "speed versus form" is the constant battleground between them. "Huw wants to be a superhero and views me as the evil villain trying to thwart his super-speedy plans."

Moving in a coordinated way requires Huw to really concentrate and so there's a limit to how much he can – or can be expected to - do. That's why his mum is pleased they discovered Feldenkrais. "It's different from the other therapies we have tried. New movements learned in this way seem to get hard-wired into the brain".

When Huw started Feldenkrais, he was using an extremely high level of spasticity and muscle tone to move. He was eager to move but he was over-controlling his movements.

Huw's therapist, Rainer Knupp, uses a combination of verbal instruction and direct touch to teach Huw how his body can move; and if Huw moves one part of the body, how the rest of his body should respond. To start with, they perform the movements together and over time, Huw learns how to create the same movement on his own.

It's done in a fun, playful way, maybe pretending to roll up like a cat, or creep like a bear. The second half of the session is more focussed manipulation on the mat and Huw listens to a story to help with cooperation.

Huw's learned to let his voluntary muscles relax and transmit force through his skeletal structure. The quality of Huw's spinal movement has noticeably improved; it has softness and roundness now. He himself can now feel the difference between tight and open joints and softness or rigidity in his muscles. His ankles function with greater connection to the rest of the leg. He is visibly more grounded and better supported, especially when standing on two feet. Huw's balance has improved and his 'good' walking looks much more confident.

Huw would love to improve his walking and add running and jumping to his range of superhero skills. Given the maturity and dignity with which he has faced what has been thrown at him thus far, we already know he will fly.

For more information, visit www.feldenkrais.co.uk or contact Rainer through www.movementpotential.co.uk

MAKING THE CONNECTION

Zelda Carr was diagnosed with TM in the cervical region of her spinal cord in July 2011 and suffered a relapse in January 2012. Despite a fair recovery, she suffers residual neuropathic pain in her feet, a weakened left arm/hand and intermittent vertigo but the biggest issue was an intense headache above her left eye, which needed daily analgesia. Frustrated with the lack of relief from traditional medicines, Zelda turned to Shiatsu. She's kindly sharing her story with us.

ZELDA'S EXPERIENCE

I tried different painkillers, relaxation and chiropractic treatments to no avail. My first neurologist diagnosed a stress headache. The second suggested that it might be neck related and recommended physiotherapy for my neck and back but I'm still waiting for an appointment.

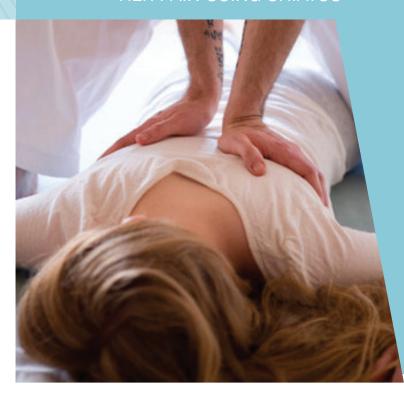
In the meantime, a friend suggested Shiatsu, a complementary therapy that I knew very little about. I attended a taster session with Teresa, a highly experienced Shiatsu practitioner, who very quickly identified that my headache originated from my neck, specifically the Bladder meridian. She was able to reproduce the headache by manipulating my neck and applying pressure above my left eye. Teresa treats the whole body and I've found that regular appointments have helped me manage the other symptoms that have resulted from the spinal cord damage. I no longer need regular analgesia and am now able to manage the headaches effectively between sessions.

ZELDA'S THERAPIST, TERESA HADLAND, EXPLAINS MORE

One of the key approaches in Shiatsu is that we treat the person and not the disease. When I first met Zelda I had not come across the condition of TM so was interested to learn how it affected her. The most troubled areas were her right hip which was causing sciatica-like pains down the right leg, and the left shoulder going up into the left side of the neck and face and causing a dull pain in the inner corner of the left eye, and 'pins and needles' in her left arm and hand. In Oriental diagnosis, the point of pain at the eye is the beginning of a long pathway that runs from the eye, over the back of the head, down either side of the neck and spine and all the way down the back of the legs, around the outside of the foot to end at the little toe. This is the Bladder meridian and many of the 'trouble' areas experienced by Zelda were along this pathway.

In Shiatsu we are always looking for ways to bring the body back into a state of 'integrated wholeness', seeing any condition as an expression of a part of the body that has become dissociated in

TRANSVERSE MYELITIS **SOCIETY**ZELDA CARR REDUCES HER PAIN USING SHIATSU



"One of the key approaches in Shiatsu is that we treat the person and not the disease."

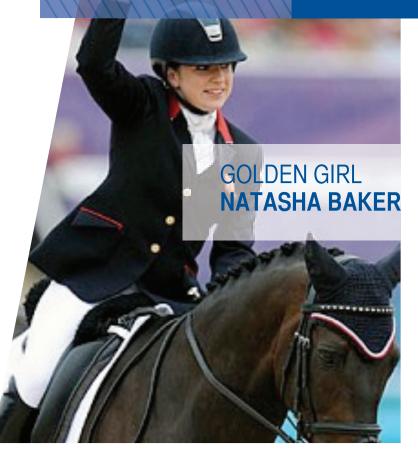
some way from the whole. The meridians trace lines of connection through the body. Symptoms such as frontal headache, pain at the back of the neck and sciatica often show a disconnection in the Bladder meridian.

Disconnection often happens after shock or trauma to the body, whether experienced on the physical or the emotional level. In Zelda's case there were a number of incidents in her history that could account for shock such as horse-riding accidents and 'whiplash' from a car accident coupled with the TM attack. These had all left residual effects in the nerves and tension in the muscles. My approach with Zelda was to help these tissues to regain their natural state and to allow the body to reconnect. For more information, please visit www.teresahadland.co.uk or www.shiatsusociety.org

Shiatsu is a physical therapy that supports and strengthens the body's natural ability to heal and balance itself. Shiatsu originated in Japan, taking influences from traditional Chinese medicine and more recent Western therapies. In Japanese, Shiatsu literally means "finger pressure" but a practitioner tends to use a combination of touch, comfortable pressure and manipulative techniques to adjust the body's physical structure and balance its energy flow.

NEWSBITES

NEWS IN BITE-SIZED CHUNKS



Our very own Poster Girl for TM not only achieved her goal to be chosen as a member of Team GB, she then went on to win two gold medals in the Para Dressage. What a remarkable achievement for someone just 22 years old and competing in the Paralympics for the first time. And we became a part of her journey, with all our e-mails, postings on facebook, and one of our members was even in Greenwich Park with handfuls of Union Jacks inscribed with the names of all the TM Society members who wished her success.

A MESSAGE FROM THE TRANSVERSE MYELITIS ASSOCIATION, U.S.A.

The TMA, U.S.A. has an updated website – www.myelitis.org. The updated site will make it easier to find the information you are looking for; there are new tools and features on the site and we have launched a blog to share stories and information with you. One of the most important features is the new membership database. Currently, there are lots of gaps in our knowledge base. We don't know the age of all our members, whether people were diagnosed as children or adults, the probabilities that the diagnosis was accurate or the therapies that you believe in. Our new membership form creates the opportunity for us to collect this information. This will allow us to better inform clinicians and researchers about TM, ADEM, NMO and ON. This should facilitate more, and more focussed, research and help us recruit people into studies and clinical trials. Please visit the new website and complete your information. We would also ask you to ensure that we have your current contact details, including your email, as we will be communicating more electronically. In order to be able to keep your information secure a username and password will be created for you when you first visit the new website.

NEWSBITES

NEWS IN BITE-SIZED CHUNKS

The East Midlands TM Group held a fabulously funny evening of entertainment, courtesy of Sally Franz, visiting from the U.S. Sally, now 61, has had an amazing life, from working as a stand-up comic in New York City, to being a Pastor, and now a published writer. Her book "Scrambled Leggs – A Snarky Tale of Hospital Hooey" tells the story of Sally's TM from initial symptoms (which began on a skiing weekend 7 years ago) through to coping with life with TM. The book pulls no punches and gives a clear picture of the conclusions people jump to and assumptions they make. The book is "an important read for pastors, caregivers, nursing students and anyone who is about to go into hospital and/or in long term health care". For more information contact Janet Ashenden, jan.nig@tiscali.co.uk

Want a good read?

A number of you have said on the TM Facebook page that you would like some recommendations for some reading material, either for yourselves, to learn more about your condition and how to cope with it, or to educate others. Always eager to please, we can start by recommending the following:

TRANSVERSE MYELITIS: A GUIDE FOR PATIENTS AND CARERS

published by the Brain and Spine Foundation http://www.myelitis.org.uk/TRANS_MYE.pdf

THE PAIN TOOLKIT: FOR PEOPLE WHO LIVE WITH PERSISTENT PAIN

http://www.paintoolkit.org/assets/downloads/Pain-Toolkit-Booklet-Nov-2011.pdf

"IN MY DREAMS I'M DANCING" BY RUTH WOOD

This is a lighthearted account of Ruth's first year living with TM. It's full of laughs, a few tears, and experiences which will be recognised by anyone who's ever had anything to do with disability.

Available as a paperback download from www.lulu.com

"KIDS BEYOND LIMITS" BY ANAT BANIEL

Based on a lifetime of experience, working with children with special needs, Anat Baniel explains how to awaken the capacity of your child's brain to heal itself.

facebook

The Transverse Myelitis Society 'facebook' page now has more than 350 members. We have Amy Edwards to thank for suggesting we should have our own page back in April 2011. We found that there was one in existence, but in name only, (it only had about 100 members), so there was no problem with us taking it over, and since then numbers have been growing daily. It's a great platform for people to be able to talk about their problems to other TMers, ask for advice, and generally air their views in a private place. Thank you to Rob Reeves for 'policing' it, here's to making it 500!

The National Institute for Health and Clinical Excellence (NICE) recently published guidance on the management of lower urinary tract dysfunction in neurological disease. The guidance offers evidence-based advice on the care and treatment of people with urinary incontinence and a neurological condition. The guidance and accompanying implementation tools can be found on the NICE website here - http://guidance.nice.org.uk/CG148. There is a also version of the guidance for people with urinary incontinence with a neurological condition and their families or carers, which will help people understand the care and treatment options that should be available in the NHS. The direct link to this version is here - http://guidance.nice.org.uk/CG148/PublicInfo/doc/English

TRANSVERSE MYELITIS **SOCIETY**

CLARE ROWNTREE REDISCOVERS CYCLING WITH THE HELP OF HER E-BIKE

RIDE LIKE THE WIND



One of my favourite sayings is "when the wind changes, reset your sails and carry on sailing", which is just as well really, as I now find myself with recurrent TM, and constantly having to adapt to varying levels of disability. Since 2004, I have had 5 episodes which has been a bit of a rollercoaster, but I count myself lucky that I've had some relatively good (albeit slow) recovery in between.

It's natural to focus on the loss of who we were and what we can no longer do, and the constant challenge is to turn that around and explore what we can still do, and find new enjoyment in different ways of living. Mostly I manage to have a 'cup half full' attitude, and knowing that another TM episode is likely to come along uninvited and unannounced one day, landing me back at square one in a wheelchair, is a great incentive for making the most of the good days.

I've always been quite active, and realising that I no longer had the physical ability to ride a bike was hard. It's not just the bike riding, it's the self image of me as an active person that gets dented, so it was great when I came across electric assist bikes, or e-bikes.

These are bikes that look like 'normal' bikes but which have a small electric motor and battery pack which assist with the pedalling. You can select different levels of assistance to help propel you along, depending on the road and how my symptoms are that day. The motor doesn't take over completely, it is still

very much an active process and can be quite hard work, but the effort and active involvement gives a sense of achievement and is a great way to exercise dodgy legs. Fatigue is a big problem for me and it's good to know that when my legs get tired, I can increase the level of assistance to get me back home. I've never been good at pacing myself!

There are lots of different styles of bike available. The good ones are expensive and it's important to do some research before you buy as there can be a big variation in performance and feel. Some are made for the commuter market and some are more specialised for leisure. There's a good buying guide available here:

www.electricbikesales.co.uk/info/buyingguide

"Having that sensation of speed and the wind in your hair is something I missed so much at the beginning of my TM. We've been out in all weathers and it just makes me feel alive!"

Alternatively, you can hire them. I recently did this to cycle round Rutland water (£30/day), a lovely off road route with handy pubs along the way –marvellous!

It's fantastic being able to go cycling with the family again, and enjoy being out in the fresh air. As any cyclist knows, on a bike you not only feel the landscape but smell and hear it too. Having that sensation of speed and the wind in your hair is something I missed so much at the beginning of my TM. We've been out in all weathers and it just makes me feel alive! We've just returned from a trip to Europe, and my husband dropped me off with my bike at the top of the Sustenpass (2259m) in the Swiss Alps, drove down and met me at the bottom – an unbelievable experience, flying down miles of exhilarating hairpins in beautiful mountain scenery!

There are lots and lots of attractive cycling routes away from traffic in the UK and abroad and many of them are now accessible to people with limited fitness thanks to e-bikes.

It's great fun and brilliant to have the freedom to be able to go cycling again – you just have to be prepared to get the predictable quips of "that's cheating!"

If only they knew.

LET NOTHING GET IN THE WAY!

MOLTEN ROCK TELL US ABOUT THEIR LATEST OFF-ROAD WHEELCHAIR



Molten Rock is a UK-based company born out of the frustrations of a group of wheelchair users, tired of sharing their lives with equipment that accentuated their disabilities instead of reflecting their lifestyles, interests and abilities. The company's remit is to develop desirable, high quality products, that embody the adventurous, outdoors spirit, and thereby take a proactive role in changing perceptions about assistive equipment. Here, they tell us about their latest off-road model.

With the Paralympics hailed as a celebration of inclusion, 2012 is the ideal year for UK-based Molten Rock to celebrate a special milestone: helping 100 wheelchair users experience the freedom of the great outdoors.

This month, Molten Rock will build the 100th electrically powered Boma off road wheelchair, and the team are excited to think where this chair may venture. "Already our customers

have used their chairs to climb Ben Nevis and Snowdon, complete Duke of Edinburgh Awards, enjoy beach holidays and even herd sheep! We have Boma chairs in the highlands of Scotland and in the mountains of New Zealand". And the Boma chairs have certainly made a difference for many pet dogs; although the Boma is expedition-proven, the chair is mainly used for everyday activities like taking the dog out for a walk in the local park!

Designed for easy transfer and rider safety, the awesome Boma7 is custom-made; built to meet individual requirements. With a choice of controls, including handlebar, head/chin control and Joystick operation, the Boma7 can be enjoyed by riders with limited arm and hand function. Specialist seating and supports are also available to ensure rider comfort and security.

After 16 years as a wheelchair-user, Molten Rock Director

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Chris Swift is very aware of the challenges facing those with mobility impairments in outdoor environments, and stresses the importance of design in overcoming them. "Enabling people by providing a well designed product like Boma7 is extremely rewarding. I know that travelling off tarmac into a previously inaccessible forest is exhilarating for any wheelchair user."

So what's next for the Boma? With increasing numbers of enquiries from the U.S., the Molten Rock team are hoping the Boma chair will soon be available for purchase in America. In the meantime, the team are wondering how to celebrate the 100th chair; a Gold Boma perhaps?!

For more information, or a demonstration, you can contact Molten Rock using the details below.



Email: info@moltenrock.co.uk Website: www.moltenrock.co.uk

Tel: 01908 585648

TALK TO YOUR DOCTOR

BARBARA BABCOCK ADVISES HOW TO GIVE FEEDBACK TO YOUR HEALTHCARE PROFESSIONALS

IT IS A TRUTH UNIVERSALLY ACKNOWLEDGED THAT TMORS CAN HAVE DIFFICULTIES COMMUNICATING WITH THEIR GPS, NEUROLOGISTS OR OTHER HEALTHCARE PROFESSIONALS. GIVEN THE RARITY OF THE CONDITION AND THE WIDE RANGE OF OFTEN HARD-TO-DESCRIBE SYMPTOMS, PERHAPS IT IS UNSURPRISING THAT DIFFICULTIES CAN ARISE. BUT THAT MAKES IT NO LESS FRUSTRATING WHEN TRYING TO GET HELP OR ADVICE.

BARBARA BABCOCK IS A TMS COMMITTEE MEMBER AND A PROFESSIONAL COACH AND CONSULTANT IN THE CORPORATE AND CHARITY SECTORS. SHE'S PROVIDED US WITH HER THOUGHTS ON HOW TO GIVE FEEDBACK ON LESS THAN SATISFACTORY EXPERIENCES WITH HEALTHCARE PROFESSIONALS.



Barbara says:

There are several things to keep in mind when attending appointments with healthcare professionals.

- Your needs and desires are important. Letting people know what they are, can help you get them met. And it's up to you to respond. Look after #1!
- If possible, have someone come with you to your appointments for support. S/he can also act as an advocate.
- Despite all their training and experience, the GP/neurologist may sometimes just not have 'the' answer let alone 'an' answer.
- The GP/neurologist is human too and has all the foibles that brings. S/he may not like knowing little about TM and not having an answer for you. Some may be more comfortable than others with that lack of knowledge.

You will find some GPs/neurologists will tell you that they do not know very much about TM and ask to work in partnership with you to find out more and determine next steps. If you experience this, great!

Other GPs/neurologists may come across as dismissive of your questions and needs. (It could be their unconscious way of pushing their discomfort on to you.) If you experience this, here are a few pointers in dealing with the GP/neurologist.

If you don't like how your GP/neurologist talks to you or you feel that your questions and needs are being dismissed, it is important to look after and manage yourself. This gives you choices in how you respond to your GP/neurologist. If you hear yourself saying, 'That person made me feel...', stop for a second. Whatever you felt, you felt it and that was very real for you. But sometimes those feelings can stop us from speaking up for ourselves when we need to. Or the feelings may dictate our responses and we respond in such a way that we don't serve ourselves and our needs very well.

The language - 'that person made me feel' – assumes that the other person is responsible for our feelings and we have no control over how we feel; all the power and control

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in the relationship lies with the other person, we just react to them. Is that helpful or not helpful for you in dealing with what has happened?

What if you had an element of choice in these situations? You could choose how you feel in response to what the person said or did. You could choose how to respond. It's like choosing to believe that the person cannot make you feel something without your personal stamp of approval. A relationship that works well is like a two-way street, a give and take, where the balance of power is relatively equal. Own and exercise your power.

What you say or do next will vary depending on the situation, the person you are dealing with and your relationship. So these are general guidelines and you may want to flex them for your situation.

- 'If you don't ask, you don't get.' Politely state what you would like. You may not get it, but at least you asked; you looked after your needs. If the response is 'no', ask what other options there are and what else you can do to get what you want. Even then if the GP/neurologist says no, politely ask who else they can think of who can help. And if they still say no, you can speak to people in the TM Society who are here to provide information and support.
- If you are not happy with an aspect of the service, especially if it is recurring, tell the appropriate person. This could be the GP, neurologist, practice manager at the local surgery, complaints department at the hospital, community health professional, nurse, etc. You may need to put it in writing.
- First, state the facts, i.e. the action taken, by whom, what was said. Keep it factual, i.e. I said and did, s/he said and did. For example, 'The GP/neurologist said that because s/he could not find anything wrong, there is nothing wrong with me. S/he sighed and was reading my files as s/he said that and not looking at me.'
- Second, describe the impact it had on you (and others if it did). When talking about yourself, use statements

starting with 'l'. For example, 'I felt that my needs were being dismissed.'

• Third, say what you would like more of, less of, or done differently. Describe it in specific terms, what someone could see or hear being done. For example, 'What I would like is for the GP/neurologist to express empathy with how I am feeling, to look at me when s/he is talking to me. Also, if s/he cannot find what is wrong with me and I am still not feeling well, I would like to be referred to someone else for another opinion.'

You can use this three-step approach when giving feedback about really good service too.

I hope that helps you in managing your relationship with your GP/neurologist and all the other healthcare professionals you may work with.



KATIE HAMILTON ENLISTS IN THE PAIN MANAGEMENT PROGRAMME IN LIVERPOOL



Katie Hamilton has suffered with TM for over 4 years. Her excruciating neuro-pain had become unbearable. She felt dosed up to the eyeballs, taking a cocktail of over 40 pain tablets every day, including Morphine and Pregabilin, and yet could get no relief. Her pain management consultant referred her to The Pain Management Programme in Liverpool (the "PMP").

The PMP aims to help people cope with chronic benign pain when all other attempts at relief have failed. Many people with ongoing, severe pain become depressed and inactive. They may over use medication and take on a sick role within their family. Self confidence usually declines and these people feel lonely and isolated. This downward spiral leads to worsening pain and ever-increasing levels of distress and disability. The PMP aims to reverse this downward spiral by teaching people to cope effectively with life despite having constant pain.

Treatment is provided in a group setting over a 6-week period. Each day is carefully structured by a treatment team that includes doctors, psychologists, occupational therapists, physiotherapists and a Pilates instructor. Katie attended 4 days a week for the first 2 weeks and then 2 days a week for the remainder of the course. Structured sessions ran from around 9 to 4.30pm and hotel accommodation was provided for her and other attendees who lived too far to travel in each day.

Katie says:

Before starting the course, I walked with two sticks and had zero self-confidence. I hadn't been me since before I got TM – slowly it had chipped away at me and I didn't know who I was anymore. The first thing they did was to take me off every single medication I was on.

The psychological sessions taught me that I wasn't alone and I was completely normal in how I had been feeling. This was hard for me to accept at first and some days were highly emotional. But there was also a lot of humour. People in pain seem to have a fantastic sense of humour!

"After the first day of exercise, I felt so good and actually, properly tired. I slept the whole night through for the first time in nearly four years!!!"

I had stopped exercising since my TM because of concerns about what was safe, but qualified instructors and PTs introduced me to pilates and hydrotherapy and I also did some work on the gym ball. I surprised myself by finding this all so easy and enjoyable. I wondered what on earth I had been worrying about. After the first day of exercise, I felt so good and actually, properly tired. I slept the whole night through for the first time in nearly four years!!!

Occupational therapists taught us how to set appropriate goals and pace our activities, ranging from taking control of personal care or domestic tasks, trying new hobbies and leisure activities or returning to work. We were shown how to gradually build up activities step by step so that, despite the pain, patients eventually achieve their personal goals. Previous patients gave us tips about how to carry on practising what we learned when we returned home.

The course literally helped me turn my life around. I can now walk with one stick (which is a huge achievement for me after 4 years of using two). I am currently medication-free, aside from Lidocaine patches, and still able to work 40 hours a week. I exercise daily for at least 30 minutes, even it is only stretching. The difference is amazing as my body is stronger, I sleep so much better and my pain is nowhere near as bad as it was before. I have made some incredible new friends but, most importantly, I feel like I'm me again.

THE GREAT DEPRESSION

DR MAYUR BODANI TALKS ABOUT THE RELATIONSHIP BETWEEN DEPRESSION AND TM



Transverse Myelitis (TM) and clinical depression are two different conditions. The pathological changes caused by TM can be imaged using magnetic resonance imaging (MRI) of the spine. The changes in the brain that lead to depression are less focal, and involve the circuits connecting brain areas, including the prefrontal cortex, hippocampus and cingulate gyrus.

We know that neurological conditions like TM, MS and Parkinson's can cause depression as a secondary consequence. This can be triggered by the sudden onset of physical disabilities and deterioration in physical skills. Unremitting pain, especially if unresponsive to standard painkillers, can lead to feelings of profound helplessness and depression. Depression (or anxiety) can also be a possible presenting symptom of neurological disease, as in the case of dementia. However, there remains poor understanding of the correlation between specific neurological lesions in the brain and the presence of depression.

"The time taken for changes in brain neurochemistry as a result of antidepressant use can typically be several weeks, although sideeffects occur over days."

Dr Mayur Bodani MRCPsych FRCP Edin is a Consultant Neuropsychiatrist at Sevenoaks Hospital. He is trained in both General Medicine and Psychiatry. He has extensive experience in the psychiatric management of individuals with long-term neurological conditions and acquired brain injury. Here, he talks about the relationship between depression and TM.

The symptoms of TM will be very familiar to readers of this journal. Depression can manifest with both biological symptoms (such as sleep disturbance, loss of appetite, weight loss, and reduced energy), and psychological symptoms such as loss of enjoyment, social withdrawal, and poor motivation.

The management of both TM and depression involve the use of drugs and rehabilitation approaches. Drug use in TM (such as steroids) is aimed at potentially reducing inflammation or immune system activity.

THE GREAT DEPRESSION

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Psychotropic drug use to manage depression has a less obvious target, but is thought to help boost brain neurotransmitters implicated in mood disorders, such as serotonin, dopamine and noradrenaline. The treatment of depression in neurological disorders usually requires combination antidepressants.

There are many classes of antidepressants, some old and some new. The older antidepressants include tricyclics (such as amitriptyline, imipramine, lofepramine, and trazodone); and monoamine oxidase inbibitors (such as phenelzine, and moclobemide). More commonly used classes today are SSRIs (Selective Serotonin Reuptake Inhibitors, e.g. fluoxetine, and citalopram); SNRIs (Serotonin and Noradrenergic Reuptake inhibitors, e.g. venlafaxine, duloxetine); or novel mechanisms (e.g. mirtazepine).

"In the future (next decade) the science of genomics will much more accurately determine the choice of drug prescribed and will be based on an individual's genetic profile."

All antidepressants have beneficial effects, and both class and individual side-effects. For example, tricyclics are associated with sedation, and weight gain, and anticholinergic side-effects (e.g. constipation, urinary retention); SSRIs with gastroenterological side-effects, and occasionally cardiac (e.g. QT interval prolongation). The choice of drug used presently is determined by experience, and assessment of possible tolerable and intolerable side-effects. In the future (next decade) the science of genomics will much more accurately determine the choice of drug prescribed and will be based on an individual's genetic profile i.e. drugs likely to be effective or predicted to cause side-effects.

Antidepressants can have a withdrawal syndrome (e.g. tricyclics);

but addiction in the sense of tolerance with a requirement for increased dosing simply to avoid withdrawal is not a feature. The latter is commonly misunderstood and often the reason why patients will inappropriately refuse treatment, to their own detriment.

There is little point to the use of antidepressant medication under six months. The time taken for changes in brain neurochemistry as a result of antidepressant use can typically be several weeks, although side-effects occur over days. The benefits of antidepressant use depend on dose used, compliance with treatment, and effective monitoring for efficacy. Too often GPs start a drug, fail to demonstrate a benefit, and switch to another, also at initiation dose, repeating the cycle of failure. Drugs need to be titrated up, and under specialist supervision, classes are commonly combined synergistically for better outcomes.

Drugs are not a complete answer. Whether coping with the symptoms of TM or depression, there are benefits from parallel psychological approaches. Carer and general support is vital, particularly that found in the sharing of experiences through voluntary organisations and support groups.

The Raphael Medical Centre

Tanesh Baugubaun of the Raphael Medical Centre in Tonbridge spoke at the South East Support Group meeting recently. The centre specialises in the neuro-rehabilitation and neuro-psychiatry of adults. They offer a unique, holistic service for people suffering from complex neurological disabilities, chronic pain syndrome, cognitive impairment and complex psychological needs. They aim to lead patients from medical dependence to functional independence through an active medical, therapeutic and nursing process. They combine complementary — or anthroposophic — therapies with conventional medical care, in partnership with NHS facilities. They have a huge team of professionals on-site for both inpatients and outpatients, 7 days a week. For more information, see www.raphaelmedicalcentre.co.uk.

MY STORY

HEATHER COLTMAN LOOKS BACK OVER THE PAST 5 YEARS AND SHARES HER TM JOURNEY

22nd September, 2007. That was the day my life changed. I lost my ability to walk within 3 hours. After a few telephone conversations with an unhelpful NHS direct, and a paramedic, I finally got to the hospital. I used to be a nurse many moons ago, so understood things weren't too great when an A&E doctor stuck her finger in my bottom and told me to squeeze. And I couldn't.

I had altogether 10 months in hospital. I had total paralysis from T11 (my waist) down and bladder and bowel problems. I also managed to develop pneumonia and a pulmonary embolism. DVT socks 'r' me.

I found the loss of dignity very hard. My excellent medical team tried to motivate and reassure me. "Don't worry, we'll sort this out." "It's not a problem." "See this all the time". When I was a nurse, I said many of the same things – and I meant them. I did sort it out; it wasn't a problem and I certainly did see it all the time. But now, on the other side of the bed rail, the platitudes didn't console me. I was 48 years old, and couldn't wipe my own bottom.

I only found out my diagnosis on my day of discharge, when I read my medical notes. It wasn't for lack of trying on my consultant's part. I used up my family's quota of MRIs (5), lumbar punctures (4) and CT scans (3), and cannot even begin to put a number on x-rays and blood work. If only there were a loyalty card for hospital tests...

"in my professional career as a nurse, I had seen so much worse. That is my mantra. Say it often enough and you believe it."

Going home after 10 months in hospital was very strange and a big eye opener. It became clear that we needed to remodel the house to accommodate me and my wheelchair. I had to come in through the back door (I am a big girl so wide load). We levelled the access to the kitchen, added a wetroom, a new living room and an external deck. It took several months but eventually allowed me more than a 2- room existence and easy access to fresh air. That saved my mental bacon.



I am very fortunate to have a supportive family and network of friends, but won't lie that my life changed big time. Living on a hill, wheelchair bound, I was rather housebound. I had to learn to accept help from others - which didn't come easily for me – and also to try to do as much as I can for myself. But in my professional career as a nurse, I had seen so much worse. That is my mantra. Say it often enough and you believe it. And although I still have my "needy days", I have tried to learn to cope and make the best of it.

My one regret is that my daughter had to witness the worst in me. Whether my condition influenced her choice of university programme, Occupational Therapy, I will never know. But she and her father, have undoubtedly been my unfailing support and the difference between me learning to cope and not.

Other support came through the support group meeting in Tunbridge Wells. At my first meeting, I talked to people who understood the pins and needles and pain associated with TM. Immediate empathy. No need for explanation.

My next challenge is working from home. After much deliberation, I'm embarking on a proof-reading course and starting to make plans. I feel like I'm growing up... again.

NEWS FROM THE UK SUPPORT GROUPS

TRANSVERSE MYELITIS **SOCIETY**FIND OUT WHAT'S HAPPENING AT A SUPPORT GROUP NEAR YOU

LONDON SUPPORT GROUP

NEXT MEETING: SATURDAY 20TH OCTOBER AT 2.00PM

Venue: ECHQ, 34 York Way, London N1 9AB. The venue is wheelchair friendly, and car parking is FOC from 1.30pm on Saturdays in York Way. There is no London Congestion Charge on Saturdays. ECHQ is a short 3-4 min walk from King's Cross Station. For further details please contact Yvonne Kolesar, yvonnegk50@msn.com tel. 01737 552869 or Lew Gray, lewgray@blueyonder.co.uk

SOUTH EAST SUPPORT GROUP

NEXT MEETING: SATURDAY 1ST DECEMBER 12.30PM (THIS WILL BE CHRISTMAS LUNCH)

Venue: Pembury Village Hall, High Street, Pembury, Kent TN2 4PH. It is wheelchair friendly with disabled loos. There are 2 disabled parking bays and 10 further parking places outside. Additional parking on the road. For further details contact Annie Schofield, annie.schofield@myelitis.org.uk, Carol Preece preece.carol@googlemail.com, or Peggy Hughes, mail@peggyj.com

POOLE/BOURNEMOUTH SUPPORT GROUP

NEXT MEETING: SATURDAY 27TH OCTOBER AT 2PM

Venue: St George's Church Hall, Oakdale, Poole, Dorset, BH5 3EU. From 2013, we will move to a more accessible and pleasant, new venue at the MS Centre at Parley. For further details please contact Group Leader: Lance Harris, lv.harris@hotmail.com or Secretary: Barbara Houston 01425 673173 barbs@houston19.freeserve.co.uk

BRISTOL SUPPORT GROUP

NEXT MEETING: SUNDAY 9TH DECEMBER AT 1.00PM

Venue: The Reception area of the Holiday Inn, north Bristol. For further details please contact Steve Collins, steve.collins@blueyonder.co.uk

EAST MIDLANDS SUPPORT GROUP

NEXT MEETING: SATURDAY 16TH MARCH 2013

Venue: The Village hall, Lullington, Nr Swadlincote. DE12 8EG. For further details contact Janet Ashenden, jan.nig@tiscali.co.uk

TELFORD SUPPORT GROUP

NEXT MEETING: THURSDAY 25TH OCTOBER 2012 AT 2.00PM

Venue: Ketley Community Centre, Holyhead Road, Ketley, Telford, Shropshire, TF1 5AN. The venue is wheelchair friendly with easy access. For further details please contact Anna Paulsson-Habegger on 07581708597 annaph@blueyonder.co.uk

NORTHERN IRELAND SUPPORT GROUP

Venue: The Dunsilly Hotel in Antrim, easily accessible via the Motorway, it is also wheelchair friendly. For any further details please contact Eileen Bradley, ebtm@hotmail.co.uk or 02829557114

TRANSVERSE MYELITIS SCOTLAND

NEXT MEETING: SATURDAY 24TH NOVEMBER AT 2.00PM

Venue: Conference Room opp. Day room, Philipshill Ward, Spinal Injuries Unit, Southern General Hospital, 1145 Govan Road, Dates of our meetings are posted on our webpage www.myelitis.org.uk/scotland. For any further details 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

0844 800 4361 www.carers.org

Continence Foundation

www.continence-foundation.org.uk info@continence-foundation.org.uk

Depression Alliance

0845 123 2320 www.depressionalliance.org

_Disability Information Advice Line (DIAL)

01302 310 123 www.dialuk.info

Disability Law Service

0207 791 9800 www.dls.org.uk

Disabled Living Foundation

0845 130 9177 www.dlf.org.uk

_Disability Now Magazine

01454 642 444 www.disabiltynow.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

0845 456 4566 www.motability.co.uk

_Neuromyelitis Optica (NMO) [Formerly Devics Disease]

www.nmouk.nhs.uk

_NMO: The Walton Centre, Liverpool

Nurse Specialist

0151 529 8357

NMO Service Coordinator

0151 529 8131

nmo.advice@thewatoncentre.nhs.uk

_NMO: John Radcliffe Hospital, Oxford

Nurse Specialist

01865 231 905 NMO 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

_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 Yvonne Kolesar
(chair) 01737 552869 or
Lew Gray (Secr) 020 8568 0350
Email: lewgray@blueyonder.co.uk

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