

The Multiple Sclerosis Resource Centre's Bi-monthly magazine



# new Pathways

March/April 2003

The MS magazine of choice

Issue 19



**Round the  
World with  
Greame Brown**



**Aqua girl  
Sylvia Brown**



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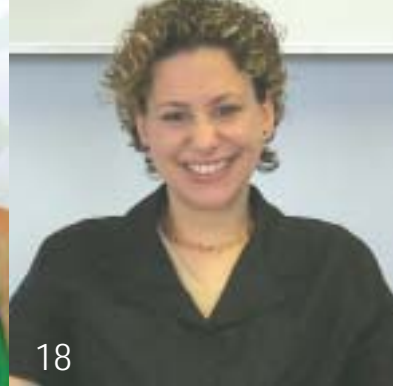
The MS 24 Hour Telephone Counselling Service: 0800 783 0518 & press 1



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Graeme Brown and his wife

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Do you ever buy books, CDs, household goods, computers, clothing, wine? If so, buy them on-line via the MSRC website and help us raise money.

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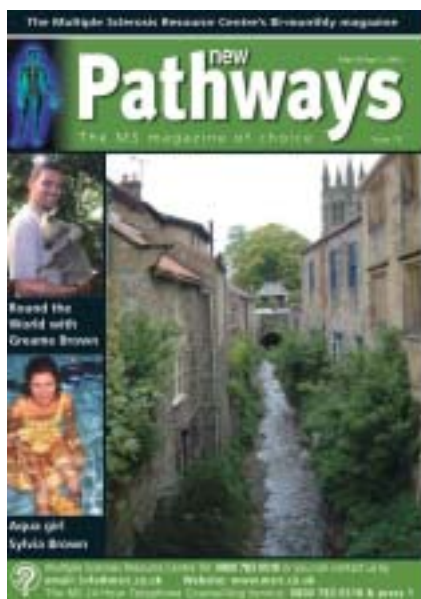


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# Dear New Pathways Readers



After three years, we still haven't run out of things which can help MS and I doubt that we ever will. In this issue you can read about the benefits of the Aquagym (page 10) and Conductive Education (page 24.)

Sylvia Brown may be the intrepid type, but you don't need much of that to take a dip in your local pool and do a session of Aquagym. The watery workout really does help make your movements more fluid.

It's a similar story with Conductive Education. Maggie Samuelson thought of herself as 'wheelchair-bound'. But after some sessions of Conductive

Education, she finds she can take a few steps. OK, they may be a bit ungainly, but they're still steps!

Of course, not everything works. And when you read of all the hundreds of bee stings Henny Lichy went through to get her full dose of Bee Venom Therapy, you wonder how she put up with it. If you've had better luck with BVT, by the way, we'd love to hear from you.

Have you ever wondered how doctors with MS treat themselves? We asked two former GPs to tell us what they prescribed for themselves. Not surprisingly to us, they chose Hyperbaric Oxygen, Diet and Supplements over drugs.

Please read the inspiring tale by Graeme Brown who went round the world with his wife Kirsten. When he got back, he was diagnosed with MS and his consultant told him to 'put travel

on hold'. But did he? Quite the opposite. Graeme now says he has a list of places to travel to 'as long as his walking stick'. That's the attitude – Graeme. Life IS for living.

After each London Marathon in April I'm always amazed by the sheer grit of those who run for us – especially those with MS. What a fantastic achievement! I hope they all bask in the afterglow for years to come – they deserve it.



Best wishes,  
Judy Graham, Editor

## Prize Draw

You might have been lucky enough to receive, with this issue, a book of five Prize Draw tickets. Under draw regulations we are only allowed to print 4000 books, so some of you will, unfortunately, miss out this time round! If you have been one of the lucky ones, please buy or sell these tickets and return your money and stubs to MSRC as soon as you can. You might be lucky again! Please don't waste the book – we really need the support!

**new Pathways**

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## Cannabis Spray Will Be Cleared For NHS Use

The world's first cannabis-based medicine is expected to be approved by government regulators this summer.

'Sativex', an aerosol drug sprayed under the tongue, will be available on NHS prescription by the autumn after approval by the Medicines Control Agency (MCA).

The drug helps alleviate pain and spasms in MS.

GW Pharmaceuticals, who make 'Sativex', applied for a licence to sell the drug at the end of March. The MCA may approve the drug as early as June.

Ministers are said to be keen

to license the drug, partly because of the embarrassment caused by people with MS breaking the law to treat their illness themselves.

GW Pharmaceuticals has been licensed to cultivate 40,000 pure marijuana plants at a secret location in southern England.

A study by the Joseph Rowntree Foundation shows that home cultivation of cannabis is now so widespread it may account for half of all cases related to the drug being drawn to the attention of police.

*Sunday Times April 13, 2003*

## Multiple Sclerosis and Epstein-Barr Virus

Yet again, scientists have found a firm link between the Epstein-Barr Virus and multiple sclerosis.

In a study published in the prestigious *Journal of the American Medical Association*, scientists found that a diagnosis of MS followed on average four years after infection with the Epstein-Barr Virus.

From more than 3 million military personnel with blood samples collected between 1988 and 2000, 83 cases of MS were indentified. These were tested for the Epstein-Barr virus and matched against controls.

*The Journal of the American Medical Association Vol 289, No 12. 1533-1536*

## The Epstein-Barr Virus

Is one of a family of herpes viruses. The Epstein-Barr virus is present in up to 90% of the world's population but most never show any symptoms. It usually lies dormant until eg stress or illness upsets the immune system. It causes glandular fever (infectious mononucleosis.) The virus remains with you for life.

## Statins May Treat MS

Another study has shown that people with MS may benefit from treatment with cholesterol-lowering statin drugs, according to a small study presented in April at the American Academy of Neurology meeting in Honolulu, Hawaii.

"Our findings show that statins may have potential in the treatment of multiple sclerosis," said Dr Timothy Vollmer, a neurologist from St Joseph's Hospital and Medical Center in Phoenix, Arizona.

In the study, 28 patients received one daily dose of the drug simvastatin (Zocor) for six months. The patients ranged in age from 18 to 55 and had at least one multiple sclerosis-related lesion according to brain scans.

During treatment, patients had fewer relapses than during the three month observation period before starting on statins. They also had fewer multiple sclerosis lesions; before treatment patients had an average of 2.35 lesions, and after treatment they had an average of 1.31.

The volume of the lesions also

## Clinical Studies of Fampridine – SR

Acorda Therapeutics have recently started the Phase 2 trials for this drug. It is quite a small study, with around 180 patients, and they are not looking for anyone else at this stage.

They write: "We understand many of you are anxious to participate in our clinical studies of Fampridine-SR and may be disappointed that you will not be able to participate in the near future. Please be assured that we are working as diligently and as quickly as we can to bring this drug to market."

decreased, Vollmer said. Although the investigators are still analysing results, they have documented no serious side effects in patients.

Statin drugs appear to have anti-inflammatory properties in addition to their ability to cut cholesterol and are being studied for the treatment of autoimmune diseases such as multiple sclerosis and rheumatoid arthritis.

Vollmer and his colleagues said that if statin drugs are shown to work in multiple sclerosis, they would offer certain advantages because they are taken as a pill and are safer and less expensive than current treatments for MS which are all taken by injection.

However, a larger study is needed to confirm the preliminary findings.

*American Academy of Neurology, Reuters Health*

*The study was funded by Merck, Inc. the manufacturer of Zocor.*

## What Are Statins?

Statins lower LDL cholesterol more effectively than other drugs. They have general anti-inflammatory effects, stabilise fatty plaques, and restore the flexibility of blood vessels.

Since 1998, Acorda has completed two clinical trials of Fampridine-SR in in MS. Patients demonstrated improved walking ability and lower leg strength.

If you wish to check the progress of the trials, go to [www.clinicaltrials.gov](http://www.clinicaltrials.gov)  
The Acorda website is [www.acorda.com](http://www.acorda.com)

## Disability Rights Handbook 28th Edition (April 2003 –April 2004)

*All the benefits, all in one book.*

*Available from mid May.*

*Concession price (on benefits) £9.60. Full price £14.00*

*Available from: Disability Alliance, Universal House, 88-94 Wentworth Street, London, E1 7SA*

## Meditation Aids Immune System

Meditation can improve the immune system and aid positive thinking. Scientists found that volunteers who meditated for a short time every week showed lower anxiety levels than those

who did not.

They also had higher levels of antibody levels in their blood, suggesting they would be more able to fight infection.

*Ref: Journal of Psychosomatic Medicine*

## MS Team In Brain Cells Breakthrough

One day people with MS could be treated with a transplant of their own brain cells.

Experiments on animals suggest brain cells damaged by the MS disease process could be successfully replaced.

A team of Italian doctors report in the journal *Nature* that

an injection of adult stem cells from the brain cured almost a third of mice with experimental MS.

*Nature 422, 688-694 (2003)*

*"Injection of adult neurospheres induces recovery in a chronic model of multiple sclerosis" Stefano Pluchino et al.*

## Poor Circulation, Stress and Pycnogenol

Circulatory problems may result from blood vessels being constricted by the stress hormones adrenaline and noradrenaline.

Muscles surrounding arterial blood vessels have receptors for stress hormones and they constrict the vessel in response to these.

A study at the University of South Florida, Tampa, has

demonstrated that Pycnogenol (pine bark extract) enhances the body's own response to overcome blood vessel constriction. Pycnogenol increases production of nitric oxide by the cells lining the inner wall of blood vessels.

*Ref: Fitzpatrick DF et al. Endothelium-dependent vascular effects of Pycnogenol. Journal of Cardiovascular Pharmacology 32:509-515*

## Happy Relationships Help Fight Illness

New research from Ohio shows that the state of our relationships actually does affect the state of our physical health.

Couples who argue and who use negative behaviour during conflict, especially criticism, sarcasm and put-downs had a weakened immune response, as measured by the activity of the

T lymphocytes. They also had higher levels of the stress hormones adrenalin, noradrenalin, cortisol and adrenocorticotrophic hormone (ACTH) – substances that can further reduce immunity.

*Ref: www.med.ohio-state.edu/mindbody/kiacolts\_glaser.html*

*Centre for Stress and Wound Healing, Ohio State University.*

## Alan Caldwell on BBC Radio Scotland

Alan Caldwell, who will cycle the 1000 miles from Seattle to San Francisco to raise money for research into diet and MS, was interviewed on BBC Radio Scotland about his trip and how the Best Bet Diet is helping him. Also joining the discussion were Dr John Meldrum and Mike Hazelwood, Director of the MS Society in Scotland.

Dr Meldrum said that in Nutritional Medicine, MS is not in fact regarded as a "degenerative disease" but rather "an inflammation or irritation of the nervous system". He went on to say that if the cause of this inflammation in the individual can be uncovered, then it is possible to alleviate MS symptoms. He stated "there is no doubt that certain foods, particularly the ones Alan has been avoiding, can – in certain susceptible people – create a sensitivity which affects their nervous system".

Alan intends to continue the debate about dietary research with the MS Society of Scotland.



## MS Study Confirms Benefits of High-Dose, High-Frequency Beta Interferon Regimen

New findings presented at the American Academy of Neurology Annual Meeting in Honolulu, Hawaii revealed clinically relevant differences in disease activity after increasing the dose and frequency of beta interferon therapy in relapsing-remitting MS patients.

The results also showed that reducing the dose and frequency of beta interferon is associated with increased disease activity.

Professor Luca Durelli, Chief of the MS Centre of University Department of Neurosciences, Turin, Italy, and principle investigator of the study, said, "These data confirm the benefits of high-dose, high-frequency beta interferon and demonstrate the risks of changing to a lower-dose regimen even in the absence of clinical or MRI disease activity. These findings will help guide prescribing choices for MS patients."

*Source Prof. Luca Durelli - University MS Centre, University of Torino*

## Whoops!

Correct address for Air Conditioning Company (page 16 last issue)  
Summit House,  
40 Highgate West Hill,  
London, N6 6LS  
Tel 020 8340-8000

## Dr David Horrobin dies

Dr David Horrobin, who championed much of the research on evening primrose oil and also the Cari Loder Treatment, has died of pneumonia after suffering cancer of the lymphatic system.

## Tolpa News

Tolpa (named after the Polish professor who developed and pioneered the use of peat as a medicine) has been shown to enhance and balance the immune system, making it ideal for autoimmune diseases.

A one-year double blind trial started in September 2002 in Wroclaw, Poland, to evaluate the benefits of Tolpa Peat Preparation for MS. The trial, lead by Professor Ryszard Szechiski, neurologist, and Professor Podemski, is for relapsing/remitting MS, with 90-120 patients aged 16-60 years. One third of the patients will be given 5mg Tolpa per day (one tablet), one third 10mg (two tablets), and one third a placebo. Results should be made public after September 2003.

Studies have also been carried out on Tolpa for adult periodontal disease. Although the researchers carried out sub-gingival scaling, curettage and bite adjustment where necessary on all patients, recovery

was markedly improved with Tolpa tablets (oral administration) and 'tampons' soaked in a solution of Tolpa and water, applied locally. Since the solution was only 2% Tolpa, the researchers concluded that application of Tolpa Chamosaldont Gel would be even more effective.

**TOLPA TABLET SPECIAL SUMMER OFFER for NEW PATHWAYS READERS (valid for 3 months)**  
1 bottle (21 tablets) £16.00; 4 bottles and over £15.00 per bottle (4 = £60.00); 10 bottles and over £14.50 per bottle (10 = £145.00) Also available: Tolpa Chamosaldont Gel £6.00 (10gm tube) for problems within the mouth; Tolpa Dent (toothpaste) Paste/Gel £4.50 (75/65gm tube); Tolpa Hypocalen Gel £10.00 (50gm tube) for sores and slow-healing wounds. Payment by cheque to New Leaf. Prices include post and packing. Please write NP on your order. New Leaf, 5 Riverside, Wellington, Somerset TA21 8LJ

# 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: Judy Graham, Editor, New Pathways, MSRC, 7 Peartree Business Centre, Peartree Road, Stanway, Colchester, Essex CO3 0JN  
Tel: 0800 783 0518 or 01206 505444 Fax: 01206 505449 e-mail: info@msrc.co.uk

## New Pathways 'brilliant'

Dear New Pathways,  
A huge thank you for the magazine. It is an invaluable communication for those of us



diagnosed with MS and our carers. I and fellow MSer's who are in receipt of it here in Plymouth think it is "brilliant".

Marks out of 10? Ehmmmm . . . Only 12, I'm afraid!  
Best wishes,  
**Tony Watters, Plymouth**

## 'Positive Outlook Keeps Us Going'

Dear New Pathways,  
I was surprised to read the letter from Anne Almond who was rather fed-up of reading all the "GET UP AND GO" articles.

I think she really missed the point that it is people who are disabled and use wheelchairs that are doing these wild fundraising



ventures. I can only walk short distances and have no balance, but I still did the Skydive and the Abseil. Mike Taylor uses a wheelchair but he still swam the Channel.

And anyway, just because I can't walk far doesn't mean I don't think it's wonderful when another person with MS more able than me climbs a mountain or runs a marathon.

However, I do agree that the real challenges in this life are in living with MS on a daily basis. I think most of us realise that and I do think *New Pathways* cover that aspect too, articles about the real lives of real people with MS getting on with it and focusing on what they CAN DO as opposed to what they can't!

Through the internet I have met some amazing people with MS who achieve so many things in spite of being bedbound. Also don't forget without the dramatic fundraising stunts, the MSRC would be no more. They need us to raise as much money as possible especially at this time! So I will cheer each and every one of us on every step of the way irrespective of my abilities or lack thereof!

Please don't tone down your positivity *New Pathways* as that's what sets you apart from other organisations and keeps many of us going!

Best wishes,  
**Sylvia Brown, Sheffield**

## Pilates Worked For Me Too

Dear New Pathways,  
I was interested to read Judy Graham's article on Pilates in the latest issue of *New Pathways*. I bought a Pilates Performer 4 months ago, having experienced this exercise a few years ago in South Africa.

I had an attack last Oct/Nov. My legs were like sticks due to muscle wastage. (I have been a wheelchair user for 18 months now and this combined with the

attack led to severe weakness).

My husband helps me use the machine by holding my feet on the bar, helping my legs in the air (the neighbours must wonder what we are up to!). At first I started on one strap for resistance, now I am up to 4 on some exercises and can sit up unsupported to do the "Tree Hugging" exercise, where at first my husband had to hold my back.

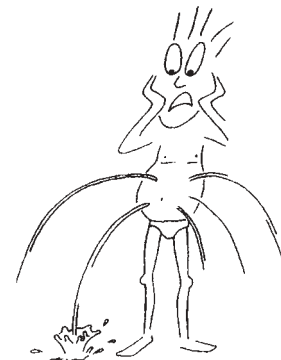
We can see improvements all the time. My legs now have some shape and my posture is much better. I would certainly recommend this to anyone – wheelchair user or not.

Best wishes,  
**Georgina Young**

## Multiple Food Sensitivity

Dear New Pathways,  
I was diagnosed with primary progressive MS in '95, but am now much improved – both physically and in my approach to myself and my MS.

However, I have many dietary allergies, as a result, I believe, of a leaky gut. I recently tried to modify my diet in an attempt to rid myself of candida – which I have been host to since my teens (I'm now 53.) The result of this was the discovery that I'm now sensitive to many more foods, including all the anti-fungals and acidophillus!



**I think I've sprung a leaky gut !!!**

# Postbag Your Letters

This attempt to de-candidise myself resulted in IBS (which is a bugger if you can't run) and the loss of a stone in weight – I was only 9st to start with. I'm now back on my usual regimen and as candidified as of yore – any suggestions?

Also, I would like to say that I am very supportive of your positive attitude; this helps a great deal in many people's approach to MS and to their own situation in particular. I believe that the mental concept of self help re MS is so important, that there can never be too much of a positive sentiment in your magazine.

Thank-you,

**Clive Robinson**

[clive@robinson3927.fsnet.co.uk](mailto:clive@robinson3927.fsnet.co.uk)

*See Susie Cornell article page 32*

## Seattle to San Francisco

Dear New Pathways,

This issue of *New Pathways* was wonderful as usual . . . you clearly work so hard on this!

I am over £1.5k 2 weeks into fundraising! Further contributions welcome.

**Alan Caldwell**

**Mill of Ross, Comrie, Perthshire  
PH6 2JR**

*Cheques to the MSRC or direct to  
Alan Caldwell.*

## Amitriptyline Helps Head Pains

Dear New Pathways,

In response to Steve Ashton's Letter regarding Head Pains I wish to say I know exactly what he means. I was diagnosed on the 4th November 1998 at 27 years old and went through all the symptoms that have been described and thought I was going totally mad and all I kept being told was it was a virus.

I then left my permanent job because nobody would understand what I was on about, especially my pins and needles. I then went temping which lasted 3 weeks because I was then told

my illness was MS and I didn't think it was fair to keep them waiting because I felt so ill.

Then I moved back up north because I was so ill. It got to the stage with my head as if it was going to explode and no matter how many headache tablets I took nothing worked. I also started with pains in my face as if it was toothache. I was backwards and forwards to the dentist and doctors because I couldn't decipher what it was. In the end my MS Nurse said it was probably neuralgia.

I was then given Amitriptyline 10 mg which didn't work so eventually I upped it to 30 mg which did the trick to dampen it down. I was probably on them for about 6 months.

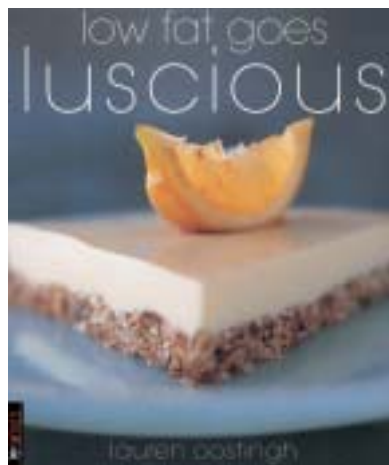
So I hope this helps that there are other people very similar.

**Amanda Brumby  
Bury, Lancs**

## Low Fat Diet Cook Book

Dear New Pathways,

I have had a few e-mails as a result of your article about my book. There have been requests for the book so I thought I'd let you know that it is being adapted for publication in the UK at the



moment and they are going to print 2500 copies. I'm not sure exactly when it will be ready but it should be within the next couple of months.

Thanks so much.

Kind regards

**Lauren Oostingh, South Africa**

## Cuba Clinic 'Unique'

Dear New Pathways,

Having lived with a rare neurological illness for quite some time now for which there is no 'orthodox' medical treatment, I have used many complementary therapies.

Not all that I have tried have helped and none by themselves has brought about a miracle cure. There is however little doubt that the parlous state I was in five years ago where I could not walk or feed myself has improved a hundredfold due to the help of some of these therapies.

My experiences led me to begin writing a book on complementary therapies for neurological illnesses. During part of my research for this book I read about a hospital in Havana, Cuba, dedicated to the treatment of neurological illnesses. What made the hospital unique was that from what I read it appeared to treat a wide range of neurological illnesses with the integration of both complementary and orthodox medicine.

After many months of planning I found myself in Cuba of January of this year at the CIREN (Centre For Neurological Restoration). I spent a week at the hospital observing the way in which it works. Each day I spent many hours speaking to the doctors, neurologists and neurosurgeons who work at the CIREN. Many times I was in tears, their dedication to what they were doing and their desire to help and heal people was overwhelming.

The neurologists at the hospital term their approach to treatment as Multi Disciplinary. It is what is entailed in this approach that makes this hospital a place of tremendous hope.

When a patient is admitted to the hospital a week of intensive assessment begins. Where



possible within this week if there is not already a diagnosis one is made and a treatment plan is developed.

The objective of the treatment plan is to meet both the emotional and physical needs of the patient. The majority of treatment plans includes a mixture of both orthodox and complementary therapies. The range of complementary therapies that are used is enormous and includes Ozone, Acupuncture, Chinese Herbs, Flower Essences, Visualisation Techniques, Kinesiology and much more.

Patients normally stay at the CIREN for two months. Once treatment begins at the end of each week all the professionals involved in the care of the patients will meet. The progress of the patient is discussed and any changes to treatment are made. Health practitioners meet on equal terms. The neurologists recognise the value of complementary medicine and that at times it can help even more than 'orthodox' treatments

The CIREN is the most awe-inspiring example I have seen of the fact that there does not have to be a battle between these two fields of medicine but that the two can work in unity together. There is so much that can be learnt from this hospital.

**Anne Ivers, London**  
**anneivers@hotmail.com**

*Info: The clinic has an excellent website (in Spanish.)*

**www.ciren.ws/clineuromus.htm**  
**email: cineuro.sld.cu**

## Hypoglycaemia Article 'Confusing'

Dear New Pathways,  
I am not normally critical of your excellent magazine in any way, but the Susie Cornell Column on low blood sugar and MS was over the top in my opinion, and likely to cause undue concern and worry to your readers.

My husband and I have a very clear and extensive knowledge of hypoglycaemia and diabetes. We have set out a number of indisputable facts accepted worldwide by the medical profession and the WHO in

defining parameters to diagnose and recognise symptoms of diabetes and hypoglycaemia which directly conflict with Susie Cornell's article. We are poles apart.

Yours sincerely,

**Anne and Tony Bradley**

## Penta Water

Dear New Pathways,  
I thought you would be interested in a new product that I have been using. I started drinking "Penta" water which is processed with oxygen. After a few days I felt better. Two days ago I forgot to have a bottle and yesterday I felt worse. Coincidence? Not sure.

The web site is  
**www.pentawater.com**  
Best wishes,  
**Maria Hunter**

## Trauma and MS Questionnaire

*William Bliss, an Essex psychotherapist and hypnotherapist has written to New Pathways.*

Dear New Pathways,  
I wonder if it is possible to ask your readers for some help with a study I am carrying out.

I regularly work with people who have degenerative conditions and their carers. My work is centred on helping them to become more positive and deal in an effective manner with the stress that these conditions can generate.

In a significant number of cases I have noticed that MS has been diagnosed within five years of a severely traumatic and possibly life-changing event. By this I mean that some of my clients past and present have undergone a strong emotional shock before MS has been identified.

I am looking into the possibility that something like the death of a loved one or an accident at work can produce such a severe change in us that MS can develop in much the same way that hypertension can be caused by stress.

In order to help me with developing this idea I would ask anyone who is willing to complete a questionnaire about lifestyle and this question of

trauma to contact me.

I will be happy to send a copy of this completely confidential set of questions. I can assure everyone that the results when published will totally anonymous and there will be no follow up from any source.

Thank you for your help.

**William Bliss,**  
**Clinical Psychotherapist,**  
**Hypnotherapist, Counsellor,**  
**8 Inchbonnie Road,**  
**South Woodham Ferrers,**  
**Essex CM3 5SX**  
**email: positive\_health@msn.com.**  
**Tel: 01245 426414**

## Positive Plymouth Group Wants New Members

Tony Watters writes about an MS self-help group in Plymouth called PAMS – Positive Attitudes to Multiple Sclerosis, who are looking for new members.

PAMS meets once a month to support one another, share experiences and feelings, organise social events and discuss the latest information about research and developments in treatments, including alternative therapies.

We had our first meeting in July 1994. At that time it was called YAMS – Young Adults with Multiple Sclerosis. There was a real need for younger adults with MS and their carers to meet each other, and this group fulfilled that need.

It was and still is an independent group. Although facilitated by Health and Social Services representatives, the group is run by people with MS, for people with MS, and carers too. It is solely dependent on its own fundraising.

Regular speakers include Dr John Zajicek, Consultant Neurologist, who has national and international recognition for MS Research and Neurological Psychologist Dr Sue Copstick.

Co-ordinator: Jackie Burt,  
Social Services, Rowans  
Rehabilitation Centre,  
Derriford Rd, Plymouth PL6 8BQ  
(It's actually in Derriford  
Hospital's grounds)  
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# Aquagym

By Sylvia Brown

**"I always notice an increase in my mobility after having been on the Aquagym. I can walk faster and more fluidly."**

**I** am lucky to live just across the road from a great little swimming pool, Uppertorpe, in Sheffield. The pool is very disabled-friendly with wheelchair access, a ramp, chairs to wheel you down into the pool, a hoist and a variety of floats.

There's a yellow float which clips around your torso. This is particularly useful for people who have limited strength in their legs. Though my legs move pretty well nowadays in the water (I am a great kicker!) I use this float to help me when I first get in.

The staff at Uppertorpe are very helpful and friendly. The disabled sessions are three times a week and the water is nice and warm. Best of all, the swim



doesn't cost much and your carer goes free!

Added to all this, the swimming pool even has an Aquagym. I could not believe my luck five years ago when I heard that they had just installed one!

The Aquagym consists of multi-gym equipment, like in a normal gym, but it's all in the water! The beauty of it is that you can work your muscles in the warm water, which also supports you as you do so.

This was just what I needed because gym equipment on dry land would have been too strenuous for me, but with the support of the water you are eased into it much more gently. Talk about perfect, ideal for strengthening my muscles and getting my legs moving. The Aquagym only costs 70p extra.

There are seven pieces of equipment, each of which works different parts of your body. There's an AquaCycle, AquaRower, AquaStepper, AquaClimber, AquaAbs, AquaStrider (legs and lower back) and AquaPulldown (arms, shoulders and upper back). My favourites are the AquaStepper and the AquaClimber, as these really give my leg muscles a good work out.

## Using the Aquagym

Before you use the equipment you are given a short induction session to train you in how to





positive attitude) play a crucial role in halting the progression of my 'progressive' MS.

Though in the short-term the exercise does take it out of me, and I generally find that I have to rest up afterwards, the long-term benefits are vast. I gain in strength, so I can stand longer, walk further and balance a bit better and the key is to build on this strength.

I would highly recommend using the Aquagym. If you don't live in Sheffield maybe you could persuade your local pool to invest in one?



### Postscript by Frank Naseby from Sheffield

Using the Aquagym suits me down to the ground. Swimming has become really important to me now and even though I am extremely tired after each session, once I have had a rest I feel much better both mentally and physically.

It is totally relaxing and you can let your mind wander. I love the rowing machine and in my mind I row to all kinds of places! It's nice to meet up with the other regular swimmers which includes Sylvie and Steve.

use each machine properly. You are advised to warm up by swimming a few lengths before you start using the Aquagym. I find it best to alternate swimming and exercising on each machine, so as to ensure you pace yourself.

Each machine has a timer on it so that you can set the number of minutes you want to exercise. This is good because you can try to increase the amount of time you spend exercising gradually from week to week.

A few years ago when I could

hardly walk at all, I would be pushed into the pool on a chair. But after using the Aquagym, I could walk out, it was like a miracle!

Since those days I have gradually built up the amount that I can do and nowadays I can generally walk into the pool. Even so I always notice an increase in my mobility after having been on the Aquagym. I can walk faster and more fluidly.

I am convinced that these forms of regular exercise (alongside diet, nutrition and a



## The best Marathon ever - with amazing runners (so

By Helen Yates

**T**he 23rd Flora London Marathon had always looked like it was going to be one of the most exciting marathons yet. For the world at large, the focus of the day would rest on Paula Radcliffe's world record attempt, which she achieved. But for teamMSRC there was a different approach.

Some of our team were predicting times of less than 2hrs 30 mins, while the truly mad were insisting that 26.2 miles was not enough of a challenge and wanted to complete the course in some kind of crazy costume! We had Mickey Mouse, Harry Potter and our own Big Pink Fairy.

Crazy or not, they all turned out on the crisp and sunny Sunday morning of April 13th to be a part of one of the best marathons in the world (some would argue, THE best!)

As ever, MSRC staff and volunteers alighted mini buses at some unearthly hour of the morning and headed for The Economist Building where we hold our runners' reception each year (they very kindly allow us to use this space for free).

Having unloaded enough boxes to build Hadrian's Wall, the most important job of the day was performed . . . the tea urn was switched on! For the next few hours the building was abuzz, boxes unloaded, tables set up, balloons filled with helium, physiotherapy paraphernalia positioned and

cups of tea distributed to all and sundry.

Having only just got balloons tied along the road, banners strung where all could see them and the whole reception set up and ready, we were (unsurprisingly) greeted by our first runner – the now famous Darran Bilton!



Darran Bilton

### Darran Bilton Came In First

Darran completed the course in 2 hours 20 minutes (and 50 seconds!). The smile on his face spoke volumes – he had come 3rd in the British runners, 20th in the male race and 23rd overall! He achieved all of this and yet as he entered the reception he looked like a man who was still looking for the start of the race and had just had a brief stroll in the park. What an amazing performance and one of which he should be justly proud – we are!

After a brief lull in proceedings, the runners started to arrive thick and fast (well, quite slowly for most of them, the marathon runners' gait is a sight to behold!). One after another runners walked, crawled and staggered their way into the building to be greeted by a very loud cheer of appreciation from MSRC staff, volunteers and their own supporters. Having had their mug shots taken (in a kind of police line up fashion!) they were all gently guided round to our sports physiotherapists to have a much needed and well earned massage.

### Amazing Runners With MS: John Trory, Karen Pitchley, Kate Flawn and Elaine Kemp

It is always difficult to separate out any of our runners; they are all amazing people with such commitment and tenacity, but there are always some who stand out: John Trory, Karen Pitchley, Kate Flawn and Elaine Kemp are all people with MS who completed the gruelling 26.2 mile course as members of teamMSRC.

Elaine you will remember from the last issue of *New Pathways*. John runs the marathon time and time again, fundraising throughout the year from his Brighton base. Karen and Kate both had huge smiles on their faces as they arrived and their supporters had lumps in their throats as they greeted them.

# - a truly wonderful event some of them truly mad!

## TV Stars

Incidentally, Eric Wright, the Big Pink Fairy, was teamMSRC's first ever television star! Eric was interviewed during the race and the teamMSRC running vest was on full display – thanks Eric, it gave us all a thrill!

Surendrah Irani, a man determined to get himself on TV, ran last year dressed as Charlie Chaplin and this year came back as Harry Potter (I still don't understand why he didn't just get his Nimbus 2000 broomstick out and fly the course, surely it would have saved so many blisters!).

Then there is the 'invisible' support. Emily Burgin was really unsure about her fundraising abilities when she first approached the MSRC for a guaranteed marathon place. Some months later she telephoned our office to let us know that she was well on the way to raising £3000 with the incredible support of all the children at the Archbishop Cranmer School in Taunton. These kids got right behind her and, as she informed us on the day, were to be found on Sunday glued to the television with her running number in front of them trying to pick her out of the 33,000 strong crowd of runners!

Many who ran were raising money directly for their local MS therapy centre. The MSRC has offered hospitality to these runners for the past two years, and, as ever, they were welcomed as though they were the first person ever to complete



*The girls made it home!*

a marathon. For many of them the massage, showers and the tender loving care offered made all the difference.

## A Big Thanks To Everyone

The Flora London Marathon is a truly amazing event, raising millions for charities up and down the country ; the teamMSRC marathon effort is a wonderful and significant part of that whole event.

Everyone at the MSRC is proud of our runners, humbled by their efforts and delighted by their sense of achievement. We are also deeply grateful for the ongoing commitment of our volunteers who get out of their beds in the middle of the night, give up their Sunday and work like Trojans all day to ensure that the runners are given as much care and support as possible.

To all those who massaged (especially Clare Strong who

gave a much needed piggy back to a badly blistered runner!), shook collecting tins, made tea (thanks Jeanette, you kept me 'watered' all day!), blew up balloons, stood at the finish line for hours looking out for our runners and all the other volunteer jobs . . . **Thank You.**

**To all our runners – it was a joy for us to finally meet you – well done and Thank You!**



*Marathon runners en route*

When a GP gets MS, what treatments do they prescribe themselves? We asked two doctors, who both chose non-drug methods.

## HBO worked for me

By Dr Janet Willis

Trained as a GP, Dr Janet Willis found out first hand what it's like to be a patient with MS who comes up against conventional medicine. "Some neurologists say 'don't touch HBO with a barge pole.' But I ignored their advice and had it anyway. It helps with fatigue and bladder problems."

**I**t was the autumn of 1994. I was on a train to Sheffield to a graduation reunion. The book I selected from the station bookstall was 'MS – A Personal Exploration' by Dr Alexander Burnfield. As I read, I realised that the various symptoms I had experienced over a number of years, such as sensory loss and numbness, were due to MS. On my return home I arranged to see my GP.

I had trained as a doctor but was so ignorant about MS! The cases of MS I had met only had motor problems; most of them were in wheelchairs. I had a lot to learn.

The GP was new to the practice. I vividly remember walking into his room. He asked, 'What can I do for you?' I said: 'I think I've got MS.' This was followed by shocked silence. He referred me to a consultant



Dr Janet Willis

neurologist who I had heard of via a friend with MS. Before long, I had an MRI scan, and the diagnosis was confirmed.

My friend had already discovered the Bristol MS Therapy Centre in Nailsea, so I headed off there and soon began Hyperbaric Oxygen Therapy.

### Doctors Didn't Approve of HBO

I was soon to discover that the medical establishment did not approve of Hyperbaric Oxygen Treatment. Some, like my own GP, take the view, 'If it does you good, OK.' Others (not a million miles from here) tell patients: 'Don't touch it with a barge pole!' Thankfully, many – like me – ignore that advice and come to the Centre anyway.

My reading about hyperbaric oxygen therapy led me to some reports that it had been assessed in patients with MS and dismissed! I felt at the time, and still do, that the initial studies were flawed and should be repeated, using the same criteria as the current studies on beta interferon use i.e. mobile patients, of relatively recent diagnosis, confirmed on MRI scanning.

The study reported in the Lancet on 9/2/85 looked at patients under 60 with chronic MS

who had to be able to sit unaided. They received daily treatment at 33 feet for 18 sessions!

I feel that proper studies should be done in the light of recent experience i.e. lower pressures, and a longer period of oxygen treatments. I even got as far as drawing up a research protocol, but organising a suitable study was very daunting and I ran out of steam!

Other reports from Dr Philip James in Dundee were more encouraging and so I decided to carry on with my own treatment sessions.

I have had extra sessions when I have had a relapse, but otherwise try to go once a week. I find it helpful in counteracting the fatigue, and it improves the bladder problems.

I also take starflower oil, Forceval capsules (a suggestion from the centre's dietician and available on prescription), folic acid and cod liver oil capsules.

I combine my weekly visit to the centre with an exercise group, run by the physiotherapists – a morning very well spent!

### Info Box

Bristol MS Therapy Centre,  
40/42 Southfield Road Trading  
Estate,  
Nailsea, BS48 1JE  
Tel 01275-622936

Dr Bob Lawrence, a former GP in South Wales, says

# "I found diet and supplements to be the best medicine"

Bob Lawrence was born in Plymouth in 1941. He left school at 14 to work in the grocery trade. After serving in the RAF, he continued his education then went to Bristol University. In 1967 he suffered a serious road accident. He gained a medical degree in 1974. He is married with three children and lives in Swansea.

His medical career included General Medicine and Surgery, Accident and Emergency, Anaesthetics, Intensive Care and General Practice. From 1982-1986 he was employed by the Ministry of Defence as Ship's Surgeon with the Royal Fleet Auxiliary. He saw service in the Falklands and other parts of the world.

**W**hen I was first diagnosed with MS, I had been aware of symptoms for a number of years. At that time there was no available treatment for MS except steroids and, knowing the penalties of such drugs, I was reluctant to consider these as an appropriate long-term therapy.

The obvious alternative was to research all the information then currently available. From this, I soon discovered a wide range of mainly dietary factors, which appeared to be relevant to treatment.

Gradually, I started making changes to my diet and adding an increasing range of supplements, which I considered of potential benefit. Slowly I started feeling better until at the present time I seem to remain generally well and, as far as the MS is concerned, stable with no relapses and a minimal rate of disease progression.

## The Zenwa Method

The method I have developed (known commercially as the Zenwa Dietary Treatment Method) is admittedly not curative but it does appear to be



Dr Bob Lawrence

effective in stabilising the condition to a major extent.

The dietary method has been developed and tested since 1986. Initially devised specifically as a treatment for MS, it was later found to be equally, or even more, effective in the treatment of numerous other conditions such as migraine, asthma, eczema, MS, PMS and post-natal depression. It is, I believe, completely new in concept and relies almost entirely on dietary means to establish its effect. Absolutely no drugs are used at any stage of the treatment. The penalty of drug side-effects is thus completely avoided.

The method primarily involves the exclusion of certain foods, which are known to have a detrimental effect on the production of certain prostaglandins.

Some of the foods which need to be avoided include:

- red meat
- cow's milk
- wheat
- caffeine
- citrus fruit
- tomatoes
- alcohol
- spicy food.

You may have already noticed that such foods tend to promote an increase in symptoms. Tobacco too is strongly detrimental and should therefore be avoided.

## Supplements

The diet is supplemented with vitamins, minerals and essential fatty acids expected to increase the production of beneficial prostaglandins (see box.)

The most important supplements include those found to be commonly deficient in MS.

These include:

- zinc
- copper and
- vanadium.

Both zinc and vanadium deficiency are closely associated with depression, a common symptom in MS.

Vitamin B complex is important, and this should be

# Alternative Treatments (continued)

additionally supplemented by an extra supplement of vitamin B12. This is essential for the repair process of remyelination, which restores the myelin damaged by auto-immune attack.

## Antioxidants

Since 1997, I have also been testing a group of compounds referred to as anthocyanidins. Doses used have been between 80 and 480 mg/ day.

Anthocyanidins (otherwise known as OPCs or oligomeric proanthocyanidins) are natural plant flavonoids, derived from sources such as pine-bark, grape-seeds or various other fruit seeds, and have very powerful antioxidant properties. Coupled with certain dietary restrictions they appear to be effective in maintaining the blood-brain barrier. This prevents cells of the immune system from reaching the central nervous system where they are capable of attacking the myelin cells of the brain and spinal cord.

I take Lamberts Colladeen (Anthocyanidin Complex) £14.95 for 60 x 160 mg tablets (plus 90p postage). Dose: 250–500 mg/ day.

### In addition:

- selenium
- vitamin C
- vitamin E and
- beta carotene are essential.

Both vitamin E and beta carotene should be the natural variety of the vitamins, not the synthetic alternatives, which are much less beneficial.

## Essential Fatty Acids

Essential fatty acids (EFAs), such as evening primrose oil and cod liver oil, are of particular benefit in MS as these fats form the 'building blocks' from which myelin is produced. EFAs are also converted into beneficial prostaglandins, which, apart from many other essential functions, have an additional purpose in supporting the immune system.

Thus, an adequate quantity of EFAs in the diet is critical in the repair process, which will permit recovery from acute relapses and long-term disability.

The advised quantity of omega 6 oils (evening primrose or borage seed oil) is a minimum of four grammes each day. Much more may be taken if desired.

For omega 3 (flaxseed or fish liver oils) a maximum limit of two grammes of fish oil is recommended (particularly in pregnancy) plus two or more grammes of flaxseed oil.

## Vitamin D

Another essential vitamin in MS is vitamin D. Vitamin D is commonly deficient in MS. Dr Ashton Embry recommends the maximum dose of 4000 international units (100 mcg) but even lower doses have been shown to be beneficial.

### Info Box

Full details of the dietary method are available in booklet form, for £29.00, plus £3.00 postage. This price includes the provision of the zinc taste test, for determining the extent of zinc deficiency, which, almost invariably, is a feature of MS.

Dr M R Lawrence MRCS, LRCP,  
Dietary Research Ltd,  
Gwynfa House,  
10 Heol Gerig,  
Treboeth,  
Swansea,  
West Glam SA6 9BP  
Tel 01792-417514.  
bob.lawrence@ntlworld.com

### Products

Dr Bob Lawrence can provide products made by Lamberts and Solgar. Or a very wide range of brands can be obtained from The Nutri Centre, 7 Park Crescent, London, W1N 3AE  
Tel 020 7436 5122.

For most basic products, Dr Lawrence recommends Healthspan. Based in Guernsey, they are VAT-free. Their prices are low and their quality is apparently excellent. Their cod-liver oil was among about thirty different manufacturers recently tested by the Food Standards Agency and Healthspan was found to be the most pure.

Freephone 0800 73 123 77) for orders by credit card.

No charge for postage.

## Prostaglandins (PGs)

The earliest effects of increasing PG levels are the resolution of inflammation and an increase in the rate of healing. In MS, this has the effect of reducing the inflammation, which mediates the auto-immune attack thereby reducing the extent of the damage caused. The increased availability of EFAs, and the factors supporting their function, also increases the efficient repair of those myelin cells damaged in the immune attack.

Increasing PG levels also has the effect of selectively moderating abnormal over-activity of the immune system. At the same time, the efficiency of the immune system appears to be improved giving a greatly enhanced resistance to infection. This latter effect may be seen in the much-reduced incidence of common virus infections, such as colds and influenza, in users of this dietary method.



# Poem 'Gatecrasher' by Graeme Brown

Life had always been a big party for me.  
I chose the roads which enticed me –  
I was young and I did as I pleased.  
No restrictions – Apart from money and morals  
maybe.

I settled though and married my perfect match.  
A remarkable woman – Vibrant, fun-loving and  
beautiful.  
She was my soul-mate, my lover, my best friend –  
My everything.  
We travelled the world together  
Living and loving every minute.  
Sharing extraordinary experiences throughout.  
Highs and Lows.  
Experiences that drew us ever closer-  
if that were possible. Was it all too perfect?

Out of the blue, this GateCrasher showed up.  
He shook my hand (!)  
Introduced himself as "MS".  
A complete stranger to me.  
I didn't know who he was or where he'd come from.  
We both knew he was trouble –  
(No real sense of humour either.)  
I didn't take to him at all!  
He didn't fit in – wasn't part of the plan  
And he was spoiling our party.

It wasn't long before he started asking for things of  
mine he had no right to have.  
Just like a bailiff knocking on the door of life.  
I wasn't going to give him what he wanted –  
but he threatened everything I had.  
I got it into my head that he was a potential home-  
wrecker!  
I was f\*\*\*\*\*g seething inside at that.

So I picked a fight with this 'MS' guy.  
But he was a bit of a hardman.  
A bully and a cheat.  
He always hit me when I wasn't looking.  
And so, at the start, I came off second best.  
Weakened and disheartened.

When fighting didn't work, I tried to run –  
but he'd even taken that away from me.  
So instead, for a while, I pretended he wasn't there-  
Just ignored him.  
But he was always there – lingering . . .  
Asking for more stuff  
Taking away more stuff.  
Things that you take for granted until they're gone.

He was wearing me down.  
He gave me something new to think about every few  
weeks.  
He was having a laugh – taking the piss in fact.  
"Look what I can do to you" he would taunt.  
"What ya gonna do about that then"??!

He could do so much that scared me (terrified me)  
And the more I fought physically – the weaker I  
became.

It was like thrashing around in quicksand  
With "MS" watching from the side howling with  
laughter!!

Eventually, I'd had enough – He'd broken me I  
suppose.  
Beaten me into submission.  
"What d'you want from me??!" I cried out in anguish  
one day.  
I didn't expect an answer so soon –  
but found one from somewhere through all the fog.

"I want a little respect" MS sighed.  
"That's all – We don't have to be best mates or  
anything. I know I'm not the easiest to live with (!) –  
I mean I might cramp your style (as well as your  
muscles!) but look at it from my point of view . . .  
Nobody ever willingly invites me round to stay.  
Nobody wants me – but I'M HERE NOW – so we  
might as well at least try and get on even though  
we've not always seen eye to eye in the past!!  
Why don't we start again? – Let's 'shake' on it!" (I  
told you "MS" had a crap sense of black humour!)

So I went away and thought about all this.  
I still wasn't happy – but what could I do??  
I could hardly chuck him out!  
Nobody knew how!!  
Anyway, he might be encouraged to leave on his  
own accord sometime – somehow – if I showed  
enough respect.  
A bit like a stroppy teenager fleeing the nest.  
But probably not for a while yet.

So I weighed up my options and agreed.  
I learnt to respect him.  
but I couldn't befriend him yet –  
(Maybe that comes later.)

We still have our scraps – our disagreements –  
But on the whole we've learnt to get along OK.  
And if the truth be known –  
"MS" has actually taught me quite a bit.  
(But don't tell anyone.)

He's drawn me closer to my family –  
Shown me who my real friends are.  
He's introduced me to a whole bunch of people I  
love and admire.  
He's shown me a side of myself I love and admire!  
He makes life more challenging –  
but ultimately more rewarding.  
He forces me to stay really amped up and positive  
To embrace life, to live life and to love life.

In quite a bizarre way, he's moulding me into a  
better man.

We're not best buddies yet, 'MS' and me.  
But one day – perhaps we will be.  
So Hey!!  
LET'S GET THIS PARTY REALLY STARTED!!  
You're all invited!  
Graeme and 'MS' xx



# Bladder problems

By Suzanne Stevens  
Nurse Advisor with Astra Tech Ltd

## Bladder function and MS

The messaging system within the spinal cord needs to be working properly for normal bladder function. Any disruption to this and things can go wrong. It's very common in MS.

## The Bladder

The bladder is a muscular organ that acts as a reservoir for storing urine and emptying it when appropriate.

It is made up of a 'balloon' type muscle called the *detrusor*, which expands on filling and contracts to empty.

The bottom of the bladder funnels into what is known as the bladder neck. A 'sling' of muscles called the *pelvic floor muscles*, which help continence, support the bladder neck.

There is also a *sphincter*, located at the neck of the bladder, which acts as an opening and closing mechanism. At rest, the sphincter remains closed, thus maintaining continence.

At the bottom of the sphincter is the *urethra* through which urine passes out. In women, the urethra is fairly short, only 3-5cm in most cases. It is straight as it runs through the pelvic floor muscles. In men, the urethra is generally 18-22cm long and forms an S curve.

Most adult bladders can hold up to 500mls of urine and normal voiding generally occurs every 3-4 hours in a day and once at night. However, this can range between different people and yet still be classified as 'normal'.

## How the Bladder works

The bladder really is the Waterworks of the body. Urine has to flow freely to promote a healthy system. Nerve supply to the bladder is very complex. As the bladder starts to fill, messages are sent to the brain.

However, the brain will send other messages back to the bladder telling it to 'hold on'



Suzanne Stevens

until an appropriate toilet is found.

When a toilet is found and you are ready to empty your bladder, the brain tells the detrusor muscle to contract and the sphincter 'opens' thus allowing you to pass urine. When you have finished passing urine, the detrusor relaxes and the sphincter closes again and remains closed so that you can remain dry.

It is also important to remember that bowel function can affect the bladder as well. Generally, both systems have to work well independently for them to work well together.

## How the Bladder is affected by MS

In MS, the nerve signals between the brain and the bladder can be impaired or damaged, which changes how the bladder works.

The sensations felt in the bladder can be altered so that either you don't always feel the need to pass urine, or you feel the need more frequently and/or urgently.

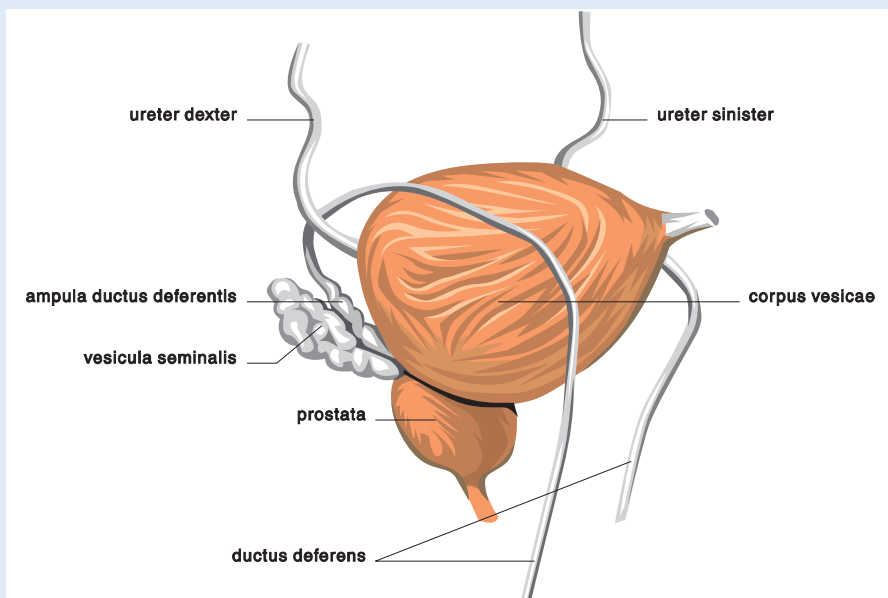


Diagram of the bladder – male

Some types of bladder dysfunction are very common in MS:

**1 Detrusor hyperreflexia** – sometimes called an irritable or unstable bladder.

This is generally caused when the brain tells the bladder to empty although it's not quite ready. This can result in feelings of frequency and urgency and can often lead to spontaneous wetting.

It can be worsened by a full bowel (for example, when you are constipated) which then presses against the bladder making it sense that it needs to empty.

Drinks containing caffeine can irritate the bladder and worsen detrusor hyperreflexia.

**2 Poor bladder emptying** – When nerve messages are disrupted between the brain and the bladder, you may suffer from a bladder that fails to empty completely. This can lead to *urine retention*, which often results in urine infections because the urine is being left in the bladder for too long.

In addition, poor bladder emptying may cause the detrusor muscle to become

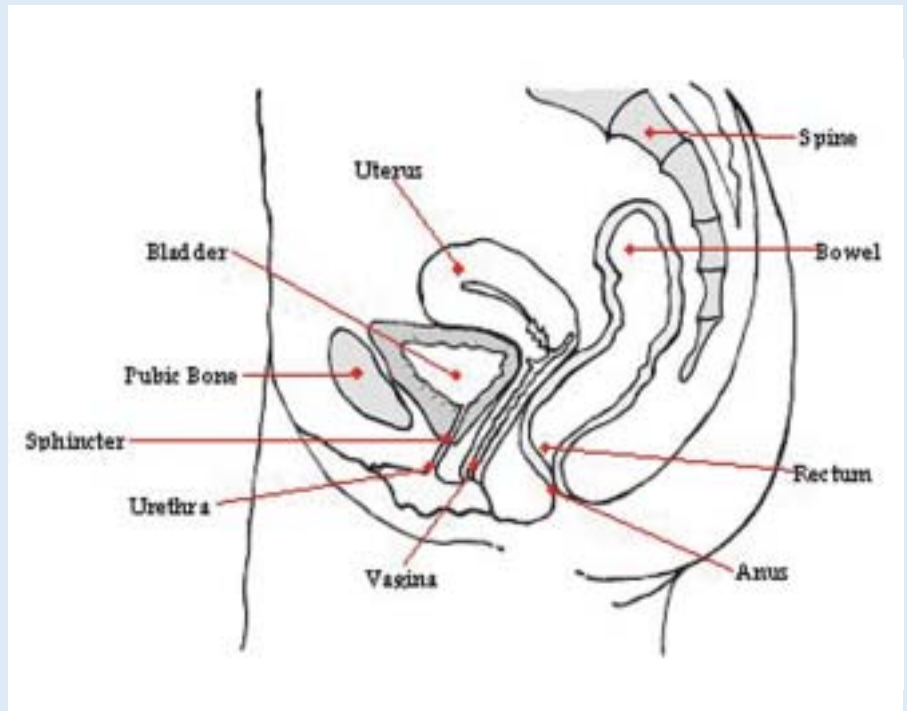


Diagram of the bladder – female

overstretched and then the sensations felt may be weakened.

An overfull bladder can lead to wetting because the urine has nowhere to go. This is called *overflow incontinence*.

Again, you are more at risk of urine retention if you are constipated because the full bowel will push on the bladder.

**3 Detrusor/sphincter dysnergia** – In this type of bladder dysfunction, there is lack

of coordination between the detrusor muscle and the sphincter, which means that the muscle could contract but the sphincter does not open at the same time.

Thus, you may find that it is difficult to pass urine and you may feel like your bladder does not empty properly. You may then find some similar symptoms as you would with poor bladder emptying and detrusor hyperreflexia.

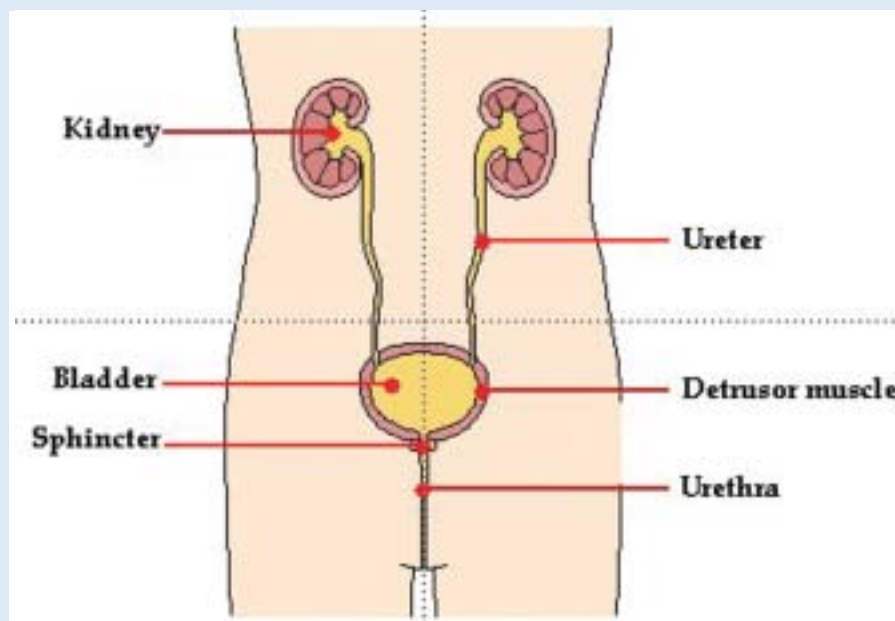


Diagram of major muscles used in bladder control

**In the next issue – drugs, natural remedies, intermittent catheterisation, pads.**

Please let us know what works for you! Just drop a line or an e-mail to the MSRC.

## Info Box

### Where to go for Help

There are good Continence Advisors and Urology Nurse Specialists. Find out who your local one is through the Continence Foundation 0845 345 0165 [www.continence-foundation.org.uk](http://www.continence-foundation.org.uk)

Graeme Brown, 35, is a self-employed pharmacist, but is thinking of going into property development, writing, and doing more travelling. He lives with his wife Kirsten in Linlithgow, Scotland.

## Round the World Trip

By Graeme Brown

Graeme Brown swapped his briefcase for a backpack and set off round the world. "The trouble with travel though is that the more you see, the more you realise there is to see. The more you learn, the more you realise how little you know."

**C**all me impulsive – but a while ago I packed in my job, sold my car, rented out the house, swapped briefcase for backpack and took off round the world.

I'd travelled throughout Europe before but this was more ambitious and I found myself worrying! Snakes, toilets, snakes in toilets(!) tropical disease, muggings, false imprisonment – sharing your jail cell with a Thai ladyboy(!) . . .

As always – life's real problems are things that never cross your worried mind.

I certainly never imagined that I would return home with a broken leg and an MS diagnosis looming! So – roll with the punches and leave worry behind – there's enough to carry!

It could not have been a more horrific start. We were in New York on Day Six of the trip (Sept 11th 2001), heading downtown to take an early helicopter trip round the Twin Towers that fateful morning. I struggle to describe the horror of it. We escaped unscathed. Why? Destiny decides I suppose? I have no answers.

We eventually departed New York knowing the appalling images etched on our minds could never be left behind. New York taught me how remarkable human resilience can be in



*Graeme Brown in New York*

adversity. It gave me a sense of perspective.

Our journey continued around a world of fresh uncertainty. I felt a painful mixture of grief, fear and outrage but largely guilt for still being alive. Living the moment suddenly took on a new poignancy.

### Reviving the Soul

The majesty of the Falls at

Niagara followed by the wondrous beauty of sunrises over the Grand Canyon helped breathe some feeling back into the soul. The Canyon is vast beyond description, its serenity and range of ever-changing colours make it a truly mesmerising place.

Next stop, Las Vegas! – glitzy, brash, gloriously O.T.T. – and we doubled our dollars in the casino!

San Francisco was full of character, trams, and ridiculously steep hills! A lot of the hippies from the Sixties had never got round to moving on. They sat hunched on the pavements with placards and outstretched hands. My favourite sign read "Homeless my ass – I just wanna get high!" (He got my spare dimes!)

We did the touristy stuff –



*Graeme and Kirsten take an elephant ride in Northern Thailand*

rode the trams, visited Alcatraz, even drank in 'The Squat and Gobble' in the gay community of Castro! We hired a car from 'Thrifty's', drove over the Golden Gate Bridge and visited too many Californian vineyards!

## To the Southern Hemisphere

On Rarotonga in the Cook Islands they have two buses. The clockwise and the anti-clockwise! Life is uncomplicated here! The locals all wave and smile. They have much to smile about – white beaches, coconut trees, sunshine . . .

We hired kayaks and motorbikes, we learnt local war dances and we ate with our fingers out of banana leaf baskets.

The living costs here? – £4 a day for a three bedroom villa. We were back on budget! Fiji was more of the same but hotter! Think hammocks by the sea, mango trees and kids playing rugby on the beach – with coconuts!

We drove a campervan round New Zealand's islands for five weeks and were stunned by its diversity. Boiling mudpools, geysers, volcanoes, glaciers, fjords, rolling green hillsides – it was all so untouched. The ancient Maori culture fascinated



Graeme with Koala friend in Australia



The colourful traditional dress of Thailand me. Such proud people and so respectful of Nature.

We hiked up glaciers with pick axes, panned for gold, paddled through glow worm caves and 'grew some balls' to leap 149 ft off Kawarau Bridge on bungee cords! Sweet ground rush! The highlight though was Kaikoura – swimming with wild dolphins in the Pacific – amazing creatures – the connection really affects you.

We started a five week dash round Australia in Sydney which has to be one of my favourite cities. It's incredibly relaxed and so damned trendy! There's an immediate feel-good factor with its harbour, bridge, Opera House, cafés – the whole deal really.

We re-scheduled to return to Sydney a few weeks later in time for the Hogmanay fireworks over the harbour. It was a good call and a spectacular event!

From Melbourne we drove to Adelaide along the Great Ocean Road past surfing meccas and astounding rock formations. Flew to Alice Springs in the Red Centre, then drove miles through dusty outback wilderness to Ayers Rock (Uluru). This is the spiritual home of the Aboriginals and was a wonderfully mystical and inspiring place. We ate

crocodile salad under the stars listening to didgeridoos and dingos.

Everyone heads to Cairns to scuba dive off the Great Barrier Reef. It's unimaginable. The vivid colours of the coral, giant clams, eels, huge shoals of brightly patterned fish darting all around you – it's a spectacular world down there!

We also went croc spotting in the Northern Territory and stood in awe dwarfed under the rainforests of Cape Tribulation. Then we bussed it back down the Gold Coast, breaking the journey to Brisbane with two island breaks and a Christmas barbie on the beach!



Underwater thrills



*Plenty of choice in the markets of South-East Asia*

## The Lure of the East

Hong Kong was a claustrophobic culture shock with its shiny high rises and moving mania of people. Everyone was in a rush! It was an intriguing but exhausting blur.

My fondest memories are of South-East Asia: Thailand, Laos, and Vietnam, so different from anything I'd seen before.

Ornate temples, vast Buddhist statues, glittering palaces, monks in flowing, saffron robes – conical hats and bicycles, river boat markets, endless acres of paddy fields, the terror of tuk-tuk rides through Bangkok traffic, the red tape of Communism in Vietnam.

We river-rafted and rode



*Bungy jump from Karawau Bridge*

elephants through the jungles of Northern Thailand; we trekked through opium fields to meet the long-necked Karen hill tribe; we bartered in the markets, attended Thai cookery classes in Chaing Mai and spent 15 hours on a bus skirting Laotian minefields sitting on sacks of fish heads! You have to expect the unexpected, you feel so alert and alive – the colours, the noise the sights and smells – it was an exhilarating and spiced up mix of so many things – truly re-wakening the senses.

## Go Break A Leg!

The muscle weakness and fatigue was worsening due to my undiagnosed MS and annoyingly, this caused me to stumble down a rock-face in Vietnam and break my leg in three places! I've had better days – we still had Cambodia and Malaysia to visit!

The rural hospital was a nightmare, blood swabs on the floor, malaria patients, a US Army X-ray machine from the Viet Cong War and an offer of painkilling injections using Vietnamese needles! I checked myself out with splintered planks of wood for crutches vowing never to slag our NHS off again!

We headed for Saigon by bus then chilled out on Thai beaches for the remainder of the tour. I needed a rest!

The trouble with travel though is that the more you see, the more you realise there is to see. The more you learn, the more you realise how little you know.

When I was diagnosed with MS, I was advised to "put the travelling on hold"! I have a list of places I want to visit which is as long as my walking stick. It starts with China in November.



*Buddhist monk in Thailand*

(I'll send a postcard Mr Consultant.)



*The busy water market*

# You Shop – We Gain

## Go shopping at your favourite high street store on our website: [www.msrc.co.uk](http://www.msrc.co.uk)

You can buy things from John Lewis, Boots, Argos, Dixons, Littlewoods, The Co-Op, Amazon and many, many more – All from Our Website – YOU SHOP – WE GAIN! Lawrence Wood, MSRC Chief Executive, explains how.

**T**hrough the MSRC website, you can buy the things you need AND help raise money for the MSRC.

Our scheme is called **YOU SHOP – WE GAIN**. You can find it easily by getting on to our website at [www.msrc.co.uk](http://www.msrc.co.uk).

Once there, simply click on **YOU SHOP – WE GAIN**.

You will see that you can buy almost anything from the following list:

- Books
- CDs, Videos and DVDs
- Electrical Goods
- Clothing
- Department Store Goods
- Computers
- Wines
- Make Travel Arrangements
- Money

You can shop at well trusted places such as Amazon for books, CDs, videos and DVDs, The Co-Op for electrical goods, catalogue shops and department stores such as Argos, Kays, Littlewoods and John Lewis for just about anything, Dixons and PC World for computers, wines from Virgin Wines, travel from Lunn Poly and even mortgages from Nationwide.

This is just a sample. In fact, all the major stores are represented. If we haven't got the shop you use, we can put it

there if you let us know.

How it works is this: Every time you get into one of the above links via the MSRC website, we earn some money! (OK, you could go straight to their websites, or via one of the big advertisers like Yahoo, MSN, or AOL – But we need the money more than they do!)

When you use **YOU SHOP – WE GAIN**, you will get exactly the same deals as if you had gone direct to these sites.

All we ask is that you give it a try.

All we ask is that you pass **THIS ON TO EVERYONE IN YOUR ADDRESS BOOK** and ask them to do the same.

If you are interested in helping in this way we can make the process even easier. Just email us asking for the shopping details and we will send you an email that you can then simply forward to everyone you know.

We work hard to ensure that the bulk of our income does not need to come from those we are here to support. When an opportunity arises where we can give you the chance to raise money for the MSRC at no cost to yourselves we do rely on your support to make it work.

As ever, this only works if lots of you become involved. Please

don't leave it to the others – they might be doing that too!!

If you log on to our Website and get on to the **YOU SHOP – WE GAIN** page, this is what you will see:

### **YOU SHOP – WE GAIN**

Welcome to our shopping area, where every time you buy something, register or even ask for a quote you will be helping MSRC at no cost to yourself.

On this first page we have listed the different categories available and if you follow the links they will take you to a page listing the companies involved.

You then click on their banner or link and they will know you came from this site and pay MSRC accordingly.

We want you to use this site, email your friends to use it too, obtain permission to tell everyone at work and generally encourage anyone you can think of to support our work in this 'free' way.

**REMEMBER:** You pay the standard on-line price so it doesn't cost you a thing. You win with attractive prices and good service, we win with commission on your purchases etc and the suppliers win through increased business. NICE!

# It worked for me

**“It may not have been the most elegant of walks, but I was walking! And this was happening to somebody who thought of herself as wheelchair-bound.”**

## Conductive Education

By Maggie Samuelson

**Thanks to Conductive Education, Maggie Samuelson re-learned how to stand, breathe, move – and walk. Maggie, 51 from Hull, was diagnosed with MS in 1984. It has been secondary progressive for the last 5 years. After 17 years as a secondary school teacher and 10 years as an Education Advisor, Maggie took early retirement last year.**

**W**hen I first heard about Conductive Education I had only a vague notion of what it was all about – something to do with the Peto Institute in Budapest and the treatment of children with cerebral palsy. Then last year, by chance, a physiotherapist mentioned The Institute of Conductive Education in Birmingham and I followed up her suggestion that I might find it helpful.

The Institute exudes charm, welcome and peace, broken only by the delighted laughter of staff and clients. I was nervous about such a challenging venture. But I needn't have worried; the 'conductors' are unfailingly calm and confident and work on the assumption that they and their clients will achieve success.

I arrived with a healthy scepticism about some of the wilder claims for Conductive Education such as 'transforming

lives; restoring hope; offering real choice', but that scepticism was soon to disappear.

From the start, I was struck by the way the conductors worked in such a precise and focused way. Movements were almost inch perfect. The main aims of this early work were effective breathing and secure standing.

### **Better breathing and good standing posture**

Better breathing had rapid and far-reaching effects. First, there was a huge improvement in blood circulation. Before, I had swollen ankles and cold hands and feet. As early as the end of day one, my ankles had gone back to their normal size and my feet were beginning to feel warmer.

The explanation of how to achieve a secure good standing posture was a huge revelation to me, especially since countless treatment sessions with 'traditional' physiotherapists had not shown me how to do this.

The key to it all is to identify and use the centre of gravity. This made real sense to me, even though I didn't always find it easy to achieve in the early sessions.

I cannot deny that my first visit to the Institute left me feeling shell-shocked. Learning to re-educate muscles and bones into long lost habits was



*Maggie Samuelson*

undeniably painful and taxing. But by the end of that first visit I knew how to breathe and how to stand.

When I came home I spent a lot of my waking hours checking that I knew where my centre of gravity was, that I was sitting symmetrically in my chair and breathing properly. After this initial concentrated effort, I thought that they had become more assimilated and so I did not need to devote so much effort to trying to establish them.

At the time of my second visit to the Institute in January 2003 I was very tired and finding it increasingly difficult to transfer from my wheelchair to bed, toilet, or chairs and had virtually given up driving.

So I was dumbfounded when – from the very first session – I was able to do things I thought I just couldn't do. Under the tutelage of my conductors Agnes







and Mel, I was making movements that I could not do when I arrived on the Monday morning. Soon, I could move both arms above my head with increasing strength, reliability and control.

More amazing still, all of these improvements continued and gathered pace as the days went by. Things that I struggled to do when I went back to my hotel for the evening, for example move my left foot, were improving as the evening wore on AND these improvements were still evident when I went



back next day.

More surprisingly, the same positive effects were happening with my standing, balance and co-ordination. Already, by the end of the first session of my second visit, I was taking tentative steps along parallel bars – with each successive day I took more steps with the support of a short arm walking frame.

### **I was walking!**

On the Friday, I walked up six stairs of the staircase in the hall. It may not have been the most elegant of walks, but I was walking! And this was happening to somebody who thought of herself as wheelchair-bound.

General shock and delight accompanied this feat – just as well that the whole thing was being recorded for posterity on video camera. [I have to say that I did have Mel and Agnes to hand where needed and I was using an elbow crutch]



Up until then, both my consultant and various physiotherapists had told me to keep my standing to a minimum – to conserve my energy. But now I was telling my brain that walking was on the cards again and this was difficult to come to terms with. Had I been

pretending that I couldn't walk for all this time?

Mel offered me a very convincing hypothesis about how this could be. My brain had assimilated the key messages from my first visit about centre of gravity, good breathing technique and so on – and it was only now, with the help of the conductors, that I was able to transfer these to a range of activities. What was happening was more a case of COGNITIVE Education rather than Conductive Education.

Now back at home, I cannot do all the movements I achieved under the close supervision of the conductors in Birmingham. I can, however, manage more control over everyday movements such as transfer from my chair AND I can still walk a few steps helped by either handrails or a short-arm walking frame.

I feel my two visits to the Institute have been very valuable. MS has not gone away, nor will it ever do so. I won't run the Marathon or return to the ski slopes. For anyone outside the MS world, it might seem that my new-found (or should that say re-found?) ability to stand, better balance and control, co-ordination and



## What Is Conductive Education?

- Conductive Education is a rehabilitation system which teaches adults and children with neurological damage how to overcome problems. The underlying philosophy is that everyone can learn - no matter how severe the damage to the nervous system.
- It was developed by the doctor Andras Peto in Budapest, Hungary, in the years after the Second World War.
- It is based on active learning rather than passive treatment. Its practitioners are called 'conductors.'
- It teaches people that their co-ordination is much more under their control than they and their families or carers may have thought, and that there are ways in which they can achieve much more.
- Conductive Education came to public attention in the U.K. following the BBC documentary 'Standing Up for Joe.' The programme followed a British family who took their son Joe who has cerebral palsy to the Peto Institute in Hungary. The programme generated a huge response and raised the question of why Conductive Education was not available in the U.K.
- Over 11,000 enquiries and a national campaign led to the creation of a national charity - the Foundation for Conductive Education in 1986- to establish Conductive Education in the UK. The National Institute of Conductive Education was opened in 1995 by Diana, Princess of Wales.
- The Institute runs sessions for people with MS as well as for those with cerebral palsy, Parkinson's disease, traumatic head injuries or strokes. There are also carers' courses.

circulation are minor.

But I feel these things represent a significant move away from a passive role in the disease's progression. I am now playing a much more positive part. I have some control over what is happening to me now.

MS is such an unpredictable illness, but I live in hope that my work with Conductive Education will have long term benefits. I heartily and sincerely recommend Conductive Education to you.

### Info Box

The Foundation for Conductive Education/ The National Institute of Conductive Education  
Cannon Hill House, Russell Road  
Moseley, BIRMINGHAM B13 8RD  
Tel: 0121 449 1569  
Fax: 0122 449 1611  
[www.conductive-education.org.uk](http://www.conductive-education.org.uk)  
Cost: £41 per hour for individual sessions. £411 for a 2 week course as part of a group.



“It just didn't work and was very painful.”

## Bee Venom Therapy

By Henny Lichy

Henny Lichy, 59, from Sevenoaks in Kent was diagnosed with MS in 1981. She works as a reflexologist and reiki practitioner.

**T**he idea for trying Bee Venom Therapy came from reading Celeste Pepe's book 'Reversing Multiple Sclerosis.' In her 9 point step to recovery, being stung by bees is Step 9. Well it hit me. I thought, 'I have to try this; gruesome as it sounded.

My partner and close friends were speechless, gasping "live bees stinging you?" But they all knew there was no stopping me once I got going.

In late January last year I devoted one whole day to finding out about BVT in the UK. Not easy. I tried one Apitherapist who was not very encouraging. Then I called 'The Bee Lady of Waldorf' USA, Pat Wagner, who has MS and has done well on BVT. We discussed her experiences and her book 'How Well Are You Willing To Bee?'

She also gave me Peter Dalby's phone number in England. He turned out to be a wealth of information and was most encouraging. He sent me Pat Wagner's book, which I read in one evening. I was getting more excited about the idea.

### I Needed Friends To Apply The Bees

Next I had to ask some of my friends to help me apply live bees on specific points on my body which I was unable to reach myself. I think this is a horrendous favour to ask but

three were very happy to help.

After that, I went to see my GP to get an 'Epipen' in case of an allergic reaction. My wonderful GP prescribed it immediately.

In early March my very good friend Mary and I set off to Hertfordshire to see Peter Dalby. Peter and his lovely wife greeted us warmly and talked with us for a long time about all the pros and cons of BVT.

He then introduced us to his beehive. I had a trial sting on my right wrist. After 20 minutes I had no bad reaction, so I was ready to have my first two stings on either side on my lower lumber region – painful but bearable. This was to be increased by two stings each session, three sessions a week e.g. Monday, Wednesday, Friday. He didn't charge anything.

In my search for beekeepers closer to home I eventually found Peter Hatton of the Kent Beekeepers Association, who was supportive, enthusiastic and encouraging and willing to supply bees. I also found two more beekeepers willing to supply me.

### The Pain With Each Sting Did Not Get Easier

My good friend Pam became a real expert in catching the bees in a jar by their wings with the tweezers and applying them on me. She then let them fly out of the window for a peaceful death.



At the height of my treatment I was having 14-24 stings per session, three times a week. But I have to report that the pain with each sting did not get easier. I used Aloe Vera juice immediately after to soothe the sting. Even so, it took approximately one hour to get over a session.

I must say this is the most painful but the cheapest therapy I have ever undertaken. None of the beekeepers wanted to accept any payment, but I insisted on a small sum (£5) for their inconvenience. Two accepted, one did not.

On the plus side, my sleep and fatigue improved but this did not last long. However, the main purpose of BVT was to improve my mobility, which did not happen.

### Info Box

Peter Dalby: 01992 622645  
<http://www.radix.net/~honeybs/pat.htm>

Sue Ferreira from Cambridge, who sent us this story, says: "Although not having MS herself, Jacquie Welland has always been there for me so knows a lot about the problems of MS." A grandmother with four children, she lives in Nova Scotia, Canada.

# Oh Oh Oh Delilah!

By Jacquie Welland

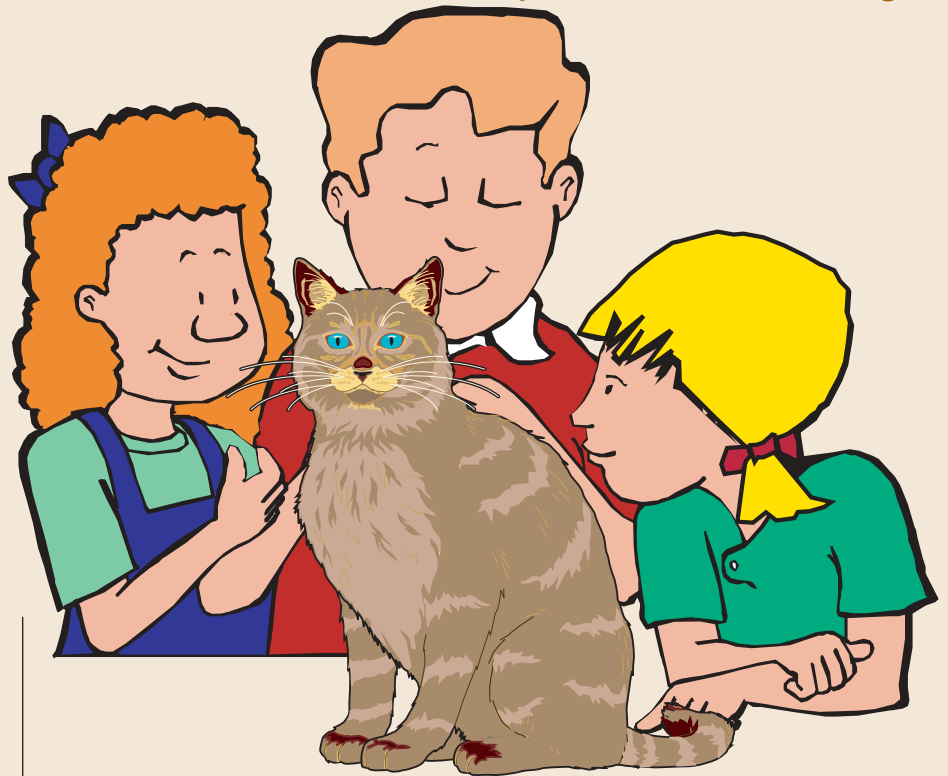
**A** ccording to the three children walking back from school, the little kitten sitting under the hawthorn hedge by the roadside was a stray.

The Marsh family children, Frankie, Amanda and Beth, nearly six, had made their way from school as usual, but just before turning onto the path to the new housing estate where they lived, they saw a kitten.

It was awesome. So pale! It reminded them of cream fudge with chocolate delicately painted on its ears, nose, paws and tail. Its eyes like blue jewels made it look more like an ornament, except that it was not an ornament. It was a real cat with the most persistent wailing.

The three children had just lost their pet 'Tomkins'. He died of old age and they had buried him in the tulip border just a few weeks back.

So they were attracted to the little cream-coloured kitten, and made soft noises as they crouched in front of it, not wanting to frighten it away. It let itself be touched, lifted up in their arms and finally it



exchanged its ear-piercing noise for contented purrings.

"Strays need a home," said Frankie.

"It's lost," said Amanda.

"Let's take it home then," added Beth, anxiously.

"It's a stray," declared Frankie. "And mum says that strays need a home and we haven't got Tomkins any more, have we?"

The kitten, who was a slave for attention, was weaving

trustingly in and out of their ankles. The children could resist no longer! Without hesitation, they popped the kitten in Frankie's school bag and started up for home at a quick pace. They knew they were late.

The school bag was not a very dignified place for such a classy creature, who objected by complaining highly and loudly. The three children quickened their step even more.

Their mother, Violet Marsh,

had started to worry about their lateness from school, so when she heard them, she greeted them with relief and joy.

"Look mum, we've got a stray!" exclaimed all the children together.

Astonished at their find, Violet Marsh said: "Children, I'm afraid it's not a stray. It's a Siamese."

"What's a Simonese?" asked small Beth.

"Not Si-mo-nese, silly" said ten year-old Frank. "Si-A-mese."

Their mother felt very sorry for her brood's loss of old Tomkins and understood their need for another cat. But while they were busy giving their new-found joy a dish of cream, she said:

"Listen, children. This little kitten certainly belongs to someone, and that someone is probably being driven crazy with worry looking for it at this very moment. You must show me where you found it, and together we'll look for the owner."

Beth picked up the little kitten and buried her sobs in the soft fur around its neck, while still calling it her 'Simonese.'

### Maybe the children should have another pet

After tea, they all walked in silence to the place they'd found the kitten, transporting it in Tomkins' old carrier. Along the way, Violet Marsh explained to her children that they would not have liked it one bit if someone had gone off with their Tomkins when he was alive. The children understood that, but were sad.

They rounded a corner and Frankie showed his mother where they had spotted the kitten under the hedge. The land belonged to a house which was not visible from where they stood, but they followed the

long, curving drive up to the front door. Violet rang the bell.

In seconds, the door opened. There stood a tall man who Violet recognised from a local community meeting. He was Harry Benton, and they were already on first-name terms.

By now, the kitten was miaowing its head off, making its presence known – as only a Siamese can do.

Much relieved at the sight of his kitten in the carrier, the tall man exclaimed: "DELILAH!"

"Delilah." The children repeated. They liked the name.

"I am so grateful," said Harry. Then he asked them all to come in.

Frankie spilled Delilah out of the carrier on to the hall floor. The children immediately engaged the kitten in a rollicking game of feather and mouse, while Violet explained how they had come upon the little cat on their way back from school, thinking it was a stray.

"I've been calling and calling her without any luck," said Harry, smiling with relief. "I was worried she might have got run over or something."

Violet and Harry chatted while he made a cup of tea. "We lost our cat Tomkins not long ago," said Violet.

"Well, maybe the children should have another pet," said Harry, watching the happy children play with Delilah. "I have an idea which could suit both your family and myself. You see, I am retiring at the end of this year and I want to take a long boating holiday. I've never had the chance until now.

Would you like . . ."

"Are you offering Delilah to us?" asked an incredulous Violet.

"Well, I've been



giving a lot of thought to Delilah and what would be best for her," said Harry. "It wouldn't be a very nice life for her to be restricted on a boat and the alternative would be to board her in a cattery for months on end."

"Oh Harry! My children would be in heaven to have a cat again," said Violet. And they were. Thanking Harry profusely, the Marsh kids danced with joy at the news that Delilah would be theirs.

With Delilah in the carrier, the children walked her to her new home.

But this time, the only sound coming from the Siamese kitten was a loud purr.



Liz Brice – alias Clare Hodges of the Alliance for Cannabis Therapeutics – has written a paper for a professional journal entitled 'Personal Account of Medical Use of Cannabis.'\* This is an extract.

## "Cannabis Lifts You to Normality"

By Liz Brice

"There is no doubt that my condition has improved in different ways. I do not have to take as many prescribed medicines. I now eat better, sleep better and feel more positive and motivated."



I discovered I had multiple sclerosis 20 years ago when I was 25 years old. For several years I was only mildly affected. I carried on working as a television producer, married and had two children. Slowly, my condition became worse, so that I was constantly uncomfortable and tired and had difficulties sleeping.

The medicines prescribed only gave limited relief and often with unacceptable side effects. Over the years I've been given steroids, tranquillisers, pain-killers, muscle relaxants and anti-depressants. At best they only helped in the short term, and many have intolerable side effects.

My main problem was that my bladder was in constant spasm, and no prescribed medicines helped me. For several months, I took oxybutinin. This didn't help, but I persevered. It gave me side-effects of blurred vision and headaches. My nights were so disturbed by the bladder problems I was given tamazipam to help me sleep, but they left me slow and 'hung over' the following day.

### Cannabis helped me cut back on medicines

Using cannabis helped me cut back or stop these medicines. I much preferred using cannabis because not only did it seem just as effective, but I also felt I had control over my medication, which was very important.

I've been using cannabis for nine years. There is no doubt that my condition has improved in different ways. I do not have to take as many prescribed medicines. I now eat better, sleep better and feel more positive and motivated.



Liz Brice, 45, a former television producer, is married with two sons and lives near Leeds in Yorkshire.

In 1992 I read an article in a U.S. journal about how some doctors had observed cannabis could help people with MS. Before I did anything I talked to different doctors. None of them knew much about it, but said they thought it wouldn't do me much harm in moderate quantities, and indeed cannabis was probably safer than many of the medicines they could prescribe.

As I was a middle-class mother of two very young children, I had a bit of a problem obtaining cannabis. My life revolved around the local mothers and toddlers group and it was sometimes quite embarrassing asking people if they could assist me, but eventually I found a woman who did help me get some and showed me how to use it.

### A woman showed me how to roll a joint

Like most people, she was happy to help someone in trouble, and came around one evening when the children were in bed. She brought some cannabis, tobacco and papers, and showed me how to roll a joint. She smoked some

with me, talking me through what I might be experiencing. She advised me to go slowly and not take too much.

The physical relief was almost immediate. The tension in my bladder and spine was eased, and I slept well. I was comfortable with my body for the first time in years. Just as important, I felt happy that there was something, after all, that could help me. It was as if a huge weight had been lifted from me.

My MS symptoms vary considerably. Sometimes I can appear very well and at other times I look and sound very handicapped. Similarly, I can be cheerful about my situation, but when the MS is bad I become very introspective and gloomy. Very simple tasks take enormous effort and leave me exhausted. Cannabis helps to stabilise my health and I find I can now do simple things that I hadn't been able to do, like go to the shops, or cook my children's dinner.

## Learning to get the dose right

It took a couple of months to work out how to self-medicate. To begin with, it was easy to take too much or too little. If I took too much I became uncoordinated and confused.

I have now established a routine which helps. I take 9 grams of herbal cannabis per week, drinking it in milky drinks during the day and smoking it at night before I go to bed. To make the drink, I simmer the cannabis in milk for a few minutes, sieve the milk to remove the leaves, then drink the milk.

I do not smoke cannabis with



tobacco, but with a herbal tobacco mix you can buy in health food shops. I've found smoking is the easiest way of taking it to treat MS as it is much easier to regulate the dose. Over 24 hours I would usually expect to take four joints, of half cannabis, half herbal tobacco, though it can be as few as two or as many as six. It's vital to have some control over how much you take and how often.

I don't feel in any way addicted to cannabis, or tempted to take harder drugs. I don't crave it or suffer withdrawal symptoms when I don't take it when travelling abroad; the MS simply gets worse.

My neurologist was very impressed by how much better I was. He put me in touch with two other MS patients who also used cannabis. That was how the ACT started in the UK.

Years of hard work with many others in the ACT finally enabled us to play a vital role in getting GW pharmaceuticals a licence to research cannabis.

Over the years of my involvement with the ACT, I've had thousands of letters, and

some go into detail about how cannabis has helped their MS. There is a recurring theme through all these letters: **Cannabis helps them because it not only eases their physical problems, but also improved their mood, lifts their spirits, and give them a better quality of life.**

One common physical effect of cannabis is that it relaxes muscles, which is one reason why people enjoy using it. But when you have MS, relaxing muscles is not just fun – it's very important. Relaxing muscles is not just a way of 'chilling out', it can also mean you can function more normally.

## To get high? Or not to get high?

I and many others think that the psychoactive effects are vital to the therapeutic value of cannabis. For many people with MS and their families, being depressed and demoralised is the hardest aspect of the disease to live with. As one man wrote: 'Cannabis lifts you to normality!'

*\* Journal of Cannabis Therapeutics  
Vol 2 Numbers 3,4 2002*



Susie Cornell is a healthcare practitioner who runs an assessment centre for people with symptoms of MS

## Candida, Yeast Infections and MS

### What Is Candida?

Candida is a single-celled yeast. Normally it does no harm because it is kept in check by beneficial bacteria (probiotics) like acidophilis. But when beneficial bacteria are out of balance or destroyed, the natural balance of the gut bacteria can change and Candida can grow out of control.

The toxins produced by the yeast can cause many unpleasant symptoms including the immune system not working as it should. Candida needs to be sorted out first if you want to regain good health.

### Beneficial bacteria can be destroyed by:

- high levels of stress
- too much sugar –even one tablespoon can upset the immune system
- use of antibiotics
- high levels of stimulants
- certain drugs, steroids, the contraceptive pill and HRT
- elevated mercury levels

### How to diagnose Candida

Analysing past health history and current symptoms can be more accurate than stool samples and blood tests.

### The Link Between Candida and Leaky Gut

Candida can enter the bloodstream through a leaky gut and invades every part of the body. It accumulates in the central nervous and endocrine systems affecting the pituitary, thyroid, hypothalamus and the adrenal glands. This causes many symptoms.

### Candida Symptoms

- Fatigue
- Foggy brain
- Dizziness
- Eye problems with difficulty focusing
- Constipation or diarrhoea
- Cold hands and feet
- Depression
- Repeated urinary and vaginal infections
- Weight loss or weight gain
- Short-term memory loss
- Problems with concentration
- Headaches
- Poor balance
- (In Women) PMS, early menopause, endometriosis.

### Why Does Candida Keep Coming Back?

#### Mercury Toxicity

Mercury toxicity damages the immune system so it cannot effectively fight Candida, parasites and viruses.

When the body is overwhelmed by mercury it is excreted as methyl mercury, the most toxic form. This is absorbed through the intestines and can pass through the blood brain barrier.

The body then finds it very difficult to detoxify Candida and mercury. Then, essential Glutathione levels are used up and amino acid supply is depleted. This makes it harder to make

### Home Self Test for Candida

This is a reliable self test to do at home to see if you have Candida.

First thing in the morning, before you put anything in your mouth, get a clear glass. Fill it with water and work up a bit of saliva, then spit it into the glass. Check the water every 15 minutes or so up to one hour.

If you have Candida you will see strings (like legs) travelling down into the water from the saliva floating on the top, or 'cloudy' saliva will sink to the bottom of the glass, or cloudy specks will seem to be suspended in the water. If there are no strings and the saliva is still floating after at least one hour, you are probably yeast free.

If you have a bunch of threads or cloudiness and especially if it develops quickly and sinks to the bottom you have a serious case of Candida. A few threads or light cloudiness indicates not a serious problem.



enzymes, so harder to digest protein. (A good reason to take digestive enzymes.)

For many years I have been hearing that **Candida** yeast infections are related to mercury toxicity. I also discovered why people with MS were consistently being reinfected with **Candida** yeast infections. It seems that if you have a yeast infection that keeps coming back it may mean that there is elevated mercury involved.

### The Importance of Oxygen

Also the system needs to be oxygenated. Lack of oxygen at cellular level means that cells cannot detoxify adequately. A yeast infection can thrive in a low oxygen environment.

Oxygen kills both mycoplasma (**Candida**) and viruses and most other pathogens. It is non-toxic and helps to detoxify cells, improve memory and increase energy levels.

Many people say that hyperbaric oxygen treatment (HBOT) is of great benefit. Some, like myself, say that it helped for a short time, but wore off. HBOT does force oxygen into the cells, but the effects don't last long. Using liquid oxygen can enhance the benefits of HBOT. We need to CREATE oxygen INSIDE cells if we want to fight mycoplasma (**candida**) and viruses.

There is a programme of supplementation that needs to be taken at a high therapeutic level for a long time to fight mycoplasmas and viruses.

### How To Heal A Leaky Gut and Gut Wall

Getting rid of mercury and **Candida** is not easy. The liver picks up toxins from the bloodstream, but mercury and **Candida** get routed back into the body via the leaky gut. So toxic waste is recycled, causing

the immune system to be continuously stressed and on 'auto-immune response'.

That's why it's important to heal the gut wall when detoxifying **Candida** and mercury.

When the gut lining is damaged, repair cannot take place without extra glutamine. Large quantities are recommended (20 to 30 grams a day) therapeutically and then a maintenance dose.

Betaine HCL tablets and digestive enzymes and a probiotic such as acidophilus are also needed to help restore the balance in the gut.

### Treating Candida

The conventional treatment is strong anti-fungal drugs such as Nystatin. But these may cause liver damage, **Candida** can develop a resistance to anti-fungals and killing off yeast increases the amount of toxins, triggering 'die-off' reactions which many people find unbearable.

I have been using an exciting product in my **Candida** Treatment Programme called 'ThreeLac **Candida** Defence'. It's in powder form that dissolves on the tongue. It must be followed by food to assist this powerful product in reaching the small intestine. It contains three forms of spore-forming lactic acid bacteria. These live micro-organisms purge the intestinal tract of the parasitic, fungal form of **candida**. At the same time Threelac helps to balance the pH levels in the body.

Using a digestive enzyme containing cellulase together with ThreeLac will help break down the cell wall of **Candida** so the yeast cell dies without releasing a flood of toxins – thereby preventing the 'die-off' reaction.

It is also important to take a calcium supplement to help make the body chemistry more alkaline.

A good probiotic is

### The Candida Diet –

(This is a very simplified version!)

#### OK

- Chicken, fish, vegetables.
- Wholegrains OK for some people.
- Bottled spring water (NOT tap water.)

#### LIMIT

- Fruit in early stages of diet.

#### AVOID

- Products made with flour – bread, cakes, biscuits etc.
- Vinegar, mayonnaise and all fermented things.
- Processed Meats
- Alcohol • Caffeine

#### ELIMINATE

- All sugar and foods made with sugar, sucrose, dextrose, glucose, any kind of syrup.
- Anything made with yeast.

recommended during treatment and for maintenance of the gut flora.

### Treatment Summary

As well as the diet, supplements need to be taken at a high therapeutic level for a long time to fight mycoplasmas and viruses.

- Anti-Candida Diet
- ThreeLac **Candida** Sachets or Candex
- Hydroxygen Plus (liquid oxygen supplement)
- Digestive enzymes and Betaine HCL
- Coral Calcium
- L. Glutathione and Milk Thistle (for liver support and detoxification)
- Probiotics (Acidophilus bifidus, Udo's 8 probiotic)
- Antioxidants



Healthy products don't need to be dull, boring and taste like cardboard. Tessa Buckley picks out the best products which are free from gluten, wheat, dairy, soya, eggs and yeast.

## Foods free from gluten, wheat, dairy, soya, eggs and yeast

**I**f you follow the recommendations of the Best Bet Diet group, you will be on a gluten-free (GF) diet. There's a huge range of GF foods available – new products are appearing all the time – but they are often very sugary, high in fat, and made out of highly processed grains. In fact many of them are far from ideal if you want to follow a low-fat diet or cut out other ingredients such as dairy-produce, or yeast. Many are expensive and some taste horrible. So how do you find your way through the gluten-free maze? Here's a quick guide.

### WHAT IS GLUTEN?

Gluten is a protein which occurs naturally in wheat, oats\*, rye and barley. It is the binding agent in the grain; that's why GF food can be very crumbly.

### Gluten-Free v Wheat-Free

Since wheat contains gluten, you'd expect all GF products to be wheat-free, but in fact many

#### Key:

GF: Gluten free  
WF: Wheat free  
MF: Milk free  
EF: Egg free  
SF: Soya free  
YF: Yeast free

are made from Special Wheat Starch, which has had the gluten chemically removed. Likewise, wheat-free products are not necessarily gluten-free; they may contain barley, oats or rye. All products listed here are gluten-free (GF), wheat-free (WF), milk-free (MF), egg-free (EF), soya-free (SF) and yeast-free (YF) unless otherwise stated.

### Breads and Bread Mixes

Most European manufacturers of GF bread use yeast as a raising agent. To help the yeast rise, and to make up for the lack of gluten, they add lots of dairy produce and sugar. I can't think why this is.

The best GF bread comes from Australia, where they use a chemical raising agent called glucano-delta-lactone and avoid all the additives.

The good news is that ORGRAN, an Australian wholefood company, is now marketing a range of GF products in the UK. Their GF BREAD MIX \*\* is easy to use, with a good texture and a pleasant taste and it freezes well. Unlike many GF breads, it actually tastes better fresh rather than toasted. They also sell a GOURMET PESTO BREAD MIX. Both these breads can be



Tessa Buckley

made in a breadmaker – instructions on the pack. You could also try:

**Sourdough breads** These are small, dense loaves, quite unlike normal bread. SUNNYVALE and BIONA make several varieties. BIONA loaves come ready-sliced and go well with cold meats. ENER-G breads \*\* are GF, WF, MF, EF, and SF but contain yeast. Their SEATTLE loaf is America's favourite GF loaf. Give their WHITE RICE LOAF a miss though – weird texture, smell and aftertaste.

NB: GF bread should be kept in the fridge, or sliced and stored in the freezer.

### Breadmakers

Making GF bread in a breadmaker cuts out a lot of the hard work, but you can't just substitute GF flour for normal flour and expect a perfect result. Here are a few tips:

- Use recipes specifically for GF bread, either from the machine manufacturers, or from the suppliers of the bread mix.
- Follow instructions for quantities and ingredients meticulously.
- GF breads usually rise more quickly, so use the shorter programme.

If you can, use a breadmaker with a special GF programme, like the Panasonic SD253. Panasonic have an Advice Line if you need help: 01344 862 108

## GF Flours and Baking Products

GF baking works better if you use a mixture of flours. The most common GF flours are: Rice flour, soya flour, millet flour, buckwheat flour, corn or maize flour, tapioca flour and potato flour. I make up my own mix of 5 parts brown rice flour, 2 parts cornflour and 1 part potato flour. Some good all-purpose flours are:

- Doves Farm GF Flour (brown rice/potato/corn/buckwheat)
- Innovative Solutions GF Flour (white rice/tapioca/potato)

Some products to help your baking:

- XANTHAN GUM has revolutionised GF cooking – it helps prevent crumbling. From INNOVATIVE SOLUTIONS and ENER-G.
- ENER-G Egg Replacer and ORGRAN No Egg.
- GF Baking Powder from ALLERGYCARE or RITEDIET.

## Pasta and Noodles

There is a vast selection on offer. Be warned – those made entirely from white rice are very delicate and easily overcooked. Here are just a few:

- ENER-G brown rice macaroni, spaghetti and lasagne. \*\*
- ORGRAN pastas come in many

different shapes, flavours and colours. Not all are wheat or sugar free, so check the labels.

- BLUE DRAGON GF rice noodles – for your Oriental dishes.

## Crackers and Crispbreads

Again, there is a huge variety, but many contain wheat and dairy produce, or have a tendency to break easily. My favourites are:

- GLUTANO GF Crispbread \*\* The only one which is WF, MF, EF, and YF. It also tastes nice!
- GLUTAFIN GF Crackers \*\* Good taste and texture, but contain yeast.
- GLUTAFIN GF High Fibre Crackers \*\* Very 'moreish', but do contain soya.

## Breakfast Cereals

Beware – a lot of GF breakfast cereals are very sugary and GF mueslis can taste stale.

- BARKAT GF Porridge Flakes
- BIG OZ have four varieties of sugar-free cereals: Rice Puffs, Millet Puffs, Corn Puffs and Buckwheat Puffs

## Miscellaneous Items

- ALLERGYCARE Gravy Powder
- MARIGOLD Vegetable Bouillon Powder – unlike most stock cubes, this is GF and YF. Really useful for soups, gravy and stews – one of Delia's favourites!
- ORGRAN Buckwheat Pancake Mix.

## Convenience Foods

It is possible to buy GF convenience foods; however most of them tend to be very fatty and sugary and full of ingredients you may want to avoid. Here are a few of the healthier options:

- BARKAT Mexican Rice Pot Meal and BARKAT Rice and Tomato Pot Meal (Gluten Free Foods) NB. Contains yeast.
- ORGRAN Fruit-filled Bars.
- VILLAGE BAKERY GF Fruit Cake (WF, MF, YF, and sugar-free.) Contains egg.

## Suppliers

Many of the products mentioned here can be found in your local health food shop. Most are also available mail order from GOODNESS DIRECT or ALLERGYFREE, both of whom supply a huge range of special dietary products and have comprehensive and informative websites (see Info Box).

Products marked \*\* can be ordered from your pharmacist. You may even be able to find what you want in your local supermarket (see below).

## Supermarkets

**SAINSBURYS** now have a 'Wellbeing' section which stocks:

- Their own range of GF flour and biscuits.
- TRUFREE GF range – all WF, MF and EF.
- Ready-to-eat GF and WF meals by DIETARY SPECIALITIES
- BIG OZ breakfast cereals.

## TESCO

- Have 100 products in their 'Free From' range. All are GF and WF. Many are also MF, EF, YF and SF.
- Tesco Finest Pork Sausages are now GF.

**ASDA** also has a 'Free From' range. This includes:

- BAKER'S DELIGHT Bread (GF, WF, MF, and SF)
- ENER-G and BARKAT products, SALUTE pastas and Xanthan Gum.



## Info Box

ALLERGYFREE  
Tel: 01865 722003  
www.allergyfreedirect.co.uk  
GOODNESS DIRECT  
Tel: 0871 8716611  
www.goodnessdirect.co.uk  
ORGRAN  
Tel: 01455 556878  
www.orgran.com Sue McGrath will give help with any baking problems.

# Just Brilliant! Amazing! A Fantastic Experience!

When we ran our BSM Mobility Competition, we thought it would just be a free driving lesson for three lucky winners. But it turned out to be much more than that. It gave them back their confidence to enjoy life behind the wheel again. One was Helen Wallage, 47, who lives in Cumbria. She was diagnosed with MS eight years ago.

**“It was a fantastic experience and a great opportunity to try out the hand controls – something I wouldn’t have done if I hadn’t won the competition.”**

**W**hen I first heard I was a winner of the BSM mobility driving session, I admit to being very nervous. Not because of the driving, but because I knew I would need the loo at some point during the two hour lesson!

When Sue, my instructor, rang to fix a date and time I told her about my loo worries. She said no problems, she probably knew every loo in the area! After that, I started looking forward to my lesson.

I hadn’t driven for a few months as my legs were going through a bad patch, so actually getting behind the wheel of a car again was great.

## **I Felt Like A Learner Again!**

Sue was a lovely chatty lady originally from Australia. She sat me in the driving seat of her specially adapted car and explained the workings of the push/pull lever for the brake and accelerator, and made sure that the steering knob was comfortable. She also adjusted the height of the seat for me. So, feeling like a learner all over again, we ventured out of the drive and onto the road.

It really wasn’t as difficult as I thought it would be. The steering control was obviously quite straightforward, but getting used to the push/pull

lever was like being a complete beginner again, where I tended to snatch at the lever instead of doing it gradually.

Sue kept saying, “Think of using your hands as you do your feet.” We did have a laugh as I accelerated too quickly once or twice and we were momentarily pinned back in our seats. “The ‘G’ force.” Sue said!

I had to get used to the brake in the same way, but soon we were cruising

along. As well as the main roads, we went down all sorts of little roads to get used to steering and braking. We practised reversing round a corner, which reminded me of my driving test!!

Then we took a short break in a car park and tried out a different size steering knob.

All too soon we were back home. I couldn’t believe two hours were over. It was a fantastic experience and a great opportunity to try out the hand controls – something I wouldn’t have done if I hadn’t won the competition.

I really felt quite at home with the controls and will certainly think about having them fitted to my car. Many, many thanks to *New Pathways*, BSM and Sue for the session – just brilliant.”

## **Jane Payne**

### **“How I Lo**

Jane Payne, a mother from Nottingham, has found driving dreams in the

I’d been driving a when my Motability expired, I wanted so started to look around needed a car that:

- Would carry my R scooter with a ran
- Would cope with
- Was automatic, w central locking an it would need to b controls.
- Would be easy to We spotted an ad magazine *Lifestyle* fr Renault Kangoo by C Sussex, and ordered Hire Purchase schem Constables did all necessary paperwork excellent customer s



Helen Wallage in her car

## The Lesson was Truly Amazing. It has given me the Confidence to start Driving again – Something I thought I'd lost!

By Ani Kelsang Shanti from Bristol

I'm a Buddhist nun, recently moved to Bristol. When I found out I'd won a driving lesson I was stunned – I never win anything!

The lesson was truly amazing. I was nervous to begin with, although my instructor Michael said it didn't show. He was open and kind, able to direct me in my driving, but happy to let me practise – that's what I needed – to be able to practise in a safe environment.

I've had MS for four years now. It's still not that bad, but I had to stop driving after the early attacks left me too weak to handle a car (or a motorbike – my last vehicle.) I'd been scared

by my sudden inability to judge where I, or other cars, were on the road. Even navigating familiar routes I was easily lost. This hit hard, as I've been driving for half my 30 years. I'd been forced to give up my precious independence for the joys of public transport and helpful friends.

For the lesson, we drove a little automatic around Bristol, first the quiet outskirts and then – unbelievable – the busy centre. It was a slow start, and I was grateful that Michael was there to pull on the steering wheel when I strayed a bit. I love driving. It was exhilarating just to be there.

This has given me the confidence to start driving again, which was something I thought I'd lost.

I also found out about automatics, which I hadn't given a thought to before. I'm now looking for a small automatic van so I can visit my family and friends and escape to the hills when I need to. If anyone knows where I can get one, please let me know on: shanty-varmana@whale-mail.com



## Already has the perfect car/van for getting around Love my Little Roo/Pooh Renault Kangoo"

er of three from  
und the answer to her  
ne Renault Kangoo.  
Vauxhall Astra, but  
contract period  
something different and  
nd for inspiration. I

ascal 306 4-wheeled  
mp for ease of access.  
a family of 3, plus dog.  
with powered steering,  
d all the trimmings, as  
be fitted with hand

drive.  
vert in the 'Motability'  
or a conversion on a  
Constables in East  
one on the Motability  
e.

the boring and  
k involved, and gave  
service from the outset.

They made two journeys (Sussex to Nottinghamshire) to demonstrate the ease with which I could drive the scooter into the vehicle, exit by one of the side sliding doors and put up the ramp.

I also had some extra grab rails fitted, in addition to those which help you in and out of the driver's and front passenger seats; these are standard for all Kangoos and very helpful on those 'wooden' sort of days!!

The scooter or wheelchair is fixed into position with some adjustable straps, and if required the passenger can remain seated as there are seatbelts for the scooter/wheelchair. From this position one can obtain an incredible view through the front windscreen.

We had decided to name the car 'Roo' the Renault, but our daughter Poppy insisted the name was 'Pooh', during one of the Constable visits. This fact had been remembered, so when the

car was delivered there was a new 'Pooh' toy sitting on the dashboard!

I am extremely happy with 'Roo/Pooh', and this was made clearer recently when the Kangoo had to go into Nottingham for some repairs, and I had a courtesy car (without the trimmings!). I was able to have the car fitted in minutes with slightly different hand controls, but I really did miss the car I was used to.



Jane Payne with her 'Roo/Pooh'

See page 43 for BSM voucher



Our expert on rights and benefits is Heather Wardle from Scotland. A former social worker, Heather has MS herself so she has first-hand experience of claiming benefits. If you have a query you would like Heather to answer in New Pathways, please write to:  
**Help From Heather, MSRC,**  
7 Peartree Business Centre,  
Peartree Road, Stanway, Colchester,  
Essex CO3 0JN.

## Good News! You DON'T lose out for life

However, the good news is you will not lose out for life. As soon as you have built up the contributions you would be able to claim Incapacity Benefit again if the need arises. Furthermore, when you do get IB and remain incapacitated you should be able to get the benefit for life.

If you are still concerned, the Inland Revenue produces a booklet entitled '*Resolving Benefit Involved Cases*'. It is number CA 75 and is available from the Inland Revenue.

I hope this puts your mind at rest.

## Be careful to fill in forms fully

Finally, I would like to point out that the Department of Works and Pensions do not keep the information you provide them with indefinitely. In fact most records are only kept for four years maximum, some only weeks. This is because they use the Data Protection Act 1998.

So if you are renewing a claim, such as DLA, or Incapacity Benefit, don't write 'condition unchanged' on the form. If you do you will probably lose the benefit as there will be no record of what your condition was before.

Complete the forms with as much detail as possible for the best chance of success.

Best wishes,  
Heather Wardle

## Do I lose out on Benefit for Life?

Dear Heather,

It seems I may have lost out on being able to claim Incapacity Benefit as I did not pay any National Insurance contributions for one year in 1999. I have been paying self-employed NI contributions since April 2000, and before 1999 I was employed.

I have been paying National Insurance payments since the age of 18. (I am now 34). It was only in 1999 that I did not pay any.

Now it appears that, due to one year of not paying, when I was not working, I may lose out on a benefit for life.

What can I do? Is there anyone I can contact?

Thanks,

Peter R. Lawrence

Dear Peter,

I'm sorry to hear of your experience and hope I can clear it up for you.

Entitlement to Incapacity Benefit depends on two things:

- The 'benefit year' you are in.

- The relevant tax years (or contribution years) for your benefit year.

To complicate matters, 'benefit year' and tax years are different. A 'benefit year' starts on the first Sunday in January and ends on the Saturday before the first Sunday in January the following year. A tax year starts on April 6th and ends on April 5th.

For Incapacity Benefit, the relevant tax years to satisfy the second condition are the two complete years (April to April) before the beginning of the tax year in which your incapacity began.

For example, if your claim started in June 2001, your contribution years would be April 1998 to April 1999, and April 1999 to April 2000.

If you did not have complete years in which you paid National Insurance contributions during that time, you would not, unfortunately, be able to claim Incapacity Benefit.

## Benefits Agency

Benefit Enquiry Line for people with disabilities  
0800 88 22 00

Look in your local telephone directory for your nearest office.

Website: [www.dss.gov.uk/ba/](http://www.dss.gov.uk/ba/)

[www.msrc.co.uk](http://www.msrc.co.uk)

# Benefits Rates

The rates will go up from April 2003. Here are the new rates:

<b>ATTENDANCE ALLOWANCE</b>	2002	2003	<b>INCOME SUPPORT</b>	
higher rate	£56.25	£57.20	Personal Allowances:	
lower rate	£37.65	£38.30	single person under 18 - usual rate	£32.50      £32.90
<b>DISABILITY LIVING ALLOWANCE</b>			under 18 - higher rate	£42.70      £43.25
Care Component				2002      2003
highest	£56.25	£57.20	18-24	£42.70      £43.25
middle	£37.65	£38.30	25 or over	£53.95      £54.65
lowest	£14.90	£15.15	couple both over 18	£84.65      £85.75
<b>Mobility Component</b>			dependent children up to 16	£37.00      £38.50
higher	£39.30	£39.95	<b>Premiums</b>	
lower	£14.90	£15.15	family	£14.75
<b>EARNINGS RULES</b>			disability	£23.00
Permitted work earnings limit			carer	£24.80
(from October 2002)	£66.00	£67.50	<b>INVALID CARE ALLOWANCE</b>	£42.45      £43.15
<b>INCAPACITY BENEFIT (ICB)</b>	2002	2003	<b>SEVERE DISABLEMENT ALLOWANCE</b>	
long term	£70.95	£72.15	basic rate	£42.85      £43.60
short-term under pension age			Age-related addition	
lower rate	£53.50	£54.40	higher rate - under 40	£14.90      £15.15
higher rate	£63.25	£64.35	middle rate - 40-49	£ 9.50      £ 9.70
short-term over pension age			lower rate - 50-59	£ 4.75      £ 4.85
lower rate	£68.05	£69.20	<b>STATUTORY SICK PAY (SSP)</b>	
higher rate	£70.95	£72.15	earnings threshold	£75.00      £77.00
increase in long term ICB for age			standard rate	£63.25      £64.35
lower rate	£ 7.45	£ 7.60		
higher rate	£14.90	£15.15		

## Message Board

**Have you seen the Message Board on the MSRC Website?**

If not, you're missing some good stuff!

Just go to [www.msrc.co.uk](http://www.msrc.co.uk) and click on 'Message Board.'

There are messages on all kinds of subjects from all kinds of people.

Here's one example –

### Discussion on Low Dose Naltrexone:

"I am trying to decide whether the Low Dose Naltrexone has been helping me, or whether I just believe it has."

*"I 100% believe it has halted progression and is helping me. I haven't experienced any side effects. I'll keep taking it as long as I think it's working for me!"*

"What I find is about an hour after taking it I have very lively, my legs bend more easily. If I take it at midnight and am still awake two hours later I feel better than

than I have felt at any time during the last year or so. I walked 20 yards recently for the first time in a long time. That was after I'd taken LDN about an hour before."

*"I found that within a couple of days of taking it I had less tremor, great reduction in tingles, slightly stronger bladder control and more stamina! Is it placebo? Am I kidding myself? Frankly, I don't really care! I feel better, I do believe it IS making a difference and although £75 is £75, it's still a lot cheaper than some of the other drugs out there."*

# Diagnosis Story

Once a self-confessed slob, at age 30 Charlie Gee turned into a fitness freak. But one sunny spring, his legs didn't work. How would he tell his friends and his parents he had MS?

**"I lived on doughnuts and chips for three years and not surprisingly I became rather ill. I must have been pretty bad because when my father was in hospital with a heart attack, they kept me in!"**

By Charlie Gee

**W**hen I was younger, I had a fear that something calamitous would happen to my health, and multiple sclerosis was my number one nightmare! As I got older and bad things always happened to others and nothing seemed to happen to me, I began to relax.

Up until the age of 30 I didn't really take care of myself, in fact I would have been a perfect example of what not to do if one wanted to live a long and healthy life!

I became a vegetarian in 1969 and I didn't like vegetables. I lived on doughnuts and chips for three years and not surprisingly I became rather ill. I must have been pretty bad because when my father was in hospital with a heart attack, they kept me in!

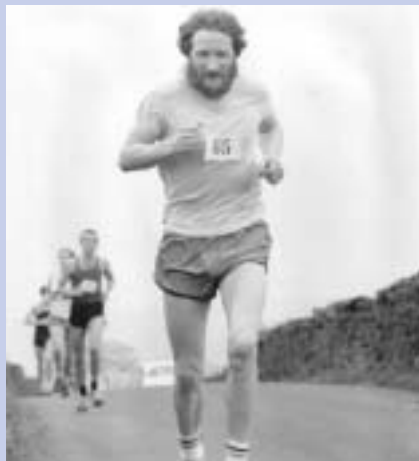
Then, whilst watching the first London Marathon on television I underwent the transformation from reprobate slob into fitness freak! I started to train, at first rather slowly. For the first week I would walk up a hill then run back down again, but soon I was running miles.

## Out Came The Running Shoes

There was something wonderful

about setting out on a long training run. After the first six miles I would drift off into a trance listening to the pitter-patter of my feet and watching the world bobbing up and down before my eyes. It was a wonder I didn't get run over by a car! I can still feel the sense of exhilaration just thinking about it.

The next year I put my name down for the London Marathon but was unable to get into it so I finished up running the British Marathon in Bolton and the next year I ran it again. I didn't run any marathons after that, it seemed a bit masochistic, but every year when it came round to March and the weather improved I would get my super lightweight running shoes out of cold storage and go running.



Charlie Gee running

One March, I think it was 1993, I went out for my first run of the year and I didn't seem to be able to get myself going. What was it? Was it that 'old age thing' that I'd heard people talk about? Then I reasoned it must be because I'm not feeling so good today. I would try again in a couple of days' time, but a few days later I was just the same. After a few more failures I decided to leave it for this year, and try again next. I never did!

My stepdaughter, Victoria, who is an EEG technician (brain scanner), moved to Australia about 1990 and in 1997 she came to visit me for the first time in two years. Because she hadn't seen me for so long she noticed how much my health had deteriorated since last time we'd met and insisted on paying for me to go to see a specialist in London. Then she went back to Australia. A few weeks later she rang to tell me I had multiple sclerosis!

## I found out I had MS in a phone call from Australia

The specialist had got in touch with her because she thought it best for me to receive the news from someone I knew. So I found



out I had MS in a phone call from Australia.

It all felt so unreal I didn't feel ill enough to have multiple sclerosis. Anyway, surely I was too old to 'catch' it! I had always been under the delusion that MS was a young person's disease and when I reached 40 surely I'd be safe. Obviously not! You live and learn, don't you?

My immediate reaction on being diagnosed was to exercise like mad. I would get rid of it before it arrived! There was a small gap between my bedroom wall and the bed. I would dance in this gap to reggae music in

the knowledge that if I fell over I would land on the bed.

Then it came to the problem of telling friends that I was ill. At first I didn't tell anybody and then something happened that I felt was rather odd. The pub that I went in most often had a benefit concert with all proceeds going to the local MS Society. Apparently somebody else who went to the pub had a brother who had MS. It was a perfect opportunity to tell the truth to everybody I know. So I did.

The thing I found most difficult to do was to tell my parents, but they lived about 25 miles away

so I didn't have to see them every day. At the time they were both in their late seventies. I thought my mother would be okay; I'd always been able to talk to her, but my father?

I was sure that if I told him the truth he would look on it as a failure on his part. So for about a year I told them that I had an in-growing toenail and was convinced I had them fooled. Then my dad died and I went over to be with my mother. The first thing she said as I walked through the door was 'Right, tell me what's wrong with you. You can't fool a mother!'

## Book Review

Reviewed by Samuel Long, PhD

# Placebo: The Belief Effect

By Dylan Evans

Harper Collins, London, 2003,

ISBN: 0 00 712612 3

**I**f 'New Pathways' subscribers read this book and take it to heart, their health definitely and wallets possibly may benefit.

As all adherents of complementary medicine no doubt are aware, placebos are "rapid readjustments of the body's own natural healing mechanisms to a surge of hope".

Evans reports that the range of conditions to which placebos respond is quite limited: pain, inflammation, lockjaw, anxiety, depression, and ulcers. Unfortunately, placebos seem incapable of curing cancer or schizophrenia.

Certain beliefs elicit placebo responses:

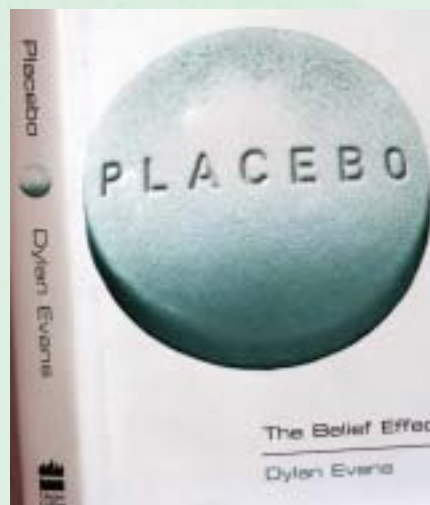
1) that one possesses a potent medicine or treatment,

2) that works,  
3) for one's illness.

Evans concludes that experience and information imparted by an authority are the chief sources of the belief effect.

Complementary medicine receives fair but probing treatment in *Placebo: The Belief Effect*, with the author being especially critical of the 'crackpot theories' associated with the various treatments. Interestingly, Evans is relatively supportive of complementary medicine when it's compared to the traditional variety.

Indeed, in exploring complementary medicine's time spent with clients, the enthusiasm of its practitioners, the use of ritual, and the greater physical contact offered, the



author concludes that complementary medicine is more likely to have greater impact on clients because of its placebo-enhancing approach. Indeed, Evans concludes,

"It is therefore quite possible that, in the context of actual clinical practice, certain kinds of alternative therapy may be more effective than orthodox medicine at relieving certain conditions, even though they are pure placebos."

## Gluten-free Muesli

From Tessa Buckley

"This has been my staple for years. I have it almost every morning and never get fed up with it. You can have it with any sort of milk and also with hot water. It's also nice with any sort of fresh fruit. It's high in fibre, so keeps me regular. It takes about 15 minutes to prepare and cook, which I do once a week. The following lasts a whole week. You have to make it in a large glass microwavable bowl. Once you've made it you have to keep it in the fridge as it has no preservatives in it. It will keep for up to a week."

### Ingredients

- 250g Rice Flakes (available from local health food shops)
- 30g Kellogg's Rice Krispies or Corn Flakes
- 30g Coconut Flakes (no brand – health food shop)
- 60g Sesame Seeds (no brand – health food shop)
- 60g Sunflower Seeds (no brand – health food shop)
- 2 dstsp Dairy-free margarine
- 2 dstsp Sunflower Oil
- 2 dstsp Honey (optional)
- Large handful mixed dried fruit according to taste (choose from raisins, sultanas, chopped prunes and apricots etc.)

### Method

- 1 Mix all the dry ingredients together, apart from the fruit.
- 2 Melt the margarine and the honey in the microwave.
- 3 Mix melted margarine, honey and oil with dry ingredients.
- 4 Cook on HIGH in microwave for 2 min 30 sec. Stir. Then repeat for another 2 min 30 sec.
- 5 Mix in the dried fruit.

This is good with chopped fresh fruit at breakfast or, used as a topping on stewed fruit, makes a sort of crunchy fruit crumble. Add more honey if you have a sweet tooth!



## Coral Calcium

In the last issue of *New Pathways* we mentioned one brand of Coral Calcium which comes in little sachets which you add to a bottle of water. We have now heard of other brands.

Stewart Edwards writes: I have 100 grams of 'Sango Coral' for £15 from Regeneration 01481 832917 (orders), enquiries (John Claydon) 08707 446850. This version comes as a very fine white powder that dissolves completely after 15 minutes or so in a glass of water. You can then drink the whole glass in one go if you wish.

TrueBlue is another company. They claim theirs is superior because it does not come from the sea-bed but the reef itself. 147 grams \$36 <http://www.cures4you.net/coralwhich.htm>

Coral Calcium from Okinawa, Japan, also comes in capsules, made by Source Naturals of Scotts Valley, California. [www.sourcenaturals.com](http://www.sourcenaturals.com)

Coral Calcium contains the alkaline minerals calcium and magnesium, as well as other essential trace minerals. This increases blood alkalinity, which is critical for overall health.



## 'Waves of Hope' Conference on Neurological Diseases

Anne Ivers is organising a conference on treating neurological diseases. The Conference, entitled 'Waves of Hope', will take place on June 20th 2003 at the Friends Meeting House, 173 Euston Road, London 10 am to 7pm.

One of the aims of the Conference is to raise awareness of complementary medicine for neurological problems.

Speakers include: Dr Marcos Diaz, Founder and Former Head of Holistic Medicine at the CIREN in Cuba. He will give a talk on the work of the CIREN and its multi-disciplinary approach to the treatment of different neurological disorders by the integration of complementary and orthodox medicine.

Dr Gordon Skinner MD(Hons) DSc FRCPath FRCOG, who has spent many years researching

and treating people with undiagnosed thyroid problems, will speak on how symptoms can sometimes mimic those of neurological illnesses. Dr Jack Levenson, President of the British Society of Mercury Free Dentistry, will speak on the dangers of mercury fillings in relation to neurological illnesses, how he tests for sensitivity to mercury and how to detox mercury from the body.

Cost of tickets; £120.00 Concessions £70.00 (applies to all those who are unable to work due to illness, those on a low income, and carers.)

Contact details: Waves of Hope, Suite 51, 58 Queensway, London W2 3RW Tel 0208 563 1073 email: info@wavesofhope.co.uk website: www.wavesofhope.co.uk



### Thank you

The MSRC would like to thank Peter Brookes of MUTV for donating a Rio Ferdinand signed shirt to be auctioned and Paul Vickers for his kind personal donation of £500 and the Trinity Mirror Group for their donation of £1000.



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