WINTER 2013/14

# The Magazine


***Nadine Shenton runs half marathon for TMS*** *Page 11*

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# LETTER FROM THE EDITOR

ANNIE SCHOFIELD

We're into the festive season so, like many magazines, we're celebrating with a bumper edition. And as Christmas is all about children, we would like to introduce 3 wonderful youngsters to you, Penny, George and Hannah. You may remember Penny & George from our last edition, when we told you about their fantastic fundraising achievements. It was pointed out to me that there wasn't much in our magazine for children, so we suggested they might like their own page, and they leapt at the chance. They have joined up with another friend, Hannah, and will now have their own page, for kids, by kids. Any budding young reporters out there, who might like to write an article for the next edition?

Everyone is talking about PIPs at the moment, the new benefits scheme that was implemented in June. I know I'm not the only one who found it impossible to work out the implications, then I read Leonie's article, and suddenly, there it was, in plain English for everyone to understand! If you're worried about your eligibility, you could take a simple test by going to www.benefitsandwork.co.uk/personal-independence-payment-pip/pip-self-test.

You may be aware of the TMA Symposium held in Dallas last month, and we were lucky enough to have our very own roving reporter, Andrew Hinder, there. He has written two articles for us, the first an overview of the symposium itself, which includes some exciting news on the drug Ampyra, then in our next edition he will address the questions he was asked to pose by TMS members.

Although this is called the TMS Magazine, there was one glaring omission – news from the TMS itself. This has now been rectified, and not only will you get to hear the latest news from the Society, we will also be profiling the committee members, starting with our Secretary, Lew Gray

Elsewhere we have a humorous take on present giving from Ruth Wood, and a few tips on coping with Christmas fatigue from Colleen Oakley. Of course, while everyone around you is seemingly in the festive spirit, it can be hard if you're trying to come to terms with the impact of TM. So, we have asked Isabel Moloney, consultant psychologist, to talk about some of the processes we may go through when TM strikes. I hope this article is of some help, but if you are feeling really awful, please pocket your pride, and seek help from friends, or professionals with the skills to help, such as the Back Up Trust (www.backup.org).

As you will know by now, we feel it's really important to talk about as many issues to do with TM as possible, and not to shy away from the more delicate ones.

In the next edition we plan to talk about relationships/sex, post TM. Inevitably there are changes and adjustments to be made, whether it's needing help from your family, or in the bedroom. And this one we really need your help with. Would you be willing to talk about how TM changed your life? Just e-mail me - and your comments can be completely anonymous.

And finally, Clare, Zelda and I would like to take this opportunity to wish you everything you wish for this Christmas, and the coming year.

***Annie***

annie.schofield@myelitis.org.uk

# A STRING OF CHRISTMAS THOUGHTS

RUTH WOOD TAKES A LIGHT-HEARTED LOOK AT THE JOYS AND PITFALLS OF CHRISTMAS SHOPPING

It's that time of year again – is it really only once a year? It feels like yesterday that I was gong through this whole exhausting process, but it is, in fact, nearly twelve months since I last heard those awful songs repeated ad nauseum everywhere I had the misfortune to shop.

When I was first disabled – seven years ago now – I decided to try shopping online. It seemed the obvious solution – no pushing through heated crowds in my wheelchair, and listening to screaming children at their own height

However, it wasn't as straightforward as I'd thought it would be.

> *"I soon realised it can be quite a disadvantage if you can't see the products, as some of the goods arrived looking distinctly tatty, despite their picture being wonderful."*

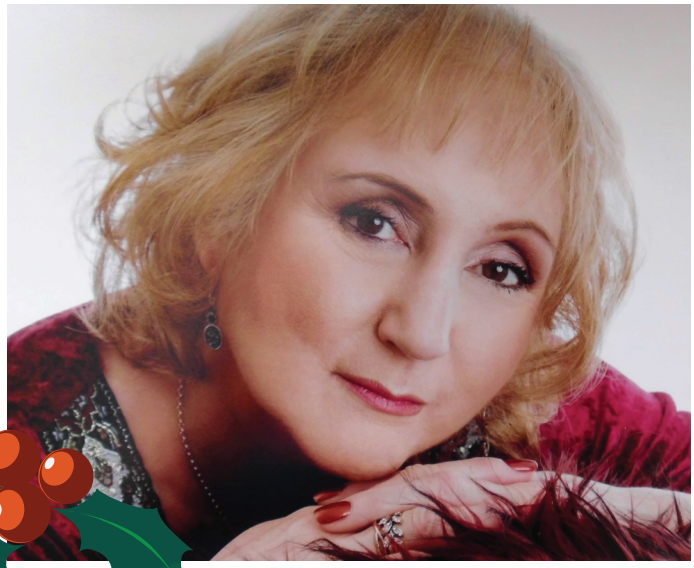
I always start with a list of people I'm buying for – inspiration hopefully strikes when I'm thinking of that person and looking at gifts. I haunted online shops, especially Amazon and e-bay (no-one will know if it's not exactly new, will they? It's the thought that counts after all).

I saw a beautiful table candelabrum – well, it wasn't actually for anyone else, I fancied it myself, but I felt perfectly justified. After all, I need some pleasures in life! Triumphantly I put in the winning bid and it was mine!

It arrived, promptly, two days later – and I discovered why the postage and packing had looked such a bargain price. Yes it certainly was a candelabrum – but it was only eight inches high. I'd forgotten to look at the dimensions.

Still my mother's sure to love it, I thought, wrapping it up, (she did, luckily).

Anyone can make that mistake, I thought, undaunted. Next was a DVD for my father. He's almost impossible to buy for, so I felt quite smug. When it arrived I was in the process of wrapping it up when my husband spotted it had the wrong area number on it – it wouldn't play in the UK. Right – change of plan. It went to my son who's got an all regions player. If he was surprised at my choice of train DVD, he was too polite to say so.



Well, I'd really got the bit between my teeth, and I ploughed on with my purchases, getting neck ache because I was on the computer so long. I began to realise it can be quite a disadvantage if you can't see the products, as some of the goods arrived looking distinctly tatty, despite their picture being wonderful.

Finally I lucked out with a limited print edition of a border collie that looked just like my daughter-in-law's parents' dog. It cost a little more than I would have liked to have paid, but it was so perfect I went for it, anticipating their joyous faces on Christmas morning with glee.

On Christmas day we were all sitting around the tree. My daughter-in-law's mother opened my present, and I waited with bated breath for her reaction.

She glanced at the print, laid it down casually beside her, remarking, "everybody's giving me dogs this year," before starting to open the next gift. I felt very deflated.

So this year, I'm resolved – I'm going to brave the exhaustion and the shops so I can see what I'm getting, I'm not paying more than £10 for anybody – and I'm only buying for people that I actually like.

I'll let you know how I get on, as I sit and look at my lonely Christmas dinner!!!!

*Greetings of the season to you all!!*

# UNDERSTANDING PIPs

## YOUR GUIDE TO THE NEW BENEFITS SYSTEM BY LEONIE ASHENDEN

Disability benefits for everyone in the UK have changed as of 13th June 2013. From that date all new claims for disability benefits will be covered by Personal Independence Payment (PIP). The only exceptions are people under 16, who are to remain on Disability Living Allowance (DLA) until their 16th birthday, and people over 65.

Anyone who is on a fixed term DLA award will also remain on DLA until they are brought into the PIP system sometime between 2015 and the end of 2017.

Like DLA, PIP has two components – daily living and mobility. Both components are payable at standard or enhanced rate, which will be decided during the PIP process, to establish the ability of a claimant to complete a number of key everyday activities. Individuals will receive a point score for each activity. The total scores will determine the rate at which PIP will be awarded. The entitlement threshold for each component is eight points for the standard rate and twelve points for enhanced.

The activities, which are assessed for the Daily living component, are, preparing food, taking nutrition, managing therapy or monitoring a health condition, washing and bathing, managing toilet needs or incontinence, dressing and undressing, communicating verbally, reading and understanding signs, symbols and words, engaging with other people face to face and making budgeting decisions.

For the mobility component the activities are planning and following journeys, and moving around.

To make a new claim for PIP you need to telephone a free phone number. If re-newing a DLA award, you will be written to and asked to telephone the same free phone number within one month. If you fail to make the call within the one month period it will be assumed that you no longer wish to claim the benefit.

During the call you will be asked for your full name, NI Number, full address with postcode, date of birth, bank details, daytime telephone number, GP and other health professional details, and nationality. I have been advised that during the telephone call, claimants with TM should tell the advisor that they have a rare neurological condition – and what it is, both Capita and ATOS (UK occupational health service providers) have been given a condition insight report.

*" Anyone who is on a fixed term DLA award will also remain on DLA until they are brought into the PIP system sometime between 2015 and the end of 2017."*

# UNDERSTANDING PIPs

## YOUR GUIDE TO THE NEW BENEFITS SYSTEM BY LEONIE ASHENDEN

The Department for Work & Pensions (DWP) will then send out a form called 'How your disability affects you' by post. The forms will all be bar coded and have basic information on it about the claimant. You have one calendar month to complete and return the form to the DWP in a pre-paid envelope.

The questions in the form are to give an idea of how the health condition impacts on a person's everyday life. The questions are to establish whether a person is able to carry out tasks safely, to an acceptable standard, as often as they are reasonably required and in a reasonable time period.

Other questions ask about whether the person uses aids or appliances or has help from another person to carry out activities. This section gives three tick boxes for each question, yes, no or sometimes. There is

also a section on the form called "Extra Information" where a claimant can explain how their health condition affects their ability to carry out activities, the difficulties they face and the help that they need.

***" All PIP awards will have a time scale; Up to 2 years where it is expected that there will be changes to the needs, longer awards of 5 or 10 years where changes are less likely"***

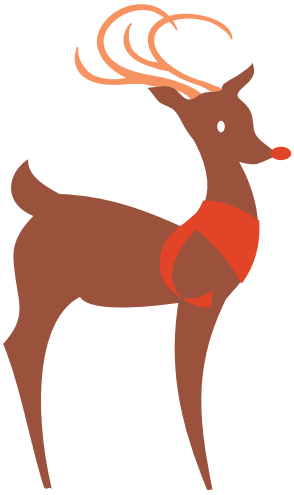
The PIP information booklet suggests that claimants may want to write down a list of things that they have needed help with or found difficult over a number of days, and for a record to be kept for some time in the run up to the assessment.

The next stage is that you will be invited to attend an assessment. All claimants are encouraged to take someone along to support you, this is beneficial because the person will be allowed to participate in the discussion, and may therefore bring up things that you have over-looked.

During the consultation the claimant will be asked about their health condition, their disability and how it affects their daily lives. The health professional may carry out a short physical examination, but claimants will not be forced to do anything that causes pain, embarrassment or discomfort.

The DWP decision maker will make a decision on entitlement. If PIP is to be awarded they will decide the level and length of the award. All PIP awards will have a time scale; there will be very few lifetime awards. Short term awards of up to 2 years will be given where it is expected that there will be changes to the needs of the claimant, longer awards of 5 or 10 years where changes are less likely, but all claimants should expect reviews to assess whether change in needs has occurred.

If PIP has not been awarded, the letter will give the same information as the award letter, including a full explanation for the reasons for the decision. The letter will also explain what the claimant needs to do if they are not happy with the decision and how they can request a mandatory reconsideration. After the decision letter has been issued, if a claim has been disallowed or an existing award reduced the DWP decision maker will try to phone the claimant to discuss the decision and explain the reasons for making the decision. The reason for the call is to ensure that the claimant understands the reason why PIP has not been awarded or has been reduced, and to give the claimant the chance to ask any questions about the decision.



# TMA SYMPOSIUM

ANDREW HINDER REPORTS FROM DALLAS

## *Rare Neuro – Immunologic Disorders Symposium, Repair and Recovery, Today and in the Future.*

*Dallas, Texas : October 25th – 26th October 2013.*

Sandy Siegel (left), President of The Transverse Myelitis Association, Andrew Hinder, and Chitra Krishnan, Executive Director of The Transverse Myelitis Association (right).

The Transverse Myelitis Association symposium included nineteen detailed academic presentations over two days. Dr Benjamin Greenberg, the coordinator of the symposium, stressed from the outset that the focus was on repair and recovery for the rare neuro – immune diseases of transverse myelitis, and neuro – myelitis optica.

Friday's presentations included activity based rehabilitation (ABRT), gait training and cognitive rehabilitation. Dr Cristina Sadowsky's talk on ABRT revealed that her therapy sessions last four hours per day, and in so doing address the neurological totality of all TM symptoms. Dr Daniel Becker, familiar to many London TMS members presented. The effectiveness of Functional Electrical Stimulation (FES) highlighted the encouraging message that recovery never stops, and FES and exercise are proven to stimulate nerve cell repair. Later in the proceedings Dr Carlos Pardo emphasised the essential mantra of 'exercise – exercise – exercise!'.

Sessions dealt with surgical based rehabilitation, including device implantation for neurogenic bladder conditions. Spasticity management, presented by Dr Donna Graves, emphasised the importance of stretching exercises, the use of drugs including baclofen, and the possibility of using botox injections to target individual muscle groups.

The potential of the new drug Ampyra, which blocks the escape of potassium from demyelinated nerve cells, thereby improving electrical conduction, was outlined by Dr Michael Levy. This drug hitherto used for MS patients, is currently being trialled for TM sufferers.

The second day began with a presentation by Dr Lindsay Horton on recovering vision after Optic Neuritis, and was followed by an examination by Dr Allen DeSena of the use of suitable drugs in the management of sleep deprivation, spasticity, and cognition.

Sessions on drug based repair therapies included a presentation by Dr Greenberg on the blocking of LINGO-1, a brain protein which seems to prevent remyelination. Human trials are now in progress, and Dr Greenberg urged us all to keep exercising in order to be a suitable recipient of the new drug in the near future!

The use of human derived antibodies to promote remyelination was presented by Acorda Therapeutics Inc., and the symposium concluded with a consideration by Dr Levy, and Dr Barbara Krynska, of the possibility of stem cell trials for the treatment of TM.

Important messages from the symposium included the debunking of the myth that if no substantial improvement occurs within the first six months of the onset of TM, then significant recovery is unlikely. Another oft quoted assertion that recovery only continues for up to two years was similarly rejected. Then the 'one third, one third, one third' formula ie. one third of people affected with transverse myelitis will recover, one-third will show only fair recovery, and one-third will not recover was called into question.

There was much to consider and take away from this symposium, but the overall message was one of optimism for new therapies and rehabilitation.

The full agenda for the symposium is available on The Transverse Myelitis Association website, and video links of the presentations are to appear shortly.

# TM KIDS

*My name is **Penny Winton**, I am 10 years old and I live in Aberdeenshire, Scotland with my mum and dad, two sisters, a brother and two border terriers! I found out I had TM in October 2011 when I was 8 years old.*

## WHO IS YOUR ROLE MODEL?

I met Anjali Forber-Pratt at the T.M. camp this summer. She is in the USA Paralympic team and she has T.M. She was pretty cool. I like Natasha Baker she is amazing! I would love to meet her!

## HOBBIES

I have just started playing the euphonium, which is a lot of fun, (although a wee bit noisy!) I am a lone guide, (guiding from home via email) I like playing hockey and mucking about outside in the garden.

## HOW HAS YOUR LIFE CHANGED SINCE T.M?

Since having T.M. I find it harder to do things like running fast with my friends or just going to the toilet by myself. But if I hadn't had T.M. I wouldn't have met George and Hannah. They are two really amazing T.Mers!

*My name is **George Henry Bowyer**, I am 9 years old and I am from Craigston near Turriff, but I was born in Malton in North Yorkshire. In my family there is my Dad, Richard, my Mum Caren, my big sister Hattie and my little sister Tabitha. I was diagnosed with TM when I was 7 years old, I had my 8th Birthday when I was in hospital, but now I'm nearly 10, well on the 23rd of March.*

## WHO IS YOUR ROLE MODEL?

My role model is Danny MacAskill a Scottish Trials cyclist who does amazing stunts. One day I would like to ride a BMX like Danny does.

## HOBBIES

My hobbies are: Ballet, Street dancing, weather watching, BMX riding, skateboarding, tennis, swimming and reading about Science.

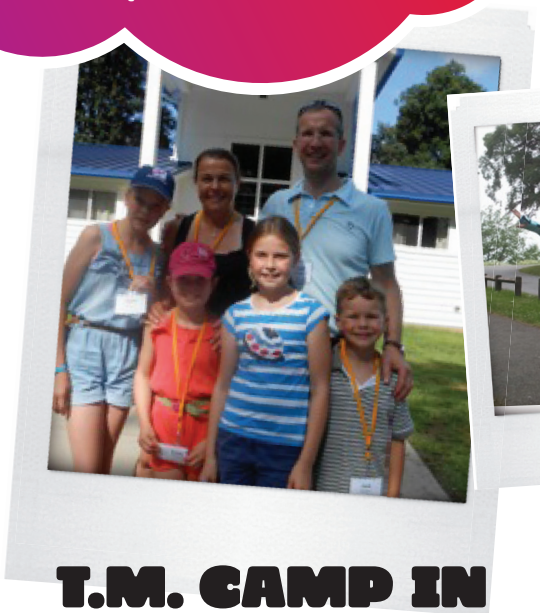
## HOW HAS YOUR LIFE CHANGED SINCE T.M?

My life has changed a lot since TM. My bladder doesn't work very well anymore which is a pain for me. Sometimes my back hurts and I feel tired and sick and I get a lot of headaches. But I am very glad my legs work again and I don't mind if they get sore because I remember what it was like when they didn't work. A lot of good things have happened too though, like meeting Penny and being asked to help with the magazine. Penny and me are good friends now.

# TM KIDS

**A COOL FACT ABOUT TM**

TM IS REALLY RARE, ONLY AROUND 2-5 PEOPLE PER MILLION GET IT!!! THAT MAKES US PRETTY SPECIAL!!!



*My name is **Hannah Harper**, I am nine years old and I live in Birkhill (near Dundee) with my mum, dad, and little brother aged 4. I was diagnosed with TM when I was only 4 months*

### WHO IS YOUR ROLE MODEL?

My role model is Martin Dougan because he is in a wheelchair and now he is doing the Olympics and is now a TV presenter

### HOBBIES

I like doing swimming, basketball and sometimes in the summer I play a bit of tennis

### HOW HAS YOUR LIFE CHANGED SINCE T.M?

Sometimes TM can frustrate me because I am in a wheelchair and obviously I want to walk but I can't and it's very frustrating. TM has affected my bladder as well as I can't go to the toilet as well as other people do. I have a special thing in my tummy called a Mittroffanof that is a little open hole that I insert into my stomach and that helps me do the toilet. I do sometimes get upset on what's happened to me in the past but do think onto the future

## T.M. CAMP IN KENTUCKY 2013

*I went to the camp this year with my family, it was held in Kentucky in America.*

*The best bit of the camp was the wood work shop and swimming in the pool. I also enjoyed the messy games, but the best thing about the camp was on the last morning we had ice cream, sweets, chocolate sauce and whipped cream for breakfast!* ***Penny***

*Thank you for reading our page, tune in for the next edition where we will have more interesting facts about T.M.*

***Penny**, **George** and **Hannah** would like to say a big thank you to our family & friends for helping us.*

# WANT A STRESS FREE CHRISTMAS?

PLAN AHEAD SAYS COLLEEN OAKLEY

**Fatigue can be a challenging feature of living with TM and its related conditions at any time of year, but at Christmas the demands on our time and energies increases greatly. Here Colleen Oakley shares her personal coping strategies:**

I am 54, married with a twenty one year old daughter and a seventeen-year-old son. I joined the TM family in November 2010 and fatigue came to the party in April 2011. It has been (and still is) a tough learning curve, with many ups and downs along the way.

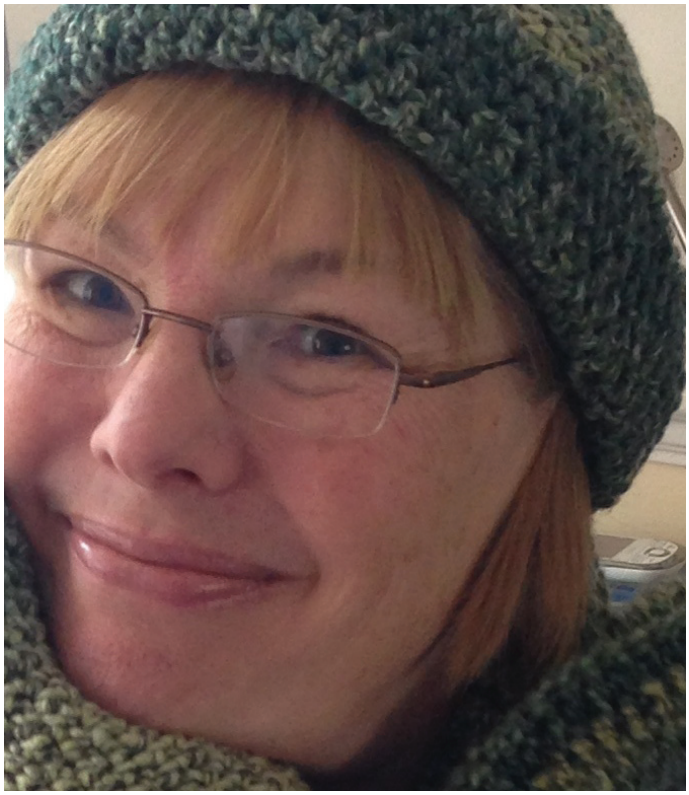
With Christmas around the corner I would like to share some of my coping strategies with you.

- Work within your capabilities. I have about two hours of productive time a day, so I need to plan Christmas a long time in advance. I shop online for gifts and try to make as much as I can (crafting is therapy for me). I was a very energetic Christmas person, now I have to delegate a lot, and drop a lot - and that's fine.
- Let go of the guilt - not easy, but essential!
- Plan the week before and the week after Christmas. I know that I will be fatigued after the big day, so I keep the following week completely free of obligations. I try to keep the week before as empty as possible too.

> *" I was a very energetic Christmas person, now I have to delegate – and that's fine "*

- Watch your diet. At this time of year, lots of sugary, starchy foods are going into our bodies and I find I don't cope well with this. Find out what foods make you worse and avoid if you can. Gluten free definitely makes a difference for me.
- If you are the cook in your family, make sure you keep some meals in the freezer for when you have no energy. Shop online, so you avoid the crowds and madness. I use my slow cooker a lot - put ingredients in the pot in the morning and it's ready for supper - job done.

Finally, some words of wisdom from a cousin of mine who has had chronic fatigue for many years:

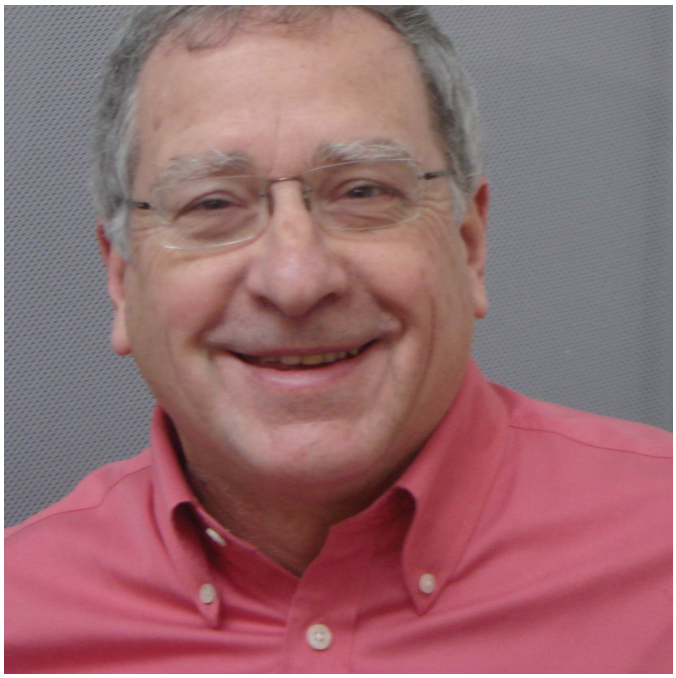


- Take wheat out your diet.
- Take 20-minute lie downs throughout the day
- Get comfortable with under performing!
- Dare to be average. If something's worth doing, it's worth doing badly
- Read.
- Sleep with earplugs.
- Wake up at exactly the same time each day.
- Silence.
- Low carbs
- Be kind to yourself

## Happy Christmas!

***What coping strategies have you found helpful? We'd love to hear from you, write to me annie.schofield@myelitis.org.uk and let us know what works for you.***

# MEET THE COMMITTEE -



## LEW GRAY, SECRETARY OF THE TMS

I was born in USA and still have a big family there. In 1974 I moved to the U.K., then 10 years later, by now with a young family, I got TM (T4 level). I was treated at National Hospital, Queens Square, London – before MRI was invented! I then received good rehab at the Wolfson Centre in Wimbledon, before getting back to work (in software) after 6 months.

Over the years I have deteriorated slowly from walking with 1 stick, to 2 sticks, shorter and shorter distances, to nearly full-time wheelchair use at home.

Back in pre-internet days, I helped to distribute TMA Newsletters by post in the UK and Europe. Then in 2004 I joined up with Sally Rodohan and Geoff Treglown to form the UK TM Society, and took on the role of Secretary. I handle the New Member's welcome packs, Members List, general correspondence and the new Neuro-Physio Bursary scheme.

I retired from work in 2005 and sadly was widowed in 2007 after 32 years of marriage. But now I have 2 little grandsons living in Sweden. One of them is disabled, and all the issues of raising a disabled child have been a real eye-opener for me. My main hobby is competitive bridge, and I also enjoy music of all kinds.

## SURVEY TO SET PRIORITIES FOR RESEARCH INTO TM

We often say we wish there was more research into treatment or prevention of spinal cord injuries caused by an accident or illness such as TM. Now a consortium of charities, which includes the TM Society, and medical professionals interested in spinal injury, have joined together to find out what people living with TM, their carers and healthcare professionals think are the right priorities for research in this area.

This consortium has designed a survey to capture your 'unanswered questions' regarding TM. For example, you could ask 'Why do people with TM keep getting recurrences?' or perhaps 'Which non-drug therapies are most effective for neuropathic pain?'

Your questions will then be prioritised into a Top 10 Priority List for researchers in early 2014. There is a good track record of these priorities being picked up for investigation. Using this method, patient priorities can drive research instead of financial considerations.

So help inform the research agenda in the UK and click here to complete the short survey - http://www.smsf.org.uk/sci-psp.html

The closing date is 9 December and it is open to any UK residents over the age of 18 who have TM.

## LAUNCH OF NEURO-PHYSIOTHERAPY BURSARY SCHEME IN 2014

Earlier this year, the TM Society piloted a neuro-physiotherapy bursary scheme where it paid for members to have an initial assessment and follow-up session with a physiotherapist who has experience working with people with neurological conditions, specifically TM.

We were delighted with participating members' feedback. The majority of participants reported that they found the treatment they received "hugely beneficial", the highest possible rating. During the sessions participants felt they improved their walking and balance. They were given useful exercises to increase strength and improve body movement. Participants also had the opportunity to try specialist equipment, including Functional Electrical Stimulation (FES).

The TM Society would now like to extend this scheme nationally to all UK-based members in 2014. Even after many years of living with TM, the neuro-physiotherapy pilot has shown that many of us could learn to improve our gait and/or balance, reduce stiffness and spasticity, improve sensation and even reduce pain.

The bursary will fund an initial assessment by a physiotherapist who specialises in working with people who have TM/ADEM/NMO (or MS) and a follow-up session afterwards. The intention is to equip you with the knowledge and exercises specific to your needs to help you maintain the benefits from those two sessions over the longer-term.

If you would like to take part in this scheme in 2014, please register your interest with Lew Gray at lew.gray@myelitis.org.uk.

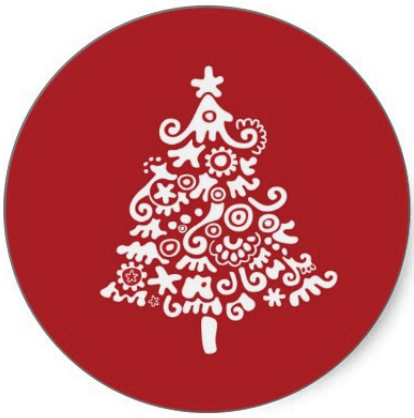
*Also, if you can recommend a physiotherapist who specialises in working with neurological conditions (TM/ADEM/NMO/MS), please send their details to Lew Gray at lew.gray@myelitis.org.uk.*

## HAVE YOUR SAY

The TMS Committee is interested in knowing what you think it should/could work on in 2014 for the benefit of TMS members. Please send your suggestions to

barbara.babcock@myelitis.org.uk. For a list of the 2013 priorities and suggested future priorities, click here -

http://www.myelitis.org.uk/uploads/1/5/8/2/15824690/2013_priorities__the_future_v3_2.pdf



# THANK YOU FOR YOUR SUPPORT

Thank You

MORE FUNDRAISING STORIES


***NADINE SHENTON ran the Royal Parks Half Marathon on 6th October raising money for the TMS. Here is her story***

' I am not a runner. However, lying on my hospital bed two years ago with TMS diagnosed and with great uncertainty ahead of me, I vowed that if i could walk out of the hospital and should my body gradually recover to whatever degree, I would one day participate in a race on behalf of TMS. So, for the last six months I have trained and prepared for a half marathon. It has not been easy with constant restrictions of TM demanding and dictating how i feel, race day finally arrived.

The weather was ideal, the crowds uplifting and loud. My running partners Prof Nick Peters, Cranial Facial surgeon Niall Kirkpatrick, together with his son Guy, were constant encouragement from start to finish. I completed my first half marathon in 2 hours 7 minutes feeling on top of the world.

I am so extremely thankful to many of you that have sponsored me and, so far, have raised over **£2767**.

Would I run the half marathon again.....

YES, most definitely'

## *Ian Farrow's Terrier Triumph*

Triumph's Edward Turner rode from Land's End to John O' Groats on a 149cc Triumph Terrier in 1953 as a publicity stunt. This year, a commemorative anniversary ride took place, following the same route - the Gaffer's Gallop. Following last minute preparations (including a complete rebuild of his Triumph, not to mention the small matter of passing his bike test) Ian Farrow joined the group. After his niece was struck by the condition earlier this year he wanted to raise money for the TMS, and his efforts raised £345.

Derek Viljoen and 6 friends will be running the GRIM Challenge on 30 November 2013, in memory of Derek's uncle who had TM. It's an 8-mile course over the British Army vehicle testing tracks. The run promises to be a very muddy affair! Their target is to raise £1500, and if you would like to donate, you can via Derek's Just Giving page - http://www.justgiving.com/Derek-Viljoen

*Our facebook page is now up to **624 members** – that's over half the entire membership of the TMS! Not only can you reach out to other members for advice and tips, it can also lead to some lively debates. And, it's a closed group. Search for Transverse Myelitis Society on facebook.com to join*

**find us on facebook**

# A NEW MENTORING SERVICE FROM THE BACK UP TRUST FOR TMS MEMBERS

## A problem shared is a problem halved

Back Up is a national charity that helps rebuild lives following a spinal cord injury, through a range of services that improve confidence and independence; this includes support for people whose spinal cord has been damaged through Transverse Myelitis. Back Up understands that spinal cord damage can be devastating, but believe it should not prevent anyone from getting the most out of life. Their accredited mentoring service links people who have spinal cord injuries, including those affected by Transverse Myelitis, with a trained volunteer mentor or family member with relevant life experiences so they can discuss the issues that matter to them.

This service is open to both those affected by Transverse Myelitis and their family members.

***"The mentoring service has helped me to grow in confidence and filled me with hope for the future. I am no longer so angry, scared and frustrated. I see a massive difference in myself from the day I called Back Up and how I am now. I did not think that such changes could happen only through mentoring, but it has helped so much."*** Alexandra, mentee

Back Up's mentors come from all walks of life and depending on whether you have TM or are a relative of someone who has, you will be connected with a mentor with TM or family mentor whose life experiences are relevant to you. Back Up makes every effort to match you with a mentor or family mentor whose experience has been similar to yours.

Once Back Up has matched you with a mentor you and your mentor will arrange how often your mentor makes contact and whether you speak regularly over the telephone, or if possible meet up. Most mentoring relationships take place over 10 sessions and can cover issues including the following:

- Adjusting to life with Transverse Myelitis
- Gaining confidence after the onset of or changes in Transverse Myelitis
- Going back to education or work
- Finding out about activities and sports
- Being a parent with transverse myelitis or starting a family
- Increasing independence and wellbeing

For more information about the mentoring service, please email or call ***Justin Layzell*** at the Backup Trust.

***justin@backuptrust.org.uk***
***020-8875-1805***

## Are you interested in volunteering as a mentor with Back Up?

The Back Up mentoring service is accepting applications from people interested in becoming mentors, whether you have Transverse Myelitis, or are a partner, parent or adult sibling of someone with Transverse Myelitis.

For more information about being a mentor and how to apply, go to http://www.backuptrust.org.uk/about-us/volunteering/mentor or contact Justin Layzell.

The next training weekends will be

- For partners, parents and adult siblings who wish to become family mentors – March 2014
- For people with Transverse Myelitis who wish to become adult mentors – May 2014

# LOSS AND GRIEF

## A LOOK AT SOME OF THE PSYCHOLOGICAL IMPACTS OF TM

**Isabel Moloney, Consultant Clinical Psychologist, looks at an important issue which often arises with people who have a long term physical health problem, the experience of loss and grieving**

### *Experiencing loss and grieving*

Developing a physical health problem such as TM is like any other unwelcome and unwanted event in your life. No matter what the event is - it could be losing your job, the break-up of a relationship, moving house, losing the chance of a future hope, or as in this case becoming unwell, each of these losses will need to be recognised and grieved for. Grieving often happens naturally, in its own time and at its own pace, although that's not to say it's easy. People often know, when asked, if they have been able to grieve or not.

What does normal grief look like?

Normal grief is usually thought of as having phases which people move through, or in and out of although it's rarely as tidy as the descriptions suggest. First there tends to be shock, disbelief,

> ***" Developing a health problem such as TM is like any other unwelcome and unwanted event in your life. . . each loss will need to be recognised and grieved for"***

confusion or emotional numbness. This stage acts like a buffer to protect you from taking in the full picture before you are ready. In the short term it is protective, but if it goes on for too long it may start to cause problems itself, and we might begin to refer to it as denial. Usually this temporary "buffer" stage passes, and the person starts to grieve more actively as the reality of the loss sinks in. This is the time when feelings such as sadness, crying, anger, anxiety and fear are most in evidence. This is the time when the necessary processing of the loss happens. We also say that the work of grieving is happening. Support from others - family, friends and if needed professional helpers who can just listen, and accept the distress is important. Distress comes in waves which settle once expressed or shared. In between waves, a person may feel

normal or nearly so. Gradually the strength of the waves settles down as the grieving runs its course. A person may realise that they have started to remember good, as well as difficult memories, and can focus on other things. Looking ahead with optimism can feel easier. The last phase of finding a new way forward includes picking up the threads of normal life as far as possible, for some it can also create new opportunities.

### *How long does grieving take?*

It varies, depending on how someone was given and received their diagnosis, the severity of the event, and its meaning for the person, how strong their support network is, the number of secondary losses, and the amount of other unrelated stresses going on.

### *Have I grieved, do I still need to grieve?*

Try asking yourself these questions:

"Have I grieved or come to terms with the diagnosis or the changes and losses it has brought?"

> ***" if you feel stuck, or wonder whether the initial shock has turned into longer term denial don't worry, because there is effective support available"***

If you have come through grief for other losses before this, is your reaction familiar?

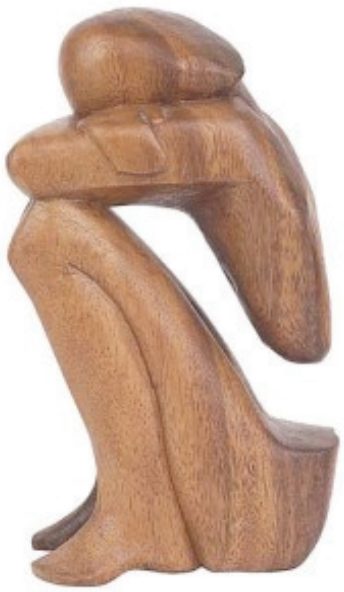
"Have I got the support I need from others?"

"Am I able to let myself get upset when I feel it and share this with my friends and family?"

"Do I have times when the feelings of distress well up, followed by settling down afterwards?"

If the answers to these are all, or mostly "Yes" then it sounds as if grieving has already, or is resolving naturally. On the other hand, if you feel stuck, or wonder whether the initial shock has turned into longer term denial, or your answers are more "No" than "Yes", then don't worry, because there is effective support available. Your health professionals, including your GP, Consultant, and their associated staff teams are used to helping people who need a bit of extra support, and just a bit more time. They may suggest meeting with a health professional who can offer help - a practice counsellor or a trained therapist from the primary care mental health service.

If this article has raised issues for you, I would encourage you to ask for help. Often starting with your GP is the best place. The support described works, and will allow many people to move on from grief into ways of living well despite the TM.



# NEWS FROM THE UK SUPPORT GROUPS

FIND OUT WHAT'S HAPPENING AT A SUPPORT GROUP NEAR YOU

## YORK SUPPORT GROUP

FIRST SUPPORT GROUP MEETING: ***SATURDAY 16TH NOVEMBER 3-5PM***

Venue: Acomb Methodist Church. 20 Front Street, York YO24 3BX For further details: Contact: Janet Ashenden jan.nig@tiscali.co.uk

## NORTH EAST SUPPORT GROUP

NEXT SUPPORT GROUP MEETING(S): ***SATURDAY 22ND MARCH 2PM***

Our first meeting went really well. 14 people attended, blue ribbons were handed out to all, and everyone had a great time

Venue: Walter Best Hall (within Cornerstones), Chester-le-Street Methodist Church, North Burns, Chester-le-Street,DH3 3TF

www.cornerstonescentre.co.uk. Cornerstones is situated in the centre of Chester-le-Street and has full disabled access including provision of Changing Places facilities for people with severe disabilities.

Car parking is available within the town at a rate of £1.10 per day indicated by the P on the map.

For further details: Contact Doreen Cawthorne, doreencawthorne@btinternet.com, phone 0191 419 3161 or 07737 705458

## LONDON SUPPORT GROUP

NEXT SUPPORT GROUP MEETING(S): ***SATURDAY 18TH JANUARY 2PM***

At our last meeting Joy Sinclair from the Spinal Injuries Association spoke to us about the ways in which the SIA could support TM patients and, 'Adapting to life with TM in later life'. Look out for her presentation notes on the website

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. We are a short 3-4 min walk from King's Cross Station.

For further details contact Yvonne Kolesar, Yvonne.Kolesar@myelitis.org.uk, Tel. 01737 552869

## SOUTH EAST SUPPORT GROUP

NEXT SUPPORT GROUP MEETING(S): ***SATURDAY 7TH DECEMBER (CHRISTMAS LUNCH) AT 12.00 & SATURDAY 15TH MARCH 2.00PM***

Our annual Christmas lunch has proved to be a real hit with our members. So why not come along and enjoy a great social occasion.

Venue: Pembury Village Hall, High Street, Pembury, Kent TN2 4PH. It is wheelchair friendly with disabled toilets. 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, Tel: 01435 864 662

## EXETER SUPPORT GROUP

NEXT SUPPORT GROUP MEETING(S): ***SATURDAY 9TH NOVEMBER 1.00 -3.00PM.***

Venue: Holiday Inn Express Exeter,Guardian Road, Exeter EX1 3PE The meetings will take place in the main reception area. For directions go to: http://supportgroups.myelitis.org.uk/exeter. For further details contact Rob Reeves, rreeves@myelitis.org.uk

# NEWS FROM THE UK SUPPORT GROUPS

FIND OUT WHAT'S HAPPENING AT A SUPPORT GROUP NEAR YOU

## POOLE/BOURNEMOUTH SUPPORT GROUP

NEXT SUPPORT GROUP MEETING(S): ***SATURDAY 18TH JANUARY 2.00PM & 19 APRIL 2.00PM***

Venue: The Multiple Sclerosis Society Bournemouth Branch, The Osborne Centre, Church Lane, West Parley, Ferndown, Dorset, BH22 8TS For further details contact Group Leader: Lance Harris, lv.harris@hotmail.com, or Secretary Barbara Houston 01425 673173 barbs@houston19.freeserve.co.uk

## BRISTOL SUPPORT GROUP

NEXT SUPPORT GROUP MEETING(S): ***SUNDAY 8TH DECEMBER 1-3PM***

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 SUPPORT GROUP MEETING(S): ***SATURDAY 15TH MARCH 2-4PM***

We hope to have a speaker on fatigue management.

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

## TELFORD SUPPORT GROUP

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

## TRANSVERSE MYELITIS SCOTLAND

NEXT SUPPORT GROUP MEETING(S): ***SATURDAY 23RD NOVEMBER AT 1.30PM***

This will be a Pot Luck Luncheon where each member is asked to bring along some finger food to share e.g. sandwich/quiche/ sausage rolls/crisps/fruit etc. It will be a social gathering and we hope many of you will be able to attend for a catch up before the Christmas festivities begin

Venue: Conference Room, Philipshill Ward, Spinal Injuries Unit, Southern General Hospital, 1145 Govan Road, Glasgow G51 4TF

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

Zelda Carr and Katy Measey are looking to set up an Oxford Support group. The first meeting is planned for Spring 2014, and we would like to hear from anyone in the region who has suggestions for locations, or would like to assist with arranging the first meeting. Please contact Zelda on zelda@cqc-ltd.com, or 07795 155205.

# 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 Barbara Babcock
(chair) barbara.babcock@myelitis.org.uk
Lew Gray (Secr) 020 8568 0350
Email: lewgray@blueyonder.co.uk

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