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MS-UK's bi-monthly magazine

July/August 2013 | Issue 80

new Pathways

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"SO MUCH FREEDOM & EXERCISE!"

Page 24



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- Pain Therapy Page 18
- My Constant Shadow Page 26
- Walking back to happiness Page 38

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Crossword Answers

Dear readers,

We like to tell you about things which can make a real difference to MS symptoms. Pain is one of them. Until now, the only answer was drugs. But now, a new machine being tested in Bedford offers substantial relief from pain. You can read how it works and the excellent results it's been getting on pages 18-20.

When Jerry Hartley told his neurologist he was suffering from constipation, she waved away his concerns. So he took it upon himself to find ways to get things moving. You can read his excellent tips to relieve uncomfortable constipation on pages 44 and 45.

We're told that you can't reverse MS. But the philosophy of New Pathways is to challenge that, and to feature people who challenge that too. One of these is Janet Orchard, who would not accept her neurologist's prediction that she would never get out of her wheelchair and walk again. She devoted three months to a gruelling programme of daily physiotherapy and exercises. Now she can walk, one step at a time, holding on to handrails. Read her inspirational story on pages 40-42.

As I write this, the long awaited summer is here with a vengeance and I am surrounded by high-power fans. But what else can you do to keep cool in the heat? In our Tried & Tested article on pages 28 and 29 we give reviews (good ones!) about a new cooling towel and cooling vest, with a Reader Offer.

We all know that having MS can confront you with some very tough moral decisions. On pages 24-26 we grasp the nettle of Moving On. What does a partner do when the one with MS becomes very ill? In one case, a husband chose to find a new partner; in another, a devoted wife stayed until the end. We welcome your own experiences of Moving On.

When actor Chris Briggs could no longer go on stage due to MS, he wanted to use his creative talents to do something to help others with MS.

By chance, he came across a French young woman with a beautiful voice, and between them they created a CD called 'My Constant Shadow', full of soothing lyrics and music. Read the full story on pages 26 and 27.

To turn heads, all Maire Masterson has to do is ride her very snazzy trike. Not only does she and it look great, the trike also gives her endless hours of exercise and pleasure. Read her article on pages 24 and 25.

Does the supplement Acetyl-L-Carnitine give you energy? Can Reflexology help MS? And who can you turn to if you're having relationship problems. Answers on pages 30 and 31 in the Q&A from MS-UK's Information & Advice team.

Plus we have a bumper crop of News, an interesting Postbag, a challenging Cryptic Crossword, a nice holiday spot in Elba, a feature on Mums with MS, a very healthy kale smoothie recipe, a Reader Giveaway and much more!

Best wishes,



Judy Graham
Editor

Do you have something that you would like to share with our readers?

We would love to hear your news, views and stories and share them with others who are affected by multiple sclerosis (MS).

Whether you have MS yourself or care for someone who does, your story could help us raise awareness of MS and ease someone into feeling that they are not alone.

It's really easy to share your news and experiences with us. Simply email info@ms-uk.org or call us on 01206 226500.

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MEDICOTECH

News

High MS rates in dairy workers

Dairy workers have higher rates of MS than people who work in other occupations, according to a large scale study carried out in Denmark. This is believed to be the first study to show an increased risk of MS among those working in the dairy industry. Previous studies have linked MS to drinking cows' milk.

The new study, done in Copenhagen, looked at rates of MS among workers enrolled in a pension fund that insures more than 300,000 Danish workers against critical illness.

Between 2002 and 2011, 389 people in PensionDenmark were diagnosed with MS. The highest rate of MS was among agricultural workers, and dairy workers were twice as likely to develop MS as other workers.

The new study builds on other research which has shown a link between cows' milk and MS. A study published in the journal *Virology* in 1992 found a correlation between cows' milk and MS. The link appeared to be lower as the milk was processed. There was a low but still significant correlation with MS and eating cream or butter. No link was found between eating cheese and MS.



Source:

(1) *Effect of occupation on risk of developing MS: an insurance cohort study.* Horwitz H et al, *BMJ Open* 2013 Jun 20;3(6). pii: e002894. doi: 10.1136/bmjopen-2013-002894. Print 2013

(2) *Correlation between milk and dairy product consumption and multiple sclerosis prevalence: a worldwide study.* Malosse D et al, *Virology* 1992;11(4-6):304-12

'Holy grail' discovery - immune system successfully re-set

The 'Holy Grail' of MS research – how to stop auto-immune responses while keeping the normal function of the immune system intact – has been discovered by an international team of researchers. The immune systems of nine MS patients were successfully 're-set', reducing their abnormal reaction to myelin by up to 75 per cent.

Specially processed white blood cells delivered billions of myelin particles into the bodies of the MS patients. The patients' immune systems then recognised myelin as harmless and developed tolerance to it. Patients who received the highest dose of the specially processed white blood cells had the greatest reduction in myelin reactivity.

Most importantly, the white blood cells did not reactivate the patients' disease and did not affect their immune reaction to genuine invaders. The research was led by Professor Stephen Miller of the Northwestern University Feinberg School of Medicine in the USA.

"The therapy stops autoimmune responses that are already activated and prevents the activation of new autoimmune cells," said Professor Miller. "Our approach leaves the function of the normal immune system intact. That's the Holy Grail," he added.

The study sets the stage for a larger phase 2 trial to see if the new treatment can prevent the progression of MS. Scientists are currently trying to raise \$1.5 million to launch such a trial.

Source:

(1) *Northwestern University Feinberg School of Medicine press release (11/06/13)* http://www.feinberg.northwestern.edu/news/2013/06/ms_breakthrough.html

(2) *Antigen-specific tolerance by autologous myelin Peptide-coupled cells: a phase 1 trial in multiple sclerosis.* Miller SD et al, *Science Translational Medicine* 2013 Jun 5;5(188):188ra75. doi: 10.1126/scitranslmed.3006168

Toxin test for smokers adapted for MS

A test developed to measure acrolein, a toxin found in smokers has been adapted to measure the same toxin in people with MS. This may offer a new tool for monitoring and treating the illness.

Detecting and measuring acrolein in a non-invasive way represents a major new treatment advance as drugs have been developed which can reduce levels of the toxin.

In MS acrolein damages the myelin sheath surrounding a nerve cell's axon, preventing nerves from properly conducting electrical impulses. It also damages mitochondria, which provide energy for cells, say scientists from Purdue University, USA. Acrolein causes further harm by reacting with proteins and lipids that make up nerve cells.

Two drugs, hydralazine and phenelzine, have been shown to be effective in reducing acrolein levels. They are approved by the U.S. Food and Drug Administration (FDA) for hypertension and depression.

In laboratory animals, hydralazine has been shown to delay onset of an animal model of MS for several days,



which could mean several years in humans. Tests with animals also suggest the drug could help to reduce the most severe symptoms once the disease has progressed.

Source:

Determination of urine 3-HPMA, a stable acrolein metabolite in rat model of spinal cord injury. Zheng L et al, *Journal of Neurotrauma* 2013 May 22. [Epub ahead of print] <http://www.ncbi.nlm.nih.gov/pubmed/?term=Lingxing+Zheng%2C+Jonghyuck+Park%2C++Walls+M++Tully+M>

Background information: MS, Acrolein & Lipid Peroxidation

Acrolein is a toxin produced by cigarette smoke and air pollutants such as car fumes and burning oil. It is also created inside the body when nerve cells are damaged. The finding that it may be a contributory cause in MS was discovered in 2010 by the same team at Purdue University in the USA as the above reference.

Researchers believe acrolein is partly responsible for the dismantling of the myelin as well as inducing the creation of free radicals, compounds that cause further injury to tissues that are already damaged due to trauma or disease.

Although the drugs hydralazine and phenelzine were effective in laboratory mice, they can have worrying side effects in humans. Scientists are now looking for drugs with a similar chemical structure but without the harmful side effects.

Are there natural ways to stop Lipid Peroxidation?

There may be more natural ways to stop lipid peroxidation. Possibilities include hesperidin, a natural citrus flavonoglycoside, anti-oxidants including natural vitamin E, resveratrol, glutathione, vitamin C, some herbs such as



basil and oregano, spices such as turmeric (curcumin), and plants such as green tea, pycnogenol (from the bark of the maritime pine), salvia, and mangrove (avicennia officinalis). Practitioners of Ayurvedic Medicine and Traditional Chinese Medicine (TCM) may use herbs and bark etc with powerful antioxidant properties when treating patients with MS.

Abstract from the 2011 Research Into Acrolein and MS:

Oxidative stress is considered a major contributor in the pathology of multiple sclerosis (MS). Acrolein, a highly reactive aldehyde byproduct of lipid peroxidation, is thought to perpetuate oxidative stress. In this study, we aimed to determine the role of acrolein in an animal model of MS, experimental autoimmune encephalomyelitis (EAE) mice. We have demonstrated a significant elevation of acrolein protein adduct levels in EAE mouse spinal cord. Hydralazine, a known acrolein scavenger, significantly improved behavioral outcomes and lessened myelin damage in spinal cord. We postulate that acrolein is an important pathological factor and likely a novel therapeutic target in MS.

Source:

Anti-acrolein Treatment Improves Behavioral Outcome and Alleviates Myelin Damage in EAE Mouse. Gary Leung¹, et al, *Neuroscience*. 2011 January 26; 173: 150–155.



High vitamin D levels link to low disease activity in patients taking Betaferon

Higher vitamin D levels in MS patients taking Betaferon are linked to a decrease in the number of lesions found in their brains, indicating low levels of MS disease activity.

These results come from a study called BENEFIT - Betaferon in Newly Emerging MS For Initial Treatment which looked at clinical data from 468 patients with Clinically Isolated Syndrome who were taking Betaferon.

The researchers noted that the highest levels of vitamin D among Betaferon patients were associated with the lowest number of lesion counts. 'There is about a 57% reduced risk of new lesions with every 50 nmol/liter increase in vitamin D,' said study author Kassandra L. Munger. She said the results suggested that higher levels of vitamin D were contributing something to the lower lesion counts found in the patients.

Source:

25-Hydroxyvitamin D and MS Activity During Therapy with Interferon Beta-1b (Poster DX10, May 30, 2013) Munger K et al

5th Cooperative Meeting of the Consortium of Multiple Sclerosis Centers (CMSC) and the Americas Committee for Treatment and Research in Multiple Sclerosis (ACTRIMS). <https://cmscactrims.confex.com/cmscactrims/2013/webprogram/Paper1448.html>

New drug relieves constipation but can cause Diarrhoea.

A new drug treatment for constipation in MS increased bowel movements in a small group of patients. However, in a few cases the drug was too effective, resulting in diarrhoea.

Lubiprostone (Amitiza) is approved in the US for relieving chronic constipation in conditions such as irritable bowel syndrome. A trial looked at whether this drug would help to relieve MS-related constipation. 20 MS patients were given the drug twice daily for three weeks.

BG-12 - significant improvements in quality of life

People with MS who took the new pill BG-12 (dimethyl fumarate) for six months saw major improvements in their physical health and wellbeing compared to those who took a placebo. It is thought the drug modulates the immune system, promoting anti-inflammatory activity. It also has antioxidant and neuro-protective properties. BG-12, which has been used for decades as a treatment for psoriasis, was approved by the US Food and Drug Administration as a treatment for relapsing remitting MS earlier this year. BG-12 is expected to be available in Europe later in 2013.

In a study 733 patients with relapsing remitting MS completed a health survey, answering 36 questions about their health and wellbeing after taking BG-12 for 6, 12 and 24 months. They also completed a quality of life survey. Those taking BG-12 reported significant improvements in physical and mental functioning, whereas those taking a placebo got worse.

Source:

5th Cooperative Meeting of the Consortium of Multiple Sclerosis Centers (CMSC) and Americas Committee for Treatment and Research in Multiple Sclerosis (ACTRIMS). Poster SX18. Presented May 30, 2013.



A further 20 received a placebo or dummy drug. Among those taking Lubiprostone the rate of spontaneous bowel movements more than tripled. However, three patients taking suffered from diarrhoea, suggesting that Lubiprostone may have been too effective.

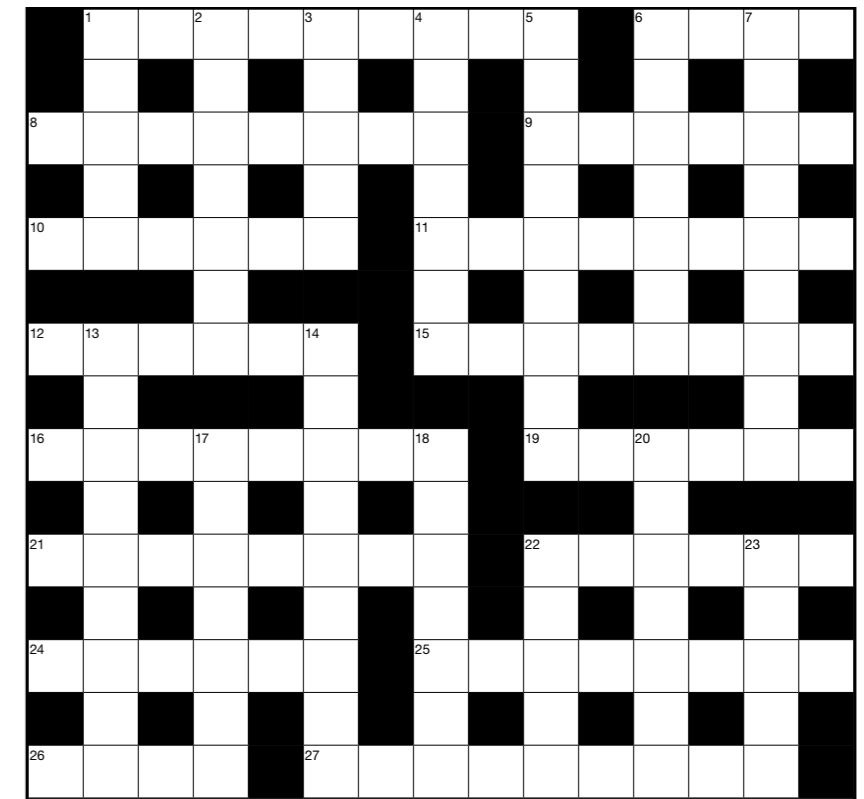
Source:

"Lubiprostone for multiple sclerosis-associated constipation" Irish C, et al. CMSC-ACTRIMS 2013; Abstract SX16.

Cryptic Crossword

By Charlie Gee

Answers, with some explanations on page 54.



CLUES

ACROSS

1. Drawings, of Mickey or Donald possibly. [9]
6. Miller perhaps or a secluded valley. [4]
8. Is opener revamped and they are the first? [8]
9. Rearrange danger, you'll dig this! [6]
10. A cocktail of lemonade and champagne or a plant [6]
11. Reputation or influence arising from success, Peg tries to disperse. [8]
12. Humbug! [6]
15. Disliked intensely when Ed tested for a change. [8]
16. They are mostly below the water. [8]
19. If need changes explain the meaning of a word. [6]

21. When I see an elephant fly! [5, 3]
22. On bail abroad lacking pigment. [6]
24. A starry girl. [5]
25. Irish tin for breaking to get an inflammation of the nose. [8]
26. Julius Caesar was told to beware them. [4]
27. Can be found on the coast of northern Russia or Gabriel maybe. [9]

DOWN

1. Liberal is bounded by major road to get a proof of innocence. [5]
2. He told of a bladder soothing tea in the last issue. [3,4]
3. The centre of an amphitheatre is found in Karen and Julie's home town. [5]

4. Bland is in dip around. [7]
5. No attention is paid to when decent leg is fractured. [9]
6. The outside of Germany before taxes of a sort and moves in a circle or spiral [7]
7. This type of tree is always naïve by the sound of it. [9]
13. Vast numbers cut undone for reorganizing. [9]
14. Pot which in my experience helps with MS [9]
17. In the words of the song, like my dreams they fade and die. [7.]
18. Ironical taunting behaviour racist I for redevelopment. (7)
20. Telling porkies! [7]
- 22 and 23 down.
She said that practising Energy Medicine helped her MS in the last issue. [5,5]
23. See 22 down

Postbag Your Letters

Do you have something to say or helpful information to pass on? Whether it's gripes and groans, a pat on the back, or hints and tips, we'd love to hear from you. Please write to: New Pathways, MS-UK, Unsworth House, Hythe Quay, Colchester, Essex, CO2 8JF Tel: 01206 226500 Fax: 01206 863721 Freephone: 0800 783 0518 email: info@ms-uk.org

Assisted suicide

Dear New Pathways,

I enjoyed reading my latest edition of New Pathways but felt I must write in response to your feature on Assisted Suicide. At the top of your Postbag page you encourage readers to pass on gripes and groans as well as complimentary notes and I do hope you decide to print my letter.

I have lived with MS for over 20 years and fully understand the depths it can take you to. As a writer I have contributed to a number of MS related publications including academic journals and been privileged to write about MS from 'both sides of the fence' and meet a wide variety of people with all types of MS.

We all experience our MS differently and have our own unique coping strategies, personalities and opinions. It is vital that any publication aimed at people affected by MS - directly or indirectly - offers balanced editorial content on sensitive issues. I would like to have seen two contrasting case studies used in this feature in order to provide this essential balance of opinion.

Kind regards,

Leonie Martin,
Derbyshire

Ed says: Thank you Leonie. The article on Assisted Death was not in Postbag. It was a topical news story based on the fact that these two men with MS are attempting to challenge the law. Had there been other people with MS who were making the journey to London to present the other side of the story, of course we would have reported this. I take your point about fairness and balance, but would state that - over several issues - we have covered both sides of this story fairly and will continue to do so.

Ginger beer helps my UTI

Dear New Pathways,

I have MS. When I have a UTI, drinking Crabbies alcoholic ginger beer seems to make a difference. I have a catheter so I can see if my urine is cloudy because of the transparent tube to my bed bag. (If I have a UTI, my urine becomes cloudy).

I would not take antibiotics for a UTI.

Yours sincerely,

R M Ventom,
Lowestoft,
Suffolk



Anyone taking Propax Gold?

Dear New Pathways,

I would like to know if any of your readers have taken the nutritional supplement Propax Gold with Ntfactor plus Resveratrol & Co-Q10. I have been taking it for six months. I got it from a UK company called Natural Dispensary (www.naturaldispensary.co.uk). It costs me about £80 a month.



I saw a nutritionist who told me it helps repair myelin and that it works at a cellular level. I also read the self-help guide on MS which talks about supplements and diet.

I am still waiting for this product to help me with walking or getting back to normal. The eye hospital told me my eyesight has improved and am waiting for the results of an OCT test.

If anyone is taking Propax Gold, I would like to know if it helped and how long it was before you noticed any difference.

Regards,

Anne Moon

Ed says: If anyone is taking this supplement, please send your comments to us and we

will publish them in a future issue. info@ms-uk.org According to websites which sell this product, Propax Gold contains a wide range of vitamins, minerals, amino acids, essential fatty acids, antioxidants including resveratrol, and other nutrients including Co Enzyme Q10. It also has something called 'NT Factor', a name they have trademarked which is based on their company name, Nutritional Therapeutics, which is based in New York state, USA. Their website states: "NT Factor is made up of food components and a nutrient that most closely matches the primary nutrient found in the cell membranes throughout our bodies." It seems to do this through lipids - essential fats. It says that NT Factor includes phospholipids from soy, 1560 mg. The claims it makes for itself are that it "reduces fatigue by over 40%, repairs cellular damage, reverses the effects of ageing such as hearing loss." If you look at the individual ingredients of Propax Gold, some of them - such as Vitamin D - are lower than someone with MS should be taking. Propax Gold contains 333.33 IU Vitamin D, whereas the ideal dose in MS is 4,000 - 10,000 IU a day - a big difference! This product is very expensive! £88.71 for 60 packets. It is cheaper in the US. I am pretty sure it would be possible to buy all the individual ingredients from a UK supplier at doses suitable for MS, for less. You can easily buy essential fatty acids - which help with cell membranes - individually, including high dose marine oil and evening primrose oil - Judy Graham, Editor.

Getting it up - this works!!!

I must have ticked the box that means you get sent tons of junk mail. One leaflet I received for 'Erexin' had some bold claims so I decided to try it. You spray it on the penis and rub it in. IT ACTUALLY WORKS. I haven't seen my John Thomas that angry for a long time! Google 'Erexin' to get lots of hits, as they don't have their own website, that I could find. Erexin spray comes from a company based in Jersey called Regal Health. Tel 0845 - 166- 7070. A 50ml bottle costs £14.99; two cost £29.98.

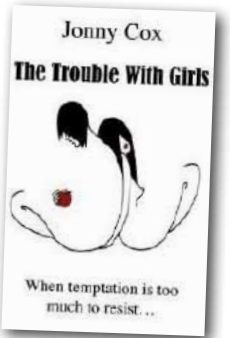


I also bought some Natural Hero Ginger muscle rub that Amazon pushed my way. It is very effective at softening the muscle tissue in my calves and does significantly reduce the stiffness that can be painful. It is not greasy, is easily absorbed and smells nice. It is a bit pricey. I also inadvertently (honestly) found that it helps with Trouble With Girls (ie inability to get it up). It stings a bit but does promote the desired response.

All I needed then was a willing wife, I'm sure I had one. Ah, too late. One of the other things I have recently discovered is that dealing with my MS is too much for my wife; it constrains her life too much.

At least this provides the sequel to my book 'The Trouble With Girls'. I was going to call the sequel 'Taming the Beast', the premise being that

love can endure over any adversity, even MS. But the sequel is now entitled 'King Solomon Was Right: it is better to live in the wilderness than with an angry or contentious woman.' Proverbs: Ch21, v19.



Yours,

Lt Col. Jerry Hartley,
Bedfordshire.

http://www.amazon.co.uk/Trouble-Girls-Jonny-Cox/dp/1909039845/ref=sr_1_1?s=books&ie=UTF8&qid=1346145616&sr=1-1

How are you? Pleasantry or platitude?

Dear New Pathways,

Having a complex, degenerative and incurable illness inevitably changes one's perspectives on life. At first, when somebody would ask "how are you?" I would answer in the normal sort of way with something anodyne like, "fine, and you?" But the lack of honesty in such a response began to grate on my conscience.

I have symptoms which - to say the least - make life a lot more challenging in a variety of pretty unwelcome ways (although the last thing I want is sympathy or least of all, mollycoddling - doubtless an atavistic male inadequacy, but there you are).

I decided to be a little more honest when people asked how I was. Depending on how I was feeling and what had happened recently, the responses would range from the bland "not so bad thanks" to "pretty

>>



average" if I was trying to be funny, to "pretty awful actually". With true British stoicism when things were bad, it may have been "could be better", or, if I was feeling particularly peeved – "you really don't want to know."

When people really do want to know why you're feeling pretty awful, the quandary is, do I give them chapter and verse, take 15 minutes and sound like the hypochondriac I'm most definitely not, or do I fob them off? For me, this has become a tricky question when it's not meant to be and shouldn't be so. Best distinguish between the quick pleasantries and the question born out of understanding and genuine concern from those in the know, as it were.

Having written this, I'm all too aware of the thousands of times I've greeted somebody with "how are you" without the slightest regard of what I'm really saying. Now of course I'm more circumspect because I know that the answer may not be what I expect or can easily deal with.

But my somewhat addled brain can't come up with a good alternative, other than just saying "hello" when I really just mean to say that and saving the "how are you" for when the time and occasion warrants it.

Now, when somebody asks "how are you?" I'll hope to know in what mode they are asking the question and answer appropriately.

Come what may, I certainly won't

be saying the standard greeting attributed to psychologists: "hello, how am I?"

Good Wishes,

**Nigel Bartram,
France**

Well done Istanbul - Ataturk Airport!!!

Dear New Pathways,

Recently, I decided to visit my in-laws in Aden in Yemen. As I have MS, all my journeys need careful planning, but I knew this one would need more thought than usual as it would be the first time I would be travelling with my mobility scooter. On previous occasions I was able to walk with crutches. My wife and son were already there, so I would be travelling by myself.

I would be flying with Turkish Airlines via Istanbul Airport, a place I had never been to so didn't know what to expect. I made sure the airline knew that I was a disabled passenger and would be taking my scooter right up to the plane door. I sent emails, told them I had the right sort of battery, and even went to Manchester Airport beforehand to make sure my scooter would be okay.

On the day of travel I made sure I brought the emails with me. The service was great! Turkish Airlines together with Manchester Airport made sure that people at the gate knew I was coming and what the procedure was with me and my scooter. It was good to see the care they both gave to disabled passengers. This was very reassuring and gave me peace of mind at the start of my journey - just what I needed.

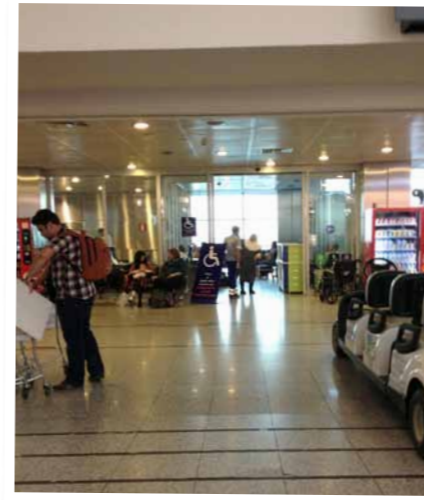
At the gate I was pleased to see a couple of other wheelchair users and some airport employees who were there to help us. As advised, I

was able to take my scooter up to the plane door. I told the relevant people that on arrival I would need my scooter to be brought right up to the plane door, and not with the rest of the luggage. (IMPORTANT!)

Once inside the plane, at my request I was given a seat near the toilet. All my needs were taken care of and I was offered assistance when going to the toilet. The staff were very good and showed empathy. As we were about to land, I made sure the cabin crew knew the request about my scooter.

At Istanbul Airport one of the service staff from the Port Clinic (the people who look after passengers) came straight to where I was sitting on the plane and told me and the other disabled passengers what would happen. He said they were getting my scooter from the plane's hold. This man was very good, making sure he knew where we were all going and whether, like me, we had a connecting flight. His English was good and he was polite and courteous.

To get all the disabled passengers off the plane, they used a piece of machinery which lifts you from the plane to ground level. In the terminal, I was okay to use my scooter, but wheelchair users and those with walking difficulties had escorts who helped them. Once again staff were organised, they knew where we had to go and how to get there.



Istanbul Airport is very modern, bright, busy and clean but from what I saw it is completely accessible, with disabled toilets. Generally signage is very good and in English too! I also noticed a number of info points,

which can be used if required. There is a special waiting area for disabled passengers, clearly marked. From here I was escorted to the gate and on to the plane for the next part of my journey.

Overall I was thrilled with Istanbul Ataturk Airport! Before I travelled I was very apprehensive and worried about facilities and if I would be able to use them, but was more than happy with them.

Well done Istanbul - Ataturk Airport!!! I also had a fantastic experience with Turkish Airlines and would certainly use them again.

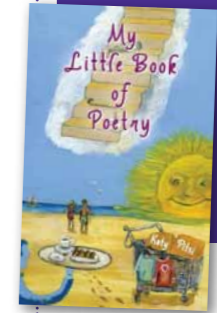
Good Wishes,

Kaz Laljee

POEM BOOK

Katy Pitsi has published a book of her poetry. She says: "This is a selection of my poetry and short verse collected over the years; some happy, some funny, some soppy and sentimental,

some inspiring and uplifting, and some just plain silly! A few are also written taken from the view of my disability, MS. Multiple sclerosis.



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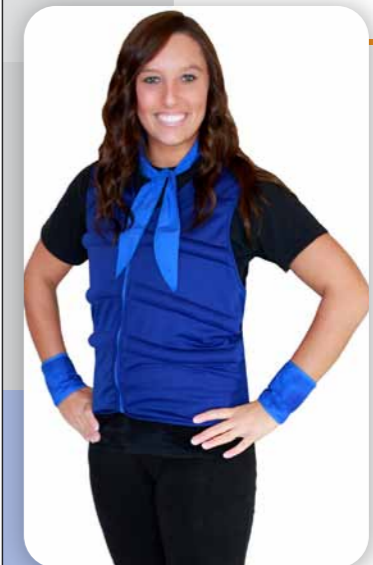
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News *contd.*

Stress and MS link – new study

A study into stress and MS has found that major negative stressful events can lead to an increased risk of new MS brain lesions, whereas positive stressful events like winning the lottery can lead to a decreased risk. Stressful life events have long been suspected of contributing to MS disease activity, but the new study is larger and more sophisticated than previous ones.

More than 100 patients were given MRI scans every eight weeks during the 48 week study. A total of 121 people with MS completed a questionnaire assessing stressful life events. They reported any stress, anxiety and depressive symptoms, which were then used to predict the presence of gadolinium-enhancing (Gd+) and T2 lesions on MRI scans 29-62 days later. Major negative stressful events typically led to new or enlarging MS brain lesions whereas positive stressful events led to a decrease in new lesions.



Source:

Do positive or negative stressful events predict the development of new brain lesions in people with multiple sclerosis?
Burns MN
Psychological Medicine May 17:1-11. 2013 [Epub ahead of print]

Myelin skin patches reduce relapses and stop progression

A myelin skin patch reduced the number of MS relapses and in some cases completely stopped disease progression, according to Polish research carried out on 30 MS patients. Scientists looked at whether wearing myelin skin patches on the upper arm could sensitise the body to myelin and persuade the immune system to stop attacking it. The myelin skin patches are made from three proteins thought to be autoimmune targets in MS - myelin basic protein (MBP), proteolipid protein (PLP), and myelin oligodendrocyte glycoprotein (MOG).

Sixteen patients wore low dose patches, 4 wore high dose patches, and 10 wore placebo patches. They were then switched around. The patches all looked the same and neither the patients nor the medical staff knew who was on what.

Patch wearers showed the best results with no relapses and less disability progression. The low dose patch more effective than the high dose one.

Source:

1. Transdermal application of myelin peptides in multiple sclerosis treatment,
Walczak A, et al
JAMA Neurol 2013; DOI: 10.1001/jamaneurol.2013.3022;

Jack Osbourne adopts special diet to fight MS

Reality TV star Jack Osbourne, who was diagnosed with MS last year, has cut out dairy, salt and sugar from his diet in a bid to combat MS symptoms and prevent deterioration.

The 27 year old told *Us Weekly* magazine, "I've made a lifestyle change, minimising stress, exercising regularly. At the core, MS is inflammation so I try not to eat foods that create it, like dairy and salt. I also cut out processed food and sugar."

Jack Osbourne says he is determined to make the most of his good health while it lasts and has ignored doctors' advice to cut back on his CrossFit core strength exercise regime. He says, "I still go on hikes and do CrossFit workouts. Doctors tell me, 'You've got to stop this and that', but I'm not going to craft my life according to the disease."

Source:

Us Weekly magazine <http://www.usmagazine.com>



Chemotherapy drug shows promise in progressive MS

New evidence supporting the use of Mitoxantrone in secondary progressive MS has emerged from research carried out in Sweden.

Researchers based at the University of Gothenberg found that Mitoxantrone, a chemotherapy drug given by intravenous drip, removed damaging immune responses from the brains of people with secondary progressive MS, helping to protect their nerves.

A group of 35 patients with progressive MS were studied before and after 12-24 months of treatment with Mitoxantrone. Samples of cerebrospinal fluid were analysed with researchers looking for levels of three indicators of axonal nerve damage - neurofilament light protein, (NFL), astrogliosis glial fibrillary acidic protein, GFAP), and B-cell regulation (CXCL13). It was found that following Mitoxantrone treatment NFL level decreased by 51%, CXCL13 reduced by 55% while GFAP levels remained unaffected.

The researchers say their study shows that 12-24 months of immune-suppressive therapy reduces axonal nerve damage in progressive MS, particularly in patients with continuing disease activity.



Source:

Immunosuppressive therapy reduces axonal damage in progressive multiple sclerosis.
Axelsson M et al.
Multiple Sclerosis May 23, 2013.

Copaxone may be given three times a week instead of once a day

The US Food and Drugs Administration (FDA) is to consider allowing Copaxone to be given to patients by injection three times a week rather than once daily. The new treatment regimen would involve patients taking the drug in higher doses.

Copaxone is now approved in more than 50 countries worldwide, including the United States, Russia, Canada, Mexico, Australia, Israel, and all European countries.



Source:

Teva Pharmaceuticals press release
<http://www.tevapharm.com/Media/News/Pages/2013/1825380.aspx?year=2013>

Scotland - new MS clinical trials unit gives major boost to research

A new MS clinical trials unit is being set up in Glasgow to give Scots with MS access to cutting edge medical treatments.

Consultant Neurologist James Overell, based at the Institute of Neuroscience at the Southern General in Glasgow, has been awarded a three year fellowship to test new MS treatments.

Dr Overell says: "In Scotland we have the highest incidence of MS in the world. We have a large number of patients and drug companies want to come here – we really do have the opportunity to do some amazing work and help people try new therapies and to tackle this degenerative disease."



"We have seen in recent years that more drugs are available to help with the relapse and remission stage of the disease and people can stay in this stage for 20 years before moving into secondary progression. We need to start looking at these newer drugs to see whether if taken earlier or for longer they could have an impact in delaying secondary progression. We also need to look at developing drugs specifically to treat this secondary part of the disease."

Scotland already has a research centre in Edinburgh for MS, The Anne Rowling Regenerative Neurology Clinic – named after author J.K Rowling's mother, who had MS - which is conducting pre-clinical research into many potentially beneficial therapies for MS. Dr Overell sees this work as being essential and complementary to the new unit in Glasgow.

Source:

Press release NHS Greater Glasgow and Clyde. http://www.nhsggc.org.uk/content/default.asp?page=s1192_3&newsid=16336&back=s8_1

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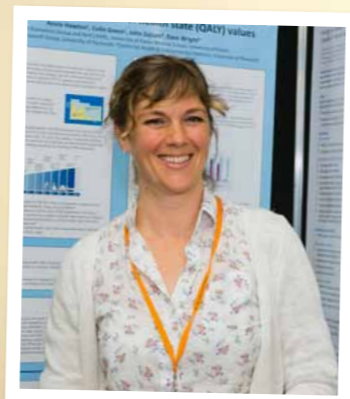
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A pain therapy that really works!

"I am very impressed with the results"

by Miranda Olding

Miranda Olding is an award-winning MS Specialist Nurse with an integrated approach. She works at the Beds and Northants MS Therapy Centre three days a week and also a private practice with holistic therapies.



Above: MS nurse Miranda Olding
Photo: Sarel Jansen



Left: Jackie Clarke
having an APS
therapy treatment

The MS Therapy Centre in Bedford has been trialling a new therapy for pain called Action Potential Simulation (APS) Therapy, with very good results for neuropathic pain – the most difficult kind to treat.

I found out about APS Therapy from a nurse friend who runs a pain management team in Hull. They had seen some exciting results for people with MS who had chronic pain, so I thought we would try it in Bedford. We began just after Christmas and are getting the first results now. It's very exciting to be working with such a new, drug-free treatment.

So far, we have used APS Therapy to treat a variety of different pains, many of them neuropathic. Neuropathic – or nerve pain – feels like pins and needles, stabbing, or burning, and is more difficult to treat than ordinary pain. Often it only responds to anti-convulsant medication, which can have unwanted side-effects, like weight gain and tiredness.

We have treated neuropathic pain in the limbs, feet, pelvis, shoulders and knees. We also used the therapy for normal pain in the hips, back, shoulder, knees, and for headaches, tennis elbow, spasticity and fatigue.

To be eligible to use APS Therapy you need to be able to drink a litre and a half of water a day and have none of the following: heart attack, deep vein thrombosis, stroke or pulmonary embolus in the past 3 months, cancer, epilepsy, or pregnancy.

Case: Jackie Clarke, 45, from Bedford

"Before I started the treatment I had the 'MS hug' really badly. Most of the time the pain score was 5/10, but at times it was 11/10! Since I started the APS Therapy three weeks ago I haven't had the really bad pain at all. The fact that I no longer notice

pain shows the improvement. It's just so nice not to have to constantly think about pain.

This treatment has also had a real impact on my sleep and fatigue. I usually wake up four or five times a night with pain, but last week I only woke once. Also, I don't have that overwhelming feeling of tiredness. Last week I did so much! I took my brother, who is mentally disabled, on holiday, which involved so much walking. Normally, I would have been exhausted, but I just wasn't. My numbness is less noticeable too."

Case: Poppy

"I want to bottle this treatment and give it to everyone I know!"

"For most of my life, I've been in some kind of pain, lacking in energy and not sleeping properly. Now it's my fourth week using the APS machine and for the past couple of weeks I've been active every day. Three weeks ago my mum came to visit for the weekend. We walked everywhere but then I had to spend the Monday in bed. By contrast, I did the same amount of walking the

other week when a friend came to visit and the next day I was up and active at 6.30am! Now I'm sleeping well at night and nothing is such an effort any more. I want to bottle this treatment and give it to everyone I know!"

What is APS therapy?

APS stands for Action Potential Simulation. Action potential is the passage of electrical energy along nerve cells. Simulation means 'a copy'. APS Therapy transmits a copy of the action potential signal through the cells of the body, using a very tiny (micro) amount of direct current electricity. It is this current and signal that makes it different from TENS electrical pain relief.

The increase in communication between cells allows faster removal of waste products and the products of inflammation, and also stimulates the body's natural healing processes, leading to reduction or alleviation of pain. APS Therapy also stimulates an increase in the production of ATP, the molecule that helps to generate energy in the body.



Above: Poppy

What happens during an APS therapy treatment?

The therapy is administered using stick-on electrode pads on the skin. Each treatment time is 32 minutes broken up into 4 eight minute sessions. After 8 minutes, the pads can be moved to a different place if required, or stay where they are. Once the pads are applied, the current is switched on, and then turned up until a tingle is felt. It is then turned down again, and nothing is felt during the treatment. Usually, for the first eight minutes the pads are placed at the top and bottom of the spine. For the second and third sessions, the pads are placed in the area of most pain. For the last session, the pads are placed on the palms of the hands and the soles of the feet. At the Beds & Northants MS Therapy Centre, we are doing six week courses of three treatments a week. If the therapy proves useful, long term therapy may be needed to maintain results. People will be able to buy or rent their own machine.

“APS Therapy may be able to completely and permanently eradicate the pain.”



Above: Christine McNaughton

Good results for pain

So far, 18 people have used the APS Therapy at the Centre, 17 with MS and one staff member. Fifteen people have used APS Therapy for pain. Of these, 13 (87%) have felt a significant reduction in pain, and two (13%) have not. Two also report a significant increase in energy. Of those with pain, five have become pain free. For two of these, the pain has not come back since completing the course, one needs to maintain therapy once a week, and two are still completing their course of treatment. Disappointingly, APS Therapy did not provide any significant benefit to two people with MS fatigue and one with MS spasticity. So, from what we have seen so far it seems that APS Therapy may be able to completely and permanently eradicate the pain. For others, it may significantly reduce or resolve the pain, but need to be continued to keep getting the effect. For some, it doesn't help at all.



Case: Christine McNaughton, 58, severely disabled and uses an electric wheelchair

“It’s amazing what this machine is doing to me. This is the first time for years that I haven’t had severe pain under my feet, and my knee pain is completely gone. I haven’t taken any oramorph (a morphine-based pain killer) since just after I started on the machine two weeks ago, and I’m really happy with it.”

Info Box



Miranda Olding, RGN MSCN MCMA, has APS machines available for rent or to buy. These are slightly smaller than those used in the Centre. They come with a full assessment, screening, training and support. This can be done in person or via Skype. At present, Miranda is the sole distributor and trainer of APS Therapy in the UK. She does not take commission on sales of machines sold to people with MS.



Above: An APS machine

Rental Option: To see if APS Therapy works for you, a 4 week rental is probably the best option to start with. Cost: £60 a week for the first 4 weeks, and £40 a week for any following weeks.

Buying: Miranda can supply APS Therapy machines at cost price to people with MS but needs proof that you have MS. Machines are only sold with training so you get the best results. This can be done via Skype for half the normal price. So the total cost of buying an APS Therapy machine Mark 4, with electrodes, carry bag, postage, individual training and treatment plan is £984.

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* Chartier-Kastler E et al: Randomized, crossover, prospective, multicentre study comparing quality of life related to the use of urinary sheaths versus diapers in incontinent men, British Journal of Urology, accepted for online publication Sep. 2010.

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MS birth month theory questioned

The theory that the month in which someone is born influences their risk of developing MS is questioned by Cambridge statisticians.

Previous studies have suggested that the risk of MS is higher for babies born in spring and lower for those born in winter, but now researchers from Cambridge University say these previous studies have 'skewed results'. They call for studies of risk factors such as birth month to be held to the same statistical standards as studies of complex genetics.

Source:

Confounding underlies the apparent 'month of birth' effect in multiple sclerosis. Fiddes B, et al. Annals of Neurology 2013 Jun 6. doi: 10.1002/ana.23925. [Epub ahead of print] <http://www.ncbi.nlm.nih.gov/pubmed/?term=Fiddes+B>



Education level may protect against damage to thinking skills in MS

MS patients with high levels of education have less damage to their thinking skills than those who are less well educated, say Italian researchers.

Scientists assessed the role of 'cognitive reserve' - the brain's active attempt to focus on

how tasks are processed - in compensating for MS brain damage. Of the 50 MS patients who took part in the study, 17 had no secondary school qualification and 33 had a university qualification.

It was found that MS patients with low levels of education performed worse than healthy controls. By contrast, there was no difference between MS patients with high education and healthy controls.

Source:

Education protects against cognitive changes associated with multiple sclerosis. Scarpazza, C et al, Restorative Neurology and Neuroscience, 2013; DOI: 10.3233/RNN-120261 <http://www.ncbi.nlm.nih.gov/pubmed/?term=Scarpazza+C+multiple>

Sunshine better than vitamin D in blood for MS fatigue and depression

High sun exposure lowers MS fatigue and depression better than high levels of vitamin D in the blood, according to Dutch research. They wanted to see whether direct exposure to the sun was more effective than blood serum levels of 25-hydroxyvitamin D (25(OH)D) on depression, anxiety, fatigue and cognition in MS. A total of 198 people with MS were studied. The result was that higher levels of sun exposure, rather than blood levels of vitamin D, were associated with less depression and fatigue. However, there was no link between either sun exposure or blood vitamin D levels on anxiety or cognition.

Source:

Higher levels of reported sun exposure, and not vitamin D status, are associated with less depressive symptoms and fatigue in multiple sclerosis. Knippenberg S, et al. Acta Neurol Scand. 2013 Jun 13. doi: 10.1111/ane.12155. [Epub ahead of print] <http://www.ncbi.nlm.nih.gov/pubmed/23763464>



Lonely Marathon

by Janet Hughes

Janet Hughes, 63, was diagnosed with primary progressive MS 10 years ago. She used to work in local government, is widowed, and lives in Pershore, Worcestershire. She has one daughter, 33, who was told she has MS last year.



**Pain and disease have slowed her down,
Each more a trial of strength.
And, as she climbs the stairs at night
That mock her with their length
There's nobody to cheer her on
In this - her lonely marathon**

**She struggles to the top and thinks
Of stairs she'd climbed before;
The ones she'd run up laughing, till
They reached the bedroom door.
The man she'd loved had long moved on
With memories she'd thought were gone.**

**But in his bed he thinks of her,
This man she'd loved before.
His wife sleeps while he dreams of love
On some illicit shore.
He feels her touch, he breathes her scent
And savours happiness long spent.**

**The man is walking with the dawn,
A smile upon his face,
His present life unthreatened as
The past is locked in place;
But in his mind she'll always be
Young and strong and running free**



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“My trike has given me so much freedom and exercise!”



Maire Masterson, 58, was diagnosed with MS in 1988 and has been on a strict gluten and dairy-free diet since. She is trained as a clinical hypnotherapist, psychotherapist and past life regression therapist. She lives in Castlederg, Co.Tyrone, Northern Ireland with her husband Eugene and children Eoghan and Sorcha.

“We have an apartment in Torrevieja on the Costa Blanca, Spain. One day, I saw a fisherman cycling on a trike which inspired me to find out more about them. I decided I would need one that folded up and would fit into a lift and the boot of my car.

Back home, I Googled ‘folding trikes’ and up came several sites, including Di Blasi, an Italian company who manufacture trikes in Sicily. As well as looking great, it folds up completely. I found an agent in Scotland and had it delivered to my home in Northern Ireland.

The trike has given me so much freedom as well as exercise. I cycle around Rossnowlagh beach in Donegal. As long as the sand is fairly dry, the trike moves easily but needs a bit more effort over rough terrain and soft sand.

I also cycle it around Galway city.

I took the trike folded up in the boot of the car on a journey through France down to Spain and found it really useful when we parked to find restaurant. Roscoff was especially memorable, as was Fuigeres in Spain. The trike always elicits funny comments, such as ‘Cool bike missus’ ‘Can I have a lift?’

The model I have at home is the R31 (now replaced by a newer model, R32). I’ve had it for almost seven years and it’s an important part of my life, so much so that I bought a different model – the R34 – for when I’m in Spain. I call this my Spanish trike. It differs from the R31 in that the wheels are bigger and it’s easier to mount. Both trikes are easy for me to fold up but I do need assistance to lift both trikes into the car boot and up steps in Spain.

The Spanish trike has a battery which you charge up. I haven’t needed to use the motor yet, but it’s there if I ever do. The battery is placed in the back and is activated by pedalling.

Swimming gets the feel-good hormones going

It’s amusing to see the confusion of the Spanish when I cycle down to the pier, struggle into the water and take off like the Duracell ad for a 30 minute swim three or four times a day in the summer. The cold sea water ensures my nerves communicate and I feel so much better.

I have been swimming with the Masters class in Strabane twice weekly for almost 20 years. Swimming with elite swimmers ensures positive endorphins – the feel-good hormones. I swim at my own pace, managing up to 50-60 lengths of a 25 metre pool each night. I also do yoga and Pilates weekly, and ride my trusty trike three times a week.

Sitting on a bunker



Yes, I still have difficulties with my mobility, but who cares? I told my neurologist, ‘There is more than one way to skin a cat’, to which he replied ‘You must have them well skinned by now’.

I believe the ‘universe supports me’.

Info Box



Maire’s trike is made by Di Blasi
www.diblasico.uk

UK distributor, who have a list of local shops selling Di Blasi trikes:

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12 Pield Heath Road,
Hillingdon, Middlesex UB8 3NF

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Prices:
Model R32 has replaced the R31.
R32: **£1540 incl VAT**. Delivery extra
R34: **£2580 incl VAT**. Delivery extra



My Constant Shadow

by Chris Briggs

When his acting career almost came to an end due to MS, Chris Briggs decided to do something helpful for other people with the condition. So, together with a talented young French woman, he made a music CD. Some of the money raised from its sale will go to MS-UK.



Chris Briggs came across the talented 18 year-old French singer/songwriter Anaïs Morel by chance when looking at a friend's Facebook page. They worked together on a music CD for people with MS called 'My Constant Shadow.' Chris, 67, was diagnosed with MS nearly 15 years ago. He is divorced and lives on his own in Ilmington, Warwickshire.

"The diagnosis of primary progressive MS effectively put me in retirement from my career as an actor, something I had done since leaving school. Straight out of drama school I was lucky enough to get cast in the Ben Jonson play 'Volpone' in the West End, co-starring with Leonard Rossiter. I was then in the original cast of the comedy 'There's a Girl in my Soup' where I remained for five years alongside Donald Sinden and later Peter Byrne.

My acting career has since declined due my limited mobility, though I have had some parts in radio plays. I also recently had a small role in an

independent film, which I was only able to do because the character was bedridden. My younger sister Ghislaine, who used to be an air stewardess, also has secondary progressive MS. Like so many with MS, we both lost what we loved doing.

Just what you need when MS gets all too much

I had always wanted to do something to raise money for MS research or support. But what could I do? I often hear of people running marathons, climbing mountains and jumping out of planes, all things

I can't do. They're brilliant, but I wanted to do something tangible, that people with MS could say, 'this was made with me in mind.'

Then, through a Facebook contact I came across Anaïs Morel, a talented 18 year-old French girl who is the sister of a friend. I heard a few tracks she'd done and thought they were really good. I was also amazed that she wrote, composed and performed all her own music but was not a professional.

Her music is very soothing and calming, just what you need on those days when MS gets all too much. Hearing it made me think I could do something creative to help others with MS and also raise money for MS support and research. I felt comfortable with music as I had played in musicals and once recorded a disc at the famous Abbey Road Studios.

I made contact with Anaïs and we got along well from the start. When I suggested doing a CD together she was thrilled and started writing songs. Anaïs would write and perform the songs and I would organise and fund the production of the CD. We discussed ideas over Skype.

Eventually I convinced Anaïs to come over to the UK and meet me. Being the tender age of 18, her parents were understandably anxious, but once they came to visit as a family any qualms were settled. Anaïs (who does not have MS) came a few times before we were finally ready to go to a local studio and record the album. We recruited an excellent guitarist called Chris Norman, who is totally blind, and professional violinist Marian Fleetwood to help us. After the recording, I did all the post-production.

Fighting the 'constant shadow' of MS

The lyrics of the songs touch on a number of themes including love and relationships, however throughout the album there is an underlying theme of hope, something that inspires to keep fighting the 'constant shadow' of MS. All the songs are in English.

This is not an album about MS but it was written with people who have MS in mind. The themes are universal and the music can be

enjoyed by anyone. The album's laid-back melodic pop songs range from folk to classical piano, particularly on the closing track "My Constant Shadow".

I am selling the CD in a slightly unusual way. As some people might have thought it a bit risky to buy something online from someone they don't know, I turned things on their head and decided to send out the CDs first and for people to pay afterwards. It's a risk I'm willing to take if more people can experience the CD and be helped by it."

Info Box

"My Constant Shadow" costs **£8** and can be ordered from the website www.myconstantshadow.com, or by emailing: myconstantshadow@gmail.com. For every copy of the CD sold, £3 will be split between MS-UK and the MS Society. Mention New Pathways when you order.

You can also visit www.facebook.com/myconstantshadow for more information and updates about the CD.



Cool solutions

by Ian Cook

Summer can be hell when you have MS. Heat and humidity can make your symptoms worse, leaving you feeling weak, wiped out and with blurry vision. Demyelinated fibres are poor at conducting electrical signals, particularly when your core body temperature goes up even by just half a degree. (Uhthoff's Phenomenon). But if you lower it, those symptoms lessen.

Fortunately, there is now a growing number of cooling products that can help you do this. Two of the most practical are cooling towels and vests, though there are many others.

Realx Gear cooling towel

The Realx Gear Cooling Towel is a sports towel that doubles up as cooling towel. It is made from highly evaporative material that retains water whilst remaining dry to the touch. The towel is washable and reusable and comes in a convenient container so can be stored when wet. When the towel stops cooling you can re-wet it and within minutes it's cool again.

"Holding the towel over my forearms and wrists really felt cooling and refreshing."

Tester: Dave Addey, 51, a former software development engineer, was diagnosed with MS 24 years ago. He is married to Dilys and lives in Nottingham.

"I will definitely use the towel again"

"Recently I've noticed a correlation between my body temperature and certain MS symptoms: weakness when waking up, slurred speech and confusion. GPs and consultants drew a blank, but my wife noticed a pattern. If my waking temperature was over 36.2C I was wiped out for the rest of the day and often for several days. But if my temperature was below this, I managed quite well; showering, dressing, climbing stairs and just using

Dave Addey using a Realx Gear cooling towel



a stick to help with balance. I could even use the exercise bike. My speech was reasonable and I could complete tasks on the computer etc.

Healthcare professionals seemed quite dismissive. However, the temperature difference has a significant impact on my quality of life. So I had to find ways to keep it below 36C. I contacted MS-UK for advice and they asked me to try a cooling towel which they had been sent which claims to keep you cool all day long. When wet it claims to be up to 20degrees cooler than the ambient temperature and provides cool, soft comfort to the user for hours.

I was sent a 'large' towel in a fetching shade of pink, though blue is also available (cost £13.95). I was

surprised 'large' was only 16" x 24". However, it certainly does what it claims. On a warm day recently I tried the towel out whilst sitting on our patio in the sun. Holding the towel over my forearms and wrists really felt cooling and refreshing. I also tried the towel tied around my forehead like a bandana, which also was pleasantly cooling and remained cool for quite a long while. I feel the towel could have been slightly larger to be able to do this easily or even better have a version with Velcro ends. (I have since learnt that the company also produce a cooling cap or visor).

The cooling effect lasted for about 15 minutes and could be extended by re-cooling in cold water. My temperature dropped by about half a degree and I'll definitely use the towel again, both at home and on holiday. I have also used a Chillow in bed at night and that has kept me cool too."

"I was impressed by its simple design and comfort."



ian Cook in a Kool Max cooling vest

Info Box



Realxgear Cooling Towel 20% discount to New Pathways readers!

RealXGear is offering a 20 % discount to New Pathways readers who buy a cooling towel on their website www.realxgear.com.

To get this discount add the cooling towel to the shopping cart then proceed to the checkout.

Above the billing address box there is section asking customers if they have a coupon. Enter the code **MS20** in the coupon code box and then click on the box "Apply coupon".

The discount will be valid until **31 August 2013**.

The towels are available in small (12.5" x 16.5"), normal price £11.95;



with 20% discount £9.56) or large (16" x 24"), normal price £13.95; with 20% discount £11.16). Colours: pink, blue or white. They also produce a Cooling Cap or Visor at £14.95.

KMVZ Kool Max cooling vest made by Polar Products.

Tested by Ian Cook

'Now I'm a convert!'

The Kool Max cooling vest is a sleeveless zip-up jacket which can keep you cool for 3-4 hours. It comes with eight water-based cooling packs; four fit in the back and two in each side. You can use all eight, or just where you need them. Before putting on the cooling vest you place the cooling packs flat in a freezer, until they are solid (about one hour). You then place the packs into the vest pockets. Velcro straps seal them in place. An insulated outer fabric ensures that all cooling power is aimed at the body. The cooling packs can be reused hundreds of times.

I was impressed by its simple design and comfort, almost a tailored fit. Putting the cooling packs into the jacket took just a couple of minutes. I then put the vest on over a T shirt. I wore the jacket for four hours, walking round a park on a hot, sunny day in June. When I got home it was still chilled. I had never considered a cooling suit before but now I'm a convert!

Info Box



The Kool Max body cooling vest (KMVZ model pictured) comes in several sizes, suitable for men and women. There is also a child's vest.

Made in US by Polar Products, available from Jackson Technical Solutions in the UK

<http://www.jacksonstechnical.co.uk/contents/en-uk/p129.html>
Tel: 0845 644 3171 Price: £99.95.

Questions & Answers

Do you have any questions that you would like MS-UK's information and advice team to answer? Perhaps you are confused about a symptom, or want to know more about a particular drug? Do you feel it would help to speak to a counsellor? Not to worry! Laura, Kim and Maria are here to help.



Q. Does Acetyl L Carnitine give you energy?

I take several food supplements to help with my MS such as Omega 3, vitamins D and K and evening primrose oil. A friend told me about one in particular called Acetyl- L-Carnitine. She had heard it was good for giving you energy and I wondered if it would be of use to me for my MS fatigue?

Acetyl-L-Carnitine is an amino acid (a building block for protein) produced in the body from the amino acids lysine and methionine. It naturally occurs in plants and animals. Acetyl-L-Carnitine helps the body produce energy. It is found in protein foods such as beef, fish, peanut butter, eggs and chicken and is used by the body to convert fat into energy production. It also aids weight loss and helps with mental performance.

As with many supplements, it is a case of trying them out and evaluating the benefits. Factors like your diet, environment and level of exercise could affect how effective it will be. You may need to give it at least a couple of months to see if your fatigue levels alter at all.

Judy Graham's book 'Overcoming Multiple Sclerosis Naturally' has an excellent section on nutritional supplements and is a good read generally on managing your MS. You can purchase a copy from the MS-UK webshop for the price of £12.50 or call us on 01206 226500.



Q. Can reflexology help MS?

A friend recently told me that the therapy Reflexology might help my MS. I wondered if you could tell me a bit more about it and how it may help.

Reflexology is a complementary therapy mostly done on the feet. Reflexologists work on the principle that every organ and system of the body has a corresponding point or zone in the feet and hands, a bit like 'mini maps' of the body. It aims to help encourage the body to restore itself to a natural state of balance.

Using the thumbs and fingers, pressure is applied to each of these points in a massage type sequence, aiming to release tension and any blockages that are found. It also helps to stimulate blood circulation and promotes healing of the body and mind. It should not feel uncomfortable, but if certain areas feel tender it could indicate a problem in a particular organ. For people with MS, Reflexology may help improve bladder problems, sensory symptoms and muscle stiffness, as well as promoting a general feeling of wellbeing and calmness.

New Pathways has covered Reflexology a few times. Those who have contacted us have largely had good experiences either in treating a specific symptom or for relaxation. Generally, Reflexology is said to help reduce stress-related disorders, sleep disorders, digestive problems, hormonal imbalances and many others.

It is recommended that you contact a professional reflexologist who is a member of The Association of Reflexologists. They have a 'find a therapist' feature on their website: <http://www.aor.org.uk/find-a-reflexologist>



How to contact us

If you have any questions, worries or need some advice, then you contact our Information and Advice team by emailing info@ms-uk.org or calling us on 01206 226500.

Counselling Corner

Finding support when relationships have problems

Being in any relationship can be a rewarding and fulfilling experience and we all have different ideas about what being part of a couple involves. We all bring our own values, personality, and history of previous relationships that help us set out and define our boundaries and commitments to the relationship.

When problems arise we are able to draw on our resources and find solutions so that we can move forward. When a couple make their vows they are united to face life together for better or worse, which for some can lead to feelings of guilt when those duties are not fulfilled.

Guilt makes us consider our actions. You may believe you have done something you shouldn't or that you haven't done something you should. These are not always comfortable thoughts, and you may feel torn between different commitments and needs.

When couples find themselves in situations that are difficult to cope with, finding support may begin with friends and family, whilst others may find comfort through spiritual activities or resources. Finding a support group and sharing what is going on with others who have similar experiences may help.

If you feel that talking to a counsellor or therapist may help you, these organisations will give you a list in your area.

www.relate.org.uk/home/index.html
03001 001234

www.bacp.co.uk
01455 883300

www.psychotherapy.org.uk/find-a-therapist/
020 7014 9955

<http://www.counselling-directory.org.uk/>
0844 8030 240



Anti-malarial drug promising in animal model of MS

An anti-malarial drug, loosely related to quinine found in tonic water, reduced inflammation and led to less severe disease in an animal model of MS.

The drug, called chloroquine, was given to mice infected with Experimental Autoimmune Encephalomyelitis (EAE), the animal model of MS. The mice treated with chloroquine developed mild EAE compared to those not given the drug. They were found to have lower infiltration of inflammatory cells in their central nervous systems. The Brazilian researchers concluded that chloroquine has properties which help to modulate the immune system.



Source:

Chloroquine Treatment Enhances Regulatory T Cells and Reduces the Severity of Experimental Autoimmune Encephalomyelitis.
Thomé R et al.
PLoS One. 2013;8(6):e65913. Print 2013. <http://www.ncbi.nlm.nih.gov/pubmed/?term=Thom%C3%A9+chloroquine>

Stem cell transplants plus immunosuppression - slows relapses & disability progression – but some serious 'adverse events.'

Stem cell transplants accompanied by high dose immunosuppressive therapy can slow down relapse rates and disability progression in MS in some patients for a while, but there can be serious 'adverse events' associated with the treatment.

This is the finding from a study done in Denver, USA, in which 25 MS patients were given high-dose immunosuppressant therapy and autologous hematopoietic stem cell transplants (HSCT). The patients were then assessed after 6 months,

Free cinema entry!

Carers can get free entry when they accompany you to the cinema! The Cinema Exhibitors' Association (CEA) Card is a national concessionary card for UK cinemas. The card entitles the holder to one free ticket for a carer or person accompanying someone to the cinema who is getting Disability Living Allowance or Personal Independence Payment (PIP).

If you go to www.ceacard.co.uk, you can download an application form. Together with the completed form, you need to provide proof of eligibility in the form of a document stating you get DLA or Personal Independence Payment. You also need to attach a photo to the form, and pay a processing fee of £5.50. It takes at least three weeks to process. The card is valid for one year. You may also be able to get free tickets when going to the theatre, concert, exhibition or art gallery. Ring the venue before you go to see what they offer.



one and two years. Only one patient showed lesions on MRI scans at six months and none had lesions at one and two years. Disability progression and relapses were rare throughout the two years. About 90% of patients were free of clinical manifestations of MS. MRI disease activity was also seen in only two patients.

However, data collected in a five-year follow-up showed renewed disease activity in some patients after 42-months. One patient died from MS-related causes after two years in the study.

"Serious adverse events" during the stem cell procedure were common. These were mainly related to blood or gastro-intestinal, although depression, respiratory failure and a suicide attempt were also seen.

Source:

Nash R, et al
"Two-year follow-up of the HALT MS clinical trial: interim analysis" CMSC-ACRIMS 2013; Abstract P20 http://annualmeeting.ms-care.org/index.php?option=com_content&view=article&id=222&Itemid=121

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WalkAide® System

Do you have foot drop?

You may be interested to know more about the WalkAide system!

WalkAide is designed to improve the walking ability of people experiencing foot drop without the 'fuss' of setting up wires and a heel switch.

WalkAide uses advanced sensor technology to first analyse the movement of your leg and then sends impulses to activate the muscles to raise your foot at the appropriate time during the step cycle. The result is a smoother, more natural and safer stepping motion.



Why WalkAide?

- Easy one-handed application and operation (no wires involved)
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- May improve circulation, reduce atrophy and increase joint range of motion



For further information please contact our customer service team on Tel: 0114 2618 100 or Email: info@trulife.co.uk



The MuSmate Walking Aid for Foot Drop



Key Features

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- Control your foot lift – ideal for stairs
- Range of colours
- Wear over or under clothes

Benefits The Musmate Walking Aid was developed by people with foot drop to support their own walking. An elastic cord joins a shoulder harness to a shoe connector which allows the Musmate to support the movement of the whole leg. The strength of the support is adjustable as is the height to which the foot is lifted. Trial results showed a statistically significant improvement in walking speed over a one month period (see website for details).

Contact Details

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or visit www.treworgansfarm.co.uk

Moving on

When a partner with MS becomes very ill, their spouse may decide to move on to a new relationship. Two people intimately affected tell their stories.

Tudor Spencer, who is in his 60s, is married to Hilary. Until a few months ago he cared for her at home with the help of two live-in carers. She is now in a nursing home. He lives in north London.

"For thirty years I looked after Hilary at home, but her physical and mental decline reached a stage where it became too difficult. When she went into the nursing home in April of this year I had the full support of family and friends. It had to be done.

Hilary was diagnosed with MS when our daughter was three. Against the odds, we had a long and happy marriage. Although she went from a walking stick to a scooter to a wheelchair, her illness did not define us. I gave up a jet-setting career, enabling me to be there not just for Hilary but also for our daughter during her teenage years. It was the best decision I ever made.

Hilary's physical decline was gradual but relentless. Each year on holiday it was a shock to realise how far she had deteriorated compared to the previous year. Nevertheless, we did some amazing stuff; three years running we flew to America, picked up a car and set off exploring. If I am truthful, some of the reasons for Hilary going into a nursing home were selfish; I wanted the chance to build a new life for myself whilst I still had my own health. Particularly given Hilary's marked mental deterioration, I felt it was time to move on.

Desire to find a soulmate

Whilst still caring for Hilary at home I joined an online dating site. My desire was to find a soulmate for the next thirty years; someone with whom I share that elusive chemistry which will enable me to rejoin the world of couples.

When you join an online dating site there is immediately a problem for someone in my position – what do you say in the 'Relationship Status' box? I have to choose between:

- 'Ask me later'
- 'Single'
- 'Married'
- 'Separated'
- 'Divorced'
- 'Widowed'

The problem is that Hilary, the person I lost as my wife some years back, is still alive. She has suffered a mental deterioration which has left her happy but childlike, adorable but incapable of sharing emotions. She is legally my wife but in reality much more akin to a much-loved disabled daughter. There is no heading in the box or term in general use which begins to describe our relationship. So, which box should I tick?

Legally I am still married. But if I tick 'Married', eligible prospective partners will presume I am a married man looking for 'a bit on the side' and instantly rule me out. So ticking 'married' is not an option.

'Ask me later' will not do – what is this guy hiding that he cannot be open about his relationship status? I

WARNING FROM EDITOR:
The content of this article could be distressing for some readers, who may prefer not to read it.



suppose you could argue that Hilary's mental decline has caused us to become 'Divorced', but this is not really what the box means.

'Single' is incorrect because I have been and still am married. 'Widowed' probably comes closest, but the discovery that Hilary is still alive might cause the delightful lady who I meet for an exploratory cup of coffee to feel she has been misled. Eventually, I tick the 'Separated' box because there will be fewer possible recriminations later when my date discovers the actual situation.

But I know there are many women who will only consider 'Widowed' or 'Divorced', not 'Separated' men, so I am not doing myself any favours.

I have met someone on the website and we are happy together. Friends and family, in fact anyone who knows and loves both Hilary and myself, have welcomed my new partner.

My only regret is that Hilary is no longer mentally equipped to talk about our marriage, but my commitment to her remains total."

"I wanted the chance to find a girlfriend, and maybe more."

The idea of moving on was a hard one for D (she does not wish to use her full name). Married to her husband for 45 years, they lived in Keynsham, near Bath, where she still lives today.

"My husband was just 45 years old when he was diagnosed with MS. He was devastated by the diagnosis. I told him I would help him through as best I could, but it was hard for both him and me to come to terms with it.

As time went on, it became very hard to cope with his worsening condition. There were times when I wanted to walk away from it all, but I knew I could not do that as we had two children. Our marriage vows were also important to me, to look after one another in sickness and in health. I didn't feel that I could break this vow we had made to each other by moving on.

Over the next 11 years or so, we had many ups and downs and our marriage was really affected. It got to the stage of having to have equipment in the home just to cope with everyday needs. Eventually he used an electric wheelchair which made getting around a bit easier. As the days, weeks and months went on however, his MS progressed rapidly which caused a lot of stress on my part.

I could not bring myself to stop looking after him

There was a stage when I wanted to end everything. At that point I really took stock of life. In spite of the difficult and stressful situation, I could not bring myself to stop looking after my dear husband who I loved very much.

Then there came the time when he was taken ill and had to go into a nursing home as I physically could no longer care for him. That was the most devastating time to come to terms with as I felt I had really broken that all important vow of looking after my dear husband. I wept bitterly.

The three and a half years he was in the nursing home was the most trying time of my life. I saw him every day, unless I went to stay at one of my children's for a holiday, which I really appreciated, or I was poorly myself. These times I missed him very much. In the early days we did everything together which I missed very much. I believe my husband did as well.

My husband sadly died on 1st January 2010. It has been very hard but I have coped and am now at a stage where I feel I can move on with my life. Though, even now over three years later, I still miss him very much and would give anything to have him with me again."

"I didn't feel I could break the marriage vows we made to each other."

"I could not bring myself to stop looking after my dear husband who I loved very much."

Do you have a 'Moving On' story to tell?

If so, please write in with your own experiences, we would love to hear from you. We would like to publish these in a future issue of New Pathways. Anonymity can be given if you prefer.

Please send to info@ms-uk.org



Aimspiro – modest benefit in Secondary Progressive MS

Aimspiro – an experimental drug derived from goats' serum (a blood product) – is of some benefit for patients with secondary progressive MS, according to a retrospective study. However, the benefits are fairly modest and based on doctors' notes, subjective patient diaries, charts and answers to a questionnaire. As yet, there have been no clinical tests such as MRI scans or placebo-controlled trials to back up the small improvements recorded.

An abstract presented to a medical conference said that 140 patients with secondary progressive MS were treated for up to three years with Aimspiro. This was given by injection of 4.5mg ranging from twice a week to once every two weeks. The time on the drug was as little as two weeks to three years. 122 patients improved in at least one of eight different areas of symptoms, including 40 who improved in two areas, 27 who improved in three, and 33 who improved in four or more. 16 patients showed no improvement and two got worse. There were hints of benefit in walking.

Although the research seems to contain some good news, there are concerns that it lacks an objective measure of improvement such as MRI scans. However, Dr Christopher Moore MSc, MBBS, of Queen Alexandra Hospital, Portsmouth, the paper's lead author, points out that this research was not a double blinded clinical trial, but a retrospective study based on a review of case notes and patient diaries for patients treated with Aimspiro in the past few years.

Although there was no formal calculation of Expanded Disability Status Scale (EDSS) scores, there were detailed reports of the effects of the drug in patient diaries, clinical notes and questionnaires. These were used to calculate how the changes seen after Aimspiro treatment could

be represented as EDSS scores. The improvements were considered to be equivalent to a decrease of at least 0.5 points. An improvement of 0.5 points may be seen as fairly modest, but Dr Moore points out that some patients had improvements in several areas, so overall scores may have improved by more than 0.5 EDSS points in some cases. Dr Moore also makes the point that there is as yet no treatment which can halt or improve progressive MS.

Another concern is that Dr Moore owns shares in Daval International, the company behind Aimspiro. Dr Moore says he had never hidden this fact and points out that his NHS pension has shares in most of the large pharmaceutical companies.

What is Aimspiro?

AIMSPRO includes a cocktail of immunoglobulins targeting human proteins, including proinflammatory human leukocyte antigens. It also upregulates anti-inflammatory cytokines. It was originally developed as a potential anti-HIV therapy, but Daval International later shifted emphasis to other conditions including MS as well as systemic sclerosis and amyotrophic lateral sclerosis. Although AIMSPRO has never been approved anywhere for marketing, the firm is allowed to sell the drug for use in individually named patients with a physician's prescription citing 'unmet medical needs.'

Source:

1. *Clinical benefits with Aimspiro in progressive multiple sclerosis: Open label study*, Moore C, et al; CMSC-ACRIMS 2013; Abstract SC23.(2) *Clinical benefits reported with AIMSPRO® treatment in progressive multiple sclerosis. Open-label observations* Moore C, Daval International website http://www.davalinternational.com/downloads/SPMS_Florida_Poster.pdf

Yoga better for brain than exercise

Twenty minutes of yoga can boost brain activity more than conventional aerobic exercise, research suggests. Although this research was done on healthy women, it could also apply to people with MS.

Thirty women were asked to take part in 20-minute Hatha yoga sessions including standing, sitting and lying postures, while keeping their breathing steady throughout. These were followed by meditation sessions in which the women focused on deep breathing and posture.

After the sessions, participants performed significantly better in terms of speed and accuracy when tested on their memory and concentration. When subjects were

tested for the same things after aerobic exercise, they were less able to focus mentally on tasks.

Professor Neha Gothe from Wayne State University in Detroit thought that relaxation, breathing exercises and meditation might hold the answer as to why this happened.

Source:

The acute effects of yoga on executive function. Gothe N, Pontifex MB, Hillman C, McAuley E. *J Phys Act Health*. 2013 May;10(4):488-95.



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Erectile dysfunction is usually symptomatic of a serious underlying medical condition, such as Diabetes or Cardiovascular Disease. It is essential that you seek further assessment from your GP before seeking any treatment for your erection problem.

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MS-UK Staffordshire Centre

We are here to use our collective experience to support people with MS, their carers and their families. We provide professional therapies, support and advice to help improve personal wellbeing and lifestyles in the face of managing the symptoms of MS.

If you would like more information, please call us on: **01785 611144** or email us at: staffs@ms-uk.org



**Staffordshire Centre Unit 22B, Whitebridge Estate
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Walking back to happiness

"Would I believe I must spend the rest of my life in a wheelchair? Had I accepted my (ex-) neurologist's prophesy of the fate that beholds people with PPMS? A firm 'No!' on both counts."

For 10 years, Janet Orchard was in a wheelchair. Now she can walk with support. What did she do to make it happen?

Janet, 62, was an international human resources professional. She took early retirement and moved with her husband Dave to Catalunya, Spain.

"For the last 17 years I have been grounded by Primary Progressive MS. For most of that time I have been in a wheelchair. One is conditioned to think that once you get in a wheelchair, there's no getting out. But you can, and I have. To see it happen is exciting, and the change just too thrilling for words. Now - with support - I can walk! Not well, not elegantly, and not far. I've put a lot of hard work into achieving this, and it has paid off.

This is what I've done: Successful CCSVI treatment in 2010 removed many MS symptoms and I got a sharper brain. I have stuck to the Best Bet Diet, diligently avoiding gluten, lactose, lentils, corn, egg white, nuts, potatoes and quinoa. I have swum, done yoga, used a TENS machine, a Slendertone belt, a Vibroplate and an electric mini walker.

I altered my supplements and diet to concentrate on helping blood-flow - taking cayenne, parsley, ginger, garlic, grape seed, gotu kola, ginkgo biloba, magnesium, CoQ10. I took IP-6* and milk thistle to remove iron deposits from the brain. I also increased vapourised medical marijuana, an excellent vasodilator (opens blood vessels).

I also did Craniosacral Sacral Therapy (CST) for jaw manipulation, Polarity and Energy Therapy to work on blocked currents and disharmony in my "chi" (energy field) and Emotional Freedom Technique (EFT) to remove any hidden worries. I also did my own Art Therapy to help mentally prepare me for a return to life.

All these things got me fit and healthy, but balance and walking still eluded me. Maybe I should have more angioplasty for CCSVI? Something still felt askew, so I made a follow-up visit to Ameds Clinic in Poland. There had been no re-stenosis, the blood was flowing well but some neurons (nerve cells) had died. They could do no more.

I would not accept that I would never walk again

Dilemma! Would I believe I must spend the rest of my life in a wheelchair? Had I accepted my (ex-) neurologist's prophesy all those years ago of the fate that beholds people with PPMS? A firm 'No!' on both counts.

Instead, I signed up for a gruelling, intensive course of physiotherapy at a nearby centre renowned for its excellence. (Tars, Palafrugell, Catalunya). This was going to be a full time occupation - three mornings a

week there and the same at home. I was prepared to sacrifice six months - more if necessary - to get me walking again, albeit with support. The sessions cost 30 Euros each.

At this centre I was introduced to the parallel bars that would help train me to walk again. I eased out of my wheelchair and was helped into a standing position for a few seconds. I only get out of my wheelchair to do the walking with parallel bars at Tars where I know they will not let me fall. At home I walk up and down the stairs as they have handrails. I can walk anywhere that has railings, up to about 25m. To stay upright and walk takes all my concentration.

During my sessions, my physiotherapist stretches and bends my legs. They move, seemingly by themselves. He pushes my feet until I feel a good stretch. Gradually, the stronger leg looks like my leg again instead of a rag doll's. The toes start to move.

>>

"One is conditioned to think that once you get in a wheelchair, there's no getting out. But you can, and I have."



Lying with knees bent and feet on the table, my knees have to follow the physiotherapist's hands. One leg is straight on the table and the other pulled sideways until a stretch is felt. When the legs are very spastic, they get a thorough massage. (A tip for clonus (shaking) of the foot - double the big toe under itself and hold it there for a few seconds. Invariably it stops.)

We also do balance and breathing exercises. At the first session I almost passed out with hyperventilation. They sat me on a conical rubber cushion balanced on a ball on top of a hard stool with no back support, and gave me two poles to hold on to for ground contact. No chance!



Now, I can balance on such things and even hold a conversation at the same time! I rotate my pelvis whilst

pushing back and forth on a large exercise ball. I sit upright with my legs over the edge of the table and they try and push me off - gently - it isn't ALL Spanish Inquisition there!

One third of my sessions is devoted to helping me walk. To start with, I had to learn how to get in and out of a wheelchair properly, remembering the feeling of being upright. After three months of this I was able to walk fairly well inside parallel bars and climb four steps. At four months I could walk gingerly with two quad sticks.

I was very pleased to have got that far, but still had no balance and shallow breathing plagued my sessions. Being me, I wasn't prepared to accept that I couldn't do better.

What could help balance?

What a difference a brace made – absolutely amazing!

I had heard positive talk of a TMJ (temporo-mandibular joint) dental brace which some MS friends were using. It gradually realigns the jaw, correcting imbalances in the body. I was sceptical but went to visit a specialist anyway. She told me my jaw had a lot of asymmetry. We were on to something!

A Michigan brace was the best for my deep bite. (The type of brace

differs enormously depending on an individual's palate.) After a couple of hours of adjustment, I swear I could

balance better.

I took two weeks off going to the centre to see what impact the brace had on its own.

Absolutely amazing - better breathing and blood-flow as the jaw muscles relaxed, held gently at a correct angle. I could transfer from chair to loo, standing long enough to pull up and fasten my trousers. I could also stand up unaided to clean my teeth, leaning against the wash-basin. I also have added strength and better sleep. After a month my foot drop was better and I started to clear the floor as I walked.

A nocturnal creature by habit, for the first time in my life I look forward to going to bed early. And I love my new sleeping partner, Mr. TMJ!

This has been a long, interesting journey, and I'm nearly there."

**IP-6, inositol hexaphosphate, is a vitamin-like substance. It is found in animals and many plants, especially cereals, nuts, and legumes. It can also be made in a laboratory.*



A funny thing happened...

Can you see the funny side of things? Can you tell a story about MS that can make people laugh? Nigel Bartram, who wrote the story below, is sure there are plenty of you who can and he would like to put them all in a book.

Nigel Bartram, 59, was diagnosed with Primary Progressive MS in 2009. He worked as marketing director for a firm of stockbrokers before moving with his family to live just outside Paris, where he set up a language school.



Nigel and Caroline Bartram

Bulk encounters on a boob cruise

"Being no longer sure-footed can sometimes have bizarre consequences. Mostly it's a cause of frustration and difficulty, but just occasionally it can be a source of humour.

A couple of years ago, when I was still able to walk a reasonable distance thanks to the brilliant FES (Functional Electrical Stimulation) device Stimustep, my wife and I took a cruise from Helsinki to St Petersburg. The bulk (I use the word advisedly) of passengers was Russian ladies of a certain age having a riotously fun time.

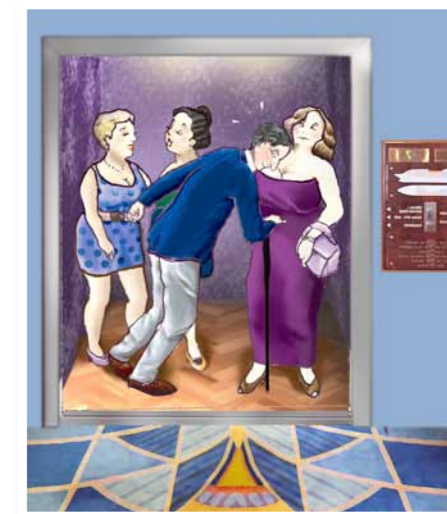
Their trademark physique was large - and - not to put too fine a point on it - adorned with the most ample of bosoms. All of which became evident almost every time I used the ship's lift, which, given my lack of mobility, was frequently. When the lift door opened it would often reveal two or more Russian ladies, very generously proportioned in the 'upper deck' region. In size... the Urals come to mind.

Mountainous cleavages

I can best describe the experience by recalling adolescent memories of frenetically jabbing at the flippers of a pinball machine to keep the ball in play as it pinged from one bumper to another.

When you lose your balance due to MS, you involuntarily lurch forward, zigzagging from one side to the other like a drunkard. I knew there was absolutely no way I could successfully tack round the dense cluster of mountainous cleavages. So, just as when I was a petrified child on the top diving board for the first time, mesmerised and staring down at the watery abyss, I knew I just had to draw a deep breath and take the plunge.

I was buffeted - with surprising force - from one lady to another in true pinball style. Unable to regain my balance and stand up straight, I grew redder and redder and more and more flustered by the nanosecond. Thankfully, the ladies didn't seem to mind - perhaps the



same thing happens back home, only with lurchers (lechers even) fuelled by alcohol rather than afflicted by illness.

A few months later I was visiting friends who I hadn't seen since my boob cruise. One of their guests was built on the same lines as said Russian ladies. This only became apparent when she and her husband were leaving. I was standing in the hallway saying my goodbyes when I started to lose my balance and momentarily swayed headlong in the direction of her capacious frontage.

Fortunately, I managed to check myself before falling into her bosom, but the experience prompted me to blurt out how it reminded me of my experiences on the cruise. It felt like an awful slow motion crash - you can see where you are headed but are powerless to escape. I struggled manfully to carry on telling the tale whilst frantically searching for an alternative ending.

But of course there wasn't one!"

If you have a funny story, please send it to us at New Pathways, with the heading 'Funny'. info@ms-uk.org

"My brace was absolutely amazing - better breathing and blood-flow as the jaw muscles relaxed, held gently at a correct angle."

"It's just poo"

Many things can help constipation, as Lt Col. Jerry Hartley has found out



Lt. Col Jeremy Hartley, 46, was diagnosed with MS in 2005. He has served as a British Army officer in war zones such as Afghanistan and Iraq and was medically evacuated from Kandahar with virally-exacerbated MS symptoms. He is still a serving army officer working for a training centre in Bedfordshire.

"I had that familiar feeling of a doctor dismissing my observations. 'It's just poo!' said my neurologist, 'We all do it, so we shouldn't be embarrassed to talk about it.'"

"But my problem," I replied. "is that I don't do it; not very often at least."

"Ah, well," she said, immediately changing her prognosis, 'some people only go every two or three days.' Presumably convincing a patient they are wrong is easier than addressing their problem.

Not pooing was a big issue for me. It made me feel unwell, tired and very

irritable. Often, I thought that I could feel a stool trying to move but being unable to do so. The muscles simply did not function properly to move the stool along and out. It sometimes caused a crisis.

Once when I was walking my dog at night I could feel my sphincter starting to work and I had to make emergency detours into the bushes. This made me reluctant to go out of the house. Reading 'Mutual Support', a magazine for Army soldiers with MS, I realised that I was not alone in this concern.

I also found that constipation increased the problem of urinary incontinence because of pressure on the bowel from a large, immobile stool. The doctor's response was to eat more fibre and drink more water. I eat up to nine portions of fruit and veg a day and - at the time - drank about two litres of water. Lunch consisted of bags of spinach and carrots followed by prunes and apricots. What more could I do?

We can work it out

I realised that the problem was to do with muscle, not bowel function. It was all quite depressing.

I recalled a joke from school about the constipated mathematician who worked it out with a pencil. This made me think about addressing the problem mechanically rather than through diet or medicine. I wrapped a piece of moist toilet tissue around my finger and then pressed on my sphincter. The result was immediate and wonderfully satisfying.

This became, and still is, a routine procedure for me. I discussed it with the MS nurse who said it is common practice. However, it is not well publicised. I wish I had known about it years ago!

Some chemist shops sell mini finger condoms which some people have used to help move things along just as I do with the toilet wipes (a bit of Vaseline might help here). This is not entirely successful for everyone and I sense that it is important to ensure that you are properly hydrated so that the stool is not too hard.

Other things that help

In Spain they have small black tablets, a derivative of seaweed, called Fuca de Mar which keep the bowel regular. Figs also help, as do Microlax mini-suppositories when applied with lots of Vaseline.

For a while, I used Epsom Salts to good effect. It is also a good way of getting magnesium into your system which is said to aid muscle function. Morrisons do their own version of health salts which are exactly the same but half the price.

I use testosterone which helps with muscle tone (it loosens muscle spasticity for me) which also helps the function of the sphincter. Testosterone also helps fluid absorption which softens the stool and aids urinary incontinence because you do not need to drink so much water.



Having sorted out constipation, I did not feel compelled to drink so much fluid. I now average about a litre a day, mainly fruit juice, and reduced fluid has immediate benefits for urinary incontinence.

Another factor here was drinking proper mineral water, such as San Pellegrino. The minerals, especially sodium, magnesium and sulphates, significantly reduce my thirst and consequently the amount of water I need to drink.

No need to wear Winnie The Pooh nappies

After a number of accidents and periods of stress I resorted to using pads when I knew I would not have easy access to the loo. Bizarrely, I first did this in Disney's Magic Kingdom in Florida. Despite 70,000 people walking about, the place is not well served with toilets. Nor are there many bushes to hide behind.

In desperation, I used one of my toddlers' nappies. Initially, this was a blow to morale but once I got over my ego, I was surprised at the sense of physical and emotional freedom that using a nappy offered.

People should not be embarrassed about this and I think this is an important message. One person said they wear both a pad and Convene (a urinary sheath attached to a tube connected to a leg bag) to cover their double incontinence and they both work fine. When necessary, I use adult pads rather than children's nappies. They are not as absorbent but they are more discreet as you don't get Winnie The Pooh sticking out of your pants.

This has been such a revelation to me that I force myself to get over my Yorkshire reserve to talk about it. Hopefully, it can help other people.

At least you know it's not just you."

Do you have any other tips to help constipation?

If so, we would love to hear them! Please send them to info@ms-uk.org We will print them in the next issue.

"After a number of accidents and periods of stress I resorted to using pads when I knew I would not have easy access to the loo."



Alemtuzumab very effective in highly active MS

Disease activity vanished in one-quarter of patients with highly active MS who were treated with the disease modifying drug Alemtuzumab.

That is one of the key findings of a recent drugs trial called CARE-MS II which compared MS patients treated with Alemtuzumab with a group treated with Rebif (beta interferon -1a).

The trial results showed there were no relapses, no sustained accumulation of disability, and no new lesions or new or enlarging T2 lesions in one quarter (24.2%) of patients receiving Alemtuzumab, compared with no patients in the Rebif group

Alemtuzumab is a monoclonal antibody which was formerly sold as a cancer drug under the name Campath. It is also called Lemtrada.

Source:

Krieger S, et al.

'Alemtuzumab is efficacious in highly-active RRMS patients in CARE-MS II' CMSC-ACRIMS 2013; Abstract DX01.

Major improvements after Gilenya treatment

Gilenya (Fingolimod) can improve four key measures of MS disease activity - brain volume loss, MRI lesion activity, relapse rates and disability progression. That is the finding of research presented to the 23rd meeting of the European Neurological Society (ENS) held in Barcelona, Spain in June.

Research also shows that Gilenya treatment resulted in a sustained reduction of annual relapse rates (ARRs) and a reduction in the rate of brain volume loss in patients who had switched from beta interferon. Doing this also increased the proportion of patients who were disease-free after just one year of treatment.

Gilenya is a once a day pill which is thought to affect the immune system by reducing inflammatory damage. The drug is also believed to promote neuro-protection and repair in the central nervous system (CNS). Gilenya is able to cross the blood-brain barrier and is thought to act on neuro-degeneration in the brain and spinal cord.

Gilenya is the only approved MS treatment shown consistently to reduce brain volume loss with a significant effect seen as early as six months. A low rate of brain volume loss was sustained for up to four years in Phase III studies and for up to seven years in patients after completing a Phase II study.

Source:

Novartis media release <http://www.novartis.com/newsroom/media-releases/en/2013/1707070.shtml>

Antibiotics tested as MS treatment – link with dairy

Three antibiotics are to be trialled as an MS treatment by an Israeli bio-tech company: clarithromycin, rifabutin and clofazimine, contained in a single capsule called RHB-104.

RedHill Biopharma is already testing RHB-104 on patients with Crohn's Disease, where these antibiotics are effective against the MAP bacterium (Mycobacterium Avium Paratuberculosis). The MAP bacterium may also be a cause of MS.

"There is an increasing awareness in the medical community to the possibility that a bacterial induced dys-regulated immune system plays a critical role in the pathogenesis of MS", says Clara Fehrmann, RedHill's RHB-104 MS Product Manager

The MAP bacterium causes disease in cattle and has long been suspected as a causative agent in Crohn's disease – an inflammatory disease of the intestines. The bacterium is widely distributed in British soils and waters. In Crohn's disease it is thought that the MAP bacterium enters the body through cow's milk. The disease is endemic in the dairy industry. A study carried out in Italy in 2011 found the presence of MAP DNA in 42% of the MS patients tested. The MS patients had an "extremely significant" immune response against the MAP protein. The researchers said their research was the first that significantly associates MAP infection with MS.

Also see news story about MS being higher in dairy workers on page 6.

Source:

Redhill Biopharma press release <http://www.redhillbio.com/wp-content/uploads/2013/06/RedHill-Commences-Patient-Screening-in-a-Phase-IIa-Clinical-Trial-with-RHB-104-for-Multiple-Sclerosis.pdf> (2) Association of Mycobacterium avium subsp. paratuberculosis with Multiple Sclerosis in Sardinian Patients, Davide Cossu et al, PLoS One April 13, 2011.



Narrow band of ultraviolet light suppresses MS

Ultra-violet (UV) radiation at a particular wavelength has a protective effect in MS, according to American research. This has nothing to do with vitamin D.

In the research, mice given EAE - the animal model of MS - were exposed to ultraviolet light at different wavelengths containing both UVA and UVB light. The narrow band of UVB radiation at a wavelength of 300-315 nm largely accounted for the suppression and delay of onset of EAE. In contrast, UVA light failed to suppress EAE severity.

Vitamin D3 levels were unchanged after UVB light treatments, suggesting that it was not the vitamin D in the UVB light that protected the mice. In previous research it was found that mice given ultraviolet radiation had lower levels of EAE than the mice given vitamin D in food.

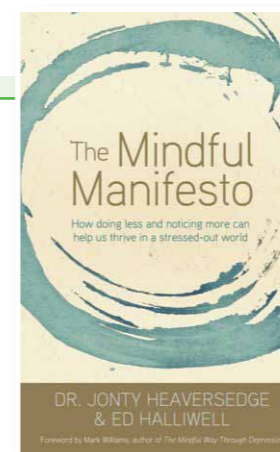
Source:

(1) Suppression of experimental autoimmune encephalomyelitis by 300-315 nm ultraviolet light. Wang Y, et al Arch Biochem Biophys. 2013 Jun 5. doi:pii: S0003-9861(13)00168-9. 10.1016/j.abb.2013.05.010. (2) UV radiation suppresses experimental autoimmune encephalomyelitis independent of vitamin D production. Becklund BR, Severson KS, Vang SV, DeLuca HF Proc Natl Acad Sci U S A. 2010 Apr 6; 107(14):6418-23.



Always be mindful

The buzzword these days is mindfulness; there are courses about it, and a plethora of books. Mindfulness is supposed to help with depression and stress. A particularly good book about it is:



The Mindful Manifesto
By Dr Jonny Heaversedge and Ed Halliwell
Published by Hay House £10.99

Bladder problems and intermittent self-catheterisation - new questionnaire on UK MS Register

Do you have experience and views about Intermittent Self Catheterisation (ISC)? If so, researchers from Glasgow Caledonian University and the UK MS Register would like to hear from you.

They have a questionnaire on ISC aimed at people with MS who may have tried to use catheters, or used them for a while and stopped, and who are still using them.

All MS Register participants are being encouraged to log on and answer the question whether they use Intermittent Self Catheterisation or not, to get as accurate a representation as possible.

It is known that ISC is often recommended by healthcare professionals as an effective way to manage bladder problems and that many people with MS find that using the 'in/out' catheters can really improve their symptoms. However, it is also known that quite a few are reluctant to start and some also stop using ISC.

More understanding is needed about how people with MS feel when ISC is suggested, and also the benefits and difficulties with using ISC. The survey aims to explore the experiences of people around thinking about and using ISC, and as a result identify the barriers and benefits of use which will enable us to better understand the needs of people with MS, and thus provide evidence for the support they require.

Registering is very simple. You just have to live in the UK, be over 18 with a confirmed diagnosis of MS and have an email address. Just go to the website (link here) and submit details on your MS and how it impacts on your life.

The site explains in more detail how the MS Register works, and you will be sent reminders about new questionnaires and updating your details regularly. There are currently 11 questionnaires on the website, including the one on catheters.

The MS Register needs more people to join if it is to have more impact and achieve its goals. So far, only around 10% of those with MS in the UK have signed up. Go to: www.ukmsregister.org/



Elba - a little green paradise!

by Eva McCracken

"It's not easy to get to, but well worth the extra effort"

Eva McCracken, who lives in Scotland, was diagnosed with MS in 1974 and has been dependent on a wheelchair since 2000. She now needs assistance with many things and takes a carer with her when she travels..

"The Island of Elba, where my sister lives with her very Italian family, is a beautiful little green paradise with many idyllic coves. It nestles between Corsica and the west coast of Italy. It's not easy to get to, but well worth the extra effort. We chose to go there in the third week of May as their high season temperatures would be disastrous for me.

It doesn't have a big airport, but the upside of this is that it is not over-developed. The downside is that prices are very high because the people involved in the island's tourism have only four months to make their annual living.

Most people associate Elba with Napoleon, who was exiled there in 1814 after his failure to win his war on Europe. In 2014 they will have a big celebration. ("You should come then" - says my niece!) There are many sites dedicated to Napoleon around the island and the palindrome 'Able was I ere I saw Elba' is another Elban legacy!

When I was still using a small three-wheeled scooter I was able to stay in my sister's four bedroom apartment in Procchio (details in Info Box below). But now that I use



a wheelchair I can no longer manage the three steps to the entrance or the narrow toilet/shower.

Last time I went I travelled in my NHS Zipper manual wheelchair and stayed at Hotel del Golfo in their beach villa on a bed and breakfast basis. This has level access but is not fully wheelchair-friendly, lacking a roll-in shower or adequate grab rails by the toilet. I urged them to put

these in.

I managed a dip in their pool and the sea. With below-average seasonal temperatures of 21C, it reminded me of swimming in the Forth as a youngster. At 30C, their outdoor jacuzzi was much more inviting!

How to get to Elba

Ryanair operates flights from Stansted and many regional airports to Pisa, the nearest airport to Elba on the Italian mainland. Elba only has a small airport, known as Marina di Campo or Teseo Tesei Airport. In the summer months ElbaFly has flights from Pisa and Milan. Most people travel to Elba by ferry from the port of Piombino. The crossing takes



The apartment owned by Eva's sister, Jennifer Mazzei



The ambulance which can transport you from the mainland



A pleasant dip in the pool

about an hour.

If you are staying at the Hotel del Golfo their minibus collects you. Unfortunately it's not wheelchair-friendly but if you don't mind being manhandled, they lift you on.

If you want to travel in your wheelchair you can book a minibus operated by the Red Cross on Elba which will meet your flight into Pisa and transport you to Elba. It is expensive for solo travel but economical for multi-users as the cost includes train & ferry, right to your destination on Elba."

"Most people associate Elba with Napoleon, who was exiled there in 1814."

Info Box

Hotel del Golfo
www.hoteldelgolfo.it

Apartments:
<http://www.elba-online.com/Appartamenti/Procchio/app.htm>
Eva's sister: Jennifer Mazzei (nee Gordon) contact:
mantore@tiscali.it
mob +393280630276

Travel & Flights

Ambulance transport details:
PUBBLICA ASSISTENZA CAMPO NELL'ELBA
57034 - Via Fucini, 17 - Campo nell'Elba (Isola d'Elba)
Tel. 0565/97.76.63 Fax 0565/97.97.21
pubblica.assistenzacampo@hotmail.it

Elba flights
See the website of Marina di Campo Airport:
<http://www.elbaisland-airport.it/>

The Write Way

by Tracy Willoughby

"Writing helped me through the most difficult times."

Tracy Willoughby, 52, was diagnosed with MS in 2006. She is married to Martin, has two grown up children and lives near Bournemouth.

"The words 'multiple sclerosis' fell into the consulting room like a hammer pounding rocks, and my world shattered. To be truthful I had known for a while I probably had MS; my neurologist had mentioned the possibility more than once. It was a relief to know that the fatigue, numbness, burning sensations and distorted vision were not all in my imagination.

The fact that I was finding my high flying job in sales near impossible didn't help as I journeyed through the tears, anger and depression that followed. Eventually I realised that I could no longer carry on with my much loved career; the fatigue was just too much.

Though surrounded by family and friends I felt very alone. I started to write a journal about how I felt. I had always loved writing. I had an abusive childhood, reading and writing my way through it building a fantasy world that aided my survival. I could write in my journal what I couldn't voice to the world.

Over time, my writing progressed into poetry, short stories and articles. I started to gain success at getting published. I realised writing had helped me through some of the most difficult times in my life. It was then I

made the decision to write about my childhood.

I took a creative writing course and started a writing group. Now I run a small company called Write World and hold two writing groups. I have also expanded my learning and pass on my knowledge and skills through the groups, postal assignments and one-to-one tuition. When my health allows, I hold small workshops on creative writing or therapy writing.

Therapy Writing Changed My Life

Therapy writing is a way of writing out your good and bad thoughts and memories. It has changed my life and helped me through difficult times. Every morning when I wake up I write down whatever is on my mind; a dream, a thought....It empties my brain of stuff that takes me away from thinking clearly, allowing me to be more logical and less emotional when things get me down.

Now I am in a relapse, the fatigue running wild! I am tired, even as I wake up, my short term memory fails me, I lose thread of what I'm saying, have trouble swallowing, my feet feel like I'm walking on hot sand, and walking is intermittent. Even so, I can still write.

I have written a book titled

'Quiet Moments' about my abusive childhood, using the pen name of Anna J West. It took me two years. The publishers I chose, Indepnpress, do both conventional and self-publishing. I chose self-publishing to allow me complete control. I did have the chance of a conventional publisher but declined.

MS has given me the chance to explore avenues that were once dreams and might never have materialised into reality. If I didn't have MS, I would not have had the courage to stand on the edge of the cliff of uncertainty and jump, letting go of a well-paid career to take a chance on becoming a writer. MS pushed me over the edge and changed my dreams into reality."

Info Box:

'Quiet Moments' is available on Amazon and at main branches of Waterstones. **£8.99**. Signed copies from www.writeworld.co.uk £1.00 from every book sold goes to the NSPCC.

Tracy Willoughby can be contacted via www.writeworld.co.uk or Twitter under WriterAddict or Anna.J.West also on LinkedIn and Facebook. She also blogs through Tumblr



Quiet Moments

by Tracy Willoughby

The next morning I awoke to a silent house. I tiptoed downstairs into the kitchen where my mother stood, holding Carl.

'Mummy?' I questioned; she did not respond. Dad stood still, his face ashen; his hands trembled as he held a match to the fag that hung limply from his mouth. There was a look on his face I had never seen before. I instinctively knew something was very wrong.

The silence was shattered. 'NOOooo.' Mum began to wail. She held Carl in her arms and rocked back and forth. 'NOOooo,' came the cry again. 'Not again not again.' A blood curdling scream erupted from her lips and shook the very ground I stood on. Her voice subsided into muted whimpers that were muffled as she buried her head into Carl's soft ringlets. He was dead.

I was too young to understand. I did not know what death meant, and no one bothered to explain. I waited every day for my brother to come back. Dad wouldn't let me out so I stood at the front room window, lifted the net curtain and gazed the length of the street. I waited hours, no one stopped me, and surprisingly I didn't get told off for being there.

I knew that Carl had gone away before, when he went to hospital; but he came back. I remember thinking that this time he was gone a very long while. I wished he would come home. Then one day a car came; it stopped at our house. It must be him; last time he went away he came home by car. The only cars that ever stopped at our house was the telly man's, the one belonging to the man who gave Mum money and she paid back at a bob a week, and the rent man's, and it was none of those. So it must be Carl.

'Carl, Carl.' I almost tore the curtain from its wire as I yanked it over my head. I ran into the hall as fast as I

could, just in time to see the arrival of a small pale blue box. It was carried to the front room and put on the sideboard. The man that carried it asked Dad if he wanted to help but he said no, then went into the kitchen and closed the door.

Lots of people came, lots of people cried. At one point Dad even cried, but I don't think Mum did. She sat stony faced. People kissed her and whispered words in her unreceptive ears. I stood for a long time outside the front room door. Why were so many people there? Why were so many people crying? Why was Mummy not talking to me? Had I done something wrong?

Eventually, I went into the room and touched her knee. She looked down at me. A faint flicker of recognition fluttered across her face, then as swift and as quietly as a butterfly, it left. A smile tried to escape from her tightly pursed lips, but it struggled and died before it met her eyes. She raised her hand to touch me, but it fell lifeless into her lap before completing the journey to its so yearned-for destination.

Neighbours stood in the street; the ones that didn't pulled their curtains out of respect. The crowd left our house, and so did the box. I was alone. I knew then, that for some reason, my brother was not coming back.

Though no one had told me, I knew that my Carl was inside that small blue box. Gone for good was the brother I had tried so hard to protect. The brother I had held in my arms willing precious sleep to come his way. The brother I sometimes lay and watched as he contentedly kicked out at the golden sunrays that fell across his cot in the early morning. The brother who had chuckled so much as I took his bare feet to my lips and blew raspberry noises on them.

All that was left on that cool spring

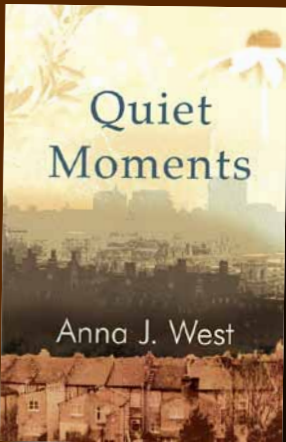
morning was a strange silence that attempted to obliterate the hole left in my heart. Though I didn't know it, this was my first experience of true grief.

Many years later I asked Mum about that day, and why no one had explained to me what was going on. She said, 'I can't remember, it was a long time ago, and why bother with all that now?'

Since then I have obtained a copy of Carl's death certificate. The post mortem revealed Carl died at home on the first of March 1964. Cause of death was listed as acute otitis media, which in layman's terms is a severe ear infection. Also acute gastritis, a sudden inflammation of the stomach lining, caused by a number of different possibilities, such as severe physiological stress, drinking corrosive substances, or a number of other reasons, as well as severe infection.

Both of these reasons for death are common everyday illnesses which are not usually fatal, but can be if left untreated. Until the day Dad died, he insisted that when Carl came home, the hospital had said they were letting him come home to die. If that were truly the case, why was his death investigated? Why were such simple illnesses as these left untreated? I have been assured that, unless there were other problems, a child with these illnesses, treated correctly, should have recovered.

I can't be sure of what happened, I was only three, but what I can be sure of is that Carl and I were suffering from one other major factor that in my mind no doubt contributed to his death: neglect.



muMS - Mums with MS (muMS)

A new support group has started for mums with MS

by Nicola Lay

Nicola Lay, 30, who set up Mums with MS, was diagnosed with relapsing remitting MS in November 2010, with symptoms of optic neuritis and numbness going back a few years. She works as a sales professional for a leading furniture retailer. She lives in Tewkesbury, Gloucestershire, is married to Jonathan and has two children, Jessica, 3 and Joshua, 15 months.

"I set up muMS UK in April 2012. What I really wanted was a group where mums with MS could support each other through our own MS journeys and have a place where we could share our experiences of being in exactly the same situation - a mum, living with MS and bringing up children.

Although there are many MS support groups which provide general support, there was nothing I could find specifically for mums with MS. Not only do we provide each other with support for our MS but we also chat about all areas of pregnancy, birth and parenthood.

Examples are experiences of coming off medication before trying for a baby, dealing with MS symptoms during pregnancy, and trying to avoid post birth relapses. Women also come to us for support during relapses, medication advice, and non-medical ways of improving symptoms. We also talk to each

other about things which have nothing to do with MS, such as weaning, teething, potty training, holidays, beauty tips, work and general day to day chit chat. When I was diagnosed I already had a daughter Jessica and I decided to hold off starting on disease modifying drugs because I wanted another baby. In August 2012, when my second child Joshua was 6 months old, I started on Avonex which I am still taking. As well as taking this medication I also take multi-vitamins and cod liver oil.

Amazingly supportive & light-hearted group

I want to promote the group to make all UK mums and mums-to-be with MS aware of what we are - an amazingly supportive and light-hearted group that women in the same situation may benefit from joining. muMS UK currently operates as a closed Facebook group so you have to request online to become a member. This is because I think there's a need to protect the privacy of the group's members. Many women want to be able to talk freely without family, friends or total strangers reading all their thoughts and feelings. Also, some of our members may not have told others that they have MS. Not only do we provide each other with support for our MS but we also chat about

Nicola with her children Jessica and Joshua



all areas of pregnancy, birth and parenthood. One limitation of being an online group is the lack of face to face contact, but some of our ladies might want to keep it that way. People require support in different ways and it is not always necessary to meet people to support them. However, in the not too distant future we will be setting up regular meet-ups so the ladies can meet face to face and hopefully create some great friendships. I love being part of muMS UK because I know that if I have any worries or queries about pretty much anything, one of the ladies will be there instantly at the touch of a button, to support me, pretty much day or night. It's a re-assuring thought if you're a mum with MS doing a night feed!"

Info Box:



muMS UK

Facebook: /www.facebook.com/groups/351614711568755/?fref=ts

Email: muMS_UK@aol.co.uk

Nicola is setting up a website for the group.

Do you have problems feeling things properly with your hands?

We have one sample of a new product called Resense to give away to the first name we draw at random. The Resense kit was recently developed at the Sheba Medical Centre in Israel for patients with sensory impairments in their hands. It is based on identification of different shapes and textures and aims to improve sense of touch, hand-to-eye co-ordination, fine motor skills, the ability to identify and match, and concentration. Sensory re-education can make the most of neural connections and existing nerve receptors.

Recently, MS patients with sensory problems in their hands such as inability to hold small items, cut vegetables or handle coins took part in a three week rehabilitation programme using this kit. At the end, trial patients demonstrated an overall improvement of 20% on sensory tests.

The kit includes 14 brightly coloured shapes with different textures, 24 flashing cards with

images of one or more shapes, and a pouch. The training session takes 15 minutes and should be done daily.

First, you put the shapes in the pouch and arrange the cards face down on a table. Next, you turn over one of the cards and use your hand to find the matching shapes inside the bag provided. After you have identified the matching shapes and placed them next to the card, you put them back in the bag and turn over the next card.

If you would like to be entered in our draw, please send us an email headed Resense Draw to info@ms-uk.org. Deadline to receive entries is **Monday August 26th, 2013**.

If anyone would like to buy a Resense kit, please contact the man who designed it: Michal Greenberg Abrahami of m.g.a product design www.resense.co.il

Each set costs around £12.



Vitamin D & Vitamin K2 Work Together For Bone Health

Vitamin K2 and vitamin D3 work synergistically together to boost your bone health to a higher level. Vitamin D – in combination with vitamin K – is the single most important way of repairing damaged bones and joints. The vitamin D and vitamin K combination works by sending calcium direct to the bones where it's needed most, instead of allowing it to clog the arteries.



Link between certain foods and memory problems

The following comes from the Newsletter of Terry Wahls MD, the American doctor who recovered from MS: More and more, research shows that diets that require a lot of insulin – those that contain a great deal of sugar, white flour, and/or potatoes - increase the risk of early memory problems. This is why I advise my patients and followers to monitor their blood sugar and carbohydrate intake closely. There are several studies that show that carrying more weight around your middle is associated with a smaller brain and more problems with your thinking ability. That's another terrific reason to eat greens, sulphur, coloured fruit and vegetables, grass-fed meat, organ meat, and seaweed !



Aid4disabled.com

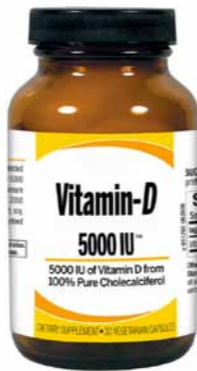
This website, set up by Patrick Burke after his MS put an end to his career as a computer consultant, is now better than ever. He says: "I now have over 100 Facebook and 150 Twitter followers. Google says that I have over 1300 unique visitors a month. Even more exciting, I won £1,000 investment in the website when I entered a Dragon's Den style competition last summer. The website now looks more professional and sharper. I am enjoying my new life, working from home. Please tell your disabled friends and relatives about the website."



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Some neurologists would take 10,000 iu of vitamin D a day! - But they wouldn't prescribe it to you!

"It makes one wonder about the humanity of our medical advisers" – Professor George Jelinek. Some neurologists say that they would take a supplement of 10,000 IU of vitamin D a day if they had one attack of MS before diagnosis (Clinically Isolated Syndrome). They would also give this amount to a member of their family. There are also some neurologists who take this amount anyway. However, they would not prescribe this amount to their patients as they say 'there isn't yet conclusive evidence from large scale randomised controlled trials.' (1) A supplement of 10,000 IU is considered safe and achieves levels of vitamin D in the band 150-225nmol/L – the level at which vitamin D has its optimal effect on the immune system and reduces disease activity and relapse rate.



Commenting on this, Professor George Jelinek, founder of Overcoming MS, says (2):

"This is a really surprising position and makes one reflect on what evidence-based medicine has done to doctors to have made them so pedantic that they would not prescribe a naturally occurring vitamin, taken at physiological doses at which there are no known side effects, that has been shown to reduce the incidence of cancers and other autoimmune diseases, as well as reduce the risk of relapse of MS, despite being enthusiastic about taking the same supplement themselves. It also makes one wonder about the humanity of our medical advisors, who would do one thing for themselves and quite another for their patients, despite being convinced enough of the value and safety of the supplement to take it themselves. While neurologists wait for conclusive trials, we hope that PwMS will follow the advice neurologists would follow themselves or give to their own relatives: Take vitamin D in doses of 5,000IU to 10,000IU a day, aiming at a blood level above 150nmol/L. Their relatives should also take vitamin D supplements, aiming at levels above 100nmol/L."

Source:
1) Multiple Sclerosis Journal.
<http://msj.sagepub.com/contents/19/2/143>
2) Overcoming Multiple Sclerosis Newsletter July 2013. Professor Jelinek also made the same comments at the OMS conference in Brighton on Sunday July 7th, 2013. Much more on this in the next issue.



Super Kale Smoothie

With its high levels of magnesium, calcium and vitamins A, C and K, it's no wonder that Kale is becoming an increasingly popular superfood in the UK. Start your day right with this Kale smoothie !

Prep time: 5 mins
Cooking time: 0 mins
Makes 2 glasses

- Ingredients**
- 1 cup kale
 - 2 cups spinach
 - 1 frozen pear (slice before freezing)
 - 1 cup chopped mango
 - 1/2 orange (no seeds)
 - 1 tablespoon flax seeds (optional)
 - 1/2 cup water
 - 1 cup crushed ice

- Method**
1. Place everything but the kale and spinach into a blender and pulse until a slush like mixture
 2. Add kale and spinach and blend until a thick creamy consistency is achieved. If you prefer a thinner consistency, try adding more water.
 3. Serve and enjoy !



Shop with MS-UK

Support MS-UK by purchasing from our online shop at www.ms-uk.org/shop or call us on 01206 226500. Below is just a few examples of the items we have in stock.

Postage and packaging cost:
£5 and under = £1 P&P
£5.01 - £14.99 = £2.75 P&P
£15+ = FREE P&P



MS-UK trolley keyring:

Fed up of always looking for a pound coin to put in your trolley or locker? This stylish trolley coin could be the answer to your problems.

£2.00



MS-UK badge:

Show your support for MS-UK and raise awareness with this trendy badge with our logo on.

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MS-UK cotton bag:

The MS-UK cotton bag is a fantastic way to help MS-UK, the environment and yourself by making sure you always have a bag on you when you are out shopping!

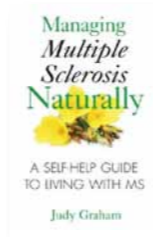
£2.00



Calm Reflections CD:

Calm Reflections is a relaxation CD for those affected by MS; it is to help look at how to manage your pain and stress through the use of relaxation techniques.

£3.00



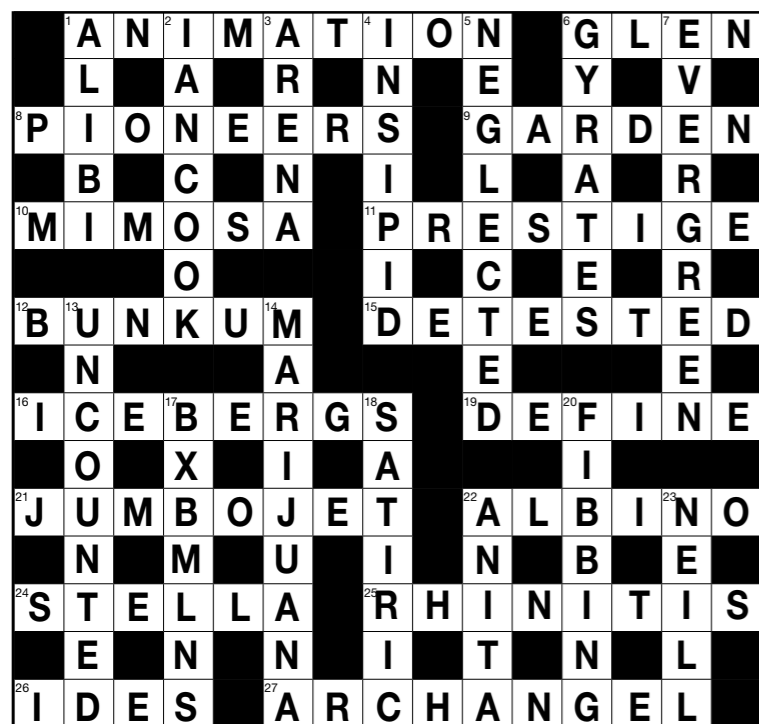
Managing MS Naturally:

Written by Judy Graham, the line she takes is that – with lifestyle changes – MS can be controlled.

£12.50

As an introductory offer, purchase all three of our new MS-UK merchandise for £5 (exc. P&P).

Cryptic Crossword answers



ANSWERS WITH SOME EXPLANATIONS

All these clues are anagrams

ACROSS : 8, 9, 11, 15, 22, 26.
 DOWN: 4, 5, 13, 18.

ACROSS

1. Mickey Mouse and Donald Duck are ANIMATION

DOWN

1. Liberal = LIB is bounded by major road A1 ALIBI
3. ... Is found in K [aren a] nd Julie's hometown
6. The outside of Germany G = Y. Taxis are a sort of rates, thus GYRATES
17. Taken from the song, 'I'm forever blowing bubbles'

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- Lets you carry out everyday activities at home or work
- Enables you to do more, for longer
- Helps you retain your independence

Find Out **Free** How the Bambach Saddle Seat can Help You

Even when you have MS, a Bambach Saddle Seat may help you to lead as normal a life as possible. The key to the Bambach Saddle Seat's effectiveness is the way it allows you to sit. On the Bambach, your sitting position is completely natural and comfortable, with your pelvis stabilised in a neutral, upright position. This results in the best possible posture for your spine, and the least possible stress on your muscles. Of course, the Bambach isn't a miracle cure – but for many people – it can make a real difference.



Sharon Shepherdson Scarborough

"I find it a great help with cooking, baking, washing up and ironing. I previously found that standing for long periods in the kitchen was giving me back pain, dizziness and making me very tired. The Bambach gives me immediate relief and I can carry on as long as I want without any of these symptoms and minimal fatigue. I really feel that this seat enables the person to participate in activities and life in the Kitchen, which nowadays is often the heart or hub of the home. The Bambach allows me to manage my MS and allows me to do what I enjoy doing. I don't know how I ever managed without it!"



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- 3 Freephone** – Call 0800 731 7831 to arrange all of this and to find out more.

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