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The unique, portable Elac ‘Edge’ Shower Stool launched this autumn has many of the same multi-functional qualities as the ‘Swift’ Commode. The Elac ‘Edge’ is the perfect fit for a small shower. It has a slightly curved comfortable seat suitable also for the larger person offering the possibility of different seating positions to suit the user’s requirement.

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Susie Cornell MBE., DL. ,

Susie is a Clinical Ecologist and has worked with MS and other difficult to treat health conditions for over 23 years.
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The Cornell Centre @ Springheath Leisure, Brian Close,
Chelmsford, Essex CM2 9DZ
Telephone 01245 268096
www.susiecornell.com, email: info@susiecornell.com
Cryptic Crossword Answers

Across
8. The soldier leaves reportedly to get model of perfection. (7)
soldier = PARA + leaves = GON
10. If here you will find the young cow. (6)
ANAGRAM
19. Sounds like you say hello to Mick and Keith for wintry weather. (9)
hello = HAIL + STONES
23. Company man and revolutionary Red Indian. (8)
company = CO + MAN + revolutionary = CHE
24. Join in citiz (en list) ening society. (6)
25. Use in mothers where old things are kept. (7)
USE in MUMS = MUSEUMS
26. In the last issue he wondered whether there was a certain personality for people who have MS. (7)

Down
1. Sort group sorted by compositor! (7)
sort = TYPE + group = SET a compositor is a typesetter
6. Mug about above leads to Watergate for example. (7)
mug = CUP + above = OVER = COVER-UP
9. Laurel follows alcoholic beverage for capital. (4,7)
Stanley Laurel + PORT = PORT STANLEY
16. Kiss material for jewellery! (8)
kiss = NECK + material = LACE
17. Sounds like you ban modern music and get classical music. (7)
ban rock = BAROQUE
18. Very warm round and becomes extremely successful person. (7)
very warm = HOT + round = SHOT

NHS Still Failing MS Patients, Says MS Trust

A survey of services for people with MS by the Royal College of Physicians’ and the MS Trust shows that the NHS is still failing to implement the 2003 The National Institute for Health and Clinical Excellence (NICE) guidelines on the management of MS patients.

Only 36% of people had access to neurological rehabilitation services and effective symptom management. If neurological rehabilitation were readily available, the severity of disability would be reduced. And although access to specialist neurological services has improved, there are still long delays from GP referral to diagnosis, with 50% of all patients waiting over 20 weeks.
newly diagnosed with MS to become very proactive and do everything reasonably possible to reduce the risks of MS-related disability.

This is the time to take action as opposed to 10-15 years later when the accumulated disabilities may have become very problematic and the chance of reducing the risk of further disability is much slimmer. One does not want to do a risk assessment about crossing the road when they already in the middle of the road.

Given the very real and rather ugly risks people with MS face, they need to let these established risks associated with MS guide their actions, just like they let risk assessment guide most facets of their life. These actions have to centre on strategies to slow and halt disease progression and the accumulation of disabilities.

Unfortunately no one, including one’s neurologist, provides a rational and comprehensive list of actions to take when one is diagnosed with MS. The only thing a neurologist will recommend to potentially reduce risk of progression is a prescription for one of the MS drugs. The current data indicate that such a strategy will, at best, only slightly reduce the risk of disease progression for most.

This is where I believe Dr Coles falls down. He obviously knows the high risk of accumulated disability and early death for persons with MS. He is also well aware of the low efficacy of the existing MS drugs.

Neurologists Don’t Help MS Patients With Non Drug Treatments

In spite of all this knowledge, Dr Coles and other neurologists fail to help their patients explore non-drug related therapies. I would be willing to bet that most have not ensured that every one of their MS patients has a circulating vitamin D level near the top of the normal range (120-150 nmol/l) despite all the information linking vitamin D deficiency to MS and the fact that such a therapy would be extremely easy and inexpensive to institute.

I would also bet that they do not advise all the first degree relatives of their MS patients to maintain a high level of circulating vitamin D in spite of knowing they have much higher risk of MS than the general public and that the current database leaves little doubt that adequate vitamin D can prevent MS in most cases.

There are many other potentially valuable actions that neurologists are not telling their patients about. It is fine that Dr Coles provides statistics on disease effects of MS and this is a service to persons with MS. However it is not fine that, despite the grim nature of the statistics, he and many of his neurology colleagues do not act on them as much as they could.

In my next column I’ll try to provide a long term action plan for someone just diagnosed with MS.
Statistics and Risk Assessment in MS

By Ashton Embry PhD

Ashton Embry says we need to know the risks facing us with MS in order to guide our actions about our future.

Statistics are very valuable for the individual, not to mention for their doctors and their insurers as they provide us with accurate risk assessments and this is most important for helping to guide one’s actions.

Risk assessment has everything to do with survival and we are constantly doing risk assessments every time we contemplate an action, from crossing the street, to changing lanes in our car.

Such genetic programming is crucial for survival and, over the millennia, most of those who were not good risk assessors were eliminated from the gene pool due to their bad and fatal decisions. This resulted in a human population of excellent risk assessors.

When one is diagnosed with MS, it is important to be knowledgeable about the risk statistics associated with the disease. The risks mainly involve acquiring various disabilities that restrict one’s capacity for different actions but extend all the way to death.

Thanks to many longitudinal studies of populations of persons with MS, such as the French study mentioned by Dr Alasdair Coles in the last issue of New Pathways, a person newly diagnosed with MS can obtain reasonably accurate risk assessments in regards to various consequences of having MS. Such a quantitative risk assessment can and should guide that person’s actions in regards to what they do about their MS.

Dr Coles has done us a favour by providing some quantitative risk assessment information on key potential problems associated with MS. It is very worthwhile for a person just diagnosed with MS to know that, if they take no actions regarding MS, their risk of substantial disability in 20 years time is about 50/50. Those are not good odds!

Dr Coles also noted there is a fair chance a person with MS will die a bit earlier than they otherwise would have if they did not have MS.

Finally, Dr Coles’ statistics made it clear that one has a very low chance of not eventually accumulating some disability over 20 years with MS (i.e. very few remain “benign” over a lifetime). All this information is not good news and hence the backlash against Dr Coles’ article (see Postbag). However it is useful news which can potentially be very motivating and lead to great benefits.

Good Reasons To Be Proactive And Reduce Risks

To me these somewhat sobering statistics should strongly encourage a person...
People with multiple sclerosis are at a greater risk than the general population for developing restless legs syndrome, a new Italian study suggests. “This is important, because RLS is one of the symptoms that can seriously affect an MS patient’s quality of life, even more than a lot of other problems MS patients face,” said lead researcher Dr. Giovanni Cossu, a neurologist at Brudzu Hospital in Cagliari, Italy. “Therapies for RLS such as dopamine agonists are normally very effective and can restore this quality of life.”

According to the study, almost 15 percent of the MS patients were diagnosed with RLS, while less than 3 percent of those without MS had the syndrome. Based on these results, MS patients run a significantly higher risk for RLS than the general population, the team concluded. They said MS should be “definitively” noted as being highly associated with RLS.

Source: HealthDay 30/06/08

The Medical Student Section of the American Medical Association (AMA) overwhelmingly endorsed a resolution urging the American Medical Association to support the reclassification of marijuana for medical use at the AMA’s annual conference in Chicago in June. From Drug War Chronicle, Issue #541, 6/27/08

The Data Safety Monitoring Board has completed a safety analysis of the drug dirucotide (known as MBP8298) for relapsing-remitting MS and recommended that the trial continues, says manufacturer BioMS Medical Corp. The fifteen month trial has enrolled 218 patients at 24 centres in 6 countries. The aim of the study is to demonstrate the safety and efficacy of this drug compared with placebo as measured by relapse rate, MRI activity and disease progression.

MBP8298 is a synthetic peptide that consists of 17 amino acids having a sequence identical to that of a portion of human myelin basic protein (MBP). The sequence of MBP8298 is associated with the autoimmune process in MS patients with certain immune response genes (HLA types DR2 and/or DR4); MS patients having these genes represent 65 to 75 percent of all MS patients.

Source: BioMS Medical Corp press release.

Stem cell research is moving from the lab to the brain. Researchers at the Salk Institute for Biological Studies have been able to manipulate adult neural stem cells still in place in the brain. They successfully coaxed mouse brain stem cells bound to join the neuronal network to differentiate into support cells instead. The discovery opens up new directions for the treatment of multiple sclerosis and other brain disorders.

Source: Nature Neuroscience
Crab, Avocado And Bacon Salad

A quick, easy-to-make and delicious summer salad.

Ingredients

- 135g bag mixed salad
- 1 ripe avocado, stoned, peeled and sliced
- 30g pine nuts, toasted
- 40g cooked crispy bacon, in pieces
- 170g can white crab meat in brine, drained
- 3 tbsp olive oil
- 1 tbsp lemon juice

Method

1. Divide the salad between 2 plates.
2. Place on top: avocado slices, pine nuts and bacon, then top with the crab meat.
3. In a small bowl, whisk the olive oil and lemon juice. Season to taste and drizzle over the salad to serve.
Win a VibroGym Domestic
WORTH £3000

Remarkable Man

Congratulations to Peter Marenghi (photo), who ran the 2008 London Marathon and raised £10,000 for the Multiple Sclerosis Resource Centre. Being diagnosed with MS in the 80’s didn’t stop him from conquering the 26 mile race.

Remarkable Offer

We at VibroGym UK believe this condition shouldn’t prevent anyone from fulfilling their dreams. That’s why we’ve teamed up with the Multiple Sclerosis Resource Centre to offer readers of Pathways Magazine the chance to win a VibroGym Domestic.

To make a bid simply call: 01206 505 444 quoting ref: ‘Auction’ or send an email with your bid in pounds to: auction@msrc.co.uk

The winning bid will be donated to the Multiple Sclerosis Resource Centre.

T: 08700 857 157  E: info@bettervibrations.com  W: www.VibroGym.com
Adidas Women’s 5k Challenge – Looking for The Ladies!

Calling all the ladies! It’s not too late to join the adidas Women’s 5k Challenge formerly known as the Hydroactive Women’s Challenge. This fantastic event takes place on Sunday the 7th of September and is for ladies of all ages and abilities.

It would be brilliant to see the MSRC ladies out in force for this event, so why not get a group of you together and have a fun day out. The MSRC staff will be at the Hyde Park event and we meet up afterwards for a picnic so you can bring along family and friends!

There are no age restrictions on who can enter – our youngest runner has been just 7 years old! If you are not a runner, then it’s perfectly acceptable to walk the 5k distance or you can use a wheelchair or scooter.

Mobile Phone Recycling Just Got Easier And Greener!

SHP have launched a new way to support charities and recycle your old mobile phone at the same time. Instead of producing thousands of polybags that, in many cases, just end up in the bin, you can now go to http://www.shpforcharity.co.uk/msrc and check the value of your phone before then deciding how much of that money comes to the charity.

The minimum percentage donated to MSRC would be 20% but you can choose to donate any percentage up to 100%.

The site makes it easier to identify your phone (there are pictures!) and is really easy to navigate your way round. Once you have found your phone and decided on the percentage to MSRC, you then just pop the phone in a suitable envelope and send to the FREEPOST address provided.

It really is that simple!

So, don’t delay, check your drawers and cupboards for those phones you had forgotten about and recycle them whilst supporting MSRC. (If you are a company with many phones to recycle, please call MSRC offices 01206 505444 and we can arrange a collection).
to go to work and do nothing. Deb seemed to think the sensation would pass and told me not to worry. I couldn't sleep that night. Part of me was overjoyed at my ability to use Deb's accident for my own gain, but real concern was setting in about her condition, which had not improved.

‘Hello again’, said my little gastric friend; ‘I’ve a feeling your real troubles are just beginning’. Deb was fully recovered the next day but I took the whole week off, just to be sure of course. The spare room needed decorating and I hated using any of my precious twenty-two days annual leave for such mundane jobs.

I'd always go sick if anything needed doing around the house. Holiday was exactly that; time for holidays. Debbie was a graphic designer and earned far more than I did. Childless, we used all our spare time and money for sun in Greece or Spain, trips round the canals of England, or skiing in Scotland. We had a great time, but for me there was always that little voice: 'back to work soon, don't enjoy yourself too much'. Life then put the boot in, big time. I came home from work to find Deb sat behind the steering wheel of the car, crying. She had been spending a lot of time with her boss's son, trying to turn him into the calibre of graphic designer she had become. He wasn't even close but was deemed competent enough to have my wife's job.

She tried so hard to find work, but Britain was in the bust years of its cyclic boom and bust economy, and graphic design wasn't high on many firms' lists of priority appointments. We managed to keep paying the mortgage, but the holidays stopped, the new car went, and most of the shopping was labelled, 'value'.

At work I was stagnating in a small pond. The recession was slowly drying it out and work colleagues were turning on each other in order to survive. The company loved it; no pay rises, no security for the staff. ‘Lucky to have a job’ was branded into my sub-conscious. After selling papers door to door and working in a supermarket, where in six months she had managed to write off two cars in inexplicable accidents, Deb managed to get a job at the local Evans, selling clothing to the ‘fuller figured’ woman. What a joke, why don’t other shops advertise for the ‘painfully thin’? I'm not promoting sloth or unhealthy living but ask most men: Marilyn Monroe or Kate Moss?

I answered the phone; “Good afternoon, can I help you?” ‘Bugger off, I'm busy doing nothing’. “Mr Lake, I’m afraid your wife has collapsed at work, she’s awake but can't move her legs.”

Living In Fear Certainly Makes You ‘Regular’

We were at the Kent County Ophthalmic and Aural Hospital building in Maidstone. (A lovely building, closed in 2003). Debbie had suddenly lost the sight in one eye. Terrified, we telephoned her specialist who told us to visit the ophthalmologist department immediately. Neither of us spoke aloud, but we both feared that Deb would go permanently blind. (A condition that had somehow passed me by, even with all those years of self-abuse). Over the previous three years her condition had worsened; she found it increasingly difficult to walk, her balance was terrible, (in fact some friends had asked if Debbie was drinking too much), and she was always tired. King's College Hospital had been unable to diagnose; the scans and lumbar puncture had not discovered anything untoward. The neurologist couldn’t (or wouldn’t) say what it was. This was the first time, however, that Debbie's sight had been affected.

The ophthalmologist began his investigation of Deb's eyes ‘So’, he asked her. ‘How long have you had Multiple Sclerosis?’

without success.

On the plus side I wasn't in need of any pro-active yoghurt or ‘Bifidum digestivum’ as the ladies on the television are so keen extol the virtues of. Living in fear certainly makes you ‘regular’. 
It seemed like an ordinary Sunday afternoon but the knots in John’s stomach told him that life was just about to take a turn for the worse.

Another Lazy Sunday Afternoon

By John Lake

Come on Keano, put your foot in!” I shouted at my own private 28 inch football stadium. United were in cruise control again, seemingly oblivious to my exhortations.

From my horizontal position on the settee I somehow managed the athletic task of reaching down for another can of the stress-relieving nectar.

God, I hated Sunday afternoons, thinking about the following five days’ drudgery in a job I had loathed in its various guises since I started work eighteen years ago.

Today was worse than normal because I had a course to go on the thought of sitting around a table discussing the possible profit margins in brake pads was not exactly inspirational. I would also have to play the M25 lottery game to get there.

Get in you beauty, about bleeding time! At least we had another three points in the bag thanks to another Teddy Cole tap in.

Why wouldn’t that knot in my stomach clear off and leave me alone? We were winning, I’d had a couple of beers and it even spoke to me. Don’t worry, though, it’ll be with you all the way. With friends like that who needs laxatives?

Bang! Over She Goes Like She’d Been Shot!

Deb got up to check the dinner. Ang! Over she goes as if she’d been shot.

That’s up, has all that chocolate given you cramp? My wife was stuck on the floor and couldn’t get up. ‘Leeding hell’, I thought to myself.

This kind of thing never happen when Corrie is on?

Fifteen minutes later and I’ve managed to help Debbie onto the settee. Perhaps your legs are still drunk from last night, I joked, trying to reassure her.

Nock, knock. I can hear the arrival of an opportunity to get a couple of days off work. I phoned the man whose job title was higher up the ladder than mine (I don’t have bosses!)

I’m really sorry, but Deb has had a fall and I won’t be able to make the Coventry trip. Hey presto! Couple of days to sit at home and do nothing rather than have...
Waterfall D-Mannose
A Fast New Way To Bladder Health

People with MS are often badly affected by bladder problems, ranging from increased frequency and urgency to incontinence and full blown urinary tract infections. Unfortunately, conventional medicine does not really provide an effective answer to these problems. Even when no bacteria are found in the urine, antibiotics are often prescribed, which in the long run may do more harm than good. All antibiotics have side effects, and the longer you are exposed to them the more harm they do to the immune system and the natural gut flora that we all need to be healthy.

Fortunately, there is a very effective alternative remedy that works even against highly antibiotic resistant E.coli and Klebsiella. It is a natural glyco-nutrient called d-mannose (a rare sugar), which sticks to bacteria around fifty times more effectively than anything else found in nature, filling up their molecular attachment points, so they slip away during urination. It also has excellent anti-inflammatory properties, so it quickly calms down most bladder and urinary tract inflammation, making it very useful against painful bladder syndrome and interstitial cystitis.

Anna McNamara and John Brenner introduced Waterfall D-Mannose to the UK market four years ago, after having a very pure grade of d-mannose extracted from sweet forest timbers for their own use. It got rid of Anna’s repeat bladder infections, and she has never had an infection since. Thousands of their customers, including self-catheterising spinal injury patients and MS sufferers have found exactly the same thing. You can stop infections and inflammation symptoms in their tracks by taking Waterfall D-Mannose at treatment level and then a regular maintenance dose keeps the symptoms permanently at bay.

Anna explains, “Some people need to take more Waterfall D-Mannose than others, depending on their individual circumstances, but unlike antibiotics it is completely safe to take, even for pregnant mothers and babies. Mannose is a simple sugar, like glucosamine, that is already present in every cell of the body. And Waterfall D-Mannose is 100% pure natural mannose and nothing else, so you know there is nothing nasty in there.”

Waterfall D-Mannose comes in 50g tubs or flat packs (enough for approximately 30 level teaspoon doses.) One tub is enough to treat a simple case of bacterial cystitis. For more serious problems, it is worth getting a couple of packs to start with to allow higher dose levels. Many people take it every day as a long-term preventative. New Pathways readers can get a special discount (normal price is £18.70 for 50g), using the coupon below, or by ordering directly from www.waterfall-d-mannose.com/newpath

Waterfall D-Mannose Discount Order Form

Please write legibly in block capitals. Tick the type of pack you would prefer and the amount.

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<tr>
<td>2 packs = 100 grams</td>
<td>£33.00</td>
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<tr>
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Or order online:
www.waterfall-d-mannose.com/newpath
existential gloom, wondering if I was ever going to get completely used to acrylic painting.

I have now found a paint thinner and solvent made from lemon oil and although I have decided that I can’t risk using it actually as a paint thinner, I will use it to clean brushes since it is much kinder than white spirit or turpentine substitute. I have a good quality air filter and I have increased my intake of antioxidants.

As my disease worsened, so did my tendency to allergies. I also developed asthma and spent every winter coughing. All this has now gone, so I feel that my immune system is balanced enough not to be perturbed by the organic solvents.

So, at the age of 50, I am entering a new stage in my life, one that a few years ago David thought I never would see.

---

**LDN Survey**

The LDN Research Trust would like people with MS to take part in their survey if ANY of the following applies to you:

- You are currently taking LDN and have been doing so for at least the last 4 months
- You have taken LDN in the past but are no longer taking it.
- You took part in their last survey.

The survey can be found online by going to: http://www.ldnresearchtrust.org/

Closing date for entries is July 31st, 2008.

Send to: New Pathways Children’s Writing Competition, MSRC, 7 Peartree Business Centre, Peartree Road, Stanway, Colchester, Essex CO3 5JN

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**Children’s Story Writing Competition – Win £50!**

Closing date for entries is July 31st, 2008.

Send to: New Pathways Children’s Writing Competition, MSRC, 7 Peartree Business Centre, Peartree Road, Stanway, Colchester, Essex CO3 5JN
painting canvases again.

To avoid organic solvents, I bought and used top quality acrylic paints rather than oil paints, and this involved learning a whole new way of working.

My mind was coming back and I was able to work out what to do. Always feeling cramped by small spaces, I not only started painting canvases again but larger canvases. I do all this with my right hand.

As a finishing note: I have just started painting with oils again. David knew I wasn’t really happy with acrylics and he suggested I should change back. I had spent much of the previous year in a kind of

Right: “Isola Capri” 2006. 130 x 85 cm. Acrylic on linen canvas.

Below: “Avant le Déluge” 1997. Oil on linen canvas, 175 x 120 cm. This was painted just before I began to get much worse and I think the gathering storm clouds were indicative of how I really felt.
Painting In Oils Again

By Sarah Longlands

Artist Sarah Longlands is married to Dr David Wheldon, an award-winning novelist and consultant microbiologist. Trained at the Slade School of Art, Sarah was no longer able to paint in 2003 due to her MS, but thanks to being the first person to use Dr Wheldon’s Combined Antibiotic Protocol (New Pathways Issue 47) she is now able to produce wonderful paintings once more. Some of her paintings hang in the ocean liner Queen Mary 2.

In late 2007 was offered the chance to do what was the biggest commission had ever been offered to paint six large paintings to hang in the penthouses of the famous cruise ship Queen Mary. I was determined to do this.

The designs were accepted and I finished the paintings in 2008. While I was working on them I became increasingly unwell and by the time they were finished I found myself unable to use my right arm. Just signing the six works took a week and I was unable to finish varnishing them without enlisting David’s help.

The ship was launched in January 2009 and much as I wanted to see my paintings hung in situ I wasn’t well enough to go.

The diagnosis was not good – very aggressive secondary progressive MS. But just weeks after this David found on the internet the thoroughly researched medical treatment developed at Vanderbilt University involving Combined Antibiotics (see New Pathways Issue 47.)

Gradually Life Came Back To My Paralysed Arm

I started this treatment in August 2009 and spent much of the first month in a delirious haze, sleeping for much of the time. A couple of months after that, though, I felt life coming back into my paralysed right arm.

I began tentatively painting in watercolour and after a few months I managed to do something that wasn’t just headed for the waste bin.

However, as a painter of large canvases, I was not going to be content with spending the rest of my life as a watercolourist and at the start of 2010, I felt I had improved enough to start
Funky Future For Mobility Aids

Amid the boring old care-home armchairs, the Naidex mobility exhibition at Birmingham NEC had on display some truly innovative, funky and colourful new mobility products. Some of the best are imported from Scandinavia, Holland or Israel. But the UK also has some snazzy new products.

A Bicycle Made For Two
This Fun 2 Go trike is designed for two people to ride together. Great idea. Made in Holland by Raam, and sold exclusively in the UK by R Cycles.

www.wrkcycles.com

Colourful Walkers
Here's a delightful change from the usual glum walkers. These brightly-coloured walkers come from TG.

Make A Statement On Your Scooter
You're bound to get admiring looks on this fluorescent yellow scooter. It's made in Israel by Tora but is not yet available in the UK.

www.tora.com

The Wet Look
If you're giving your bathroom a makeover, how about a wet room. There were several on display at Naidex and all looked great. Wet room suppliers include IMPEY, ASA and EASAGROUP.

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Anna helped me to plug my legbag into the nightbag. The other passengers didn’t seem to notice, and there was plenty of space to conceal it under the rugs we were given for the night. In the morning Anna detached the nightbag and emptied it in the toilet.

Disembarking wasn’t a problem thanks to a kind African from BA’s local handling sub-contractor. But to our dismay we found that our luggage hadn’t arrived: there hadn’t been time for it to make the tight connection between Terminal One and Terminal Four.

That meant we didn’t have our suitcases, my own wheelchair that fits me, nor the portable commode I’d brought along as we’d heard that the loo in the house was hard to get on and off.

We didn’t get our luggage until two days later, partly because of a muddle over the address where we were staying. In the meantime I borrowed a wheelchair from the airport. It didn’t have drop-down arms, making it hard to get onto.

Cape Town’s Spectacular Scenery

But we were in Cape Town, gazing out at the spectacular scenery. In 1580 Sir Francis Drake wrote: ‘This Cape is the most stately thing, and the fairest Cape in all the whole circumference of the earth’.

The city is a friendly English-speaking place and we didn’t feel the worries about security that some visitors talk about. Everything was so easy that if it hadn’t been for the African servants who cooked and looked after us we could have been staying at a villa in France.

But there was one disappointment: Lots of ramps made of hardboard had been placed where there were steps, but they were steep and I couldn’t tackle them on my own. Anna, our friend Christopher or someone else had to push me. So I was actually less mobile than I am at home. And until the commode turned up Christopher had to lift me on and off the loo once a day.

I started to realise how much independence I have at home, where, after I’ve been helped to get dressed, I can go anywhere in the house, take the lift to the bedroom, and go onto the street and get a taxi.

We left our friends’ villa and drove to Franschhoek, a lovely village in the Winelands. There we had reserved a room adapted for a disabled person in a guest house. Everything was on the ground floor and worked out fine, although it was a shame the chain to flush the toilet was way above my reach. I had to get Anna’s help to get over some gravel on the way to the breakfast room, and to negotiate an irritating lip at the entrance to the room. But it was a nice place.

Here the activity was sightseeing in our hired Renault, just like the car we have at home. Anna drove and to get in I would pull myself out of the wheelchair by the car door, and swing myself into my seat. The trick was to remain standing long enough for her to be able to whisk the wheelchair away and put it in the back of the car.

From what I could see South Africa is some way behind the UK in the level of provision for the disabled. Some of the kerbs in Cape Town and Franschhoek have been levelled to take wheelchairs but many have not and there were plenty of other hazards along the pavements. Anna had to do a lot of pulling and pushing.

However some of the restaurants we went to had made a real effort to accommodate wheelchair users. One of them was built on the side of a hill and had a long steeply sloping ramp to get them up to the dining room, but with staff waiting to help. But I would fault them for the brutal language of the sign they’d put up: ‘Paraplegic Access’. It may technically be true, but don’t rub our noses in it!

In the event it was a lovely holiday, though it did have a few anxious moments for both of us.
I'd always wanted to go to South Africa. Then one day we got an invitation out of the blue from some friends who have a house in Cape Town.

It was a wonderful invitation but also a challenge. I'm in a wheelchair and although I occasionally go on aeroplanes I haven't been on a very long flight for years.

It's a 12 hour flight to Cape Town but the time difference is only an hour or two. So, going there in early March wouldn't be too hot. And our friends told us that their house had often been used by a man who is permanently in a wheelchair after a motorbike accident.

Travel agent arranged our itinerary. We would go for a week to Cape Town, and then spend a week in the inelands, a lovely area about 0 miles away. It wasn't very ambitious but it was well-suited to my capabilities.

Reliant On Wheelchair Pushers

I wasn't very concerned about the journey as I'd managed O on previous flights. I requested special assistance and you just have to entrust yourself to the wheelchair pushers who manoeuvre you into your seat and get you out of it at the other end. The main anxiety is wondering whether they're going to turn up.

I was a little concerned about how I would manage my urine. I have a supra-pubic catheter which feeds into a legbag which I empty every few hours. At night I connect it to a nightbag. I wondered if it would be OK on a night flight.

We flew with from Edinburgh to Heathrow to join the Cape Town flight, with a departure time from Terminal 1 of 1.20. But on the snowy day we flew, the flight from Edinburgh departed almost an hour and a half late then waited in a stack for 10 minutes. It finally landed at 1:15, but then faced a further delay before it was allocated a stand at Terminal One.

Finally arrived, the other passengers disembarked and I was lifted out of my seat and out of the plane. I was pushed along some corridors of Terminal One, then had to wait for several minutes until a van arrived for the journey through tunnels to Terminal 1. It was getting so late that I began to resign myself to missing the flight to Cape Town altogether.

But the two Italian women escorting me told us not to worry, the plane will wait. Finally the van reached Terminal 1 and we were plunged into its corridors and lifts. Then we finally got to the aircraft the clock had reached 1:20, exactly the departure time.

It'd made it but it had been a white knuckle ride.

We were in World Traveller Plus which is just behind Club Class and gives you a slightly wider seat but not much more. We settled in and had supper. After watching a bit of a movie, it was time to settle down.
more confident, with my eyes closed. This required me to stand near some support, so I could have fingertip touch to keep my bearings.

**Lifestyle Skills**

Iain, the O.T, gave me practical advice to help me with everyday living. The ideas are common sense really and include:

- **Rest** - means doing nothing at all (including watching TV) - and letting the body as well as the mind relax.
- **Diet** - eat regularly and try to cut out food and drinks with caffeine that give shorter energy bursts.
- **Exercise** - keeping fit generally by regularly doing some sort of fitness activity.
- **Setting Priorities and Planning** - putting the most important activities first before running out of energy. This involves writing lists before setting out to achieve something.

All four lifestyle skills required me to keep a diary of my day's schedule and a fatigue chart. This made it possible for me to view where my energy went during the day and to organise my time and energy more efficiently.

I could see by the end of my stay that the crux of my problems (fatigue) stemmed from lack of rest (I am a bit of a live wire, and cannot sit still for more than two seconds!) The discovery that if I can manage my fatigue I will have a better quality of life was quite a revelation!

Understanding the extreme energy levels I experience from peaks to slumps during the day helped me to see the benefits of rest. Planning can help me reserve energy for the times I most need it.

**The Neuro-Psychologist**

My memory and thought processes were looked at thoroughly with psychometric tests. One of these involved looking at a set of 50 photos and then trying to remember exactly which picture I saw out of three similar ones on a page- such as pictures of the same rose bush, only with slightly different angles or details to it. Only one was correct! My memory of names was also tested from a set of picture cards. The first and last name had to be remembered. I did badly at the names test.

Information processing was also examined. This involved trying to piece together patterns from six sided cubes from a template design already made on another card. Through this, my neuro-psychologist could see my thought process working out the puzzle. The results of these tests were normal.

I believed that my memory was partly impaired because I have trouble remembering past events and names. My poor recall of names exposed a mild or very slight impairment to my short term memory. The overall results, however, showed that I had no significant problems. My neuro-psychologist suggested a remedy for this: keeping a diary. This would act as a memory jogger and help me to piece together past events.

**How I Got On**

The NRU's programme lasted only two weeks and I left feeling frustrated that my physical health had not improved more significantly. I still have to use a stick and I'm still not very confident about going out by myself.

Practice and discipline would be central to my recovery and if anything, the NRU has given me the opportunity to take stock of my life. The Rehab could only do so much; the rest was down to me. I found that all three parts of my rehab were useful in discovering where my weaknesses were and making me realise how I should remedy these.
The aim of going into rehab was to improve my physical potential and regain my independence. By the time I left I felt mentally more prepared for the outside world and able to control my shaking better than before, though I still walk with a limp and also use a stick.

Recently, my MS had been getting worse and tasks such as shopping and cleaning had become a struggle. My MS had reached an all-time low so even going out alone was frightening. I was an ideal candidate for neuro rehab as I was still young and relatively mobile.

There were 10 beds in the rehab ward, a lounge/dining area and a separate therapy room with a gym. The lounge had a widescreen TV and an exercise bike. The therapy area had eight electronic moving beds, a running machine and more exercise bikes. There were also many different sized inflatable balls for balance and co-ordination training.

I then met my rehab team, physiotherapistaura, neuro-psychologist Duncan and occupational therapist Iain, who co-ordinated the whole thing.

The objective of my treatment was to improve balance and dexterity, co-ordination, core strength and manage fatigue better.

Exercises from the Physiotherapist – Strengthening Core Muscles

These were similar to Yoga therapy with the emphasis on slow, smooth movements. The aim was to strengthen core muscles- which are the underlying muscles running the entire length of the torso that stabilise the spine and pelvis.

The exercises for this included
- Resting my leg on the ball, whilst hollowing my stomach and clenching the buttocks. I would arch my back and lift alternate hips. Repeat 5 times for each hip.
- On my hands, knees under the hips, with the back in a relaxed neutral position, I then had to make a controlled, slow movement, clenching buttocks slightly, and straightening out the hip and knee out behind me. I was told not to arch or twist my back. I repeated this 10 times for both sides.

The aim of these exercises was to strengthen hip and trunk muscles.

Improving Balance

These took the form of standing with my feet, heel to toe and also, closely placed, side by side. These were firstly with eyes open, and then when I got
At last, an MS treatment that’s easy to swallow

Do you suffer from Multiple Sclerosis (MS)?

Are you interested in participating in a Clinical Research Trial?

We are a research organisation, based in South London and are undertaking a clinical trial for MS sufferers. The medicine being investigated is thought to work in the same way as Tysabri® (also known as natalizumab) but can be taken by mouth and may have a much shorter duration of effect within the body. The treatment period will be 4 weeks.

To be eligible for this trial you need to be:

- Aged 18-65
- Diagnosed with Multiple Sclerosis with at least 1 relapse in the past 24 months
- Able to walk about 20 metres without resting, but using assistance (sticks, crutches, braces) if necessary
- Registered with a GP, who will be informed of your participation

In recognition of your participation in this study:

- You will be given £2000 for your time and travel
- Receive further access, if appropriate, to this therapy once the trial has ended

Interested in participating?

Register online at www.trials4patients.co.uk

Or call us free on 0800 085 6464 to speak to one of our Volunteer Recruitment Team.

Why not join us on one of our Recruitment Roadshows? – details on the website

Please quote Ref: PAT1

This advertisement has been approved by an ethics committee and any response to this advert will be recorded but you will not be under any obligation to participate in the trial.
Lizzie Gilchrist, 26, was diagnosed with MS in 2000. She started a music degree but was unable to finish after her MS got worse. She is currently looking for work in the police’s civilian staff. She lives in Essex.

Lizzie found the WheelieChix-Chic website on the MSRC Message Board where she posts under the name “Wizzie”. When she discovered WheelieChix-Chic was looking for new faces, she promptly contacted them. “It was fantastic to finally find a company catering for women who use wheelchairs but who still wish to be stylish”, says Lizzie.

WheelieChix-Chic’s managing director Louisa Summerfield - also a wheelchair user - says Lizzie was the right person to model their clothes. “Lizzie’s face has great bone structure which will look great in make-up. She is a very determined young woman who hasn’t let her disability get in the way of living life to the full. I greatly admire her confidence and sheer determination; she’s very much an inspiration to all young women with a disability.”

The WheelieChix-Chic collection is specifically tailored to enhance and flatter the figure while sitting. The designs ensure freedom of movement including wider sleeves, trousers which are higher at the back compared to the front, waistlines that accentuate but are not restrictive, as well as fastenings designed to ensure dressing becomes a pleasure and not a chore.

Beyond Boundaries Live
Beyond Boundaries Live is all about opportunities – what you can do, rather than what you can’t do.

At the event Lizzie will be modelling clothes from the WheelieChix-Chic Autumn/Winter collection.

The show will also feature members of the hit BBC TV disability adventure series including Ade Adepitan and Kerry McGregor, although the event is not connected with the BBC.

As well as watching the fashion show, you can also have a go at football, basketball, drama and rock climbing, or test drive the latest cars, handcycles and wheelchairs. There will be help and advice on hand from experts, information about holidays for disabled people, and cooking demos from celebrity chef Michael Caines.

The event is being held on July 25 and 26 at the Kent Showground, Detling, Maidstone. There is no admission charge. You can just turn up on the day although the event organisers recommend online registration in advance to beat the queues. www.beyondboundarieslive.co.uk Tel: 0208 971 8286.
I want you to enjoy it! exclaimed Ernd, who told me most disabled people feel really excited to go flying. You don’t feel your disability when you’re flying.

or the first twenty minutes or so, Ernd was firmly in charge as we flew over the patchwork of fields above Eversfield, then on to Portsmouth and over to the Isle of Wight.

The World From A Different Perspective

hat fun this was. Up here, you see the world from a different perspective. Look down, the cows in the fields and the cars on the roads are like dots. You can spot landmarks like the Spinnaker Tower in Portsmouth, the ships in Portsmouth Harbour and the sandy beach at Ryde.

If we weren’t sure what was below us, Ernd would get his handy little aeronautical map out and have a look. On a good day like this, you can see 0 miles in all directions. Wonderful!

So far, I had been only been a passenger. ut now came the moment of truth. Ernd turned the plane around towards home and then asked me to take control of the tiller.

this point my knuckles could have turned white, but they did not. ith commendable composure, I held the tiller firmly as we flew straight ahead. The dial which showed the horizon was on an even keel and on an even keel I intended to stay.

Turn to the left! commanded Ernd, whose day job is designing aircraft. I kept my collywobbles to myself as I meekly turned direction. Turn left more! said Ernd. So I turned left more and the dial which showed the horizon ooked worryingly off centre.

Ten minutes of this and I was happy to hand back the controls to Ernd, a real daredevil who told me he liked nothing better than flying a light aircraft in savage weather and being buffeted around by the wind and rain.

luckily, no such adventure can befall a disabled pilot as the D will only let the planes up in clement weather with good visibility.

ack on terra firma, Mrs Harries told me that around 100 disabled people fly each year, most of them first-timers. il the pilots, like Ernd, are volunteers who do it for the love of it.

My motivation is to see the smile on the faces when they get out of the plane, says Mrs. It can change peoples’ lives.
I Am Flying!
“You Don’t Feel Your Disability When You’re Flying.”

By Judy Graham

When it comes to daredevil antics, am one of life’s scaredy cats. So it was with some amazement that I found myself flying a light aircraft high above Hampshire one sunny day.

Admittedly, I was at the tiller for only 10 minutes with ace pilot Bernd Vermeulen safely by my side at the dual controls, but flying I was nonetheless - just one of the hundreds of disabled people who can experience this thrill thanks to the efforts of the British Disabled Flying Association.

The plane I was to fly – a Piper PA28 Archer with 181 horse power was parked in a grassy field at Lasham Airfield, not far from Basingstoke. It was meant to be a Bulldog G-DISA, but it made no difference to me.

But how was I to get inside it? “You shuffle on your bum along the wing”, advised Emrys Harries, my host at the BDFA, who has MS and walks with a stick but flies like a real pro. “Though they can also hoist people up if needed”.

Once inside the compact cockpit, I was faced by a bewildering array of dials. If only I knew how to read them they would tell me the number of feet we were above the ground, our speed in nautical miles, how much fuel we had, and where the horizon was - apparently very useful if you can’t see out of the windscreen.

There were also lots of knobs and levers which I was happy to leave Bernd to pull, push and twiddle, which he did frequently. The only thing Bernd had to teach me was what to do with the tiller, the black lever thing in front of me. If you pulled it out the plane went up and flew more slowly. If you pushed it in the plane went down and picked up speed, and if you steered it to the right or left, it made the plane gently roll.

As the plane goes up, you see less out of the windscreen and rely more on the gauge in front of you, and as you go down you see more - much more.
The biggest heat problem when you have MS is not so much dry heat but humidity. It saps every last ounce of energy from you and makes you feel like a wet rag.

Meteorologist Russell Johnson, who has had MS for 25 years, suffered his first symptoms of MS when he was outside in the hot and humid climates of Borneo and the United Arab Emirates. But when he went inside an air conditioned building, his MS symptoms eased.

This prompted him to study how humidity affects MS and despite increasing disability, he continued his studies until recently.

The basic result of his investigations indicates that when the dew-point temperature* is above 10 degrees Centigrade (50 Fahrenheit) it makes MS symptoms worse. He also came up with tables which show how increasing humidity affects MS symptoms (see below).

His campaign is for our weather forecasters on TV and radio to always mention humidity as well as temperature, as they do in countries like the US. But says Russell Johnson: “On their own, humidity readings are not easy to convey in a weather forecast to the general public, whereas the dew-point temperature does take account of the humidity and is very easy to produce and understand.”

---

* What Is The Dew Point Temperature?
If we have a parcel of moist air and cool it until it becomes saturated and produces water droplets, the temperature at which this occurs is defined as the dew point temperature.

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SIMPLIFIED TABLE
(Temperatures in Centigrade C )

<table>
<thead>
<tr>
<th>DRY BULB</th>
<th>DEW-POINT</th>
<th>EFFECT ON MS SYMPTOMS</th>
</tr>
</thead>
<tbody>
<tr>
<td>ABOVE 27C</td>
<td>&gt;17C</td>
<td>VERY SEVERE</td>
</tr>
<tr>
<td>25-27C</td>
<td>&gt;17C</td>
<td>SEVERE</td>
</tr>
<tr>
<td>17-22C</td>
<td>14-17C</td>
<td>MODERATE</td>
</tr>
<tr>
<td>15-19C</td>
<td>11-15C</td>
<td>SLIGHT</td>
</tr>
<tr>
<td>10-15C</td>
<td>05-10C</td>
<td>VERY SLIGHT OR NIL</td>
</tr>
</tbody>
</table>

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Beta Interferon And Atorvastatin Combination May Increase Disease Activity In MS

A study into a combination treatment of interferon beta-1a and atorvastatin found that people who took both medications had more relapses and more disease activity as shown on MRI. The dose was 40 or 80 mg atorvastatin with thrice weekly, 44 mcg interferon beta-1a.

Source: PubMed PMID: 18525027 (18/06/08)
“After my first session my whole posture felt more relaxed and aligned.”

The Mobiliser

By Julie Green

My MS is made worse by a condition I’ve had since I was a teenager, Scheuermann’s disease, which resulted in a curvature of the spine and rigid discs in my upper back. Having a balance problem with MS and being very tall at 6 feet 1” meant pain on a daily basis.

Over the years I have spent a fortune on various treatments to tackle the pain but have found that standard body massages, although relaxing, did not really give me deep or lasting benefit.

Then two and a half years ago I sought the help of Mike Duffield, a nutritionist and body worker. His massages were much deeper than any others I had ever had. He also uses specialist machines like the G5 massager and Thumper which are more powerful than manual treatment and have given me great benefit.

Six months ago, Mike Duffield introduced me to the Mobiliser. I have been having regular sessions on this, which have proven excellent for both back pain and MS symptoms. I used to have aches and spasms in my legs but the Mobiliser is so powerful that all the muscles just give in and completely relax.

I am also less afraid of falling over when standing up straight as my back feels stronger. I am now much more upright when walking and standing at my full height. I now also have more energy because I am not worn out as quickly with the pain and fatigue.

Massaging The Muscles

The Mobiliser machine looks like a slim mattress that you lie on. It also has two sets of knuckled rollers that go from the feet, up the legs and spine, to the top of the neck.

The machine is very powerful. Its twin rows of knuckled wheels move under the body. This lifts and massages the muscles and flexes the individual vertebrae from head to toe, releasing tension and greatly improving the flexibility of the spine. The mobiliser can also be set to work on specific areas as needed.

After my first session my whole posture felt more relaxed and aligned, and it seemed the more I used the machine the better the results. Now my right side, which was weaker, feels more equal to my left side.

At first use it may seem harsh or painful as things realign that perhaps have not moved for years. But with continuing treatments, I have been able to deeply relax on the Mobiliser - a far cry from my first session! This is also helped by a heated comfort pad under your back (selectable) which warms deeply as the massage progresses. Now, I have graduated to using the Mobiliser without the comfort pad which although I felt a little tender initially, is getting to forgotten muscles and loosening tight fibrous areas.

I am sure that I would be on a cocktail of pain relieving medication to mask the pain if it wasn’t for regular use of this machine.

The Mobiliser is not the only thing I have found beneficial for MS. Diet and supplements have all played an integral role.

Info Box

The mobiliser is available for a free week trial to support groups and individuals. Contact Mike Duffield on 0 0 2 5.
He also has lists of practitioners who have the machine.

Mobilisers can be bought for 25.00, no T 00 discount if you write Mike Duffield/MS to life in comments box when ordering online.

If you start by hiring a machine for a month (this costs 150) then decide to buy one, the costs of first month hiring will be taken off the purchase price.

More info www.backinaction.co.uk/mobilis
Taking Control of Multiple Sclerosis Website

Australian doctor Professor George Jelinek, author of the book “Taking Control of Multiple Sclerosis” now has a website of the same name: www.takingcontrolofmultiplesclerosis.org

Professor Jelinek says: “Although there is no cure, the medical literature has considerable evidence that MS is a modern, lifestyle disease of developed countries and that there are many lifestyle changes that modify its course. These therapies have been extensively researched and offer exciting possibilities for controlling the illness and preventing disability.

The aim of this website is to present a summary of scientific information about multiple sclerosis, about the cause, incidence, genetics, signs and symptoms, diagnosis, prognosis, and the best medical research about each of the available therapies. These treatments include diet with emphasis on dietary fats, sunlight and vitamin D, meditation, exercise, supplements, the mind-body connection and medications (such as Betaferon, Avonex, Rebif, Copaxone, Tysabri, Novantrone, and steroids). Recommendations are provided for people with MS to use in aiming at recovery.

For those just diagnosed with MS, there is every reason to hope for a long and healthy life. For those with disability, there is the real potential to slow or completely stop the progression of the illness. For some, symptoms will improve. For many people, visiting this website is their first step in a journey to regaining their health, with the potential for genuine healing. Good luck on the journey.”

Professor Jelinek, who lives in Melbourne, was diagnosed with MS in 1999. His mother died of MS in 1981. He says: “Towards the end of her life, she was totally incapacitated, unable to feed or care for herself. I was determined that this was not going to be my fate.” He sticks to his own lifestyle suggestions and has been free of relapses.
The Chillow

The Chillow is a fantastic way to keep cool at night and beat the "hot pillow syndrome". If you are not sleeping very well then the Chillow could be the answer. The Chillow is a personal cooling pad just 2 cm thick and it can be used with your existing pillow. It is activated by filling it with tap water which is absorbed into the foam core. You can either insert a Chillow into your pillow or sleep straight on it for maximum coolness.

- Suothsoft UK, Unit 10, North’s Estate, Piddington, High Wycombe, Bucks, HP 14 3BE
  Tel 08700 117174
  www.chillow.co.uk

KEEPING YOUR HOME COOL

Air Conditioning

Portable air conditioning units are usually on wheels so you can move them around. All you have to do is put the hose outside. The air that comes out of them really is pretty chilly.

Fans

Fans are an effective and cheap way to keep cool. These range from large floor fans to table top fans, ceiling fans and personal hand held fans. DIY stores or catalogues such as
- Argos - www.argos.co.uk.
- Boots hand held fans, £2.99, M & S travel fans £3.50.
your neck or head. Soaking your feet in cool water, putting your hands under the cold tap or taking a cool shower can also help cool you down.

Ice is the big chill and many supermarkets now sell ice cubes in large bags but you can always make our own. Ice shouldn’t come in direct contact with your skin as you can get ice burns.

- Ice is available at several supermarkets including Sainsbury’s (lue eld Spring after Ice Cubes 5p for 1kg) and Somerfield. (Calypso Mineral after Ice Cubes - 1. 0 for 2kg).

COOLING PRODUCTS YOU WEAR OR SLEEP ON

Cooling Ties, Scarves, Neckwraps And Hats

ool Ties are a great way of cooling down when things get a bit hot and sticky. ool Tie is a fabric scarf which contains polymer crystals. hen soaked in water the crystals absorb water and the ool Tie cools the body as the water evaporates. hen the surface next to the skin warms then you simply turn the ool Tie over for renewed cooling. In very hot conditions take the ool Tie off for a few seconds and wave it around as this refreshes the coolness. quick re-soak in cold water will help you chill out again.

- Kool Ties 10 each plus 2 p p per tie. (approx. 5. plus 1p p) afka’s ool Ties 10 .Cave Creek Road, St 101, hoenix, ri ona 5020 US . Tel (02) 11 www.kooltie.com ool Tie also has a U representative who offer a quick service. They are www.soo-cool.co.uk The Cobber ody Cooling eck rap is pretty much the same idea as ool Ties. It is made from polyester and cotton and filled with poly-crystals.

- Cobber ody Cooling eck rap .5 plus shipping. odycool Industries, Toronto, Canada. Tel (1) 10 www.bodycool.tv

- nother polymer crystal filled cooling scarf called Trekmates can be found at outdoor suppliers lacks, . .

- et Rock Hats are 100 cotton and have cooling crystals that work in a similar way to cooling ties and scarves. The crystals are stitched into the front of the inner headband of the hat. To make them work simply soak the front section of the inner headband in iced water for about minutes. ut the hat on and feel the crystals work! Depending on the temperature, the crystals will keep cooling you for days and are fully re-useable. The hats also work as sun hats.

- Arctic Heat Cooling vests. These cooling vests have special cooling crystals incorporated into the material. You simply soak the vest in cold water for two minutes. The cooling crystals can hold the temperature for a substantial period of time. Cooling vests are very popular with MSers in hot countries such as ustralia.


- Artic Heat ty td Unit 5/1 Rothcote Court, urleigh Heads, ld 220, ustralia.

- Arctic Heat Cooling Vests

- et Rock Hats available from The Complete Outdoors, ondon Road, ounnd, Hemel Hempstead, Herts, H 2RS tel 012 price 1 . plus .50 p p.
Heat and MS – Go One Degree Under

Heat causes MS symptoms to temporarily worsen. Vision can go blurry (Uhthoff’s Syndrome), you feel fatigued, weak, listless, and everything is an effort.

This happens because demyelinated fibres are worse at conducting electrical signals when the core body temperature goes up even half a degree. But if you can get your core body temperature down one degree the symptoms are reduced.

Cooling is considered one of the most effective treatments for MS.

PERSONAL COOLING PRODUCTS

Cooling sprays.

Magicool is a cooling spray that’s the nearest thing to air conditioning in a can. It’s a favourite of many people with MS and can be the perfect way to chill out if you find yourself stuck inside a baking hot car or a stuffy room.

In addition to the Magicool Hot Weather Cooler & Freshener Spray there is also a pocket sized Magicool Body Cooler and Freshener Spray and Magicool Plus Prickly Heat Spray. Boots also does a Hot Weather Cooling Spray.

- Boots Hot Weather Cooling Spray £3.89 for 125ml spray.

Kool ‘n’ Soothe Migraine Cooling Pads

These soft gel pads are designed to provide immediate cooling relief. Ready to use with no need for refrigeration they can last for up to six hours. The slightly sticky gel pads can be used on your forehead, the back of your wrist or anywhere you want to cool down.

- Kool ‘n’ Soothe Migraine Cooling Pads cost £2.99 for a pack of four. Boots also do cooling headache pads – soft gel pads price £0.99 for a pack of two. Also a range of other cooling products including Nelson’s Arnicare Cooling gel. Nelson’s is the famous London homeopathic pharmacists and the Arnicare Cooling Gel combines the benefits of Arnica with the refreshing sensation of natural grapefruit oil and menthol.
  - Arnicare Cooling Gel 4.65 for a 30g tube.
  - Arnicare Soothing Spray £4.95.
  - Antistax Cooling Leg Gel £5.55 www.boots.com

Cool, Cool Water And Ice

Cool water can be a really effective way of getting cool. A scarf soaked in water and then wrung out can be worn around...
to forget the problems of being disabled.

The wow factor in my job was starting to lose its first w. If it were to lose another consonant it would end up as one tiny insignificant ero.

If the time eannie, my wife, my rock, my shield and my friend, was also lying sleepless in England, trying to keep our life together and knowing that when I got back I would be more of a wreck than I had been the time before and that the time to recover - the brunt of which she always took - would be longer.

The seven weeks of the Rugby World Cup in France confirmed my worst fears. The last two weeks, when England reached the finals, created unprecedented demands. I got through, but only just, and only with fantastic support from my closest colleagues.

I knew that when the next big rugby event came along the gap between the demands of the job and the supply of my energy to do it would have become a chasm.

The C very kindly allowed me to bow out on my terms, at a big occasion, while I was still able to do my job reasonably well. And what an occasion, and what a day, and what an amazing display of warmth from so many people!

Now to the future. I'm not giving up work, just this particularly demanding job, and I don't feel in any way that I am giving in to MS.

I'm just finding a better way of living with it.
With increasing demands from his job and decreasing energy, Alastair Hignell has retired as a Radio 5 Live sports presenter.

Moving On

By Alastair Hignell, Patron of MSRC

Alastair Hignell, 53, was diagnosed with MS in 1999. Married to Jeannie, they have two sons and live in the Cotswolds. He has been a sports commentator since the 1980s.

A sporting legend, in the 1970s he played rugby for Bristol, Cambridge University, Gloucestershire, the Barbarians and England. He also played cricket for Cambridge University and Gloucestershire.

The “Wow” Factor in My Job Was Becoming More of an “Ow.”

I loved my job and wanted to do it the sort of justice I believed it deserved, that I had managed to deliver so far, and that was in danger of being compromised by my dwindling energy levels.

I had found myself spending increasing amounts of time lying in my hotel room in an attempt to summon up the energy to attend press conferences. I wasn’t sleeping well, and I was struggling, for the first time, with increasing demands from his job and decreasing energy, Alastair Hignell has retired as a Radio 5 Live sports presenter.

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I had found myself spending increasing amounts of time lying in my hotel room in an attempt to summon up the energy to attend press conferences. I wasn’t sleeping well, and I was struggling, for the first time,
The Esperanza NeuroPeptide Treatment Has Worked For Me...

Testimonials Of Actual Esperanza NeuroPeptide Patients:

I Am Into My 20th Year On The Esperanza NeuroPeptide! - E.C.
From Wheelchair To Walking! - S.W.
It Was Peptide Or Nothing - I Had The Birth Of My Son While On NeuroPeptide! - G. D.
Much Needed Hope! - D.H.
I Am So Lucky To Have Found Esperanza Homeopathic NeuroPeptide! - P.H.T.

PPMS And On NeuroPeptide For Four Years! - R.D.
I Can Confidently Say That I Have Experienced Only Benefits On Esperanza Homeopathic NeuroPeptide! - C.C.
The Best Decision I Ever Made ... Regarding My Health! - F.L. M

Esperanza Homeopathic Sublingual Spray Has Returned My Sense Of "Joy of Life"! - A.A.
Bless The Pioneers At Esperanza Peptide For Developing This Remarkable Treatment For MS! - J.H.
I Am Beating MS With The Esperanza Peptide Sublingual Spray! - C.B.
I Feel Better And Have More Energy With Esperanza NeuroPeptide! - F.T.
A Genuine Medication That Has And Will Continue To Give Me A New Lease On Life! - K.K.
Friends And My Partner Cried When I Danced Again! - S.F.

Full and actual treatment stories on all of the above testimonials can be found on the company website at www.esperanzapeptide.net

For more information on the Esperanza NeuroPeptide treatment please feel free to go to our website at www.esperanzapeptide.net or call our European Information centre at 01325 254420 for full details and/or to arrange a clinic booking.
email: info@esperanzapeptide.net or neuropeptide@btinternet.com
web: www.esperanzapeptide.net
Prokarin – What Is It and How Do You Get It?

Prokarin, which used to be called Procarin, is an ‘off-label’ compounded patented prescription medication in the USA containing histamine and caffeine. It is supposed to work in MS because histamine phosphate, a natural amino-acid derivative, is a potent neurotransmitter. Caffeine inhibits an enzyme that gets in the way of this.

Prokarin was first made available as a cream that had to be measured out onto a patch which was then applied to the skin. Now, there is a ready-made version of Prokarin which comes in the form of a small disc which is simply applied to the skin and worn from morning until bedtime. It does not require refrigeration.

Laine Deack, a nurse with MS, revived this treatment first done by Dr Hinton in the 10s and went on to research and patent Prokarin. She says it works for her and has hundreds of anecdotal reports from people with MS who have used it with success. Two reports at least one significant improvement in symptoms, and some many more.

What Is Histamine?

Histamine is a very small and simple molecule made by everybody from the naturally-occurring amino acid histidine. The theory goes that people with MS have trouble turning histamine into the neurotransmitter Histamine 2. Histamine 2 sends messages down the H2 pathway, but this pathway does not work well in MS. It also plays a role in balancing the immune system, making digestive enzymes, regulating stress and stimulating the thyroid.

What MS Symptoms Is It Supposed To Help?

Those who claim it has worked for them say Prokarin particularly improves the symptoms of fatigue, poor balance, walking speed, motor functions, bladder problems, brain fog, speech difficulties, numbness and poor sleeping.

Studies

Laine Deack, knowing that she needed the support of doctors, set up a double blind pilot study on Prokarin and MS fatigue at the University of Washington, later published in the peer-reviewed Multiple Sclerosis Research Journal.

In the study, 21 people were given Prokarin and 5 a placebo. The conclusion showed a modest statistically significant effect of Prokarin on fatigue. The average improvement in fatigue for each individual was . Side effects were minimal. Fatigue is often the first symptom to improve with Prokarin, sometimes obvious within hours of starting the treatment.

However, this study was rubbish by the merican national MS Society, criticising the study design, the small sample size, the difference between the subjects, and the potential confounding effects of caffeine (the amount of caffeine is half a cup of coffee per dose), a known stimulant. In short, no scientific proof.

In the years since then, arguments have raged on both sides. It there is no doubt that a larger trial on Prokarin is needed.

How To Get Prokarin

Prokarin can only be prescribed by US physicians and is made up by one US compounding pharmacy called Custom prescription Shoppe (see below). The doctors at the Tahoma Clinic can prescribe Prokarin, including to patients from overseas. You have to fill in a long patient questionnaire, and then have a one-hour telephone consultation.
rokarin is cheap compared to other things I have tried. It comes from the US. I am rather fortunate in working with many US military doctors and the US Deputy Secretary of Defense at the Pentagon arranges it for me. It is sent from the US to the UK.

I cannot get the skin patch when I need it. Either I forget it in a fridge in another country or else my bodyguards from the UK cannot bring it over to Iraq on the day that I need it. If this happens my health rapidly declines. At least that shows me that this is really working.

Sometimes I get angry. Why is it that there is such a simple solution that is not widely known about? It does not cost much, it always works and despite the distance it is readily available.

**Just Off To Meet Some Terrorists**

Meanwhile for me it is another day in Baghdad. I am just off to do a press conference, then to the US embassy, then to meet some terrorists to try and arrange a local ceasefire and the list for this day alone goes on and on.

This morning I did not finish work until 2 am having now written this it is am and it is time to get going. I am writing this from my ortakabin in the International one.

I hear the mortars and helicopters flying. The heat today is 5 C and I just have to go on and on and on. The heat here is an issue but I am very odd in that I am worse in the cold and wet than the heat.

When I come back to the UK I always get worse.

I can cope with the heat up to about 50 C. Here it reaches 0 C in August and then I have to leave. We do have air conditioning when we have electricity, which is not always.

There are indeed days when I still feel awful but the reality is that I could not do what I do without rokarin. I have tried other substances for my MS including impro which did help hugely for a while but was expensive.

rokarin could be a simple solution which takes you out of hell. Since I have been on the rokarin I have only had one relapse which was quite bad and recent.

Of all the things I have tried rokarin has been the best. It does not cure you but deals with so many of the symptoms and has no side effects. I have recommended it to other people with MS and they have all seriously improved.

When I have a relapse it is really difficult because most people do not really understand how much help I need. I usually have one member of staff with me who kind of understands it is so difficult though.
"My Life Was Transformed Thanks To Prokarin"

Says Canon Andrew White, The Vicar Of Baghdad

Canon Andrew White was told by the Church in England that he was too ill with MS to work as a vicar in this country. Now he has found his salvation in Baghdad trying to bring the warring factions together as well as being minister at the only Christian church there, St George’s. He uses Prokarin patches for his MS, which he says keep him going. Diagnosed with MS in 1999, Canon Andrew White, 43, is Director of the Church of England’s International Centre for Reconciliation. He is married with two sons and, when in England, lives in a rectory in Hampshire. He was recently the subject of an ITV documentary

My is not asymptomatic. I have good days and bad days. I struggle with my sight, my balance and many other things. I also have days when I wonder how much longer I can keep going.

I too have longed for a cure. I too have become so frustrated by all the people who send me the answers. Most of them I cannot observe because I do not have control of my diet. I have to eat what I am given. There is no chance of going out here to the shops. If I was to do so I would be killed.

I have tried many of the recommendations and finally have found one that really does work and has transformed my life. The reality is my ten years here would now be over if it were not for the one thing that has simply transformed my life: Prokarin.

I was sent a book from the US by Elaine DeLack called "It does not make Cents". Elaine Delack is a nurse who got MS. She then dedicated her life to finding the answer. It finally came in the form of a skin patch which is relatively cheap called Prokarin. Its active ingredients are simply Histamine and Caffeine.

For me it did not work overnight. It took a few weeks to work and then suddenly I realised my life was different. My wife first noticed that I had completely changed. No longer did I have mood changes. No longer did I have to spend several hours resting. No longer did I feel ill all the time. My life was transformed.

The treatment of Prokarin is so simple; one skin patch a day with no side effects. Prokarin is now in a ready-made skin patch, not the separate cream and caffeine like it used to be.

How do I manage to keep going, how do I manage to do one of the most complex and difficult jobs, in the most dangerous place in the world? It is simple - I have one skin patch a day of Prokarin.
Christine Jones ‘Rediscovers Life.’

At the end of July Christine Jones, 57, retires as Chief Executive of the MS Trust after 15 years at the helm.

“After I retire I’m going to rediscover life, and start with the “gap year” I never had,” says Christine, who now plans to go trekking in northern India and Bhutan with her husband Roger.

“I thought I should live life to the full and travel while I still can. I lost both my parents in the last 18 months and it makes you look at your own mortality. It makes you wonder how long you’ve got.”

Diagnosed with MS in 1980, Christine never thought she would be trekking 28 years later.

“At the time I was diagnosed the image of MS was very negative. It was diagnose and adios. It was at the height of those shocking ads about MS. Those images got into my head and I feared I would become seriously disabled.

“I thought, ‘I’d better order my wheelchair now.’ I expected to be very disabled very quickly but that didn’t happen. I was quite unwell for the first three or four years but then came through it.

“Now, I do have minor sensory symptoms but walking is very rarely a problem. I recently went to Scotland with my husband and walked 14 miles to get into training for Bhutan. I know I am incredibly lucky.”

At the MS Trust Christine hands over the reins of Chief Executive to Pam Macfarlane. She says “I could not be more confident in her ability to lead the fabulous MS Trust team and to continue our work to improve services for people with MS.”
At Charter Healthcare, we offer an efficient, discreet and confidential delivery service for people requiring prescription continence care and stoma care products. All products and brands can be supplied and delivered free to your home once registration is complete.

In addition, our award-winning customer service team will ensure that you always receive the best service and support. So contact us today, and you could be more free to get on with your life.

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In association with Coloplast
Diet, Supplements, Exercise & Other Therapies Can Make A Difference

The overriding positive message we must put forward is that the statistics quoted by Dr Coles do not take into account how the course of MS can be improved by doing all the things we so often write about in New Pathways - diet, supplements, exercise, alternative therapies, positive thinking etc.

Another positive way of looking at scary facts is that, armed with this knowledge, you can make decisions about your lifestyle and future. Dr Stoner may go into this aspect in more detail on pages 49 and 50.

Neurologists like Dr Coles will never take the therapies we feature in New Pathways seriously because he does not think they stand up to scientific scrutiny. If a treatment hasn't been shown to work in a double blind placebo controlled trial, then it doesn't work! - what he said to the MS Life audience (talking about DMSO).

But that's the view of a typical, old-school neurologist. Our view is that - as an individual you can improve your MS. It may be anecdotal evidence, but if it works for you, who cares?

In our view, you are less likely to need a stick at 50 or die after 10 (or 20) years with MS if you do the things that make a difference.

"I found Dr Coles' article hard hitting and brutal. A newly diagnosed person would, I believe, feel utterly dejected after reading Dr Coles' depressing statistics - do they really need to be spelled out to us?" - Barbara Lis

"I feel so upset after reading about the Myths and Facts. I haven't stopped crying." - Tracy Holmes

"To present these 'facts' in such a bald, negative, unbalanced way is, I feel, at best ill-considered and at worst crass and completely insensitive." - Chris Catchpole (Dr)

"I was really disappointed that such a great magazine printed the article Myths and Facts. It was one of the most depressing articles I have read, particularly the section "Some Hard Facts About MS." - Sandra Essex

"I read your magazine every month and enjoy it but I was horrified when I read the article on Myths & Facts. My doctor and MS nurse have been very positive about my prognosis and here I am reading hard facts that do not correspond in any way with the things I have been told." - Maria Harding

"I was disappointed and angered by the article in which Dr Alastair Coles "shattered some well-worn myths with some harsh facts about MS. As to reduced life expectancy, Dr Coles contradicts himself where he says that: "Life expectancy is reduced by 5-10 years." Given the average age of death for non-MS sufferers nowadays, even if we subtract this "5-10" years we would not be looking at dying "around 60" it would be nearer 75." - GarryTodd

"I am writing at last it seems to compliment everyone concerned with the New Pathways' magazine on its quality of information, factuality, balance and positive approach - the format is very good but your article was more than merely 'sobering', it was negative, frightening and fatalistic to all those of us who are trying to live lives as positively as possible and feeling quite proud of that mentality and sheer effort." - Graham Bedford

"I have been a subscriber to MSRC for about 6 years now and have always appreciated that, unlike the MS Society, you will publish articles in New Pathways and leave readers to make up their own mind, which is fine when it comes to treatments that may or may not work.

Sadly I must take issue with you for publishing such a destructive article from a neurologist. The magazine went straight in the bin." - Sue Holloway

"What Dr Coles said may have a high degree of truth, but it offers nothing new or constructive. New Pathways and the MS Therapy Centres do a great job of improving the lot of MS sufferers. The Myths and Facts article does the opposite." - John Riley
‘Myths & Facts’ Article – Apology & Discussion

Judy Graham, Editor of New Pathways, writes

The article that re the myths and that re he acts about on pages and in the last issue of ew athways resulted in a number of you emailing or writing to us. Here, we publish extracts from these letters, and will also attempt to address the various points raised.

But first, I owe an apology to all those who found the article upsetting. It is never our intention to do this.

I also owe an apology to Dr Iasdair Coles for erroneously putting his by-line to the article. Dr Coles did not write the article. I wrote it based on his talk at MS life.

Some of you complained that the article was unnecessarily curt, bald and harsh. Dr Coles’ delivery of the facts was somewhat less brutal than appears in the article, which is necessarily a shortened version of what he said. However, the facts are the same.

After his talk, I (being 1 and thinking my time was up after 5 years of MS) approached Dr Coles about the statistics he quoted. His reply was along the lines of ‘These are averages. Statistics reflect facts at a population level, but not an individual level.’

Dr Coles has also written an article on this topic for the MS Society website which gives the statistics about MS in a more positive light than his lecture. Why de did not present these facts instead of the ones he quoted, I do not know.

Dr Coles writes

As th s b ty rom n r s s s or s st th
rs o h stor b r n t ons n r
t o h r o o th o s h
n t ons t s r t ny or ths n m
t n o y h h o n ro b m s th oo
or n r o y h r r r n t ons
s r h s st s th t o n r
t y o o t h s o r th n th t
o th h o o t n by r n y rs
n r o s s h y s s th n o r ty
y rs t r th r rst sym toms
om rs r h sho s s r h s b n m r o n n
r n t y rs r h s to b t t r h th r
r o n t no s s m o y n r s b t
n t r r o n n t n y
ven though Dr Coles toned down the harshness of his facts in his online article, the bitter truth is that many facts about MS are negative. So the question arises Should we at ew athways flinch from publishing unpalatable truths? Should you shoot the messenger or the message?

ew athways does have a well-deserved reputation for being positive and upbeat. A reputation we intend to preserve, but must that mean that we always skirt round difficult issues or avoid harsh truths?

I don’t think so, but I do agree with those of you who say that negative facts should be counterbalanced with positive ones and put in a wider context, which we should have done in this case, what we are doing now and what we would strive to do in future.
You’ll need issue 49 of New Pathways to get some of the answers.

By Cryptic Charlie Gee
Answers, with some explanations, on page 52

Across
7. Bedtime suit. (7)
8. The soldier leaves reportedly to get model of perfection. (7)
10. If here you will find the young cow. (6)
11. Goes on for longer. (8)
12. Carry the animal. (4)
13. One of the throw away society! (6,4)
14. Striking, you have to look! (3-8)
19. Sounds like you say hello to Mick and Keith for wintry weather. (9)
22. Boast about the bird. (4)
23. Company man and revolutionary Red Indian. (8)
24. Join in citizen listening society. (6)
25. Use in mothers where old things are kept. (7)
26. In the last issue he wondered whether there was a certain personality for people who have MS. (7)

Down
1. Sort group sorted by compositor! (7)
2. See 5 Down
3. In the last issue and Louise went skiing on a bike. (6)
4. Reason for dentists. (3,5)
5. and 2. Down In the last issue Tysabri got him back to normal. (6,8)
6. Mug about above leads to Watergate for example. (7)
9. Laurel follows alcoholic beverage for capital. (4,7)
15. Burial place. (8)
16. Kiss material for jewellery! (8)
17. Sounds like you ban modern music and get classical music. (7)
18. Very warm round and becomes extremely successful person. (7)
20. The foliage goes away. (6)
21. You have to look twice for this in the playground. (6)
The course is fabulous and contains excellent support materials that have had a huge positive impact on the clients with MS that I see.

Many Thanks
Joanne Hope (Physiotherapist)

How Do I Deal With Muscle Spasm?

Dear New Pathways,

One of the most distressing symptoms of my MS is severe muscle spasm. The spasms are excruciatingly painful and completely out of my control. They can happen at any time and nothing I have tried has alleviated the pain or the severity.

It is hard to describe the intensity but when for instance, my left arm goes into spasm it feels like it is crushing me and I cannot physically or mentally make it relax. My legs also spasm and when this happens my knees lock together to such an extent when my husband tries to dress me he cannot get my trousers up.

My own GP is at a loss as although he has several patients with MS, none of them have described having spasms like mine.

Can I also ask if anyone experiences sticky hands? For me it’s like I have glue on my fingers and yet other people tell me that my hands are not sticky.

I would greatly appreciate to hear from anyone who has experienced what I am going through and would be more grateful to hear from anyone who can offer any suggestions as to what I can try to alleviate these symptoms.

Yours sincerely
Maureen Gunson (Mrs), Worington, Cumbria.

Ed says: Have you tried taking magnesium? It can sometimes help with muscle spasm.

If readers have suggestions for Maureen, please send them to the msrc who will forward them to Maureen.

How Do I Deal With Faintness?

Dear New Pathways,

I have had MS since 1974 and have been secondary progressive since 1999. I do get really bad nausea and dizziness, but in the last three years I have started to get periods of faintness which last for days or months at a time (and sometimes get dizziness and faintness together). Doctors and neurologists have not known how to treat this and I have been told it is probably another MS symptom that I have to put up with.

I would like to know if any other New Pathway readers get this faintness and how to treat it.

Yours faithfully
Anne Edwards, Portree, Isle of Skye

Help Needed With Guidebook,

Dear New Pathways,

I’m currently researching and writing a new guidebook which will be entitled “African Safaris for People with Limited Mobility”.

I am quadriplegic and a full-time wheelchair user, but this book is aimed at everyone with restricted mobility, including part-time chair users and ‘slow walkers’.

I would like to know more about the fears and barriers all these people face when travelling, and just as importantly, how they overcome them.

I’d hugely appreciate any thoughts you have. It does NOT matter if you’ve not been to Africa and you can send one tip or write a whole essay; I’ll read all replies and ANY advice could be relevant. I will not mention you by name if you prefer this.

Here are some suggested topics:

• bathrooms (understandably, the biggest worry for many is how they can use the toilet, shower or bath if they’re not as accessible as at home)
• air travel (the second biggest fear…)
• vehicle transfers (including high vehicles, like 4x4s, buses and coaches)
• steps
• tables in restaurants
• poor ground surfaces and rough paths
• narrow doorways
• lack of seating
• camping (many safaris use lodges and hotels, but some people still prefer traditional camping)
• switches and handles
• planning and packing
• temperature and weather extremes (heat, cold, wet, dry etc)
• safety and security

Thanks and I’m looking forward to hearing from you!

Regards,
Gordon Rattray
Gordon@able-travel.com
www.able-travel.com
**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, 3 Earl Street, Earls Court, London, SW10 9DG. Tel 0800 051 or 0120 505.  e-mail info@msrc.co.uk

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**Enjoyed Food Article**

Dear New Pathways,

Can I just say how much I enjoyed the article by Janet Orchard on her struggle with both MS and to find suitable ingredients for the BBD diet where she is living in Catalonia.

Is there any chance of hearing more from this lady? I’d love to see it as a regular feature in your excellent magazine.

Many thanks,
Mark Redgewell,
Sydney, Australia

The article mentioned above (New Pathways issue 47) can be downloaded from www.msrc.co.uk

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**My MSRC Wristband Is No More!**

Dear New Pathways,

The MSRC wristband is no more. It’s gone to meet his maker. You couldn’t bring the insignia back if you put 20,000 volts through it!

My left hand drags on the chair sometimes and I’ve managed to nearly wear it out!!! It’s paper thin and about to snap after three solid, uninterrupted years adorned on my otherwise inactive left hand. It has been a useful brake and speedily helps me turn the wheelchair right to left.

It’s multi-functional and I don’t know what I am going to do when it goes to the "Green wristband grave" in the sky. Yours in mourning,
Mark Jennings.

---

**I Still Use My Brain**

Dear New Pathways,

I thought it might be encouraging to counteract some of Alasdair Cole’s predictions. Although I might not be able to run marathons and cope with a lot of physical activity, I can still use my brain and motivation to give an interesting dimension to life.

After 14 years with MS I embarked on an Open University Arts Degree course, having just had to retire from my nursing career at the age of 57. The OU is very supportive of disabled students so no one should be put off and the choice of courses is large and varied: something for everyone.

Having gained my BA in 2002 I started writing a book which has just been published. It is a family history, concentrating mainly on my father who served in the RAF with Lawrence of Arabia when they were both recruits for photographic training. He went on to photograph life and events in Aden, Somaliland and Abyssinia during his service career.

From his diary covering 1940 to 1942, notes and photographs I was able to record his personal account of the siege of Malta when the island was awarded the George Cross. In stark contrast, I recall my memories of what it was like to be child in wartime Britain.

The title is: FOOTPRINTS THROUGH A CENTURY 1880s to 1980s

By JEAN BUXTON (my maiden name) and ALAN WILDSMITH TOWLE
ISBN number 978-1-84306-412-1
It retails at £14.99 and can be ordered through bookshops or directly through me by telephoning 01773 857061.

I hope this will encourage others to find satisfying outlooks to their lives even when Alasdair Coles thinks their time is nearly up!

Yours sincerely
Jean Heaney
Derbyshire

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**Thanks To Mercia MS Therapy Centre**

Dear New Pathways,

I am a Physiotherapist working at Coventry’s Mercia MS Therapy Centre and Wolverhampton MS Therapy Centre and I would like to thank them for helping to fund me to further my education and become more knowledgable in MS as I have started the Leeds Postgraduate certificate in MS,
New Pathways Issue 50 July/August 08

News & Snippets

UK Government’s National Strategy For Carers.

This sets out a ten year vision and reflects what carers said they want to see. The main points are:
• Carers should have a life of their own
• Carers should not be forced into financial hardship
• Carers should be treated with dignity and respect

There will also be more money for respite breaks, and more support from the NHS. However, there are no immediate changes to Carer’s Allowance although the Government has promised a full review of carer benefits.

CarersUK says it welcomes much of the strategy but “it offers little comfort to the hundreds of thousands of families living in poverty as a result of their caring responsibilities. Carers UK is disappointed there is no immediate financial help for carers who rely on benefits.”

Woman Seeks Clarity On Assisted Suicide

Debbie Purdy, 45, from Bradford, who has MS, has launched a legal challenge to try to find out whether her husband would be prosecuted if he helped her travel to Switzerland to commit suicide. She says if the law is not clear, she may be forced to end her life sooner than she wants to, to ensure her husband, musician Omar Puente, is not jailed.

She is a member of Dignitas, which operates clinics in Switzerland where people can go to commit suicide.

Legally, anyone who aids the suicide of another person can face 14 years in jail. She fears that if she waits too long, she will be unable to travel to a clinic alone and does not want her husband to risk jail for helping her.

The court hearing will be in October.

Cannabis May Help Ease Nerve Pain In MS

Smoking marijuana can cut pain intensity in patients with nerve pain, a new study by University of California Davis has revealed.

In the study involving thirty-eight patients, researchers examined whether marijuana produces analgesia for patients with neuropathic pain. The subjects were given either high-dose (7 per cent), low-dose (3.5 per cent) or placebo cannabis. They found that identical levels of analgesia were produced at both high and low doses of cannabis.

Source: University of California Press Release

Case of Aggressive MS After Taking Tysabri (Natalizumab)

An American neurologist has reported the case of a young woman who developed aggressive MS after going on Tysabri (natalizumab). J.D Berger, from the Department of Neurology at the University of Kentucky College of Medicine writes.

“I report a 31-year-old woman with relapsing remitting MS of 12 years duration who developed aggressive demyelinating disease four months after the initiation of natalizumab. The clinical worsening was accompanied by a significant increase in new large T2-hyperintense signal abnormalities and in both solid and C-shaped contrast-enhancing lesions. Neither the clinical severity nor the striking MRI abnormalities had been noted earlier in her disease course. Neutralizing antibodies to natalizumab were not detected. She subsequently responded to combination therapy of pulsed mehtylprednisolone and daily glatiramer acetate (Copaxone).

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Can Worm Eggs Treat MS?

An unusual treatment being tried out for MS in an American hospital is to drink a cocktail of worm eggs, which hatch inside the body. Doctors say the low-grade infection of worms, harvested from pigs, can help regulate faulty immune systems.

“The yuck factor is hard to get over,” acknowledged Dr. John Fleming, the neurologist who plans to launch a study of worm therapy next month. “But the idea has scientific merit.”

Patients with other conditions, such as irritable bowel syndrome, have tried worm therapy elsewhere. It has eased symptoms without causing known side effects. Many scientists believe the prevalence of such autoimmune conditions — including multiple sclerosis, allergies, asthma and a form of diabetes — is partly explained by a “hygiene hypothesis.” Sanitary environments in developed countries have led to more of the diseases, the theory goes, because people’s immune systems aren’t properly trained by exposure to germs and parasites.

The worm therapy offers a crash course of such training, Fleming said. “It stimulates the immune system in a good way.” He said the concept is similar to eating yogurt, which contains helpful bacteria that regulate digestion.

In the study, five patients with multiple sclerosis will sip a sports drink-like liquid every two weeks for three months. Each cup will contain 2,500 eggs of the whipworm, a tiny organism that commonly lives in humans and animals. Though the human whipworm rarely causes illness, the study uses a pig version that is benign in people, Fleming said.

The eggs hatch into larvae, the size of an eyelash, that stick to the inside of the intestine. In killing the larvae, the body unleashes an extra dose of regulatory T cells, which dampen overactive immune cells. But with the worm therapy, “instead of knocking down the bad parts of the immune system, we’re pushing up the good parts,” said Fleming, who has written about this in the Annals of Neurology.

In his study, Dr. Fleming found that over the course of 4 1/2 years, 12 MS patients who had been naturally infected with intestinal parasites had dramatically fewer relapses, less disability and fewer lesions found on MRI scans than 12 matched MS patients who had not been infected with parasites.

Ref: “Association between Parasite Infection and Immune Responses in Multiple Sclerosis.” Ann Neurol 2007;61;1.

Rising Care Charges “Leading Disabled People Into Poverty”

Rising care charges are putting older and disabled people at risk of not being able to afford to eat, heat their homes, wash or get essential support, says a new report published by the Coalition on Charging representing disabled people, older people, people with long-term health conditions and carers.

The report, ‘Charging Into Poverty?’ reveals that rising charges for people to receive care in their own homes are causing disabled and older people in England to reduce or even stop their support services.

The survey found that: 80% of people surveyed who no longer use care services say the charges contributed to their decision to stop their support. A fifth (22%) of people surveyed who are currently using support suggested they would stop if charges increased further. 29% of respondents do not feel their essential expenditure (related to impairment/health condition) is taken into account in financial assessments to pay charges. Nearly three quarters (72%) of people surveyed believe the Government should think about the charges people pay for support at home in adult care reform plans.

Source: Coalition on Charging Press Release
**Neurotoxic Effect From Mercury Fillings, Says FDA**

Simply chewing could release harmful mercury vapour from dental fillings, says the Food & Drug Administration (FDA) in the USA. They had previously advised that fillings made with mercury were safe. The FDA website now states: “Dental amalgams contain mercury, which may have neurotoxic effects on the nervous system...”

It adds that mercury vapour is released when amalgam fillings are put in or taken out, and when chewing food. Small amounts of mercury vapour escape and are passed into the bloodstream and organs.

More than half an amalgam filling is made up of mercury. It is mixed with silver, copper and tin to make a durable filling.

The FDA is now carrying out an urgent review of its rules and may end up banning mercury fillings. These are already banned in Norway and Denmark and Finland and Japan have severe restrictions.

In the UK, the Department of Health issued a statement to say that it continued to believe that mercury fillings posed no danger.

*Source: Daily Mail, June 30th, 2008.*

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**Beneficial Effects of Exercise on MS Fatigue**

Exercise works better at combatting MS fatigue than any drugs. "There is no effective pharmacological treatment for fatigue, although a few reports point towards beneficial effects from physical activity for MS patients suffering from fatigue," says neurologist Y.D.Fragoso of the University Metropolitana of Santos in Brazil.

“We devised a physical activity program for MS patients with fatigue which consisted of a 20-week series of gradual stretching, resistance and aerobic exercises, adapted to the individual clinical condition of each patient. The results showed significant improvement in cardio-circulatory parameters, as well as a significant decrease in scores on the fatigue scale.”

The researchers concluded: "The success of this program led patients to ask to continue with it after the trial was finished, and more patients are enrolling in the program, motivated by the good results reported by fellow patients."

*Ref: Neurorehabilitation journal, 2008;23(2):153-7.*

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**Ms Patients In UK To Get Own NHS Budgets**

Patients with conditions like multiple sclerosis and motor neurone disease will have their own NHS budgets to buy the care they think is best for them. The personalised NHS budgets will be piloted by 5,000 patients from early next year, under the NHS Next Stage Review. It is unlikely the patients will be handed the cash, rather the funds will be managed on their behalf and no patients will be forced to take part. There will also be safeguards so patients do not worry that they will be denied care if their ‘budget’ runs out.

*Source: Daily Telegraph 01/07/08*
40% Reduction in Relapses With New Oral Drug Laquinimod

A daily 0.6mg dose of the new oral drug Laquinimod led to a 40% reduction compared to placebo in lesions in the central nervous system as shown on MRI, reports a study published in The Lancet. The immunomodulatory drug, which is anti-inflammatory, was trialled in 51 centres in nine countries on patients with relapsing remitting MS. It is made by Teva Pharmaceutical Industries.

Whether or not Laquinimod is more effective than existing disease-modifying drugs will have to be put to the test. However, there is no doubt that a treatment which you take by mouth is more convenient than one which is injected. The drug still needs to go through more trials for safety and side effects. However, the study authors say Laquinimod shows promise as a new oral treatment for MS.

The Lancet 2008; 371:2085-2092

Distinct Types of Disease In MS Patients With Same Symptoms

People who experience the same clinical symptoms of MS may have different forms of the disease that require different kinds of treatment, according to studies on mice at the University of Michigan.

The team found that different inflammatory chemicals could bring on the same paralysis and other MS symptoms. They also showed that drugs which block one of the inflammation pathways were not effective at blocking the other. This may explain why some people respond to beta interferon or Copaxone better than others.

Ref: Journal of Experimental Medicine, July 7, 2009

Celery and Green Peppers Are Anti-Inflammatory

A plant compound found in abundance in celery and green peppers can disrupt a key component of the inflammatory response in the brain, researchers at the University of Illinois have found. These findings have implications for research into MS, aging and Alzheimer’s Disease.

The study looked at luteolin, a plant flavonoid known to impede the inflammatory response in several types of cells outside the central nervous system. The purpose of the study was to determine if luteolin could also reduce inflammation the brain.

Source: Scientific Blogging 21/05/08.

Potential Treatment for Remyelination

An antibody called rHigM22 may become the first treatment to promote myelin repair in MS. Studies are being carried out in a partnership between the Mayo Clinic and University of Minnesota.

Source: Postbulletin.com 19/04/08
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E-mail from Carole – a 20 year sufferer of MS.

Dear Sirs,

Towards the end of last year, I became aware of vibration training being available in my home town. I carried out some research on the Internet and discovered that vibration training was said to be beneficial in a number of ways, including as passive exercise for persons with multiple sclerosis improving balance and to increase bone density. I am a person with MS. Fatigue and weakness prevent my undertaking conventional exercise. As I also experienced early menopause through a hysterectomy and have a family history of osteoporosis, my inability to exercise is a concern. Unlike others, it is not recommended that persons with MS "work through the pain". I booked a course of vibration training locally to understand what was involved and to ensure that I was able to cope with it. With this understanding, I again turned to the Internet to research what home based equipment was available. The Mend Your Health Vibration Trainer was by far the best choice available. The design was far superior to other equipment intended, and priced, for domestic use.

Although I purchased the machine at the beginning of this year, a bad spell of health meant that I did not start using the machine seriously until about a month ago. [With MS, it is difficult to apply oneself to anything new when going through a bad patch.] I have been extremely pleased with the results so far.

Like all people with MS, my balance and coordination vary over time. Therefore, in such a short period, I am unable to claim any benefit in these areas. However, I do have the psychological benefit of, at least, feeling that I am doing something about them. Using the VT at home means that:

- I can use it more frequently and at times which suit me
- I can experiment to find a routine with which I can cope as well as adjust to suit the variability of my condition
- I can save money. [I use the Vibration Trainer for just less than an hour each day split over five sessions. A month of exercise at this rate at my local centre would cost more than that the Mend Your Health Vibration Trainer costs.]
- What I can do, is confirm definite improvement in my physical fitness. I have been keeping a careful record of the exercise I have done and vital measurements. My muscle tone [something that can be poor in persons with MS] has improved considerably. My legs are definitely stronger. This is demonstrated most clearly in doing the squat position exercise on the Vibration Training. This was exceedingly difficult for me initially. I could only squat slightly and had to support myself with my arms resting on the handrails. I can now squat quite easily for a minute of vibration.

My measurable improvements over the first four week period are:

- Weight: From a starting weight of 68.5kg, I lost 1kg
- Fat%: From a starting % of 22, I lost 1%
- Bust: No change
- Underbust: From a starting measurement of 32", I lost 1.5"
- Waist: From a starting measurement of 33", I lost 1.5"
- Hips: From a starting measurement of 40", I lost 0.5"

I have now changed my exercise programme to put more emphasis on toning my hips.

Regards, Carole.

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Dear New Pathways Readers

Normally in New Pathways, we accentuate the positive and play down the negative side of MS even though of course we know it’s there. So many readers of the last issue were shocked and surprised when we ran a report on some of the more unpleasant facts about MS. On pages 14 and 15 we publish extracts from your letters about this and discuss the whole topic. And on pages 49 and 50, Ashton Embry PhD argues that we need to know the risks we face in order to plan our future.

Most of the time, I am sitting at my desk working on my computer. But very occasionally, I go out and about and have a bit of fun. One such occasion was flying a light aircraft – or at least being at the controls for ten minutes while an experienced pilot from the British Disabled Flying Association was safely at the dual controls. It’s an experience I would heartily recommend, even if, like me, you are one of life’s scaredy cats. You can read all about it on pages 30 and 31.

One of my heroes is Canon Andrew White, known as the Vicar of Baghdad. Each day, this giant of a man with MS risks life and limb trying to bring the warring factions in Iraq together, braving heat and constant danger. He says the one thing that keeps him going is the drug Prokarin, which he gets thanks to American doctors and the US military. You can read what he says about Prokarin on pages 18-20.

Cooling is considered one of the most effective treatments for MS. So far during this excuse for a summer I have turned on the air conditioner only twice, but it could still turn out to be a scorcher. In case it does get hot and humid, Ian Cook gives advice on pages 24-26 about practical ways to keep cool.

Joanne Akong was lucky enough to be offered two weeks of rehabilitation at the prestigious National Hospital. On pages 34 and 35 she writes about what goes on in rehab, and how effective the training is for everyday life afterwards.

Many people disabled with MS are scared to travel any distance in case things go wrong and because of all the practical difficulties. But James Buxton and his intrepid wife Anna were not going to be put off a trip of a lifetime to South Africa just because he’s in a wheelchair. You can read about their holiday on pages 36 and 37.

Artist Sarah Longlands thought she would never be able to paint again when MS struck a few years ago. But, thanks to going on the Combined Antibiotic Protocol, she got the use of her arms back and now some of her paintings hang in the penthouses of the liner The Queen Mary. You can see some of her excellent paintings on pages 40-42.

Plus, we have a bumper lot of News, many interesting Snippets, an excellent short story, recipe, and crossword.

With best wishes,
Judy Graham, Editor

New Pathways Issue 50 July/August 08
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The latest aids and equipment on display at Naidex were surprisingly modern.

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As exhibited at MS LIFE 2008

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Prokarin My Salvation, Says Vicar of Baghdad

Paintings Fit for a Queen