



# 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.

## ***DWP: The left hand not knowing what the right hand is doing?***

After the last marathon on welfare rights in the last Pathways we are back to the usual content. But first just an update on welfare rights issues.

A significant number of members have had hard-won tribunals, and several weeks on, ESA 50 forms appear. Furthermore, feedback from members' cases shows that decisions made by the Tribunals Service, which overturn a DWP/ATOS-advised decision are not being updated on members' records. This is particularly a problem with DLA because the Decision Makers sometimes are using only DWP/ATOS decisions and not taking into account later decisions made by the Tribunals Service overturning the original. I think this is probably because there are three organisations involved, and three individual databases which are not linked. As to whether this is deliberate I am not clear, but it is working against our members' interest. With appeals now taking almost a year to be heard, I am therefore advising that where a tribunal has taken place, all the tribunal papers are attached to the ESA50 or DLA1a forms on submission. I have included a couple of check-lists to help with DWP forms. Please remember that all DWP forms need to be checked by a welfare rights advisor before submission. Most of the benefit refusals I come across are due to problems with DIY form fill outs.

I was at a recent Local Patient Involvement Group (LPIG) meeting of the Sheffield ME/CFS clinic and the issue of Vitamin D deficiency was raised. A number of members have been found deficient during routine tests with their GPs. The Sheffield Clinic does not have resources in place to pursue this issue so I've decided to major it within this issue of Pathways. Here is an introduction from Dr. Myhill's website:



### **Vitamin D and Sunshine: an essential vitamin: Protects against cancer, heart and bone disease**



Western cultures have become almost phobic about any exposure of unprotected skin to sunshine with the well-recognised association between skin cancer and exposure to sunshine. Indeed the US Environmental Protection Agency is currently advising that ultraviolet light, and therefore sunlight, is so dangerous that we should "protect ourselves against ultraviolet light whenever we can see our shadow". But a certain amount of sun exposure is essential for normal good health in order to produce vitamin D - and partly as a result of current recommendations, we are seeing declining levels of vitamin D and the problems that go with that.

Human beings evolved over hundreds of thousands of years in equatorial areas and were daily exposed to sunshine. Dark skins evolved to protect against sun damage. However, as hominids migrated north, those races which retained their dark skins were unable to make sufficient vitamin D in the skin and did not survive. Only those hominids with paler skins survived. Thus the further away from the Equator, the paler the skin became. Races in polar areas survived because they were able to get an alternative source of vitamin D from fish and seafood. There is an interesting inverse correlation between sunshine exposure, vitamin D levels, and incidence of disease as one moves away from the Equator.

Even correcting for other factors such as diet, there is strong evidence to show that vitamin D protects against osteoarthritis, osteoporosis, bone fractures (vitamin D strengthens the muscles thereby improving balance, movement and preventing falls), cancer, hypertension, hypercholesterolaemia, diabetes, heart disease, multiple sclerosis and vulnerability to infections. Multiple sclerosis is a particularly interesting example of a possible vitamin D deficiency disease. Indeed experiment-mice bred for susceptibility to multiple sclerosis can be completely protected against development of this disease by feeding them high doses of vitamin D. ► *continued on Page 9*

## You Write

**Winnie writes:** My partner is showing practically all the symptoms of ME/CFS or fibromyalgia. Her doctor has taken all the blood tests to rule out anything else and referred her to the chronic fatigue clinic in Leeds. They have said they are unable to see her because she has been previously diagnosed with bipolar depression even though the mental aspects of this and ME are very similar. She has deteriorated over the last year specifically during the last 6 months with the pains and other symptoms getting increasingly worse. I am at a loss as what to do or where to turn. I find it killing to watch her getting worse and being unable to do things she once took for granted. This coupled with having to fight the ESA through the appeal process is taking its toll on both her well being and her mental state and is leaving me frustrated, tired and feeling useless as I am feeling increasingly powerless. Any advice or practical help would be gratefully received. My partner lives in Pontefract and the clinic she was referred to was at Leeds.

*Refusal to accept a referral for someone previously diagnosed with bipolar depression is the correct outcome for the Leeds ME/CFS. This clinic is undergoing 'reorganisation', and this is going to result in loss of expertise. So I would be tempted to avoid this clinic at least for the time being. Fibromyalgia needs to be treated as a rheumatology-based disease so a diagnosis needs to be confirmed by a rheumatologist. Alternatively your partner should approach her GP for referral to the pain control clinic, which is at 'Jimmy's' in Leeds. I think that would be a good start and could see her pain-free. Treatment at pain clinics includes conventional as well as complementary therapies. For example, our local pain clinic in Mexborough offers things like acupuncture on the NHS. The DWP would also accept treatment at the pain clinic as indicating a real problem, without a formal diagnosis having been given.*

**Helen writes** My husband has just got back from GP surgery, and his blood tests show his Vitamine D level is low, so he is on two horse-tablets a day! Could this could be the reason he has recently felt so bad that the doctor has upped his anti depressant tablets? Incidentally, we were at Fairlawns yesterday; they are going to get in touch with his GP to suggest changing his medication to another anti depressant - one that has pain killing properties.

*Possibly. SSRI-type antidepressants have no place in ME/CFS treatment, unless endogenous depression (as an 'as well as') is also present. Many G.P.s tend to make the mistake of believing that the symptoms of ME/CFS are depression, and if an SSRI is prescribed, it usually make matters worse. The TCAD type antidepressants which work well at a low dose are nortriptyline or amitriptyline. A dose of 10 mg at night seems to help, particularly with pain control and sleep. Similar medicines like trimipramine or mirtazepine seem to be more sedating but work just as well. One to avoid is dosulepin also known as dothiapien as it is associated with serious heart side effects.*

**Tom Writes:** Did you know that 'Borreliosis and Associated Diseases Awareness UK' (BADA,UK) is a charity formed by a group of volunteers who were brought together by the effects of borreliosis, or Lyme disease, and associated infections. It is caused by spirochaete bacteria of the genus *Borrelia*, and is transmitted primarily by ticks and lice. The charity's aim is to raise public awareness of the dangers of tick-borne diseases, and 26 March 2012 marked the start of Tick Bite Prevention Week in the UK. Borreliosis is the most common tick-borne disease in the UK, and its incidence has increased in recent years. There are several reasons for this, including a milder year-round climate, and an increase in the number of people engaging in outdoor activities. Changes in certain agricultural practices, such as a reduction in sheep-dipping and moorland burning also reduce the curbing of the tick population. There were 1,053 laboratory confirmed cases of borreliosis in England and Wales in 2010, and it is estimated that a further 1,000 to 2,000 went undiagnosed. Diagnosis is difficult because the disease can produce a bewildering array of symptoms, most of which resemble other diseases. In more than half of cases, the patient has no recollection of being bitten. The only specific symptom is the 'erythema migrans' rash which occurs in less than half of cases. Doxycycline is the treatment of choice, with amoxicillin being used in children. Once a tick has attached itself to a host it is important that it is removed correctly, as incorrect removal can lead to further complications. If the tick's head remains attached, abscesses can form, and squeezing the abdomen can result in the tick's stomach contents entering the host's bloodstream, which can lead to septicaemia. There are only two safe ways to remove a tick.

One is with fine-tipped tweezers, the other with a tick-removal tool. *Has someone missed something out about Lyme disease? ....see our past Pathways feature on the subject. Leger ME Newsletter Pathways No. 9 Summer 2006 Page 15. This can be found on the LegerME website.*

**Carolyn writes:** I'm not sure if you are aware of this, but in my part of the world, we have a shortage of MaxEPA. I called into Boots the other day, and the lady before me had collected an 'owing' amount, but there was none for me. I was told that the makers cannot supply and I have run short. Any suggestions ?



*The large Pharmacy chains like Boots have a fast stock turnover, and if there are any problems in the supply chain, it seems to show up with Boots first. I had a word with my friend Dave, who knows about such matters. The situation is as follows; Seven Seas Health Care Ltd in Hull, is a subsidiary of Merck (a well known pharmaceuticals manufacturer) and this company markets a refined version of cod liver oil known as MaxEPA. The version that the I've seen most often seems to come from Greece.*

*It would appear that the version for the U.K. market is in short supply because the manufacturers are just not supplying. Cod liver oil from which MaxEPA is made must be in short supply. Instead they are exporting to the EU where a more profitable price is obtained. UK supplies are then purchased from the EU by an importing company in Essex, relabelled, and supplied through the NHS supply chain with a price hike. I understand that there is a more expensive alternative product by Abbot called Omacor. Looking at both products' data sheets, they are almost the same. It might be worthwhile to try and get your GP to prescribe via this route. Alternatively, I've also seen 'GLA Oil' supplied. If you can afford it, VegEPA is an alternative available without prescription.*

*For the benefit of Pathways readers, MaxEPA relieves ME/CFS joint pain and brain fog. It is not intended to treat ME/CFS, but is used by the NHS to treat a blood disorder. It is very similar to a product called VegEPA, which although expensive, can be purchased quite freely. At one time VegEPA was prescribed by a consultant at DRI, but Doncaster PCT stopped local NHS supply because of 'lack of evidence'.*

**Sue writes:** Thank you very much for your help with my recent ESA refusal paperwork. I've just been to a tribunal today and won. I am however very, very angry because my money has been reduced for 10 months, and really I blame the nurse\* who did the medical examination, because the ESA 85 she produced in no way resembled what information I gave them at the medical examination. Her report was fortunately ignored by the tribunal judge.

*\* has caused this problem with many LME members, and has a nickname of 'Brunhilda' within our group. There are a number of options to complain: Firstly to Atos, the company that did your assessment and for whom 'Brunhilda' works; secondly to the DWP directly and thirdly to your MP. Fourthly, as 'Brunhilda' is a registered nurse and appears to have got it wrong, you may be able to complain to the General Nursing Council on grounds of professional incompetence. This has long drawn out paperwork and may take up to 12 months to sort. The first three options will get a response very quickly. All you can expect is the satisfaction of complaining. What we are unclear about is whether you would be labelled at a complainer, leading to retaliation by the DWP in some way or other.*

**Gwengie writes:** I have just received another ESA 50. It was only 3 months ago that I sent one in. I only received a phone call a couple of weeks ago to say that, as I was receiving chemotherapy for cancer, they would leave me alone until all my treatment was finished. I find this very offensive and downgrading. What can I do about it, as I am not well enough to sort it myself.

*As you are receiving cancer chemotherapy you are exempt from the system under section 29 of the Act. The DWP will know this, there is NO EXCUSE for them causing you harassment through their own incompetence. However, what is likely to have happened is that Atos will have sent you out an ESA 50 form simply because their computer is programmed to do this without full consideration of individual cases. Besides damaging your mental health, this costs the Government unnecessary money. You need to complain.*

## **ME Research — Action for M.E.'s £61,000 for new research**

*(from AfME website 8/5/12)*

National ME/CFS Charity Action for M.E. has awarded a total of £61,000 to three biomedical pilot research projects at Newcastle, Northumbria and Sheffield universities. This is in line with our pledge, stated in our Time for Action campaign manifesto, that says: "We will drive the agenda on scientific research by investing in our own pilot studies to open up understanding of the biology of M.E."

Sir Peter Spencer, Chief Executive, Action for M.E., says, "These high-quality projects will examine muscle dysfunction, disturbed sleep and cognitive impairment, three key symptoms of M.E. All will extend our understanding of this chronic long-term illness that wrecks the lives of so many men, women and children in the UK." The charity's initial call for proposals, issued last October, announced that, thanks to a generous gift from an anonymous private donor, a research fund of £50,000 would be available. However, following independent scientific review, Action for M.E. decided to fund three projects at a total cost of more than £61,000, drawing on funds provided by our Supporting Membership for research purposes.

Professor Stephen Holgate CBE, Chair, Medical Research Council M.E./CFS Expert Group, says, "Medical research has to begin somewhere. Pilot projects are a brilliant way of supporting good ideas so that the researchers can then be in a much stronger position for more sustained funding. This is just what the M.E./CFS field needs at this exciting time for discovery science."

Awarded £25,000, the study 'Understanding muscle dysfunction in M.E./CFS': developing a drug pre-testing system will be led by Dr Phil Manning and Prof Julia Newton at Newcastle University. Prof Newton says, "I am absolutely delighted that Action for M.E. has funded our project. This funding will allow us to more fully understand the muscle abnormalities that occur in people with M.E. and begin to develop treatments to reverse the abnormalities that we have already seen in our muscle MRI studies. This is a wonderful opportunity for us to push this work forward and we are extremely grateful to Action for M.E. and their members."

Dr Jason Ellis at Northumbria University, awarded £11,550, will lead on 'A case controlled study exploring the qualitative experience of sleep, the roles of sleep architecture and diurnal patterns of salivary cortisol in M.E./CFS'. Dr Ellis says, "Although we have known that sleep is a significant problem in the lives of people with M.E., until now no one has systematically studied the relationship between sleep and daytime fatigue from the patient's own perspective. Furthermore, we will be doing the most detailed examination of sleep and hormonal functioning ever attempted in this population. This is an exciting opportunity to examine sleep from several angles with our overall aim being to improve our understanding and treatment of this condition."

Locally, an award of £24,832 was made to Prof Annalena Venneri, University of Sheffield, for 'Uncovering the biological correlates of cognitive impairment associated with fatigue in M.E./CFS: a pilot study of cognition and functional connectivity pre and post-exertional malaise.' Prof Venneri says, "By studying how cognitive symptoms and brain processes change when patients suffering from M.E. experience different levels of fatigue, we aim to uncover possible links with brain physiology and function that may be associated with this condition. This could potentially help in finding and directing new forms of treatment that may be beneficial to M.E. sufferers."

Prof Derek Pheby, Trustee, Action for M.E., says, "These three pilot projects have great potential for identifying underlying disease processes in M.E. They fit well with the UK scientific research agenda agreed by the Medical Research Council M.E./CFS Expert Group. Importantly, they also extend the number of universities involved in research with Action for M.E."

Action for M.E. is already co-funding the UK's first biobank for M.E. and has previously funded pilot research projects including a National Outcomes Database and feasibility study for a post-mortem tissue archive.

## **Swedish And Indian Head Massage**

*Talk Given To Leger ME on 17 May 2012 With Reference To The Condition Of ME/CFS. By Ann Fisher*

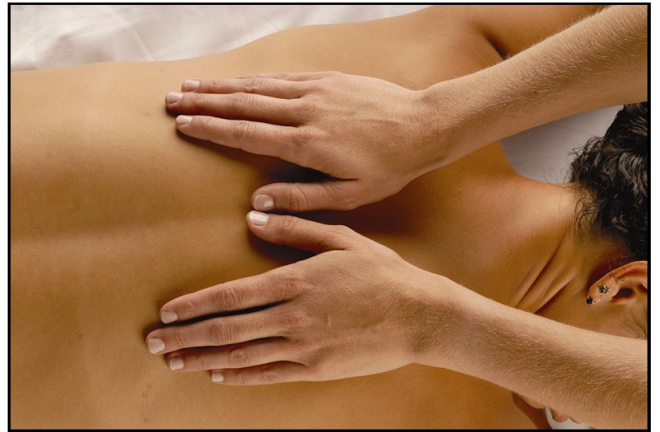
### **WHAT IS MASSAGE?**

- It is an ancient technique that has been developed in various civilisations and modernised
- As a complementary therapy it aims to add to modern medicine rather than replace it
- The act of touch gives comfort and relaxation to people
- It works on an emotional level making people feel cared for, valued and peaceful
- On a physical level it relieves muscle tension, improves the skin, increases blood flow and lymph drainage. It also helps to remove toxins from the body.
- It may increase the production of Endorphins which are natural pain killers

### **TYPES OF MASSAGE:-**

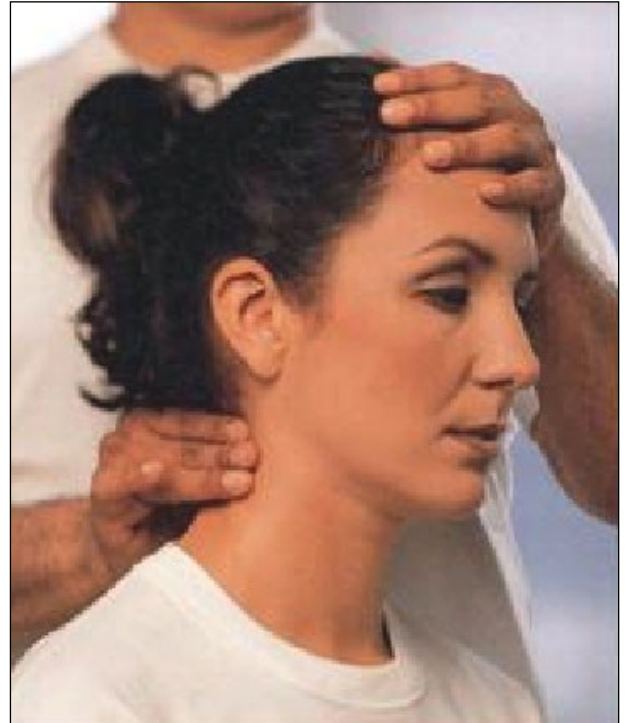
#### **SWEDISH**

- Professionally trained therapists and given usually on a couch,
- The body is covered with towels, and only the area being treated is exposed.
- The whole or part of body can be treated
- Oil, cream or talk is used as a medium to help the hands pass over the skin smoothly
- It is usually performed with the hands and arms however some therapists may use a massage tool
- A treatment will last from 30 – 90 minutes.



#### **INDIAN HEAD**

- This treatment is usually given with the client seated or leaning forward onto a couch, so it can be given in an individuals home, office, or treatment rooms
- You can receive a treatment clothed with a light tee-shirt on or with oils and a modesty towel.
- The shoulders, neck, head, face and arms are the only areas treated.
- A treatment lasts from 15 - 45 minutes
- The oils (if used) are chosen for their specific treatment of the skin and hair, essential oils may be added however these should only be used by someone who knows about aromatherapy.
- The benefits other than relaxation are in helping with tension headaches, nasal/sinus congestion, shoulder tension, nourishment of hair and scalp and fluid drainage from the face.



### **CONTRAINDICATIONS**

- Most people can benefit from a massage but it has to be tailored to the individual's needs.
- Care has to be taken when there are other illnesses present.
- A total contraindication will be any of the following - cancer, fever, non-prescription drugs, hypersensitive skin and severe skin complaints.
- A medical contraindication such as epilepsy, high/low blood pressure, diabetes, asthma, pregnancy, rheumatoid arthritis, oedema, etc. In illnesses such as these the therapist should seek medical permission before treatments commence.
- Local contraindications such as skin infections, allergies, cuts, bruises, scars etc. can be avoided by the therapist.

## CONSULTATION

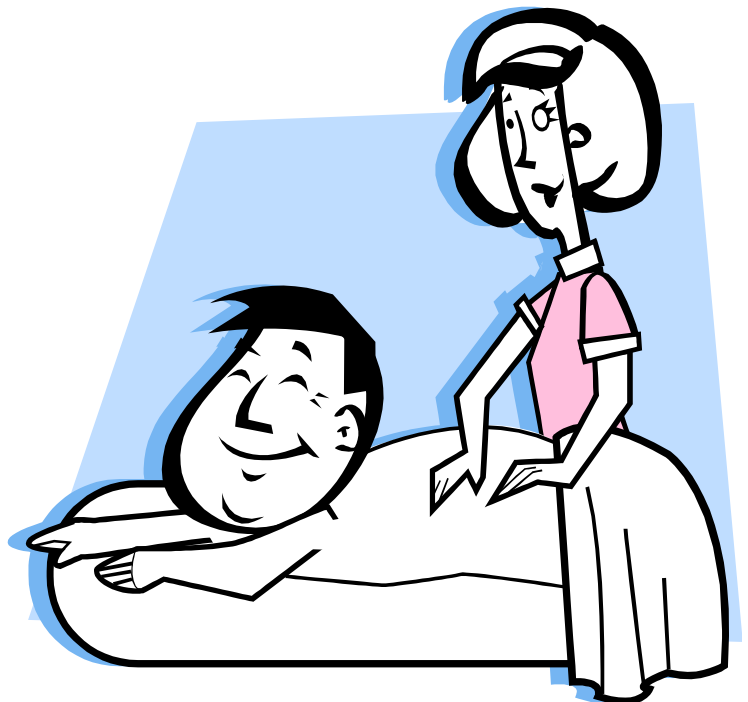
- A consultation should be a two way assessment to confirm if the therapist is able to assess which is the best form of treatment for you and also for you to feel confident and comfortable with the therapist.
- It should be thorough, assessing your medical background and your needs before the initial treatment.
- You need to be given time to explain your illness and other medical problems.
- Then discuss the best treatment for you – it may not be what you went for.
- You do not have to go through with a treatment following the consultation if you are not happy with the therapist and their knowledge of ME.

## MASSAGE AND ME/CFS

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- Talk to the therapist over phone first. Check that they understand your illness.
- The consultation may need to be done at a different time from treatment, depending on your level of fatigue.
- Some therapists may want you to have medical permission, depending on the severity of your condition or because of other conditions.
- A full body massage will probably be too much for a first treatment ( you may never be able to tolerate this amount of muscle work). Discuss having 30 min appointments working on different parts of the body to start with and you may need to leave a good gap between treatments to recover (a minimum of 1 week).
- Or you might ask for specific treatments i.e. just legs, shoulders, lower back.
- The first treatment must be very light, so as not to exhaust you. After this you can assess with the therapist if you can tolerate deeper work.
- You will need to rest longer than a normal client immediately after treatment - don't be rushed.
- Postural hypotension – massage lowers the blood pressure so take care when standing.
- Only have plain oil i.e. almond or grape seed oil unless the therapist is qualified in aromatherapy. Essential oils can cause additional fatigue and possible allergic reactions.
- Rebound reaction- You will have one. Massage is working the muscles, even though you are passive the therapist is making your muscles work so like any activity it will causes a rebound reaction.
- You may see an increase in pain and stiffness for a few days after treatment with some relief after that. Keep a written record of symptoms before and after treatments so that you can assess any improvements, if you don't improve a different treatment may be better for you e.g. reflexology.
- If the therapist is able to give mobile treatments this may help you as it cuts down on the amount of travel you have to do and you will be able to have a drink and rest immediately after treatment.

## FIND A THERAPIST –

If you wish to find a therapist in your area then try [www.fht.org.uk](http://www.fht.org.uk). This is a professional organisation whose members have to meet very strict training programmes and to be able to practise have to continue to develop their skills and prove that they are doing so.



## Harm from Fluoridation

Elizabeth A McDonagh 30.10.2007

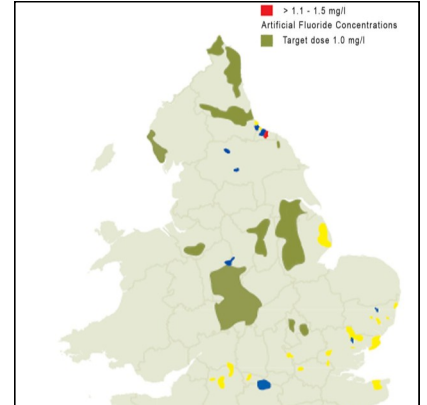
The only harm from fluoridation which is recognised by those who promote the practice is dental fluorosis (mottling of teeth). This is often described as a mild 'cosmetic effect'. However, it can have serious social and psychological consequences and is very expensive to remedy with dental veneers. The *York Review* found that, in fluoridated areas, dental fluorosis affected almost half the child population. In 12.5% the condition was serious enough to be 'of concern'.

Professor Dr A K Susheela met the then Health Minister, Ms Tessa Jowell, at the Department of Health, London on 26th October 1998. Professor Susheela is a histocytochemist and the Indian Government's Senior Consultant on the adverse effects of fluoride. She gave a slide presentation showing that fluoride ingestion has adverse effects on:

- red blood cells
- calcium metabolism
- tooth enamel
- the lining of the gastro-intestinal tract
- muscle, bone and connective tissue
- the foetus and DNA.

Ms Jowell asked "Why haven't we seen these health problems in our fluoridated areas?"

Dr Susheela replied "You don't even have a government laboratory to test fluoride levels in blood and urine. If you don't look for the problems, how do you hope to find them?"



In November 2006, because of a risk of dental fluorosis in the permanent teeth of bottle-fed babies, the American Dental Association issued 'Interim Guidelines' telling its members (dentists) not to recommend that mothers use fluoridated water for mixing infant formula feed. The (US) Center for Disease Control and the British Fluoridation Society have repeated the warning on their websites. In the event of fluoridation, what would be done to supply an alternative source of safe water for vulnerable infants?

Fluoridation gives no control on any individual's dose of fluoride because people drink different amounts and obtain fluoride from other sources besides the water supply. Fluoridation takes no account of people who are particularly susceptible to the poisonous effects of fluoride.

It is often said that 1ppm is such a low concentration in water that it could not possibly have ill-effects. It has even been said that one would need to drink seven baths full of fluoridated water to be poisoned by it. Such statements are nonsensical. They refer to the **acute** toxicity of fluoridated water (how much would be needed at one time to cause serious harm or death) whereas we are concerned about **chronic** toxicity, subtle adverse effects which may come about after consuming a cumulative poison at low doses for years. The 'Cathy's Horses' story illustrates this point.

Thalidomide was heavily promoted as safe and effective. Even at high doses thalidomide was declared to be **"so atoxic that it may be administered to even newborn and infants"** and **"...with overdose and prolonged medication, the drug's effectiveness is not impaired by unwanted side-effects"**. This claim was mainly based on the fact that it had been practically impossible to kill experimental animals by injecting any amount of the drug in a single dose. Sadly, with tragic consequences for the children it deformed, the claim proved untrue. **It has long been recognised by pharmacologists that a low acute toxicity does not guarantee that a drug will be harmless when taken in repeated low doses over a prolonged period of time.** Phenacetin and choramphenicol are drugs which could be taken at high doses with no apparent ill-effects but had serious toxic side-effects when used over a prolonged period.<sup>1</sup>

<sup>1</sup> Henning Sjostrom and Robert Nilsson "Thalidomide and the Power of the Drug Companies" Penguin (1972) ISBN 0 14 052.298 0 Page 43

## ***Ten Tips to Spring Clean with a difference?***

*From Sheffield ME Group Spring Newsletter 2012*



1. De clutter your mind: start the day with a list of 'to-dos' but keep it simple, listing a maximum of 3 things that must be done. Be realistic!
2. Don't forget anything when you leave the house. A clothes peg fixed to the door is a fool-proof way of making sure you remember what you need on your way out. The shopping list, a letter for posting, a dry cleaning slip - the list goes on.
3. Keep track of what the family is up to by fixing up a blackboard where everyone can note down their activities or what needs to be bought. (You could use an old picture frame, put white paper in place of a photo, and use a colour whiteboard or felt tip pen)
4. Never lose your keys again spend a little time labelling them up will save time and stress. (Even use an old biscuit tin/chocolate box to set up a place for spare keys).
5. Save a fortune on laundry products. Soda crystals work just as well as specialised cleaning powders and boost the power of your washing powder. You just need to mix 2 tablespoons with the washing powder for a large load, 1 for a medium load and half for a small load. They also help to dissolve grease and residue in the machine that can block pipes.
6. Never have to clean your oven again (well almost). Get into the habit of sticking a bowl of boiling water in the oven after use. The steam will prevent the grease and food setting hard. Just leave the bowl in the oven until cool, then give surfaces a wipe with a damp cloth.
7. Get shiny taps by mixing the juice of half a lemon with a teaspoon of bicarbonate of soda and rinse off with plenty of water. (This is not recommended for gold taps.)
8. Deodorise a smelly microwave by placing a few slices of lemon inside when the food is done and microwave for a minute.
9. Open jars without getting a hernia by banging firmly around the edge of the lid with a blunt knife to break the seal, so the lid screws off easily (or use a gadget which will prise up the lid to release air). If the contents seem to be glued to the lid, run the lid under hot water tap for a few seconds.
10. Defrost without using the microwave by placing the item into a sealed bag or container and placing that into a bowl of cold water. Berries will defrost this way in seconds, fish will take a few minutes.

## ***How did the Redmond Centre get its name?***

I am sometimes asked how the Redmond Centre got its name. It is named after Martin Redmond, a local Labour Party M.P. He was a local lad, born in Scawsby in 1937, educated at Woodlands Roman Catholic School, and then by day-release at the University of Sheffield. He worked as a foreman/driver of heavy goods vehicles for the National Coal Board, and was elected to Doncaster Borough Council in 1975. He became leader of the council in 1982, and was elected at the 1983 general election as the Member of Parliament for Don Valley, being sponsored by the National Union of Mineworkers. He spoke frequently in the Commons on the miners' strike.

I met him only once. At a lobbying meeting in the St. Leger Hotel, I remember him smoking cigars and being more interested in Labour party politics than anything else. He was a tall, well-built man with an eye for style, his neatly trimmed beard made him look like a cross between Henry VIII and Edward VII. Sadly he died in office in January 1997, and is remembered locally by the name of the Redmond Centre.

## **Vitamin D & ME/CFS** *(or Vitamin D according to Clinical Knowledge Summaries)*

**What is vitamin D?** Vitamin D is a vitamin that is needed for good health. Unlike other vitamins, we do not need to get vitamin D from food. A main source of vitamin D is that made by our own bodies. It is made in the skin by the action of sunlight. This is a good thing because most foods contain very little vitamin D naturally. Foods that contain vitamin D include: oily fish (such as sardines, pilchards, herring, trout, tuna, salmon and mackerel), egg yolk; fortified foods (this means foods which have vitamin D added to them) such as margarine, some cereals, infant formula milk.

### **Vitamin D and sunlight**

Ultraviolet B (UVB) rays in sunlight convert cholesterol in the skin into vitamin D. For a fair skinned person, it is estimated that around 20-30 minutes of sunlight on the face and forearms around the middle of the day 2-3 times a week is sufficient to make enough vitamin D in the summer months in the UK. However, for people with pigmented skin and the elderly, the amount of time needed exposed directly to sunlight to make enough vitamin D can be much more than this. Note: it is not the same as sunbathing; the skin simply needs to be exposed to sunlight. For the winter months, October to April, much of western Europe (including 90% of the UK) lies too far north to have enough UVB rays in sunlight necessary to make vitamin D in the skin. So, many people in the UK are at risk of not getting enough vitamin D unless they get it in their diet. Vitamin D is stored in the liver.

**Why do we need vitamin D?** A main action of vitamin D is to help calcium and phosphorus in our diet to be absorbed from the gut. Calcium and phosphorus are needed to keep bones healthy and strong. So, vitamin D is really important for strong and healthy bones. In addition, vitamin D seems to be important for muscles and general health. There is also some evidence that vitamin D may also help to prevent other diseases such as cancer, diabetes and heart disease.

**Who gets vitamin D deficiency?** Vitamin D deficiency means that there is not enough vitamin D in your body. Broadly speaking, this can occur in three situations:

#### **a) The body has an increased need for vitamin D.**

Growing children, pregnant women, and breast-feeding women need extra vitamin D because it is required for growth. So, vitamin D deficiency is more likely to develop in those groups of people. Vitamin D deficiency is even more likely to develop in women who have had several babies with short gaps between pregnancies. This is because the body's stores of vitamin D get used up, and there is little time for them to be built up before another pregnancy. Breast-fed babies whose mothers are lacking in vitamin D may be deficient. Prolonged breast-feeding can lead to deficiency as there is little vitamin D in breast milk. Vitamin D can be given to babies as drops by mouth.

#### **b) The body is unable to make enough vitamin D.**

This can occur for various reasons. People who get very little sunlight on their skin are at risk of vitamin D deficiency. This is more of a problem in the most northern parts of the world where there is less sun. In particular people who stay inside a lot, for example, those in hospital or housebound for a long time, may become deficient as may people who cover up a lot of their body when outside for example those wearing veils such as the niqab or burqa. People with pigmented skin (because less sunshine gets through the skin) may also have low vitamin D status. Strict sunscreen use can potentially lead to vitamin D deficiency, particularly if high sun protection factor (SPF) creams (factor 15 or above) are used. Nevertheless, children especially should always be protected from the harmful effect of the sun's rays and should never be allowed to burn or be exposed to the strongest midday sun.

Elderly people have thinner skin than younger people and so are unable to produce as much vitamin D. This leaves older people more at risk of vitamin D deficiency. Some medical conditions can affect the way the body handles vitamin D. People with Crohn's disease, coeliac disease, and some types of liver and kidney disease, are at risk of vitamin D deficiency. Rarely, some people without any other risk factors or diseases become deficient in vitamin D. It is not clear why this occurs. It may be due to a subtle metabolic problem in the way vitamin D is made or absorbed. So, even some otherwise healthy, fair skinned people who get enough sun exposure can become deficient in vitamin D. Vitamin D deficiency can also occur in people taking certain medicines - examples include: carbamazepine, phenytoin, primidone, barbiturates and some anti-HIV medicines.

### c) **Not enough vitamin D is being taken in the diet.**

Vitamin D deficiency is more likely to occur in people who follow a strict vegetarian or vegan diet, or a non-fish-eating diet fad or unbalanced diet.

### **How common is vitamin D deficiency?**

A recent survey in the UK showed that more than half of adults in the UK did not have enough vitamin D. In the winter and spring about 1 in 6 people has a severe deficiency. It is estimated that about 9 in 10 adults in the UK of South Asian origin may be vitamin D-deficient. Most affected people either don't have any symptoms, or have vague aches and pains, and are unaware of the problem.

**What are the symptoms of vitamin D deficiency?** Many people have no symptoms, or only vague ones such as tiredness or general aches. Because symptoms of vitamin D deficiency are often very nonspecific or vague, the problem is often missed. The diagnosis is more easily reached in severe deficiencies with some of the classical symptoms and bone deformities like rickets (see below).

**Symptoms in babies and children** Babies with severe vitamin D deficiency can get muscle spasms (cramps), seizures and breathing difficulties. These problems are related to consequent low levels of calcium. Children with severe deficiency may have soft skull or leg bones. Their legs may look curved (bow-legged). This condition is known as rickets (image to right). Growth may be stunted. Height is usually affected more than weight. Affected children might be reluctant to start walking. Children with vitamin D deficiency may be late teething as the development of the milk teeth has been affected. Irritability in children can be due to vitamin D deficiency. Children with vitamin D deficiency are more prone to infections. Respiratory (breathing) symptoms can occur in severe cases. Breathing can be affected because of weak chest muscles and a soft ribcage. Rarely, an extremely low vitamin D level can cause weakness of the heart muscle (cardiomyopathy).



**Symptoms in adults.** General vague aches and pains are the common symptoms.

In more severe deficiency, there may be more severe pain and also weakness. This may lead to difficulty standing up or climbing stairs, or can lead to the person walking with a waddling pattern. Bone pains may develop and are typically felt in the ribs, hips, pelvis, thighs and feet. This is known as osteomalacia.

**How is vitamin D deficiency diagnosed?** It may be suspected from your medical history, symptoms, or lifestyle. A simple blood test for vitamin D level can make the diagnosis. Blood tests for calcium and phosphate levels and liver function may also show changes linked to a low level of vitamin D. Sometimes, a wrist X-ray is done for a child. This can assess how severe the problem is by looking for changes in the wrist bones.

**What is the treatment for vitamin D deficiency?** The treatment is to take vitamin D supplements. This is a form of vitamin D called ergocalciferol or calciferol. Vitamin D can be given as an injection or as a medicine (liquid or tablets). Your doctor will discuss the dose, and best treatment schedule, depending on your situation, age, severity of the deficiency, etc. Briefly, one of the following may be advised

**Injection** A single small injection of vitamin D will last for about six months. This is a very effective and convenient treatment. It is useful for people who do not like taking medicines by mouth, or who are likely to forget to take their tablets.

**High-dose tablets or liquids** There are different strengths available and a dose may be taken either daily, weekly or monthly. This will depend on your situation and on which particular treatment guideline your doctor is using. Always check with your doctor that you understand the instructions - with high doses of vitamin D it is important to take the medicine correctly. The advantage of the higher-dose treatment is that the deficiency improves quickly - important in growing children.

### **Standard-dose tablets, powders or liquids**

These are taken every day for about 12 months so that the body can catch up on the missing vitamin D. This is a rather slow method of replacing vitamin D, but is suitable if the deficiency is mild, or for prevention. A disadvantage is that all these preparations contain either calcium or other vitamins, giving them a strong taste which some people dislike.

**Maintenance therapy after deficiency has been treated.** After vitamin D deficiency has been treated, the body's stores of vitamin D have been replenished. After this, maintenance treatment is often needed long-term, to prevent further deficiency in the future. This is because it is unlikely that any risk factor for vitamin D deficiency in the first place, will have completely resolved. The dose needed for maintenance may be lower than that needed to treat the deficiency.

**Preventing vitamin D deficiency.** Various groups of people (detailed earlier) are prone to develop vitamin D deficiency. Therefore, in summary, the following groups of people are advised to take vitamin D supplements routinely. The dose advised varies depending on your circumstances, age, etc.

Your doctor, nurse or midwife will advise on the dose.

- All pregnant and breast-feeding women.
- 
- Breast-fed babies. (Bottle-fed babies do not need vitamin D supplements as formula milk is fortified with vitamin D.)
- Young children up to the age of five years.
- All older people aged 65 and over.
- People whose skin is not exposed to much sun. For example, people who cover their skin for cultural reasons, people who are housebound, etc.
- People who have pigmented skin. (For a given amount of sun exposure, people with darker skin produce less vitamin D than people with lighter skin.)
- People with certain gut, kidney or liver diseases, and people prescribed certain medicines. In these cases a doctor's advice should be sought.

### **Cautions when taking vitamin D supplements**

Care is needed with vitamin D supplements in certain situations for example if you are taking certain other medicines: digoxin (for an irregular heartbeat - atrial fibrillation) or thiazide diuretics such as bendroflumethiazide (commonly used to treat high blood pressure). In these situations, avoid high doses of vitamin D, and digoxin will need monitoring more closely.

If you have other medical conditions: kidney stones, some types of kidney disease, liver disease or hormonal disease, specialist advice may be needed.

Vitamin D should not be taken by people who have high calcium levels or certain types of cancer.

You may need more than the usual dose if taking certain medicines which interfere with vitamin D.

These include: carbamazepine, phenytoin, primidone, barbiturates and some medicines for the treatment of HIV infection.

Multivitamins are not suitable for long-term high-dose treatment because the vitamin A they also contain can be harmful in large amounts.

Although vitamin D is essential for healthy bones and muscles, the majority of people do not get enough of it either through exposure to sunlight or through diet. Now, researchers have found that vitamin D3 supplements appear to provide more benefit than vitamin D2.

The study, conducted by researchers at the University of Surrey and funded by the Biotechnology and Biological Sciences Research Council (BBSRC), is published in The American Journal of Clinical Nutrition. Although vitamin D2 is often used in food fortification as it is not derived from animals, the researchers found that vitamin D3 is more effective at increasing the vitamin D levels in our blood when given as a supplement than vitamin D2.

### **Are there any side-effects from vitamin D supplements?**

It is very unusual to get side effects from vitamin D if taken in the prescribed dose. However, very high doses can raise calcium levels in the blood. This would cause symptoms such as thirst, passing a lot of urine, nausea or vomiting, dizziness and headaches. If you have these symptoms, you should see your GP promptly, so that your calcium level can be checked with a blood test. Some guidelines advise that people taking high vitamin D doses should have their calcium levels checked during the first few weeks. In practice, this is not usually done unless you develop symptoms of a high blood-calcium level.

**What is the prognosis (outlook)?** The outlook is usually excellent. Both the vitamin levels and the symptoms generally respond well to treatment. However, it can take time (months) for bones to recover and symptoms such as pain to get better or improve. Most people who are treated for vitamin D deficiency will need to be reviewed a few weeks or months after starting treatment - depending on how severe their symptoms are. A further review after one year is advised.

### ***Research into the effects of oral vitamin D supplementation on cardiovascular disease risk in patients with ME/CFS***

Investigations funded by ME Research UK and carried out by Dr Faisal Khan and Prof. Jill Belch from the Vascular and Inflammatory Diseases Research Unit, The Institute of Cardiovascular Research, University of Dundee, Ninewells Hospital and Medical School, Dundee, UK is ongoing.

Many ME/CFS patients have associated cardiovascular symptoms, such as reduced heart rate and problems with blood pressure regulation. Recent research at the Institute of Cardiovascular Research, Ninewells Hospital has shown that they also have significantly greater arterial stiffness than healthy people, an important finding since arterial stiffness is recognised to be an important factor in the development of early cardiovascular disease.

The group headed by Dr Faisal Khan at Ninewells Hospital, Dundee has been examining arterial stiffness (as measured by the gold-standard technique of pulse wave velocity) in relation to levels of vitamin D in the blood – and has discovered some evidence of a relationship between lower levels of vitamin D and increased arterial stiffness.

The question arises whether vitamin D supplementation might reverse the arterial stiffness, and in addition have positive effects on vascular function, as well as on neuromuscular functioning and chronic pain (two symptoms which are linked with vitamin D deficiency and which are facets of the day-to-day experience of ME/CFS patients). As vitamin D is easy to measure and deficiency is relatively easy to correct with supplementation, Dr Khan's group planned a clinical trial to test whether vitamin D supplementation in ME/CFS patients can lead to improvements in cardiovascular function and symptoms of ME/CFS.

The researchers have recruited 50 ME/CFS patients from the surrounding areas of Scotland. Participants will come to the unit in Dundee on 5 occasions for a variety of measurements; one half of the participants will be given high-dose vitamin D oil, and one half will be given a matching dummy placebo oil by mouth. Neither the patients nor the investigators will know which oil a person has taken, so that the results of the tests cannot be influenced in any way. Each patient will have a full medical examination initially, and the outcome measures will be performed at baseline, 2 and 6 months.

The primary aim is to see whether giving oral vitamin D supplementation improves arterial stiffness in ME/CFS patients, compared with giving a matching dummy supplement. Secondary outcomes include endothelial function; metabolic, thrombotic and inflammatory markers; and symptoms as assessed by fatigue scales, SF36 quality of life, and HAD scale.



**Recipe Corner** by Carolyn**Spiced Tuna Salad Niçoise.**

Serves 4. Cooking time under 30 minutes.

**Preparation method**

Preheat the oven to 220C/400F/Gas 7.

Spread the apricot jam over the tuna pieces.

Place the ground cumin and coriander into a bowl and mix to combine, then place the tuna into the spices. Roll to coat and leave to marinate for 20 minutes.

Heat an ovenproof frying pan until hot then add the tuna. Cook on each side for 15-20 seconds, just to lightly brown the tuna. Transfer to the oven to roast for 3-4 minutes, until just cooked but still pink in the centre, or until cooked to your liking.

Meanwhile, for the dressing, place the garlic, anchovies and egg yolk into a pestle and mortar (or a pyrex type sturdy bowl) and pound to a paste.

Add the lemon juice and the olive oil, and mix well.

Add the mustard and season, to taste, with salt and freshly ground black pepper.

To assemble the salad - place the beans, potatoes, olives and eggs into a bowl, add the dressing and mix well. Transfer onto a serving plate, cut the tuna in half and place on top.

Rub the toasted baguette slices with the garlic clove, then top with the tomatoes. Place the tomato toasts around the edge of the salad and serve.

**Ingredients:-****For the tuna:-**

4 tbs apricot jam  
400g/14oz fresh tuna steak  
2 tsp ground cumin seeds  
2 tsp ground coriander

**For the dressing**

½ clove of garlic  
2 (tinned) anchovy fillets  
1 free-range egg yolk  
½ lemon, juice only  
110ml/4oz olive oil  
1 tsp Dijon mustard  
salt and freshly ground black pepper

**For the salad:-**

110g/4oz French beans, blanched, and cut in half  
8 new potatoes, boiled until tender  
10 black olives  
8 quails eggs, boiled for 2½ minutes, peeled  
1 small baguette, thinly sliced and toasted  
1 garlic clove  
10 cherry tomatoes, roasted for 3-4 minute

**Red lentil soup**

Hearty, filling and comforting - Antony Worrall Thompson's healthy and low fat soup is perfect for a cold winter's evening.

**Preparation method**

Melt the butter in a heavy-based pan and add the ginger, allspice, cumin, chilli powder, curry powder, and ground coriander.

**Ingredients**

55g/2oz unsalted butter  
1½ tbsp grated fresh ginger  
¼ tsp each ground allspice, ground cumin, and chilli powder  
½ tsp each curry powder and ground coriander  
2 onions finely chopped  
1 parsnip, chopped  
1 stick celery  
1kg/2¼lb carrots, sliced  
85g/3oz split red lentils, rinsed  
25g/1oz long-grain rice  
1.7 litres/3 pints vegetable stock  
400ml/14fl oz tin coconut milk  
2 tbsp fresh lime juice  
3 tbsp chopped coriander



Cook over a low heat for three minutes, stirring continuously. Add the vegetables, stir to combine, and cook for a further eight minutes. Stir in the lentils and rice before adding the stock. Bring to the boil and simmer for 30 minutes or until the vegetables are tender and the lentils have started to break down. Blend the soup in a liquidiser or food processor until smooth. Return to the heat and add the coconut milk, lime juice, and coriander. Heat through but do not let it boil again. Serve immediately.

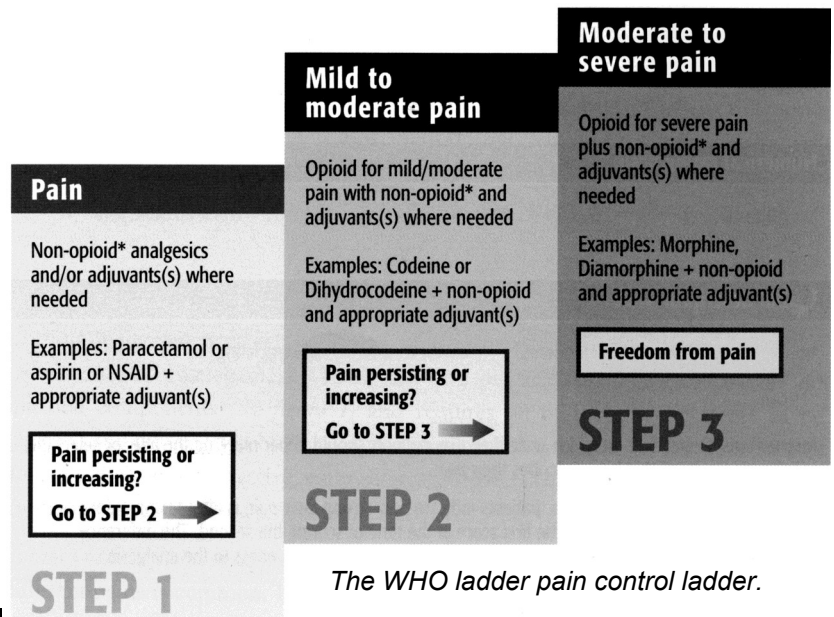
## Pain Control Update: Latest NICE Guidance on Strong Opioids

Originally the 'M' in M.E. stands for Myalgia, or muscle pain. However, many ME/CFS people do suffer from chronic pain. The NHS clinical strategy is a stepwise approach known as the World Health Organisation pain control ladder.

In many cases the pain can be controlled with paracetamol, but in a significant number of cases, strong pain killers known as opioids have to be used.

However these medicines are subject to strong legal control because of drug abuse so many doctors are reluctant to prescribe, resulting in under treatment. The latest NICE guidelines aim to tackle this problem.

The guideline is a bid to tackle the under-treatment of pain from chronic and incurable conditions.



*Below the care Pathway example*

### Opioids in palliative care: safe and effective prescribing of strong opioids for pain in palliative care of adults

Issued: May 2012

NICE clinical guideline 140  
guidance.nice.org.uk/cg140

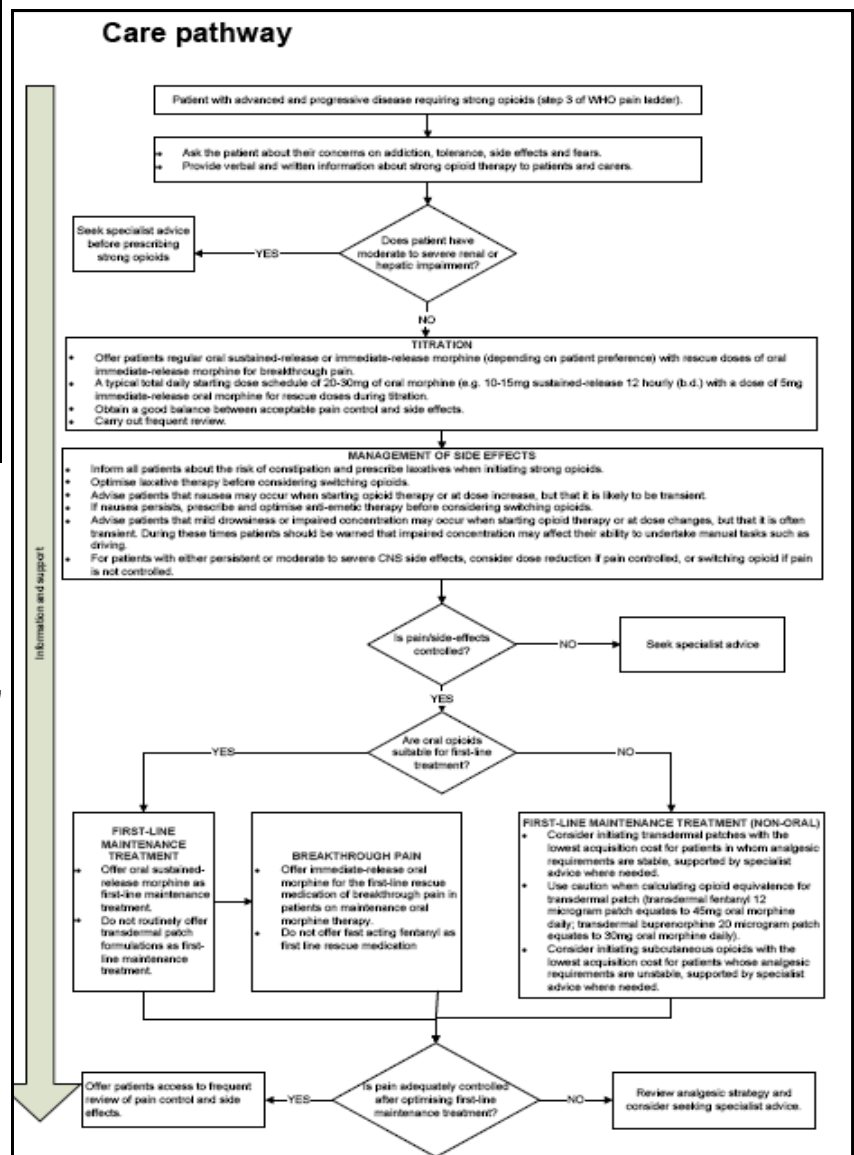
NHS Evidence has accredited the process used by the Centre for Clinical Practice at NICE to produce guidelines. Accreditation is valid for 5 years from September 2009 and applies to guidelines produced since April 2007 using the processes described in NICE's 'The guidelines manual' (2007, updated 2009). More information on accreditation can be viewed at [www.evidence.nhs.uk](http://www.evidence.nhs.uk)

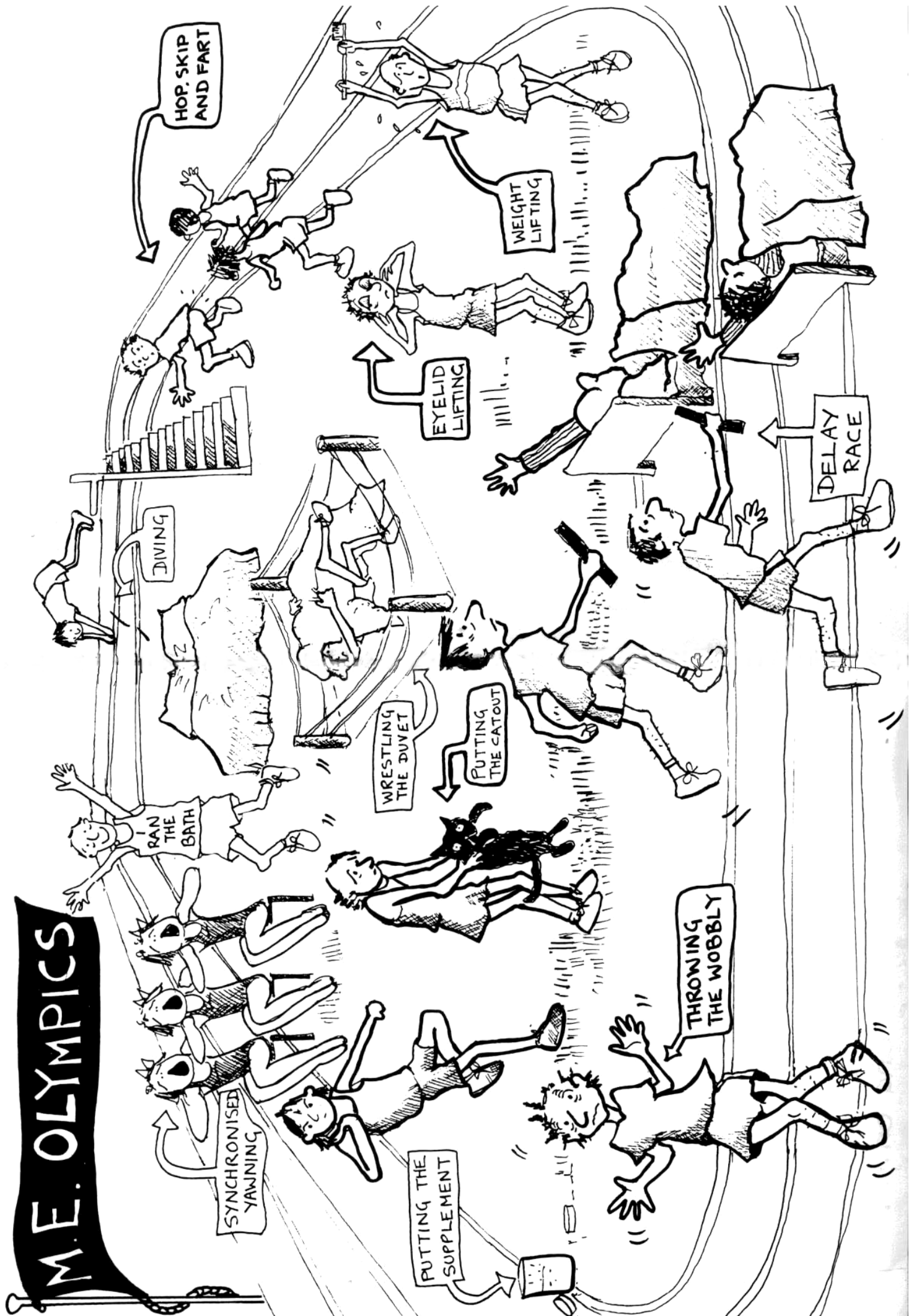


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The guideline aims to ensure safe and consistent prescribing of the strong opioids buprenorphine, diamorphine, fentanyl, morphine and oxycodone, for the relief of pain in patients receiving palliative care. In order to allay patients' concerns about: side effects and the possibility of addiction with long-term opioid use, NICE makes a number of recommendations for prescribers, centred on better communication.

Doctors should ask patients about their concerns, offer them frequent pain-control reviews and provide them with information on side effects. i.e. nausea, mild drowsiness or impaired concentration may occur when starting opioid therapy or increasing the dose.





## ***Tools to help with DWP form submissions.***

Here are two check-lists that I use at benefit clinics to help members organise their forms. Using these tools reduces the chance of a benefits refusal. These should be used in conjunction with the Work & Benefits guides. However the most effective way is to use the services of a welfare rights advisor.

### ***DWP Form Submission Evidence and Check List***

#### **Your GP**

- ☐ Record Last Appointment with G.P. and make sure it was less than 3 months ago.
- ☐ Copy of Summary Sheet from G.P. Surgery
- ☐ Copy of Repeat Prescriptions (MUR sheet, Prescription counterfoil or Surgery Printout)
- ☐ Copy of results of any tests e.g. Blood, or other diagnosis tests at the G.P. Surgery or Hospital.

#### **ME/CFS/Fibro Specific**

- ☐ Support letter from Sheffield, Leeds or other FMS/PVFS/ME/CFS clinic.
- ☐ 1 week Leger ME Daily Log sheet.
- ☐ Copy of appointment cards or letters from condition management clinic e.g. pain control clinic
- ☐ Copy of appointment cards or letters from condition management counsellor e.g. Clouds
- ☐ Copy of appointment cards or letters from community organisations e.g. SYCIL
- ☐ Copy of appointment cards or letters from private management clinic .

#### **Other Conditions (All conditions must be stated no matter how trivial or minor )**

- ☐ Support letter from Hospital or condition management clinic.
- ☐ Copy of appointment cards or letters from condition management clinic e.g. diabetic/asthma etc.
- ☐ Copy of appointment cards or letters from condition management counsellor e.g. Clouds
- ☐ Evidence of any medical devices or appliances used e.g. PFR or BM meter sheets & charts
- ☐ Evidence of use of any dietary or lifestyle management. (Diet, substance avoidance, pacing)

#### **Daily Living**

- ☐ Copy of appointment condition assessment or statement of care needs or letters from condition management clinic (e.g. Social services or SYCIL assessment report)
- ☐ List of any things used for cooking. e.g. Kettle tipper, microwave oven. trolley
- ☐ List of any things used for continence control e.g. pads, commode, ostomy bags
- ☐ List of any things used for personal care e.g. Bath or shower aids, washing aid etc.
- ☐ List of any things used for night care e.g. Bedroom adaptations, bed hoist
- ☐ List of any things used for mobility. e.g. stick, scooter, wheelchair, blue badge, mobility car

#### **Previous Claims or Tribunals**

- ☐ Copies of Past Decision Letters, points breakdown, ESA 85 or portfolio as advised

#### **Assistance & submission**

- ☐ Case Reviewed with Welfare Rights Advisor.
- ☐ Draft form checked by Welfare Rights advisor.
- ☐ Form and evidence photocopied or scanned.
- ☐ Proof of posting obtained

## ***Signs & symptoms List***

This is to help you organise your thoughts when filling out DWP forms or reporting problems to your doctor. Thanks to Action for ME.

### **Most Commonly Found**

Muscle fatigue

Early Morning Stiffness (EMS)

Emotional liability  
(includes frustration, elation, depression)

Myalgia usually affects limbs, shoulder girdle,  
spinal muscles)

Cognitive disturbance  
(memory, concentration, anomia, dyslexia)

Headache (include migraines)

Giddiness, disequilibrium dizziness

Autonomic dysfunction (  
especially circulation and thermoregulation)

Auditory or hearing disturbances  
(hyperacusis, deafness, tinnitus)

Reversal of sleep rhythm

Visual disturbances  
(mainly loss of accommodation, photophobia,  
nystagmus)

Paraesthesia, hypo & hyperaesthesia

Intercostal myalgia/weakness

Fasciculation, spasm, myoclonus

Clumsiness (usually due to impaired spatial  
discrimination)

### **Less commonly found**

Gastrointestinal symptoms (nausea/  
disturbance of intestinal motility)

Disturbance of micturition

Recurrent lymphadenopathy

Arthralgia

Orthostatic tachycardia (Fast heartbeat)

Recurrent bacterial conjunctivitis

Seronegative polyarthritis

Positive Romberg sign

### **Context**

Get muscle pain, strength fades, tremor.  
Need complete rest for at least 5-6 days

Always present, takes at least 2-3 hours to get going.  
Rebound penalty if things done in morning

Got depression & anxiety due to loss of employment  
and inability to cope and rationalise.

Chronic pain always present, worse on exertion.  
Under care of MMU pain clinic.

Always issue particularly during EMS,  
and when fatigue kicks in

A problem once fatigue syndrome kicks lasts 3-5 days  
or even months

A problem in winter months—but can happen anytime.

Always a problem (7/7).  
Feet particularly. (Raynauds absent)

Proven hearing impairment.  
Tinnitus a problem especially when tired.

Sleep phase delay 6 hours (7/7) with poor quality sleep

Bright lights unpleasant always, trigger migraines  
usually (1-2 times a month).

A problem with left leg thighs & knee 7/7

Always a problem, more prevent fatigue periods.  
Myoclonus indicates onset of fatigue state.

Possibly when tired or in fatigue state

Worse during morning stiffness, and fatigue periods.  
Dangerous when handling hot objects, e.g. kettle.

Chronic IBS symptomology, almost to the point of  
faecal incontinence. Needs avoidance & drug  
intervention

Under DRI for urological problems. BPH, urge  
incontinence.

A problem in winter months.

Arthralgia

Always a problem on minor exertion.

Issue during winter months.  
Treated by GP for dry eyes with artificial tears

Major issue, multiple joints to OA in later ME/CFS

Variable depending on fatigue state

## **Out & About with ME/CFS: Cusworth Hall Museum and Park.** from DMBC Website



Cusworth Hall is the jewel in Doncaster's crown. The grade 1 listed building is set in acres of historic parkland with lakes, plantations and pleasure ground with dramatic views across the town. The site which was extensively restored between 2003-2007 invites visitors to experience a wealth of architecture, heritage, landscape history, wildlife and exhibitions, events and activities. In 2002 the park and house received a major funding award from the Heritage Lottery Fund. It was in poor condition and desperately needed to be restored before the historic landscape was completely lost.



After careful consideration the date of restoration was set to 1909 to reflect the house. The 18th century features could be still seen, but the landscaping was practical for its use as a public park. The work in the park aimed to conserve and restore the historic features of the 18th century landscape, and yet make it more accessible for today's visitors. The grounds of Cusworth Hall consist of historic parkland and formal gardens. These include a walled garden, three woodlands, small woodland copses and hedges, grasslands, three lakes, two ponds

and a reed bed. Due to some of the unique features found at Cusworth Park the site has a diverse range of flora and fauna. This included restoring 'ye greate river' which involved major civil engineering on the reconstruction of the middle lake. The lakes are a rich habitat for many species including, water voles, kingfishers and green flowered hellebore orchids.

**How to get to Cusworth Hall and Park:** Most visitors travel by car to visit Cusworth. Cusworth Hall, Museum and Park is located 2 miles north of Doncaster, off the A638 Doncaster to Wakefield Road (York Road). It is signposted from the A1 and A638.

Admission Charges Cusworth Hall Museum: Adults £2, Over 60 and under 16s £1, Under 5s Free and a disabled lift is available. Entry to shop and Park is free.

Cusworth Hall Museum Opening Hours: Monday - Thursday 10.00am - 4.30pm, Closed Friday. Saturday & Sunday - 10.30am - 4.15pm but this varies according to season.

Tea Rooms are open every day 10am - 4pm, with a disabled toilet. Car parking charges apply, but is free to blue badge holders in marked bays. There are a further extra four bays via an access road in the car park. Public Transport to and from Doncaster Frenchgate Interchange: 42 or 219 to Cusworth, then approximately a 10-15 minute walk up Cusworth Lane. For further information telephone 01302 390959.



## **Research Project News**

*From Sheffield ME Group Spring Newsletter 2012*

The Medical Research Council (MRC) recently awarded more than £1.6m for research into the causes CFS/ME (Dec 21, 2011). The investment will fund five new projects to investigate the mechanisms and underlying biological processes involved in the illness, which could eventually lead to better diagnosis and the development of more effective treatments.

**Professor Stephen Holgate**, Chair of the MRC's Population and Systems Medicine Board, said: "There is a pressing need to understand the causes of CFS/ME, and the MRC is delighted to announce substantial funding to address this. The quality and breadth of the scientific proposals we received in response to our funding call exceeded expectations and led to us funding more studies than we had originally anticipated.

**Dr Charles Shepherd**, member of the MRC CFS/ME Expert Group and trustee of the ME Association, which has agreed to provide £30,000 to fund one of the five projects, said:

"The patient community will particularly welcome research involving biomarkers/biological fingerprints, which could lead to a diagnostic test, and immune system abnormalities, which could lead to more effective forms of treatment.

"The fact that one of the studies is being co-funded by the charity sector marks a much needed step forward in co-operation between patients and researchers in this field. This initiative could be utilised to help fund additional research involving the priorities not yet covered by this announcement."

The MRC has striven to stimulate high quality CFS/ME research for a number of years. Most recently the specially constituted MRC CFS/ME Expert Group, which involves leading researchers in the field and related areas, along with representatives from two CFS/ME charities, identified six priority areas where important research questions remained unanswered. The MRC issued a £1.5m call for proposals in these areas, aimed at encouraging fresh partnerships between established CFS/ME researchers and those with strong scientific credentials, but new to this field. The key areas were:

- **Nervous system disorders**
- **Cognitive symptoms**
- **Fatigue**
- **Immune deregulation (eg. through viral infection)**
- **Pain**
- **Sleep disorders**

In response to the high quality of the applications received, the MRC decided to provide an extra £150,000 to support the package of successful projects. The awards range in total value from £120,000 to £450,000 and the successful applicants were:

### **1 Identifying the biological fingerprints of fatigue**

Principal investigator: Or Wan Ng Institution: Newcastle University

Summary: Researchers will analyse the immune systems of more than 500 patients with primary Sjogren syndrome - a chronic condition with similar symptoms to CFS/ME, including intense fatigue. Scientists will look for immune system abnormalities in these patients to help them identify the biological "fingerprints" of fatigue. It is hoped this will improve their understanding of the mechanisms of fatigue with a view to developing new treatments. It also offers the hope of a clinical test for the diagnosis of CFS/ME.

## **2 Understanding the pathogenesis of autonomic dysfunction in chronic fatigue syndrome and its relationship with cognitive impairment**

Principal investigator: Professor Julia Newton. Institution: Newcastle University

Summary: Researchers will explore what causes dysfunction of the autonomic nervous system – characterised by dizziness and light-headedness – present in up to 90 per cent of CFS/ME sufferers. They will use functional magnetic resonance imaging (MRI) to measure changes in blood flow to the brain and how this relates to cognition and nervous system dysfunction. The researchers hope their work will lay the foundations for new diagnostic tools, a better understanding of nervous system abnormalities and the development of targeted treatments aimed at reversing these abnormalities.

## **3 Modulation of aberrant mitochondrial function and cytokine production in skeletal muscle of patients with CFS by supplementary polyphenols**

Principal investigator: Professor Anne McArdle. Institution: University of Liverpool (jointly with the University of Leeds)

Summary: Scientists will use a newly-developed technique to study the energy-generating components of muscle cells (mitochondria). Some studies have suggested that mitochondria may be dysfunctional in CFS/ME, leading to an energy deficit. The scientists hope this will help them learn more about how CFS/ME develops and becomes a chronic condition.

## **4 Can enhancing slow wave sleep (SWS) improve daytime function in patients with CFS?**

Principal investigator: Professor Oavid Nutt. Institution: Imperial College London

Summary: Researchers will study sleep disturbance – a core symptom of CFS/ME. Experts in CFS/ME, sleep and psychopharmacology will use a drug to increase deep restorative sleep in CFS/ME patients and measure the effect on their brain function during waking hours. It is hoped the research will increase their understanding of how sleep disturbance affects CFS/ME sufferers, with a view to developing new therapies.

## **5 Persistent fatigue induced by interferon-alpha: a new immunological model for chronic fatigue syndrome**

Principal investigator: Or Carmine Pariente. Institution: King's College London

Summary: Researchers will examine the effects of a protein called interferon-alpha (IFN-alpha) on the immune system. IFN-alpha is produced as a protective response to viral infection and is commonly used to treat infections such as hepatitis C. IFN-alpha also induces fatigue and flu-like symptoms in patients, similar to that experienced by patients with CFS/ME. The team will follow patients undergoing IFN-alpha treatment for Hepatitis C over a number of months to define the biological changes that occur in relation to the development of fatigue. Their work could lead to a check-list of blood measures to predict who will develop CFS/ME, as well as identifying new targets for therapy.

While the applications addressed most of the priority areas highlighted in the call, the MRC will announce shortly how it plans to stimulate research activity in those areas which were not covered.

For almost 100 years the Medical Research Council has improved the health of people in the UK and around the world by supporting the highest quality science. The MRC invests in world-class scientists. It has produced 29 Nobel Prize winners and sustains a flourishing environment for internationally recognised research. The MRC focuses on making an impact and provides the financial muscle and scientific expertise behind medical breakthroughs, including one of the first antibiotics penicillin, the structure of DNA and the lethal link between smoking and cancer. Today MRC funded scientists tackle research into the major health challenges of the 21st century.

Website: [www.mrc.ac.uk](http://www.mrc.ac.uk)

## A Summer Problem: Smelly Feet

I get all sort of enquiries on the contact line. This was a member with an embarrassing problem. She had tried many things like foot creams, powders & ointments. He had been invited over to friends next week. Last time everyone had to take our shoes off because of new expensive carpets. The problem was that she gets really smelly feet, which makes her a bit anxious. The husband has put his foot down and told her to get it sorted. I've actually had this problem for a while and my wife says it's time I got it sorted.



Foot odour, or bromhidrosis is a common problem. It commonly occurs with excessively sweaty feet. Sweat from feet causes bacterial breakdown of keratin from the skin which causes a bad smell. Poor hygiene and synthetic footwear (socks and shoes) can contribute to the problem. Many people with ME/CFS sweat excessively and are particularly prone to foot odour. Washing the feet, ensuring they are properly dried, and putting on a fresh pair of socks just before visiting the friends would be a quick solution but dealing with the problem in the long-term would give this man peace of mind. The trouble is that many foot odour products only mask the problem without dealing with the root cause.

Here are some helpful tips:

- Wash feet daily using mild soap and dry them thoroughly, especially between the toes
- Keep your toenails trimmed.
- Check your soles for hard skin and remove it with a foot file as damp, hard skin can harbour bacteria.
- Change your socks at least daily.
- Try not to wear the same pair of shoes two days in a row.
- Natural materials (e.g., high percentage cotton socks, leather uppers for shoes allow sweat to evaporate or be absorbed - avoid synthetic materials.
- Dust your feet with a medicated foot powder.
- Wipe feet with surgical spirit at night (stings—avoid any breaks in the skin).
- Use an antiperspirant foot spray for feet and shoes.
- Deodorising insoles can be used but they should be removed from shoes at night to dry out.

Anyone can get smelly feet but they're more likely if you:

are a teenager  
are pregnant  
are under mental or emotional stress  
stand up all day at work  
have a medical condition called hyperhidrosis

### When to see a doctor

Smelly feet are a common problem that usually clears up, but sometimes it can be a sign of a medical condition.

See your GP if simple measures to reduce your foot odour don't help, or if you're worried that your level of sweating is abnormally high. Your doctor can offer you a strong prescription antiperspirant or refer you for a treatment called iontophoresis, which delivers a mild electric current through water to your feet to combat excessive sweating.

### Foot soaks?

An old local remedy is Condies Crystals. They are in fact Potassium permanganate which has disinfectant, deodorising and astringent properties and some health professionals may recommend it as a home remedy, especially in cases of hyperhidrosis. However, care must be taken to prepare the correct concentration because solutions of potassium permanganate that are too strong can burn the skin. Gloves should be worn when handling the tablets or crystals. I would suggest using two or three tiny crystals per litre of water (enough to turn the water pale lilac, but not pink) or a 0.01 per cent solution (ie, one Permitabs (a brand name) tablet in 4L of water). The feet are soaked for 10 to 15 minutes. The soak can stain the skin, nails, clothing and containers with a brown stain.

## ***'The Ethel Trust Community Barge' from the Ethel Trust website***

'The Ethel Trust Community Barge' is a registered charity providing boating trips to community groups. The 'trust' is staffed mainly by volunteers and was established in 1988. We pride ourselves as being possibly the best. We work with the community for the community. Our offices are located in Sheffield city centre. We have one barge 'Ethel', which is operated from Thorne, north of Doncaster. We offer day trips or residential trips for two days or more.

Our patron is The Duke Of Norfolk. He said

*I'm proud to be the patron of the Ethel trust. In 1989 I came to see the renovation work being carried out on the old Humber barge, Ethel. That was in the early days of the project. Since that time the Trust has acquired through the generosity of many benefactors, large and small, and the dedication of all involved, a new purpose built barge, also named Ethel, specifically designed for use by the handicapped and disadvantaged of Sheffield and South Yorkshire.*

*I look upon the trips from four points of view. The first is obvious: all who come are almost miraculously helped to a richer and more rewarding way of life. A barge, properly fitted out creates an environment for the handicapped and those with special needs which is both safe and challenging. More surprisingly, here is a wonderfully creative and healing effect: there is hardly anyone who is not the better for being involved in such waterborne activities. Many are handicapped - physically or mentally, or living the life that has started to go terribly wrong.*

*My third reason for thinking a project like this is important is geographical and environmental. The River Don and the Don Navigation have played an important part of the history of Sheffield and South Yorkshire. Yet today they are neglected and forgotten. The more people who use these waterways the better.*

*The fourth reason is that my Grandmother, who was born at Broughton Hall, Skipton, and married my Grandfather, Lord Beaumont in 1893, and so lived at Carlton Towers near Selby, was called Ethel. No-one ever regrets supporting the Ethel Trust.*

The Duke Of Norfolk, Arundel Castle, BN18 9AB.

The 'Ethel' is a prestigious purpose-built community barge offering day and residential trips, on the inland waterways, to all groups from the very young to the elderly. Because 'Ethel' is fully accessible she can accommodate people with disabilities. 'Ethel' is licensed to carry a maximum of 12 passengers plus the skipper and crew. These trips are also highly valued by able-bodied community groups.



*From satisfied customers.*

The facilities include a fully-fitted galley, gas and microwave ovens, fridge and freezer, 240-volt power supply throughout, ample worktops and sink unit, 15' x 13' 6" indoor lounge with large double-glazed windows, thermostatically-controlled central heating, TV/Video/HiFi, two toilets with disabled access; one with shower, running hot water at all times, hydraulic lifts, fore and aft and a maximum 10 sleeping berths on residential trips. For safety we have safety equipment which is well in excess of Department of Transport requirements, safety rails all round viewing decks fore and aft, alarms, automatic bilge pumps, fire-resistant cladding. Each window is an escape hatch, and we have life jackets and lifebuoys.

## ***A Typical Day out on the Ethel***

Arrive at Staniland Marina Thorne at 9.45am for a 10am start. Your crew for the day will be ready and waiting for you. The



kettle is already boiling for a hot drink as we start the cruise along the Stainforth and Keadby Canal. As we pass through Staniland Marina – there is likely to be some activity with boat owners working on their boats in the dry docks or on land. Many people live aboard their boats here and are always ready to give you a wave.



As we leave Thorne behind us, the countryside opens up as we travel along and after a while we see the M18 motorway that passes over the canal. Winding our way along we can see different wildlife either on the water, in the skies, or in the fields while fishermen idle away the hours on the bankside. We pass by the ancient village of Fishlake with its Norman Church and converted windmill. As we pass through Staniland Marina – there is likely to be some activity with boat owners working on their boats in the dry docks or on land. Many people live aboard their boats here and are always ready to give you a wave.



The time is now around 12 noon and if you have not brought any food with you it is possible to purchase a fish and chip lunch to eat on board, or call in at the New Inn public house alongside the canal at Stainforth where a variety of food can be purchased at reasonable prices.

After lunch we continue towards the waterside hamlet of South Bramwith, pass through the swing bridge and on towards Bramwith Lock. We rest here, before continuing to the New Junction Canal, only opened in 1902. A short distance along is the impressive Don Aquaduct that carries



the canal over the tidal River Don. It is soon time to turn around and re-trace our journey slowly back to Thorne arriving at around 4pm.

***North of Doncaster*** Personal Comment by Trevor Wainwright

Advocacy and Support Groups, What is the difference....?

**Part 2 Support Groups****1 The Group Leader**

In this issue we look at Leadership in particular the Group Leader of which many feel they really are the boss. Sadly I have experienced it, not only in the ME world but in other groups I have been involved with. In this article and the next I hope to dispel the myth the Leadership means Omnipotency.

A good support group system is crucial to the overall well-being of patients because it addresses the needs of the patients. Therefore it needs a successful support group leader who can:

- Create a two-way relationship with participants, but responsibility for sharing and learning rests with the whole group
- Help to create and keep an environment of trust and openness where everyone feels safe to speak honestly and where differences of opinion are respected
- Provide a structure for sharing and learning, which might include setting and observing meeting times, opening and closing sessions, and keeping to an agenda and ensuring that everyone feels included and has an opportunity to participate
- Leading a group takes time and energy, as a result the following responsibilities should be shared with others once the group starts meeting on a regular basis. Ensure the "housekeeping" is done, such as preparing materials, setting up the meeting space, notifying participants and seeing that necessary preparations are made.
- However, when deciding whether or not to start a group, you must keep in mind that you may be handling many, if not all, of these responsibilities alone at one time or another:
- Facilitate the discussion, establish and enforce group guidelines and ensure they are adhered to.
- Select meeting place, dates and times and plan meeting content prior to each meeting
- Research and contact speakers relevant to meeting topics
- Ensure that all materials, hand-outs and equipment needed for each meeting are arranged in advance, and are current.
- Promote group meetings and activities; recruit new members and create a relaxed and friendly atmosphere at each meeting and encourage group member participation during meeting
- Compile, update and maintain a group-member list and prepare educational publications
- Recruit group members to participate in decision making, programming, publicity and other organizational activities

A support group leader is not, but sadly many think they:

- The person in charge: The whole group is responsible for participation. Members all have a voice in deciding the topics to be addressed regarding the running of the group..
- A lecturer, the leader is a co-learner, exploring all subjects as an equal partner and contributing individual experience to that of others.
- Necessarily an expert: Although preparing each session, the leader may not know as much about a subject as some other members of the group, but may be better suited to the task of leading. Knowledge isn't everything.
- The centre of attention: A skilful leader generally speaks less than other participants, effectively drawing others into the discussion.
- An arbiter: In collaborative leading, no one, least of all the leader, determines that some opinions are "correct" or "more valid."
- The maid: While the group leader takes initial leadership in coordinating the sessions, she or he should not become the only person who takes responsibility. In a true collaboration, no one is "stuck" cleaning up the mess or attending to administrative details every time.

In the next issue, the final part, the characteristics of a truly effective support group leader will be explored.