



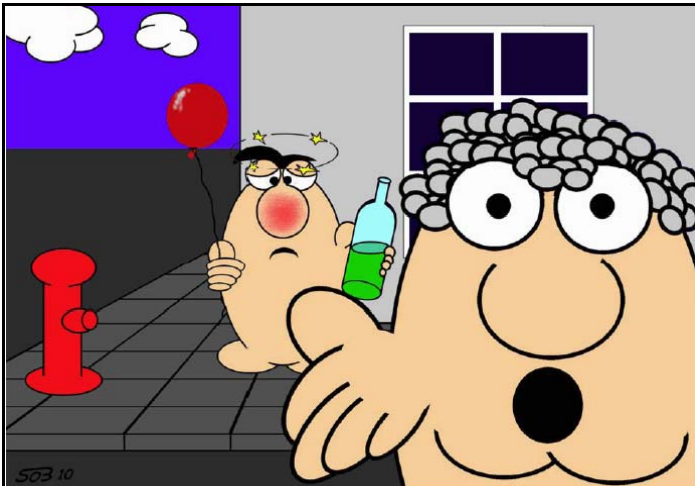
# Pathways

Price £ 2.50 (Free to members)

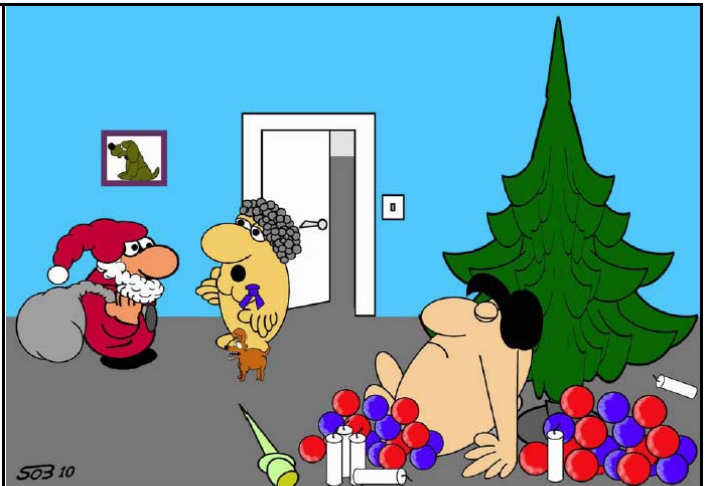
The newsletter of Leger ME/CFS Supporting Myalgic Encephalopathy or Encephalomyelitis (ME), Chronic Fatigue Syndrome (CFS), Post Viral Fatigue Syndrome (PVFS), Fibromyalgia Syndrome (FMS), Patients & Carers.

## Merry Christmas and Happy New Year

from the Pathways team: Mike (Desk Top Publishing), Liz (Proof-reader & Editor), Vicky (Distribution), Carolyn (Research) & Ross (Research).



LUCKY HIM! EVERYONE KNOWS EXACTLY WHAT MAKES HIM FEEL HORRIBLY SICK AND DIZZY AND HAVE A POUNDING HEADACHE.



I HAD HOPED HE'D FINISH DECORATING THE TREE BEFORE YOUR ARRIVAL, AFTER ALL, HE STARTED IT IN AUGUST!!



Cartoons about life with CFS  
by  
Hans-Michael Sobetzko  
**ME/CFS  
aktuell**

ONE GOOD THING THOUGH IS THAT EVERYONE ELSE HAS ALREADY FALLEN OVER BEFORE I'VE EVEN MANAGED TO LEAVE THE HOUSE.



WHAT EFFECT DOES CFS HAVE ON MY EVERYDAY LIFE? PUT IT THIS WAY, EVEN THIS PLANT HAS A MORE ACTIVE LIFE THAN ME!

## **You write**

**Chris & Simon write:** We are patient advocates; former committee members of the late Leeds & District ME Group; and co-authors of 'Listening and Learning', the survey of patients' experiences of the Leeds & West Yorkshire CFS/ME Service, 2010. There is bad news about the Leeds ME/CFS clinic. The Leeds & West Yorkshire CFS/ME Service is facing an uncertain future again and your help is needed! The latest news is that the Leeds & West Yorkshire CFS/ME Service is shortly to be relocated to the Becklin Centre. It is planned that the service will move on the 14th December. Everyone who attends the service will be notified of any changes as soon as possible, with further information on parking and public transport. The aim is for as little disruption to clinics as possible. If you have an appointment booked with a clinician in the near future then please phone 0113 305 6497 to confirm the address before attending. This move will, however, only be temporary and the new 'home' may be for as little as three months! So the future of the Service is still uncertain and our campaign for a more suitable permanent home will continue. In its temporary home at the Becklin Centre, the CFS/ME Service will still be in what is very much a mental health environment. The problems of access will also remain. The Centre is wheelchair accessible from the car park but spaces are very limited—and for those who are able to come by public transport, it is even further from the nearest bus stop than was the case for the Newsam Centre at Seacroft.

Sir Peter Spencer of Action for ME has been informed that the Leeds Community Healthcare Trust is looking into the future of the Service - and we've also heard that they're receiving lots of letters from patients. Well done if you've written in! If you haven't written yet, please consider doing so. If we can all make the powers that be aware of our feelings, we are more likely to get a successful outcome! For further information please see <http://leedsmenetwork.yolasite.com/>

*Keep up the good work! I do however think that the Leeds ME/CFS clinic needs to take a lesson from Sheffield in that:*

1) *That the clinic needs to be under new management which recognises ME as being a physical condition. Placing it under the Community Healthcare Trust would accomplish this and improve the problems of access for physically disabled patients.*

2) *There needs to be a service for children with ME in Leeds and West Yorkshire. At the moment, there is nothing for children. This isn't going to change as long as ME is under an **\*adult\*** mental health trust. - Mike.*

**Bill writes:** I've just been sent yet another ESA 50, and it is only 3 months since I filled out the last one. I notice that they've also reduced the time allowed from 6 to 4 weeks. It was bad enough trying to sort the last one out. Any suggestions?

*The government has slashed the amount of time available to complete an ESA50 questionnaire form, reducing it from 6 weeks to 4 weeks, starting with forms issued on 31 October. It makes it harder to get medical evidence with their questionnaire and leads to more vulnerable people being refused ESA because they failed to return the form in time. Personally I think it is unnecessary harassment. As you used our welfare rights service to fill out your last form, we still have it on file. All we need to do is update everything and that could be done in as little as half an hour. Make an appointment to the service at the Redmond Centre. If you receive any further harassment please contact me—Mike.*

**John writes.** I've got diabetes as well as ME/CFS. I've heard that there are some rules that apply to me, what are the implications regarding me driving?

*Diabetes of whatever type is a 'notifiable' condition, and you must notify DVLC accordingly by law. Usually, unless you pose a potential danger when driving and providing your doctor agrees you can drive, you will keep your licence. ME/CFS is not a 'notifiable' condition, but we advise ME/CFS sufferers to advise DVLC. Because of the clauses in many insurance policies about withholding 'relevant information', you must tell your insurance company about both conditions.*

*You are affected by changes to the standards for driving Group 1 vehicles (cars and motorcycles). These were introduced by the European Union and have applied since September 2010.*

*You must not have had more than one episode of severe hypoglycaemia within the preceding 12 months*

*You must not have 'impaired awareness of hypoglycaemia ('hypos')' which has been defined by the Diabetes Panel for Group 1 vehicles as "an inability to detect the onset of hypoglycaemia because of a total absence of warning symptoms"*

*You must use a blood glucose monitor which is widely available.*

*There are even stricter regulations that apply to get a licence to drive a bus or big lorry. You shouldn't be doing this anyway if you have ME/CFS. – Mike.*

**Vicky writes** Thank you very much for sorting out my forms. I'm getting phone calls from two different organisations who seem to be dealing with my case, and I keep getting confusing and contradictory phone calls and messages from the DWP and Atos. Please explain.

*The DWP is the Department of Work and Pensions which is a government organisation. The staff are civil servants and include administration staff and decision makers. Atos Healthcare is a private company specialising in occupational health, wellbeing, consulting and technology, employee assistance programme and disability assessment. They are contracted to the DWP to provide medical assessments and advice. You will have seen news of a number of demonstrations against Atos in the ME/CFS world. This in my experience is more than justified. Quite a lot of benefit refusals of our members turn out to be mistakes and maladministration by Atos. Their advisors seem completely out of touch with the realities of ME/CFS—hence the resentment. I have heard reports that they have taken legal action against some people in the ME/CFS movement. I think that there is a problem. There are two databases, Atos and DWP. The two don't seem to talk to each other. Certainly, when I have to intervene on a member's behalf to the DWP, e.g. to get an extension for ESA 50 fill out, Atos persistently harass the member as if no action had been taken. What is quite clear is that there is some sort of aggressive 'O Push Trade' ethos within the organisation, and they don't follow their own advice or recommendations. For example—after an ESA 50 medical has been carried out, we obtain the medical report submitted. In many cases the recommendation is to review in 12 or 18 months. Atos seem to be sending the ESA 50 forms out automatically after only 3-6 months. I come across cases where the DWP is not even aware that this is happening. We think that they are on some sort of commission to get people back to work regardless of their state of health. See*

<http://diaryofabenefitscrounger.blogspot.com/2011/05/3-claimants-die-after-being-found-fit.html>

There is a risk of hypoglycaemia ('hypo') if your diabetes is treated with insulin or with the following diabetes medications:

- Sulphonylureas (Glipizide, Gliclazide, Glibenclamide, Glimepiride, Tolbutamide)
- Repaglinide and Nateglinide
- Acarbose, metformin or pioglitazone – if taken with one of the tablets listed above
- Pioglitazone if taken with insulin
- Exenatide (Byetta) in combination with a sulphonylurea tablet (see above) or metformin
- Sitagliptin (Januvia) in combination with a sulphonylurea tablet (see above)
- Vildagliptin (Galvus) in combination with metformin (known as Eucreas) or in combination with a sulphonylurea tablet (see above)
- Saxagliptin (Onglyza) if taken with a sulphonylurea .

Metformin, is widely used, and on its own does not produce hypos.

#### **What are the symptoms of hypoglycaemia?**

The symptoms of hypoglycaemia will vary from person to person.. Physical symptoms may come on very quickly. The most commonly described symptoms are sweating, palpitations (racing heart beat), shakiness, becoming pale, and tingling around the lips. They may start abruptly with no apparent cause and may be exacerbated by strenuous exercise. Other symptoms can include anxiety or uneasiness, light-headedness, poor concentration or drowsiness. In people with diabetes hypoglycaemia is caused by the medication that they take. Because this cannot be 'switched off' by glucagon, their symptoms may progress to a stage where they lose consciousness. As the medication wears off, they will recover from this. In people without diabetes similar symptoms can be experienced, although it is unusual for hypoglycaemia to proceed so far, because the body's balancing mechanism will start acting more quickly. A very small number of people may get no obvious symptoms of hypoglycaemia, however, and may become unconscious, depending on the underlying cause.

This happens in some people with ME/CFS who are not diabetics

## **Dr. Skinner v. The GMC**

*Further to previous Pathways features, Dr. Skinner has won his current battle with the GMC, which has been ongoing for a number of years. Liz has attended some of his hearings and has passed on a feature to put into Pathways which covers what I intended to report. The author, Judy Cheraton, is one of Dr. Skinner's patients. She is complaining about an article in the 'Birmingham Mail'.*

It was with outrage that I read the article of 22/11/11 beginning "Reckless" Moseley Doctor....and I wish to protest in the strongest of terms at the scandalously inaccurate "spin" put on the reporting of Dr Gordon Skinner's Fitness to Practise hearing with the GMC. The outcome of this hearing was that Dr Skinner was completely exonerated and this is exceptionally GOOD NEWS! for millions of people who have been mis-diagnosed with M.E., Chronic Fatigue Syndrome, Depression, Fibromyalgia, Polymyalgia Rheumatica, Osteoporosis, Carpel Tunnel Syndrome etc. My recall, having attended both the first adjourned review and last week's review hearing in their entirety, is vastly different from that of your reporter and the most important aspects unreported, are as follows:



2000 testimonials from patients, G.Ps, endocrinologists and other professionals were submitted in support of this excellent doctor who has significantly improved and brought all his patients back to full health. In 40 years of practice, not one patient has been harmed. On the contrary, Dr Skinner's record for returning patients to optimal health in his chosen field of specialism is exemplary.

The Panel accepted that the prescription of Thyroid Hormone Replacement, to patients whose blood results were within the accepted reference interval for the UK, but showed clear signs and symptoms of under-active thyroid, was legitimate and that all patients recovered. The panel also accepted there was no problem for any doctor in prescribing unlicensed Natural Desiccated (Armour) Thyroid to patients who were clearly hypothyroid but had failed to respond to synthetic thyroxin.

The screening (TSH) blood test in the UK has a wider range for what is considered "normal" than in the USA, Sweden, Australia and the EU. Therefore, due to over-reliance on blood tests, many extremely ill people are being told by their GPs "there is nothing wrong with you". Dr Skinner, however, (as a good doctor should!) looks at history, signs, symptoms and blood test results before making a diagnosis. Many endocrinologists, (including the expert witness for the GMC) refuse to treat severely ill patients with normal blood tests due to fear of litigation. This scandalous disregard for patients' welfare is causing them real harm and is contrary to the Hippocratic Oath.

The use of the word "unorthodox" for Dr Skinner's treatment is incorrect. Before blood tests were invented, this illness was always treated on clinical signs and symptoms alone. These days many GPs and endocrinologists diagnose on blood-test results alone. We are in fact being diagnosed by Lab Technicians and told we are "normal, no action required" by the GP's receptionist! It is a sad fact that hypothyroid patients were better treated at the end of World War 2 than they are today!

Dr Skinner demonstrated "an encyclopaedic knowledge" of his specialist subject, cited research and references to over 120 publications to support his practice. Sadly, the expert witness admitted that he worked to guidelines and knowledge gleaned from GOOGLE!

My life was devastated for four years by an incurable illness, diagnosed as CFS/ME, which deprived me of everything in my world that was dear to me. At my lowest points, I was wracked with pain, housebound, almost bedridden and unable to carry out the most mundane of tasks. My life was joyless, meaningless and empty. Previously an optimistic, enthusiastic and well-balanced human being, I became severely depressed and on three occasions seriously considered suicide as the only way out of a life that seemed like never-ending torture of thyroid gland disease.

This position has recently been challenged by a group of doctors who feel that some people (not necessarily those with a diagnosis of ME/CFS) have a problem with their thyroid gland, yet still have perfectly normal laboratory results when the function is assessed using standard blood tests.

When Dr. Gordon Skinner diagnosed me as hypothyroid and started me on medication, he literally saved my life. He is a consummate professional with an amazing depth of understanding, knowledge and experience in his chosen field of specialism. His practical application of this knowledge in clinical observation, diagnosis and treatment is outstanding and, sad to say, in my experience of consultants, very rare. On a personal level with his patients he is warm, patient, understanding and compassionate. He really cares about people and you can tell that his whole world revolves around his desire to restore people to optimal health. He is also a courageous man who stands up for what he believes in and will challenge and overcome all obstacles that stand in the way of his patients regaining their health. He has my greatest admiration and undying gratitude for having the courage of his convictions and helping so many people back to health.

*Testimonial and reports like the above are the opinion of a one or several people, without a scientific basis. I do however think the view of Dr. Charles Shepherd needs be taken into account to balance the context. There are some doctors who will prescribe thyroid supplements for ME/CFS but the majority will not. Here is why.*

No proper research has yet been carried out into this particular aspect of hormonal control in ME/CFS, so it is difficult to say whether thyroid dysfunction is more common than in the normal population. My feeling is that there is no real difference, and that in the absence of such evidence it is unwise and potentially quite dangerous for doctors to prescribe thyroxin supplements as a possible treatment. Too much thyroxin in the blood can lead to serious side-effects, including fatal heart rhythm disturbances in anyone who has a pre-existing heart complaint. Long-term inappropriate use of thyroxin will cause a further increase in the risk of developing osteoporosis (brittle bone disease). It could also lead to a permanent disruption to the complex hormonal feedback mechanisms acting on the hypothalamus (the gland in the brain which controls the output of all body hormones). Thyroid supplementation must always be administered with great care to anyone with evidence of cortical deficiency (as can occur in ME/CFS) as the adrenal gland may not be able to cope with the resulting increase in the body's metabolic activities.

*In am aware of Dr. Skinners methods, and I have received reports of results from other patients treated in a similar way by other doctors, and people who have imported thyroxin via the internet in the belief that they will help their ME/CFS. Generally I find marginal improvement if the dose slightly over the normal physiological dose is given, but after that major problems occur. One of our group members who overdosed with thyroxin ended up with a permanent and potentially fatal heart arrhythmia much to the concern of the NHS GP.*

*Thyroxin is cheap enough, but the monitoring medical tests are not. If you are taking thyroxin, either prescribed through the NHS, via private doctor or from internet suppliers you must have frequent thyroid tests and medical supervision if only for safety reasons. Personally, I think the NHS and NICE are playing safe rather than sorry and further research is urgently needed.*



## ***Thyroid connections and some interesting books***

*Personal Comment by Elizabeth A McDonagh*

The issue of missed diagnosis of thyroid illness was first brought to popular attention in this country by Diana Holmes. Following polio at the age of ten, Diana's health steadily declined until she was unable to function. She was variously (and incorrectly) diagnosed as having anxiety and depression, epilepsy, coeliac disease, polymyalgia rheumatica, M.E., M.S. and myasthenia gravis. Forty years of her life were lost to illness. Finally, she was diagnosed by Dr Peatfield as suffering from 'hypothyroidism and hypoadrenalism', though hospital blood tests had recorded normal thyroid function. Within a few months, Dr Peatfield's recommended treatment had restored Diana to good health. In *Tears Behind Closed Doors*, first published in 1998, Diana related her story and called for re-assessment of the value of hospital blood tests in the diagnosis of thyroid illness. The later (2002) edition of her book is expanded to include a chapter entitled "Artificial Fluoride, The Great Thyroid Antagonist". Dr Peatfield has also written a book *Your Thyroid and How to Keep It Healthy: The Great Thyroid Scandal and How to Survive It*.

A call for the official guidelines on diagnosis of thyroid illness to be changed, with the doctor also giving attention to clinical signs and symptoms rather than relying exclusively on the hospital blood test, was made by seven doctors in a letter to the Editor of the British Medical Journal published in BMJ Vol 314: 14 June 1997. One of the authors was a Senior Lecturer at Birmingham Medical School, Dr Gordon Robert Bruce Skinner.

A few years ago, a persistent virus was believed to be responsible for the relatively new illness, M.E. (myalgic encephalopathy). A virologist, Dr Skinner had been consulted by a number of M.E. patients. He had discovered that up to 50% of them, classified as *euthyroid* (within the normal reference range for thyroid hormones) showed clinical signs of *hypothyroidism* (low thyroid hormone production) and they improved on thyroid hormone replacement.

Dr Skinner has written his 'ain book' *Diagnosis and Management of Hypothyroidism* which explains the rationale behind his treatment of thyroid illness and gives a fascinating insight into the life, thought and decision-making processes of one Scottish, caring, individualist, football-loving, doctor.

Doctor Skinner was under a regime of restrictions to his practice imposed by the General Medical Council but has now (November 2011) been vindicated. At a hearing of his case, at the GMC, on June 15<sup>th</sup> 2006, I was privileged to meet him, a healthy and radiant Diana Holmes and almost forty patients who had turned up in his support.

Twins Donna Roach and Coralie Phillips were there with copies of their book *Hypothyroidism in Childhood and in Adulthood-A personal approach and scientific standpoint*. It relates their diagnoses of hypothyroidism as children. Thyroid replacement restored their health but doctors reduced their levels of medication because of fears that it might induce osteoporosis. They became ill again and one had to give up work. They were full of praise for Dr Skinner who had reassessed their medical needs and restored them to health. Other patients had similar stories, many praising the efficacy of 'Armour Thyroid', a porcine-derived thyroid extract.

There is plenty of evidence that fluoride adversely affects the function of the thyroid gland. According to the US National Research Council, "several lines of information indicate an effect of fluoride exposure on thyroid function. Fluoride's potential to impair thyroid function is perhaps best illustrated by the fact that, up until the 1970s, European doctors used fluoride as a thyroid-suppressing medication for patients with hyper-thyroidism (over-active thyroid). Fluoride was utilized because it was found to be effective at reducing the activity of the thyroid gland - even at doses as low as 2 mg/day. Today, many people living in fluoridated communities are ingesting doses of fluoride (1.6-6.6 mg/day) that fall within the range of doses (2 to 10 mg/day) once used by doctors to reduce thyroid activity in hyperthyroid patients.

While it may be that the thyroid in a patient with hyperthyroidism is particularly susceptible to the anti-thyroid actions of fluoride, there is concern that current fluoride exposures may be playing a role in the widespread incidence of hypothyroidism (under-active thyroid) in the U.S.

Hypothyroidism, most commonly diagnosed in women over 40, is a serious condition with a diverse range of symptoms including: fatigue, depression, weight gain, hair loss, muscle pains, increased levels of "bad" cholesterol (LDL), and heart disease.. The drug (Synthroid) used to treat hypothyroidism is now one of the top five prescribed drugs in the U.S.

As recommended by the US National Research Council: "The effects of fluoride on various aspects of endocrine function should be examined further, particularly with respect to a possible role in the development of several diseases or mental states in the United States."

### Books about the thyroid gland

*Tears Behind Closed Doors* by Diana Holmes is available from Namaste Publishing, PO Box 127, Shrewsbury, SY3 7WS. Price £9.95 + p&p Telephone 01743 341303

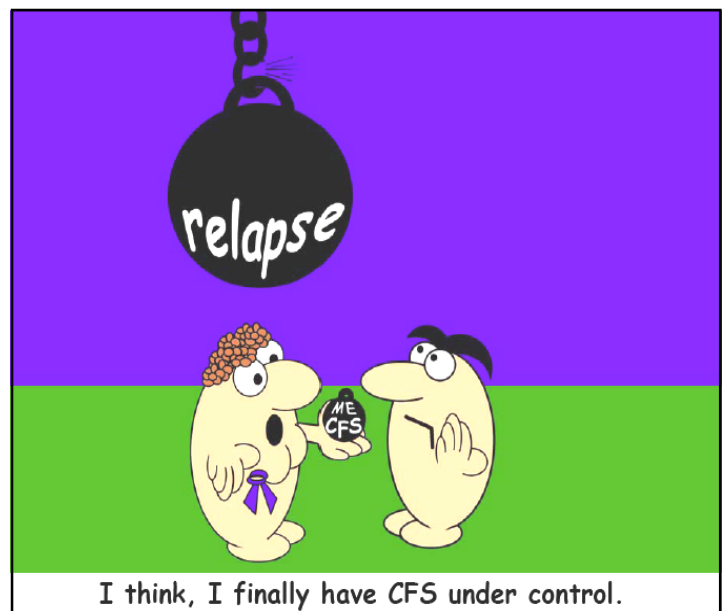
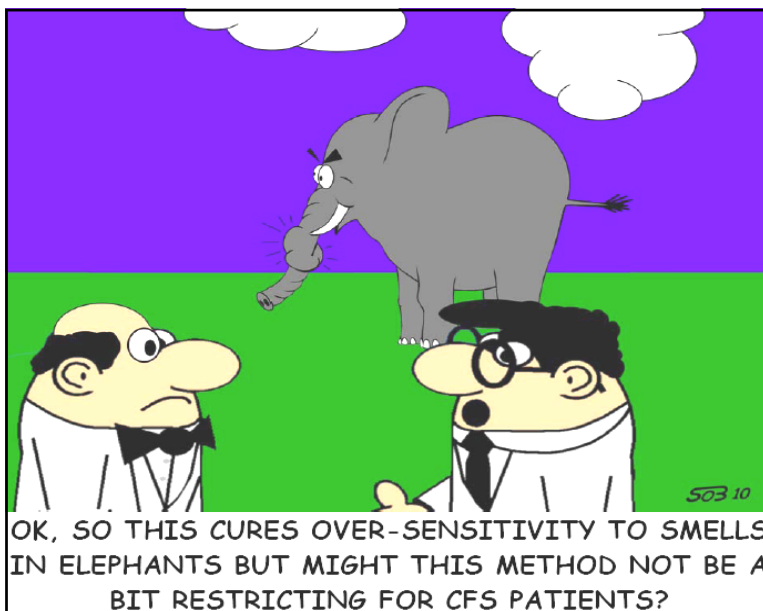
Dr Peatfield's book *Your Thyroid and How to Keep It Healthy: The Great Thyroid Scandal and How to Survive It* (Paperback) is now available from bookshops and, at a discount, online from Amazon.

*Diagnosis and Management of Hypothyroidism* by Dr G.R.B.Skinner is available from the author at 22, Alcester Road, Moseley, Birmingham. B13 8BE. Telephone 0121 449 8895 The price is £14.95 including p&p.

*Hypothyroidism in Childhood and in Adulthood-A personal approach and scientific standpoint* by C Phillips and D Roach is published by Nottingham University Press. It may be ordered via [www.nup.com](http://www.nup.com) or from the authors on 01639 641367 at £13.50+p&p.

The following websites are informative regarding fluoride and fluoridation. Fluoride Action Network (US) and the National Pure Water Association (UK) oppose fluoridation worldwide. Please give them your support. Thank you.

Fluoride Action Network [www.fluoridealert.org](http://www.fluoridealert.org)  
National Pure Water Association [www.npwa.org.uk](http://www.npwa.org.uk)



## ***New Restrictions on Motability Cars***

*From a letter by Lord Sterling, Chairman, Motability, 20th October 2011*

Despite meeting the mobility needs of disabled people for over 33 years, it is very important that we are not complacent. We must continuously strive for excellence by examining and refining all aspects of the Scheme. During 2011, we have reviewed a number of issues including the range of cars available on the Scheme and the clarity of our policies on how the cars are used and by whom. We are today announcing a number of changes following this review, specifically:

Although we know that 30% of our customers take cars with no Advance Payment and only 5% take cars with an Advance Payment of more than £2,000, over 50% of the models currently listed in the Price Guide have Advance Payments above this level. We have therefore decided to rationalise the range of cars available through the Scheme by offering only cars with an Advance Payment of £2,000 or less, approximating to a Recommended Retail Price limit of circa £25,000. These changes will be fully implemented in December 2011. We will, of course, ensure that customers whose disability-related needs require a car above this level can be accommodated. This will simplify the Scheme and focus on those who most need our help but it must be remembered that the quality of the backup service required by disabled people is key to the success of the Scheme.

With regard as to how the car may be used and by whom, the principle of the Scheme remains as it always has been - those cars must be used for the benefit of the disabled person. However, we have identified a need to refine our processes and communications around this principle, with clearer parameters so that customers can use the car appropriately and with confidence. In particular, we will now only accept nominated drivers who live within 5 miles of the customer in order to minimise the risk of the car being used other than for the benefit of the disabled person.

We will invest further in our capacity to investigate and act on allegations of abuse, as well as piloting new vehicle technologies to monitor how cars are used. Where we perceive the greatest risk of abuse we will require a Statement of Responsibilities to be signed at the beginning of each lease by the customer and nominated drivers together with the supplying motor dealer to ensure that the key responsibilities of each party have been communicated and are clearly understood.

As we all know, the cost of motor insurance has risen rapidly in the UK over recent years. In order to protect the Scheme from the most extreme costs associated with young drivers, we will no longer accept nominated drivers under the age of 21 on the Scheme from January 2012, unless they reside with the disabled customer. We will also restrict young drivers under the age of 25 to cars in ABI Insurance Group 16 or lower which also have a power output of 115 BHP or less.

At the event last Friday (14 October 2011) in Westminster Hall, one of our leading Paralympians, Sascha Kindred OBE, spoke about the importance of the Motability car to his freedom, independence and ability to train and compete at the highest levels.

We were reminded that it is a privilege for us to be able to help so many of our disabled customers but, with that privilege, comes a responsibility to ensure the Scheme remains strong and robust, to weather all economic cycles and to meet the mobility needs of disabled people for decades to come. We recognise this responsibility and will continue to meet that challenge in the years ahead, as we have done over the last 33 years.

*I have some concerns about people with ME/CFS and Motability cars. Motability cars are never yours and only on rental. The ongoing award of high rate DLA is not guaranteed, and it can only take an adverse report from a medical either ESA or DLA for you to lose the mobility car. DLA is being replaced by Personal Independence Payment after 2014 and ME/CFS entitlement criteria are unclear. In some cases it is possible to negotiate a better private deal using the mobility allowance money. Also you lose your insurance no claims bonus after the termination of the 3 year hire agreement and it can be very expensive to start from scratch again. Mike.*

## **Medicines in Use.**

**Citalopram.** A letter sent to healthcare professionals last month states the maximum dose of citalopram has been lowered to 40 mg because of new data linking it with a dose-dependent increase in QT interval. Patients taking the citalopram-containing products, including the Lundbeck product Cipramil, should be reviewed by healthcare professionals, according to advice from the Medicines and Healthcare products Regulatory Agency and manufacturers Lundbeck. The maximum dose of citalopram should be further lowered to 20 mg daily for elderly patients and The QT interval can be prolonged with high doses in those with reduced liver function. The recommendations follow data that also link citalopram to ventricular arrhythmias and research that reveals no clinical benefit of daily citalopram dosages exceeding 40 mg. The QT interval is part of the electrical control signal created by the heart, if interfered with it can create fatal disturbances in the heartbeat rhythm. The inherited form of the prolonged QT interval is related to sudden deaths of apparently young health teenagers during sports activities. Moreover, the guidance states that citalopram is not advised for patients with known QT interval prolongation and those taking other medicines known to prolong the QT interval, congenital long QT syndrome and those at high risk of developing 'torsade de pointes'. The MHRA and Lundbeck advise that doses should be reduced gradually to avoid withdrawal symptoms.



**Flu Vaccinations** Seasonal 'flu happens every year, usually in the winter. It is a highly infectious disease caused by a virus and spreads easily from person to person. Flu is far more serious than a cold. Symptoms hit you suddenly and severely and usually include fever, chills, headaches and aching muscles - you can often get a cough and sore throat at the same time. A vaccine is available every year to protect those people who are most at risk of complications if they catch 'flu. The vaccination also helps prevent the spread of 'flu amongst at risk groups.

The vaccine is available free of charge to people aged 65 or over and to the following at risk groups:

,All pregnant women

People who have long term health conditions which include:

People with diabetes, a chest problem or breathing difficulties (such as asthma, bronchitis or emphysema), a heart problem, kidney disease or liver disease

People with a neurological condition (such as Parkinson's motor neurone disease or cerebral palsy), a low immune system due to disease (such as cystic fibrosis or Crohn's disease) or treatment (such as chemotherapy), those who have previously had a stroke, a problem with the spleen (such as sickle cell disease) or in which the spleen has been removed

You should also have the vaccine if you live in a residential or nursing home or are a main carer.

About 40% of people with ME/CFS have asthma, and 12% diabetes, and so should consider a vaccination. However a 'flu vaccination is not suitable for everyone with ME/CFS, particularly if the illness is in the active immune medicated phase. A significant number of people have reported adverse effects. Flu vaccines are grown on eggs, and it is likely that traces of egg are a problem. The only non-egg-produced 'flu vaccination was recently withdrawn for safety reasons.

**Paracetamol** With the aches and pains season well established, news reports have been circulating that people who cumulatively take slightly too much paracetamol have a greater risk of death than people who take a single overdose. The maximum dose for adults is 4 grams daily, which is two 500mg tablets four times a day. Although paracetamol is a safe drug when used properly, it can be harmful if the dosage instructions are ignored. If you take more paracetamol than is recommended, you won't improve your pain control, but you may seriously damage your health. Overdose causes liver damage and can be fatal if treatment with the antidote menthionine is delayed above four hours.

The pain and fever-relieving properties of paracetamol were discovered in 1893, but it first became available, on prescription only, in 1956, and then as an OTC medicine in 1963. It is now the most widely used pain reliever in Britain. As with many medicines, the effectiveness of paracetamol was discovered without knowing how it works. Its mode of action is known to have differences from other pain relievers, but although it is thought that pain relief works throughout the body and in the brain, the exact nature of the mechanism is not clear. There have been recent reductions in the recommended doses for children, and many manufacturers have had to reprint their packaging.

**Recipe Corner: The Sweet Potato***by Leger ME member, Sandy Nye, Cincinnati, Ohio, USA.*

The Sweet Potato is a familiar vegetable served at the Thanksgiving Holiday feast, but we all would benefit from consuming this nutritious vegetable all year round. Not to be confused with yams, sweet potatoes are really not a potato at all. A sweet potato is a root. A yam has a distinctive taste, with a hardy texture and is hardly sweet. Sweet potatoes come in many varieties. Their flesh can be white, orange, yellow and purple; they come in different shapes and sizes. They are very rich in beta-carotenes, especially the deeper-coloured varieties.

Sweet potatoes are an excellent source of vitamins C, B2, E and biotin (B7). Rich in dietary fibre, sweet potatoes are packed with minerals; they provide good amounts of manganese, folic acid, copper and iron. They contain powerful anti-oxidants which help combat inflammatory conditions like arthritis, asthma, gout etc. High in potassium, sweet potatoes help to prevent heart attacks and strokes, and help to regulate blood pressure. They are safe for people with diabetes to consume because sweet potatoes actually help to stabilise and lower insulin resistance.

This wonderful vegetable strengthens the immune system, can give you a boost of energy and also keeps your digestive tract very healthy. Sweet potatoes have also been reported to help prevent colon cancer. The best way to store them is in a cool, dark and well-ventilated space, not wrapped in plastic and not in the refrigerator; and then they will last up to 10 days. There are many ways to serve this super food. Sweet potatoes are delicious baked; and they are excellent choices for soups and casseroles.

**Sweet Potato Mash with Walnuts and French Beans**

Serves 4

3 tablespoons of olive oil  
 1 onion, chopped  
 1 garlic clove, chopped  
 150 gram walnuts, chopped  
 400 gram runner beans, trimmed and cut into 2.5cm lengths  
 1 red pepper, diced  
 Salt and black pepper to taste  
 1 large sweet potato, peeled, sliced, boiled and mashed  
 1 tablespoon parsley, finely chopped  
 1 tablespoon coriander, finely chopped  
 2 teaspoons fresh oregano, chopped

**Method:**

Heat the olive oil in a heavy frying pan and sauté the onion, garlic and nuts gently until the onions are soft. Add the beans and red pepper and continue to cook, stirring continuously, until the beans are tender. Season to taste. Serve on a mound of sweet potato mash, with the herbs scattered on top.

**Tangy Sweet Potatoes**

Serves 4

2 lbs sweet potatoes, peeled and chopped  
 Half a cup of plain yoghurt  
 A quarter of a cup of orange marmalade  
 2 tablespoons butter  
 1-2 teaspoons of Tabasco or Worcester sauce  
 Salt and ground Black pepper to taste  
 Freshly grated nutmeg

**Method:**

Boil the sweet potatoes in a large pot of boiling water until tender, about 12 to 15 minutes. Drain and return to the hot pot. Mash the potatoes with the yoghurt, marmalade, butter, sauce, salt, pepper and nutmeg. Taste to adjust seasonings and serve.

## **Introducing Benefit Integrity Centres (BIC)**

*From DWP Touchbase November 2011.*

The DWP has set up a number of Benefit Integrity Centres (BIC) with the specific aim of ensuring that claimants are receiving the correct amount of money. This is part of a wider programme to review almost one million cases each year, in response to the priority the Government is placing on getting and keeping benefit claims right. BIC sites are contacting claimants by telephone and post to carry out full case reviews on claims for Income Support (IS), Jobseeker's Allowance (JSA), Employment and Support Allowance (ESA) and Incapacity Benefit (IB). They are also contacting claimants by text to remind them of the need to return forms and to notify changes of circumstances within laid down timescales. Some claimants may ask advice organisations about the new process, and the article is designed to help answer a number of basic questions.

### **Common questions about the BIC process**

**What kind of information are claimants being asked for?** The BIC review will cover all aspects of the customer's personal circumstances, in the same way as information is taken when a new claim is made. If a BIC asks claimants to provide information they must return it as soon as possible, as there is a possibility that payments may be suspended if there is a delay.

**How are claims selected for review?** Any claimant currently in receipt of benefit can be selected for a claim review. Claims are chosen across the main four benefits: IS, JSA, ESA and IB, and may be selected for review on more than one occasion.

**Some of the letters and forms from the BIC do not look official; how can we be sure they are authentic?** BIC letters all bear the Jobcentre Plus (JCP) logo and forms are standard JCP issue. If a claimant wants to check the authenticity of a letter or form, they can contact their local Benefit Centre who will be able to confirm that BIC action is in progress.

**What security arrangements are in place to protect claimants?** When a BIC contacts a claimant by telephone they always ask a set of random security questions to verify the claimant's identity. These may include the name of the claimant's bank or building society, but they will never ask for the bank account number or sort code. When we contact claimants by text the number will display "Jobcentre Plus" or "Jobcentre+". We will never ask claimants to reply to us by text and these text messages will be for information only.

**How can BIC sites be contacted if there is a query?** The BIC sites cannot be contacted directly, but if a claimant has any queries they can telephone their Benefit Centre who will arrange for the BIC to call them back within three working hours, if required.

**What is the process where there is an appointee in place?** The BIC should always contact the appointee rather than the claimant. In the unlikely event that this does not happen, the appointee should contact the Benefit Centre immediately. The BIC will then call the appointee back within three working hours to discuss the situation and arrange a time to review the claim.

**I have received a form to complete for someone else, why is this?** The only time this would happen is if the individual is named as an appointee for the person. Sometimes an appointee is a friend or family member, but it can also be a corporate body, for example a solicitor, local authority, or care provider. If the person is sure they are not the named appointee for this claimant they should telephone the Benefit Centre immediately. The BIC will then call back within three working hours to discuss the situation.

**The claimant has received a reminder letter or text, but has not received the initial letter or form. What should they do?** The claimant should telephone the Benefit Centre and tell them what has happened. They will contact the BIC who will arrange for a telephone review or another form to be sent immediately. The claimant should not collect a form from the Jobcentre as it will get returned to the wrong address and may cause a delay in their benefit payments.

**Your state benefits can be checked anywhere at any time. Don't assume they are written on tablets of stone'**

Our advice is NEVER to discuss benefit matters over the 'phone. Insist on a written letter. If you are contacted by a BIC contact the group helpline for further information guidance. Don't forget that this system is wide open to potential fraud as there is no way you can check or prove that the person at the other end of the 'phone is who they say they are.

**Will a claimant be checked again?** This is possible. A case can be selected for review on more than one occasion. The claimant will still need to comply even if the BIC has conducted a recent review, as there may have been a change of circumstances since the last review.

**Will a claimant's benefits be stopped?** The BIC will only stop benefits if the claimant has no entitlement or has not provided the information within the legally prescribed timescale. They will base their decision on the information the claimant has given to them, and will always write to the claimant to tell them the decision.

**What if the review shows that the claimant owes DWP money?** If the claimant owes DWP money, the BIC will arrange for it to be repaid. This can be done over a period of time, so the claimant does not face undue hardship. The Social Security (Claims and Payments) Regulations 1987, Schedule 9, lays down what deductions may be made from prescribed benefit, the maximum amount deductible, and the order of priority.

**What if DWP owes the claimant money?** If DWP owes the claimant money the BIC will ensure this is paid as soon as possible.

**What if the claimant wishes to appeal against the outcome of the review?** The claimant has the right to appeal the BIC decision. This should be done by phone or in writing within one month of the day the decision was made.

### ***The Work Capability Assessment: Improving customer experience.***

*From DWP Touchbase November 2011*

Following Professor Harrington's first Independent Review of the Work Capability Assessment (WCA), DWP is taking positive action to put Decision Makers at the heart of the decision making process. This includes Introducing new learning and development, Developing new Quality Checks, Establishing a decision-making forum Providing additional support for Employment and Support Allowance (ESA) claimants, by explaining decisions and discussing options.

**Learning and development.** Our new learning and development package ensures Decision Makers (DM) understand the Work Capability Assessment process, their role in it and how to gather and use all the available evidence to make better quality decisions.

**Quality Checks.** New quality checks aim to identify any errors and to establish if the Decision Maker uses a consistent approach to gathering, weighing and presenting evidence. Decisions are checked against a set of required standards covering the whole process, from the gathering of evidence to the outcome of the decision.

**Every Decision Counts.** Our 'Every Decision Counts Forum' promotes quality standards in decision making and is a channel for Decision Makers to raise issues and share best practice.

**Additional support to claimants.** As well as an additional letter explaining the WCA process, ESA claimants will benefit from Decision Makers calling them to talk through decisions and discuss options. If a claim is likely to be unsuccessful, the Decision Maker will call the claimant prior to making a final decision, to check that they have all the available evidence to make a decision and explain next steps.

**Positive about the changes.** Feedback from our sites in Wrexham and Oldham, that have been delivering additional support to ESA claimants, has been very positive, and indicates that Decision Makers are gaining confidence in the importance of their role within the decision-making process, and that the new procedures offer an improved service.

**When will the changes occur?** The changes will affect all new claims and existing claimants being re-referred for a WCA on and after 31 October. Due to the length of the assessment process it may be December before all ESA claimants start to receive the telephone calls from Decision Makers.

**NOT BEFORE TIME !!!**

## **THE MENOPAUSE AND ME**

*by Gina Bailey*

I have suffered with ME for the last 13 years following a nasty bout of pneumonia so feeling tired and achy combined with night sweats was something I have grown used to. The severity of the desire to remove everybody's head with a cricket bat was not, neither were the irregular periods and complete lack of libido. I trudged off to the doctors with the usual resignation that there was probably nothing they could do and had the obligatory blood test. I received a phone call after a couple of days saying the doctor needed to see me because my test results were in. The news that I was apparently "further into the menopause than you might think" was a relief. Like many sufferers I hate the feeling of having to justify that I am not just neurotic or imagining things when I feel ill so, whilst surprised, I had an explanation. HRT was duly offered but I opted to do some research first.

This was where I hit my first stumbling block. I wanted to know how the menopause would affect my illness and whether HRT was going to help or hinder it. I would have preferred to go a natural route but since I was only 42 I had to consider osteoporosis and protecting my bones. I checked books, websites, forums and found very little except other women who wanted answers too. From this came the idea to write an ebook. If I could get other women who had gone through this to answer some questions or tell their stories I could help myself and other women in the same situation.

As women we have been programmed to view the menopause as a negative stage of life, something to dread, the end of our childbearing years, when youth slips away, lack of sex-drive, feeling old and past it at first glance does not appear to be anything to celebrate. The bonus of no monthly periods seems little compensation for hot flushes, brittle bones and excess fatigue. The menopause is very like ME/CFS in that there appears to be no set pattern. Each woman will be different, their management of their symptoms unique to them.

I contacted the ME Association and various other groups who confirmed that there was a need for some type of information on this subject and agreed to notify their members that I needed volunteers to complete a survey. I was encouraged by their support and offers of help with this project. The women who contacted me have been kind enough to tell me their stories and how they have been affected. This project is as much a personal journey as a professional one. I am not a doctor or nurse, I am a hypnotherapist. I do not have medical training and the book I am writing concentrates on how this stage of life changes practical things; relationships with loved ones; what has worked for other people. I have also spent a long time researching the normal everyday menopause without the complication of a debilitating illness as it is women that pass through "the change" not the illness.

So far the results have offered me hope. A significant number of women have indicated that they have benefited from the menopause. The absence of monthly periods to drain them has improved their quality of life. Removing that one draining feature of being a woman with ME/CFS has eased some of their other symptoms. The transitional period of the peri-menopause does appear to need careful management but overall post-menopause there seems to be either little change or, dare I say it, an improvement. Patterns have emerged but what has become clear is that as with ME the effects are personal and individual to each sufferer, therefore the management needs to be just as individual. What I am personally finding is a feeling of optimism, rather than depression that, this isn't the end.

I would like to thank all those who have already participated or have offered their help on this project, your support is appreciated. If any one wishes to add their personal experiences to this project please feel free to email them to me at

[gina.bailey1@btinternet.com](mailto:gina.bailey1@btinternet.com)

(All names will be changed unless specifically requested otherwise)

## **Bioenergetics in ME/CFS: Muscle recovery after exercise is slower**

*From Autumn 2011- BREAKTHROUGH*

Bioenergetics concerns the flow of energy through living things, and its research involves the exploration of cellular processes, including cell respiration and the plethora of other metabolic events that result in the production and use of energy. In the past two years, researchers at the School of Clinical Medical Sciences, University of Newcastle have identified a distinctive muscle bioenergetic abnormality in people with ME/CFS. This abnormality is associated with the autonomic dysfunction found in the majority of ME/CFS patients and with a characteristic cardiac bioenergetic impairment (see *Breakthrough* Spring 2011).

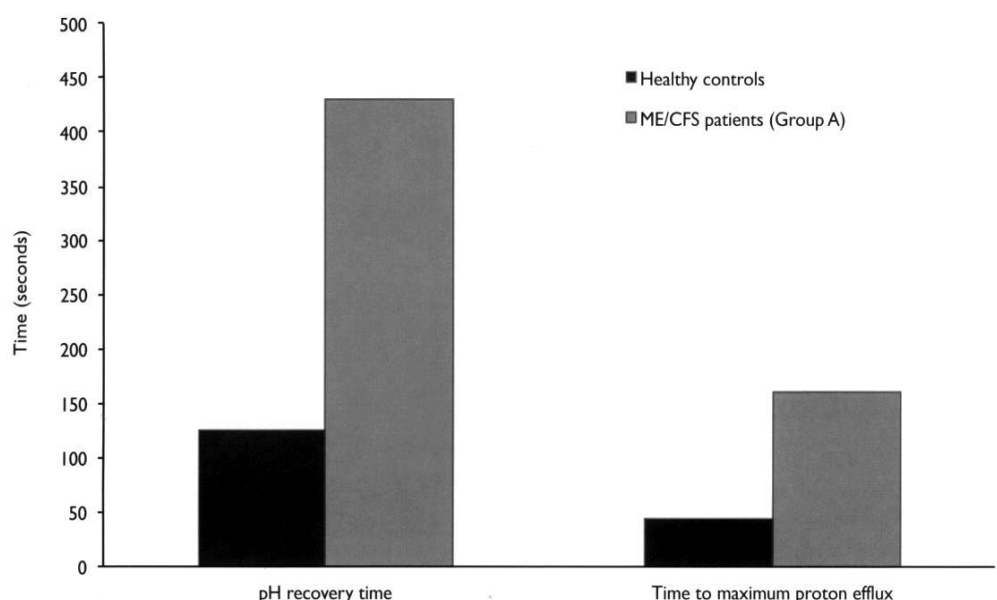
The research interests of the group (which receives funding from ME Research UK, the John Richardson Research Foundation and the Irish ME Trust) also include the chronic disease Primary Biliary Cirrhosis (PBC) which shares some symptoms with ME/CFS, notably a difficulty sustaining repeat exercise. Since the researchers recently found evidence of abnormalities in the regulation of muscle acid in PBC patients during a programme of repeat exercise, they wondered whether similar bioenergetic abnormalities might also occur in ME/CFS. To explore the issue, 18 consecutive new patients recruited from the local CFS/ME Clinical Service, and 12 matched healthy control participants attended the exercise laboratory for a range of assessments of cardiopulmonary fitness, maximum voluntary contraction (MVC), and muscle bioenergetic function using magnetic resonance spectroscopy (MRS) during repeat exercise.

To assess maximal exercise capacity, the patients undertook five 5-second maximal isometric contractions of the foot (plantar flexion) while lying down. Force generation was assessed using a calibrated strain gauge and the peak force was regarded as the MVC. For MRS measurements, subjects performed controlled plantar flexion using a purpose-built exercise apparatus within the MRI scanner. Subjects performed three 180-second bouts of plantar flexion contractions at 35% of MVC (to standardise 'work done' between patients and controls). Immediately after the MRI exercise protocol subjects were asked to assess their degree of effort, and were asked to grade any discomfort that they were feeling, and they were telephoned 24 hours later and then again five days later with the same questions.

### **What did the results show?**

The study used magnetic resonance spectroscopy (MRS) to explore the recovery of lower leg muscles during three bouts of exercise. In the ME/CFS group as a whole, there were significant reductions in anaerobic threshold, heart rate, oxygen consumption and peak work (power in watts) compared with controls. The peak force that the patients could exert (their maximum voluntary contraction) was lower on average than for healthy controls, although it varied greatly between individual patients.

### *Time taken to recover pH levels and to achieve maximum proton efflux*

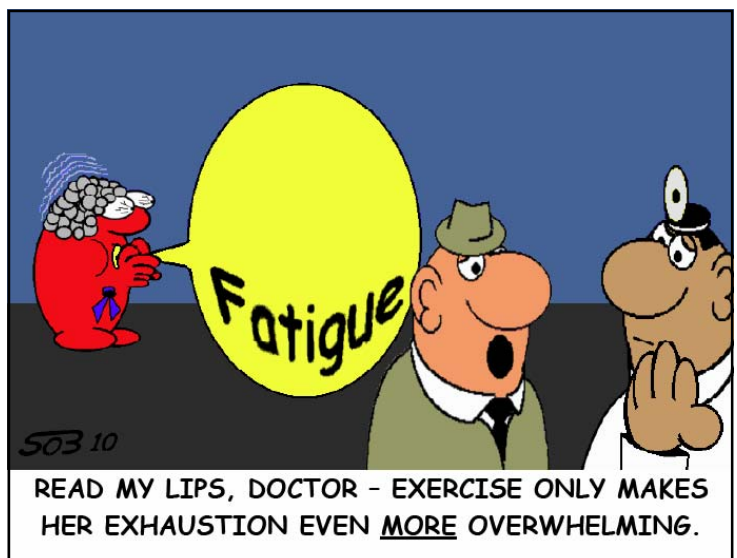


Thus, only a subset of patients (those achieving normal phosphocreatine depletion values, greater than 33%; group A) could be directly compared with controls, since only in these patients was the level of 'muscle work' equivalent to that of the healthy controls. Compared with healthy people, an increase in acidosis (decreased pH) within the muscle was seen in Group A ME/CFS patients after similar muscle work at each of the three exercise periods. In addition, these patients had a significant, almost fourfold prolongation of the time taken for pH to recover to baseline; i.e., for the level of muscle acid to fall back to normal (see the graph). The key message was that some ME/CFS patients have a profound abnormality in bioenergetic function when exercising at comparable levels to healthy people.

The key findings, published in the *European Journal of Clinical Investigation* (2011) are shown in the box below, but the major observation was that the peripheral muscles of ME/CFS patients took four times longer to recover (reduce acid levels and restore baseline pH) than those in matched control subjects, and that furthermore there was a significant slowing of the proton excretion response needed to normalise acid levels (see the graph on previous page). The net effect was a sustained and significant accumulation of acid (acidosis) in muscle during and following exercise, which could affect muscle function and contribute to the experience of muscle fatigue. The authors point out that total post-exercise acid exposure was approximately 50-fold higher in ME/CFS patients when exercising to the same degree as normal controls, with none of the apparent reduction in acidosis with repeat exercise observed in healthy subjects. Why this should be remains unknown, but - since acid is actively transported from the muscle by Na-H transporters which are in turn regulated by the autonomic nervous system - it is possible that the acid transporters are impaired (a phenomenon that might be related to the autonomic dysfunction found frequently in ME/CFS patients), although a reduction in vascular run-off may also be a possibility.

### Post-exercise symptoms in ME/CFS

In the historical literature, the hallmark of Myalgic Encephalomyelitis (ME) was marked loss of muscle power (fatiguability), often in response to minor degrees of exercise. Muscle cramps, twitching and extreme muscle tenderness were also common findings. In Dr Melvin Ramsay's words from 1978: "This was sometimes obvious as the patients winced even on light palpation of the affected muscle; but much more frequently it took the form of minute foci [points] of muscle tenderness which had to be carefully sought and for no ostensible reason were generally found in the trapezii and gastrocnemii [neck and calf area]." Even in modern times, within the diagnostic umbrella called ME/CFS, "post-exercise" symptoms are central; the NICE Clinical Guideline of 2007 informs GPs that, for a diagnosis of ME/CFS to be made, fatigue characterised by post exertional malaise "typically delayed, for example by at least 24 hours, with slow recovery over several days" has to be present. It is worth emphasising that the very presence of post-exercise symptoms greatly helps to distinguish ME/CFS from, say, and major depressive disorder.



Much of the current thinking about the role of exercise in CFS and ME is driven by simple models of "deconditioning", and the notion that regular exercise will be beneficial. But we already know that too vigorous exercise or activity can trigger post-exertional symptoms in most people with ME/CFS. We also know from research that patients respond to an exercise challenge with an enhanced complement activation, increased oxidative stress, and an exaggeration of resting differences in gene expression profile in peripheral blood mononuclear cells. So, it is entirely possible - perhaps even likely - that over-exercising causes harm, possibly because something is organically wrong with muscle metabolism, as this study in the *European Journal of Clinical Investigation* suggests. Of what value are exercise programmes in these circumstances? Fifty-two years after Sir Donald Acheson reviewed a clinical syndrome called ME for the *American Journal of Medicine*, the characteristic delay in muscle recovery after exercise is a phenomenon that few researchers have studied and few health care professionals take into consideration when examining patients.

## **Does ME/CFS run in families?**

*From Autumn 2011- BREAKTHROUGH*

News from Utah suggest that while there is anecdotal evidence from ME/CFS patients and carers that the illness can run in families - particularly mothers and their daughters or sons - is there any scientific evidence to back this up? Well, surprisingly there is. One survey of 914 students at the Lyndonville Central School in 1991 found symptoms of ME/CFS among other family members to be one of the strong predictors of ME/CFS in the student, with a high relative risk of 35.9 (other predictors included the ingestion of raw milk, and a history of allergy asthma). Again, one small family history study in 2001 found significantly higher rates of ME/CFS in the first-degree relatives of ME/CFS cases compared with the relatives of control subjects. Finally, studies on twins have shown a higher "concordance" rate for ME/CFS between monozygotic (identical) twins than between dizygotic (non identical) twins - suggesting that genetic factors might have an important role.

Building upon these reports, researchers at the University of Utah (Albright et al, *BMC Neurology* 2011) focused on ME/CFS using specialist methods previously used to investigate heritable components of diseases such as prostate cancer, influenza mortality, aneurysm, cancer, and diabetes. From genealogical records of Utah pioneers and their descendants, representing 15 generations of genealogy data, cross referenced against medical diagnosis data from 1993, a sample group of 811 was chosen. The Genealogical Index of Familiarity (GIF) statistic was used to test the hypothesis of "excess relatedness" among ME/CFS cases. The results showed that the "average relatedness" of ME/CFS cases was significantly greater than expected when all relationships were considered ( $p < 0.001$ ) - strong evidence for excess clustering of the illness in families.

This could be due to either a shared environmental factor (location, diet, infection) or shared genes, or a combination of the two. However, there was also a significant "relative risk" of ME/CFS amongst first, second and third degree relatives of existing ME/CFS patients compared with "control" individuals. As the Table below shows, first-degree relatives (parent/offspring) had nearly three-times the risk (relative risk of 2.70) of also having ME/CFS, while second-degree relatives (siblings or grandparent/ grandchild) had 2.3 times the risk. The authors point out that this strongly supports a genetic contribution to a predisposition to ME/CFS as it has been defined and diagnosed by clinicians in Utah since 1993, and that their study is the first population-based analysis to present such evidence.

### **Risk of ME/CFS in relatives of existing patients**

Degree of relative	Relatives of Cases/controls	ME/CFS cases in relatives of cases/controls	Significance	Relative risk (95% confidence Interval)
First	5,573 / 28,965	19 / 37	$p=0.001$	2.70 (1.56—4.66)
Second	15,469 / 80,206	16 / 36	$p=0.008$	2.34 (1.32 - 4.19)
Third	9,766 / 201,717	24 / 64	$p=0.009$	1.93 (1.21 – 3.07)

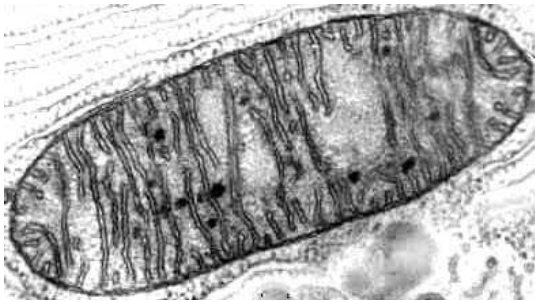
### **Research from Netherlands—Low Mitochondrial Content**

Mitochondria are found in most cells, and their main job is to generate chemical energy. Disorders of mitochondrial function are implicated in a number of diseases, including mental disorders and heart problems, as well as being involved in the ageing process. Since ME/CFS is characterised by a profound, generalised, post-exertional loss of muscle power, it seems reasonable to suggest that mitochondrial dysfunction may be involved.

The most recent mitochondrial study (Smith et al, *Mitochondrion*, 2011) comes from the Neuromuscular Centre in Nijmegen, and has compared skeletal muscle biopsies from 16 people with ME/CFS plus symptoms of muscle pain and/or exercise intolerance to those of 11 healthy controls. The group also measured mitochondrial respiratory chain complex (RCC) activity - an indication of mitochondrial function - by comparing biopsy data from the ME/CFS patients with two groups of patients with genetically confirmed mitochondrial disorders (22 people with chronic progressive external ophthalmoplegia, and 27 with an A3243G mutation in skeletal muscle).

The researchers found that citrate synthase activity (a marker of mitochondrial content) was decreased in ME/CFS compared to healthy people. However, the activity of the RCC enzymes (and hence energy production) of ME/CFS patients was not at the low levels found in patients with mitochondrial disorders who generally have deficiencies in the RCCs as part of their illness. Furthermore, the energy (ATP) production rate was within the normal range in all ME/CFS patients, whereas it was decreased greatly in three quarters of the patients with mitochondrial disorders.

The fact that mitochondrial function was unaffected in the skeletal muscle of ME/CFS patients, but that mitochondrial content was notably decreased does not support the concept of "primary mitochondrial dysfunction" in ME/CFS, as the authors point out. However, they speculate that "low mitochondrial content might be a perpetuating factor for complaints such as fatigue, myalgia and exercise intolerance" in the illness.



Above a normal mitochondrion, and below one from a CM/CFS patient



*On reading this feature my thoughts were directed to quite a few of the LME members who have had the Mitochondrial Function Test offered by Dr. Myhill and colleagues. The test offered give a series of numbers which apparently show abnormalities linked to the intensity of ME/CFS. I have reproduced the original abstractor the research paper and the most significant paper of the results.*

*The feature appears to contradict Dr Myhill's findings. However, I think what is significant is that the Myhill tests are based on the contents of a type of white blood cell, whereas the Netherlands research finding is based on muscle. I have also included an image of a normal mitochondrion, and one from a ME/CFS patient in Central Scotland. Make you own judgment! Mike.*

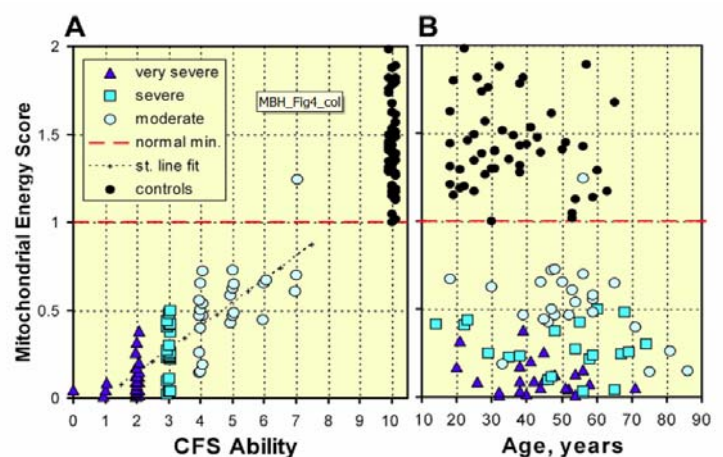
### **Chronic fatigue syndrome and mitochondrial dysfunction**

Sarah Myhill<sup>1</sup>, Norman E. Booth<sup>2</sup>, John McLaren-Howard<sup>3</sup>

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**Abstract:** This study aims to improve the health of patients suffering from chronic fatigue syndrome (CFS) by interventions based on the biochemistry of the illness, specifically the function of mitochondria in producing ATP (adenosine triphosphate), the energy currency for all body functions, and recycling ADP (adenosine diphosphate) to replenish the ATP supply as needed. Patients attending a private medical practice specializing in CFS were diagnosed using the Centres for Disease Control criteria. In consultation with each patient, an integer on the Bell Ability Scale was assigned, and a blood sample was taken for the 'ATP profile' test, designed for CFS and other fatigue conditions. Each test produced 5 numerical factors which describe the availability of ATP in neutrophils, the fraction complexed with magnesium, the efficiency of oxidative phosphorylation, and the transfer efficiencies of ADP into the mitochondria and ATP into the cytosol where the energy is used. With the consent of each of 71 patients and 53 normal, healthy controls the 5 factors have been collated and compared with the Bell Ability Scale. The individual numerical factors show that patients have different combinations of biochemical lesions. When the factors are combined, a remarkable correlation is observed between the degree of mitochondrial dysfunction and the severity of illness ( $P < 0.001$ ). Only 1 of the 71 patients overlaps the normal region. The "ATP profile" test is a powerful diagnostic tool and can differentiate patients who have fatigue and other symptoms as a result of energy wastage by stress and psychological factors from those who have insufficient energy due to cellular respiration dysfunction. The individual factors indicate which remedial actions, in the form of dietary supplements, drugs and detoxification, are most likely to be of benefit, and what further tests should be carried out.



## Old Wives Tales—Can Stress Cause Grey Hairs?

By Ben Nicholson PJ 23rd Oct 2011

So, here is another interesting 'Old Wives Tale'; does stress actually make your hairs grey? This topic opens us to some interesting science, as we will soon find, however also could have started with a certain historical event...

Marie Antoinette, wife of Louis XVI, was imprisoned along with her immediate family following the deposition of her husband during the French revolution. Shortly after Louis XVI was tried of treason and guillotined, she suffered the same fate. However, it was well noted that on the day of her execution, her previously admired hair, was now almost completely grey.

While waiting to be executed is doubtless more than a little stressful, a more accepted reason for this sudden change was either wig removal, or lack of access to hair dye during her imprisonment.

It has been proved stress can give a variety of medical conditions, such as acne or psoriasis and also trigger conditions such as telogen effluvium or alopecia areata, both of which cause chunks of hair to fall out. Therefore, while stress can cause hair loss (which could exacerbate the appearance of existing grey hairs), can it cause new hairs to grow grey from the root?

Well, the answer is no; there is no medical evidence to say stress can cause grey hairs to grow. Luckily (but only for some!) to find the reason for your grey hairs, you need look no further than your parents...

Hair is made below the scalp, as just before it emerges above the skin layer, cells called melanocytes inject the pigment melanin into the keratin which makes up the hair. Whether someone's hair is blond, brown or black depends on the concentration of these pigments in their keratin. Grey hair is therefore due to less melanin in our hair than 'normal', or a lack of it altogether.

While there is strong evidence to show our individual 'hair timeframe' can be passed down from our parents, there is still debate as to the exact cause of hair greying and hair loss. Many believe that production of the pigment melanin is mediated by special stem cells, and that before these stem cells die (due to old age) they start to make 'errors'. They suggest these 'errors' include insufficient melanin production, which can cause greying.

Several other theories are based around stem cells, as for many they are seen as the key to understanding the aging process and in doing so; learn more about a host of diseases, from cancer to Alzheimer's. There is even a chance that if the exact genetic cause of hair loss is found (i.e. how you body's ability to respond to stress is at least partly due to genetics), the same science could be used to understand other genetic diseases.

So it seems, while they trouble some, grey hairs could help us a lot more than we think...



I HAD A GOOD DAY YESTERDAY, I EVEN  
MANAGED TO KEEP UP ALONGSIDE  
GRANDAD ON A SHORT WALK.



## A well known Christmas Carol: *Silent Night.*

By Mike Valentine.

It's more than 50 years ago now since my first recollection of the Christmas Carol in when as pre school age I was offered half a crown by my grandfather if I could whistle silent night. Needless to say, it took a lot of doing and once I reaped my reward, it was whisked away by my parents into a savings certificate. Later, at quite an early age, I learned to play it on the piano, and it was my debut song when playing for the school.

Musically silent night is a very simple and easy 'entry level' carol to learn and play. It can be played single finger style using only three chords without loss of effect.

There is a very interesting story behind the carol. This dates back to the early 1820's. There is a traditional story about its authors, the Rev. Josef Mohr (1792-1848) and Franz Xavier Gruber (1787-1863), and origin. The carol was first performed in the Nikolaus-Kirche (Church of St. Nicholas) in Oberndorf, Austria, on December 24, 1818. Mohr had written the words two years earlier, in 1816, but on Christmas Eve brought them to Gruber and asked him to compose a melody and guitar accompaniment for the church service. Reputedly it was discovered that mice had chewed through vital parts of the church organ making it unusable for the service. In a desperate attempt to provide some music for the service, Franz Xavier came up with the tune, He arranged it for choir and guitar. The early version is reproduced above right. Apparently it was a great success, adopted by many churches. It has been recorded by many popular artists—and



*In doing the research for this feature I came across a early manuscript. If you understand and can read musical notation, it is just barely playable. I've tried on my organ at home, which can mimic the choir and guitar, and on the organ of St. Katherines Chapel at Tickhill Road Hospital, Doncaster. The biggest surprise was that the arrangement comes out like a dance-like tune in 6/8 time.*

*The original 'Carols' we in fact dances—the most well know one being 'Good King Wenceslas'. The more modern versions sung today are slow, meditative lullaby or devotional; hymn-like version. Although many publishers and arrangers have added their own embellishments and variations to the carol over the years, they have never matched the original arrangement.*

still is as popular today as ever. In my teens, it was one of the most common carols I played when I was a member of the local school band and Hickleton Main Colliery Band. I can recall spending Christmas Day in many places around the village and missing Christmas dinner much to my parents dismay. The version recorded by Bing Crosby is one of the fewer than thirty all-time singles to have sold 10 million (or more) copies worldwide. In recent years, the story has been made into a film.



The picture to the left is the Silent Night Museum and Memorial Chapel in Oberndorf. The original Nikolaus-Kirche was demolished in the early 1900s as a result of flood damage and because the town's centre was moved up the river to a safer location, with a new church being built in the new town, close to the new bridge. A tiny chapel, called the "Stille-Nacht-Gedächtniskapelle" (Silent Night Memorial Chapel), was built in the place of the demolished church and a nearby house was converted into a museum, attracting tourists from all over the world, not only, but primarily in December. - Mike

## **LEGER ME GROUP LIBRARY BOOK LIST**

We currently have a total of 28 books and pamphlets to lend out to members and I've set out a brief description of each of them. The library also holds newsletters from a couple of other ME groups along with several editions of the *InterAction* magazine by Action For ME and the ME Research UK magazine, *Breakthrough*. If you can find the energy to read, you never know what hints, tips and insights you may come across. Please let us know if you come across a good book or pamphlet and we will see if we can source a copy. As well as the books being available through the post, they will be at each of the meetings at The Redmond Centre. Happy Christmas & Best Wishes for the New Year.

Susan [Legerme.library@yahoo.co.uk](mailto:Legerme.library@yahoo.co.uk)

### **Pamphlets and short books**

*Pacing for People with ME - a very good guide issued by Action For ME*  
*CFS/ME Your Questions Answered – the 1998 & 2001 editions*  
*ME in the 21<sup>st</sup> Century – a leaflet by Alex Howard who set up the Optimum Health Clinic*  
*Easy Going Trails by Sheffield City Council describing easy access local footpaths*

There are several books covering nutrition

*The Complete Guide to Food Allergy and Intolerance,*  
*Candida Albicans*  
*Optimum Nutrition*

**There are some very good books dealing with almost every aspect of CFS/ME, with practical advice from managing symptoms to claiming benefits.**

*Dr. Charles Shepherd – Living with ME*

*Dr. Anne Macintyre – ME-Post Viral Syndrome, How To Live With It*

*Janet Hurrell – A Helping hand through ME*

*Dr. M. Midgley – A Life Worth Living, A Practical Guide to Living with ME*

*Drs. Dawes & Downing – Why ME? A Guide To Combating Post Viral Illness*

*Dr A Melvin Ramsay's book, ME & Post Viral Fatigue States, charts and discusses outbreaks of illness around the world from the 1900's, which are now believed to have been ME.*

*The Perrin Technique looks at the illness from the point of view of an Osteopath and we have one Yoga book, Beat Fatigue With Yoga.*

**There are also a range of books, not all specifically aimed at people with CFS/ME, but which give an insight into alternative ways of looking at illness.**

*ME/CFS & The Healer Within*  
*The Final Surrender-A Journey To Wellness*  
*Boundless Energy*  
*A Better Recovery From Viral Illness*  
*Unwind, Understand & Control Life Better*  
*The Alchemy of Illness*  
*From Fatigued To Fantastic*  
*The Natural Way-CFS*

*Zoe's Win tells the story of a child's experience of ME and is also a guide for Children and Parents/ Carers of Children with ME.*

*Alex Howard's personal story of his battle with the illness is called Why ME?*  
*A Last Goodbye is Kay Gilderdale's story about her daughter Lynn who suffered severe ME.*

## ***North of Doncaster—Personal comment by Trevor Wainwright***

The Yorkshire Epiphany: by Trevor Wainwright.

*Written initially in 1993 entirely on inspiration set in Whitby depicting life in Thatcherite Britain against a backdrop of unemployment, pit closures and fishing quotas, now modified for the 21st century against a back drop of ME and based on my own experience:*

I'd seen the light from my study window, I'd been having a break having just sent some info to a woman who had phoned, her daughter had just been diagnosed with ME after a year of being ill. I was able to send her various information and details of a local support group and TYMES Trust a national young persons group to whom I'd sent her details. Now here I was driving out of Whitby across a snow-covered landscape following the light in search of a prophecy that a saviour was coming who would make all things right, I doubted it but decided to follow the star anyway. Looking at the snow I remembered how it was before my daughter had been diagnosed ME. She'd always loved the snow "yippee" we'd hear her say, each time she opened the window after it fell, how she'd loved sledging, making snow angels and snowmen, she loved the summer when the moors were covered in a purple carpet of heather heralding the advent of autumn and bilberry-picking but winter was always special.

One day she just started feeling ill for no apparent reason and slowly got worse losing weight and eventually ending up in a wheelchair. We were totally gutted and had never felt so helpless and to cap it all even the GP didn't believe in it and saw no reason for the wheelchair, but could offer no help on how to get her out of it. That came during a conversation with a colleague while watching an item about it on TV he had thought it all in the mind till I told him, he suggested homeopathy and it worked.

My daughter's education was a farce, we'd not only had to struggle to get a home tutor who was good but we'd had to struggle to keep him and the support he got from the school was abysmal. A GP had said there was no info anywhere but our other daughter found three books in the library, two actually written by doctors who suffered but even their own didn't believe them. There just seemed no end and no hope; I'd been involved with a local overseas aid charity taking aid to war victims when I mentioned it in a newspaper interview then people started getting in touch, at least we weren't alone. I met a group of people that were involved in fundraising for a local research project, so when the overseas project finished we got together and started fundraising on a wider basis which came to an abrupt halt when one of the researchers died suddenly.

We were offered a car to raffle and accepted it were all set to go giving the proceeds to a national organisation when they pulled the plug; it was eventually raffled for the local hospice who made over £4,000 out of it, meanwhile we had come across two other projects and fundraising started again, we took our cause direct to the public who were great helping us raise well over £30,000 over the years.

There had been controversy at first when I suggested a poetry book as I had been part of an AIDS awareness campaign through poetry and saw how well the poems adapted, one group was keen but dropped it like a hot brick when they heard of the AIDS connection, I still published it though and further poems to great acclaim. But the main thing was the disbelief that ME was a real illness. I began to wonder who decided that, had they seen my daughter and others what would they have said?

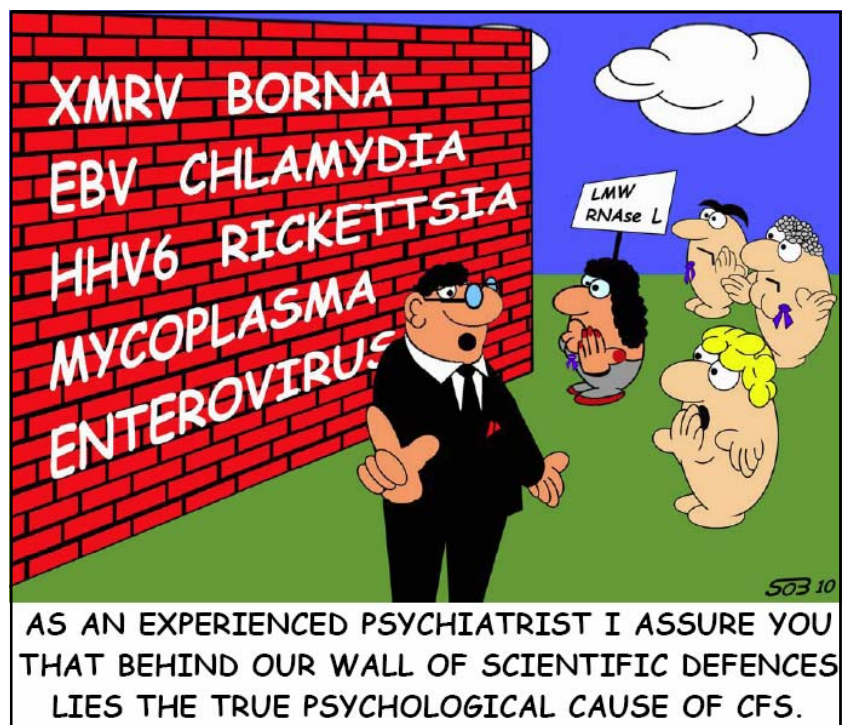
Eventually I would learn that it was two psychiatrists called Beard and McEvedy who were responsible having studied an outbreak or rather half studied it and deciding it was all in the mind, they'd caused some damage with that as a result we were still waiting for government funding into biochemical causes. Oh yes at the time there were main groups two of which criticised others for trying to make headway, even trying to stop certain events. They failed.

There would be other problems and other villains. I would get into campaigning when a group came up with the idea for a petition calling for research. A certain person posted an article saying it stigmatised psychiatrists. The four main groups had backed it until I posted an article in support of it which led to one group withdrawing its support. There wasn't much in the media either unless they came across someone who died or was supposed to have found a miracle cure. I always asked "had they really had ME and not some other fatigability illness? The argument I'd use was that as there is still no specific test how can they say they have it?"

We tried time after time to get the media interested but not much joy. We were OK at a local level but not nationally, it was strange how other illnesses got a mention, perhaps they had better patrons among the famous. On one occasion we organised a demo in London and one of the main groups said it would be counter-productive, yet the following year they tried the same with a petition. We decided again to do likewise and we beat their total in six weeks and presented it on the day planned. It took them three attempts. The very same group in the early days had once criticised a local group for publishing one of my articles in their newsletter and had backed down when they were offered a chance to go head to head with me as to why.

I found myself at the palace of the province ruler where I met two men on the same mission they were Melvin, a doctor from Scarborough and Barry, a theologian from Bridlington. Whilst waiting for info about the new birth we got talking they both seemed interested in ME, Melvin especially. I had always travelled with various info ever since our petition calling for more. I gave them an information leaflet and a carers practice sheet. I'd done carers practice at the request of some department official who had promised to get it published, this never materialised so I spoke to the local council who gave me a grant for it, later it would go across the pond, down under, be translated into Danish and Norwegian and even go to Japan. They were both pleased at the info and we chatted until an official came with the request to search carefully for the child, and when we found him return this way and let him know.

Leaving York we followed the star which eventually led us to a pub in Castleford, a former mining town. We found the baby in a store room at the back and each gave a gift and offered our congratulations to his parents. In the morning over breakfast Melvin told us of a dream he'd had, that should we go back through York all would not be well. As it turned out we all had had the same dream so we all agreed to go home by a different route. After breakfast we said goodbye to the child and his parents, before setting off home. Barry headed for the M 62; he would go home via Driffield. Melvin and I left Castleford the way we came; we drove up the A1 and cut across from Thirsk to Pickering where we stopped for coffee before going our separate ways.



The sky was clouding over as I drove along the moorland road sighting Whitby from the top of Blue Bank. Fifteen minutes later I was driving into the town thinking we were still nowhere near a cure, but two more of the unknowing had become knowing and hopefully would spread the word to others as once again the snow began to fall.

All that was about seven years ago before I retired after 2 operations but I'm still contributing and still waiting not only for the saviour but for the government to see sense and fund the finding of a cure.