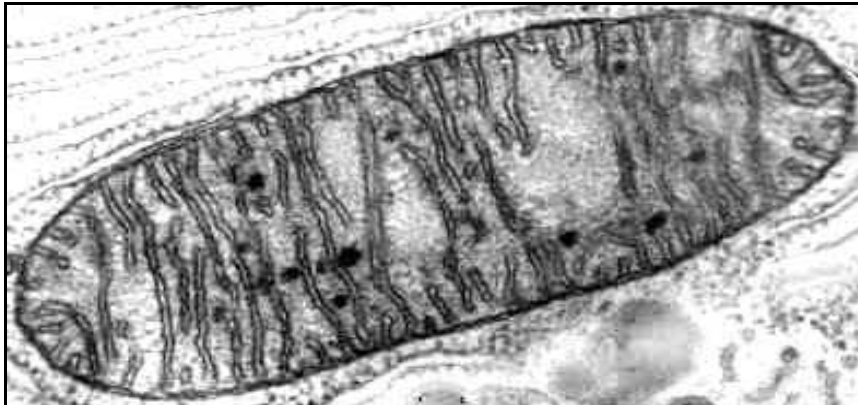
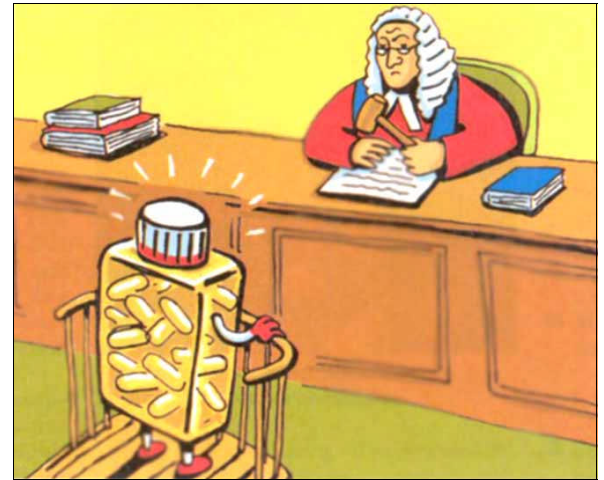


# Pathways

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



**7/7 London Bombers  
scupper Royal  
Free Vigil**  
*See page 9*



**EEC impose new restrictions on  
food supplements** *See page 13*

**More on the Mitochondria  
model of CFS/ME and an  
embryonic definitive test from  
the private sector.** *See page 15*

**Canal Boat Trip** *See page 5*



## Don't be afraid *By Carole Brown (from the Bolton & Bury Newsletter)*

Last month my husband Alan and myself were all set to go on holiday to the highlands of Scotland; namely Nairn, a sleepy little harbour side town, when you guessed it, the dratted ME struck again. Up until about a week before, I'd been going through a relatively good patch, when out of the blue – bang! You know the story. Exhaustion (goes without saying), head feeling like a vice, stomach (my usual weakest point) took flight and instead left me with something that resembled a jumbled mess, mouth not responding to the brain, but the most serious of all this time; I lost the use of my legs! I couldn't walk. My legs simply couldn't take the weight of my body without every one of my muscles screaming in pain. To say I was worried, frightened, was an under statement. To top it all everything combined together transpired to make feel **really** ill. I felt dreadful.

But, I was determined that nothing was going to get in the way of our holiday. Neither Alan nor myself had been so far into Scotland before so the attraction of going over the highlands to the tiny seaside retreat of Nairn was just too much of an enticement. So we duly went. That was to be the first mistake! It's so easy to look back with the benefit of hindsight and say that now, isn't it, but really I was too sick and should have known better.

I had considered, only considered mind, borrowing the Associations' wheelchair because I felt so almightily bad. But here's the second mistake; I let foolish pride get in the way and therefore just couldn't face the idea. **Me**, in a wheelchair? Not likely, I'd manage! So grim determination and utter stupidity got me there.

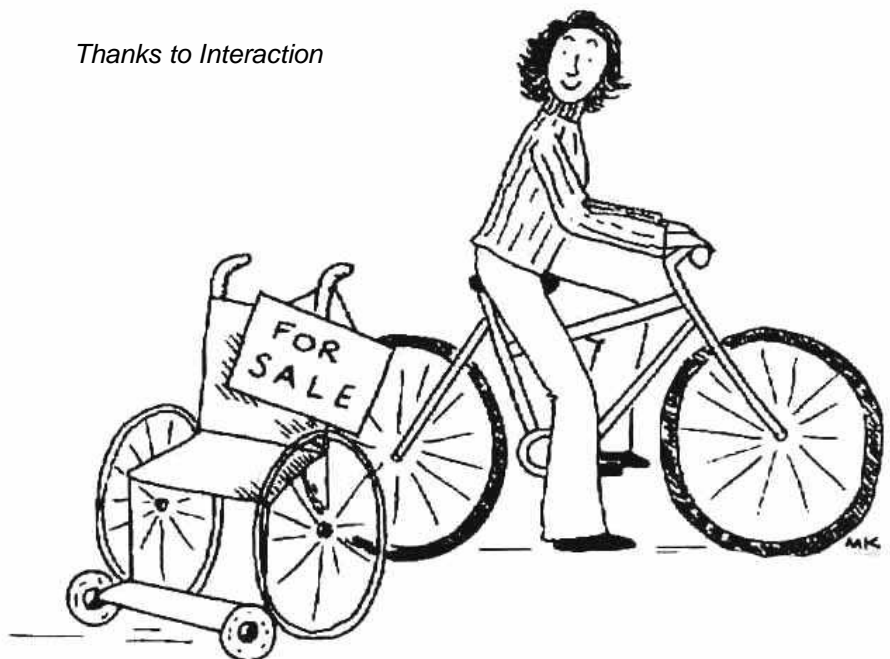
Third and what was to be the final mistake. The day after we arrived we decided to go and visit a place called Fort George. An outstanding example of a military fortification, built in 1746, that still continues to serve as a barracks for the British Army. Little did we know that it was spread over 42 ACRES!

Dilemma! What was I to do? Alan was so thrilled with the expectation of looking inside this place that I couldn't possibly cry off. But I could still barely walk and even though I felt better than the day before, I was still far from being well. In fact I still wasn't well at all.

"Why don't you use one of our electric wheelchairs?" came the enthusiastic retort from the huge, Scottish kilt-bearing man behind the desk. Somewhat taken aback and secretly mortified at the thought of someone **suggesting that I use a wheelchair**, for once in my life I was dumbstruck.

Before I had the time to find my unusually quiet mouth, a wheelchair had appeared. If I was mortified before, then I was completely crushed now. Despite being absolutely frightened to death at this prospect, I had no option but to slowly step into it, where I was duly shown how it worked. Me – in a wheelchair? I still couldn't take it in, so of course, I didn't pay attention to what the very well built Scottish gentleman in the kilt was telling me. It probably wouldn't have made a scrap of difference even if I had though, because, well before he'd got to the end, I'd

*Thanks to Interaction*



AT LAST, SHE COULD TRADE IN HER OLD SET OF WHEELS FOR A FASTER MODEL.



have forgotten the beginning! According to Alan I give blondes a bad name, so of course I had to be shown again.

But then all my previous mistakes were wiped out in one go, because let me tell you, this machine was a godsend. After about the first five minutes of getting the hang of trying to manoeuvre the thing, I relaxed and began to appreciate what it was doing for me. Not only was it enabling both of us to spend hours looking around every nook and cranny of this fascinating place, but it was also actually enforcing rest. Whilst sitting down in the chair, I wasn't trying to do anything else.

So for the next few days, I hired one of these electric wheelchairs wherever we went and I'm sure it's only due to the enforced rest that these things afford, that by the middle of the holiday I began to feel much better.

So take heed, don't be proud, don't be embarrassed, don't be afraid like me, make use of wheelchairs when you need to – you know in the long term it makes sense.

### ***A Telephone Scam Warning (courtesy of the Kirklees Group Newsletter)***

There are three scams. Firstly one for fixed telephone lines. Typically you will receive a call which is a recorded message congratulating you on winning an all inclusive trip to some exotic location, or you have won a large cash sum. You will then be asked to press 9 to hear further details. If you press 9 you will be connected to a premium rate line that costs approximately £20 per minute. Even if you now disconnect immediately the line will stay connected for a minimum of 5 minutes costing you around £100. The final part of the call involves asking you for your post code and house number. This now has really serious consequences. After 2 minutes you will be informed that you are not one of the lucky winners, and the bill will be £260. Since the calls are originated outside the UK, BT and other telephone companies are left relatively powerless to act. The only safe solution is to hang up on any unsolicited 'free offer' calls.

Secondly, sometimes calls are also made by individuals claiming to be engineers testing the line because of reported faults, and asking you to press 9 or 0#. Please do not dial 9, (or 90# or 09#) for anyone. There is a third scam operating on mobile phones. A missed call comes up, the number being s 0709 020 3840, the last four numbers may vary but the first number will be the same. If you call this number\_back you will be charged at £50 per minute. So do not call any numbers beginning with 0709.

### ***Spicy Coconut Chicken (from the Bolton & Bury Newsletter)***

Coconut Milk is a delicious alternative to milk and contains anti-candida substances, so will be good for those on an anti-candida way of eating. Creamed Coconut can also be used: Make it up to the required volume as instructed on the packet. Chickpeas also work well in this dish. Increase the chilli in this if you want it hotter. Chicken can be substituted with Quorn or Tofu.

#### Ingredients:

2 skinless chicken breasts	1 tbsp sunflower oil	1 onion	2 garlic cloves
200ml/7fl oz coconut milk	2 tsp coriander	1 tsp cumin	1 tsp turmeric
½ tsp ginger	½ tsp chilli	2 tsp water	Juice of ½ a lemon
½ tsp cinnamon	½ tsp salt		

#### Method:

Chop the onion. Slice the garlic and fry gently in oil, adding all the spices after one minute. Remove everything from the pan and set aside. Cut the chicken into small pieces and brown on all sides. Add the onion mixture, water and lemon juice; simmer for 15 minutes, adding a little more water if needed, but don't make the mixture too liquid. Pour in coconut milk, add salt and cook for a further 5 minutes. Serve with brown basmati rice.

## ***Epilepsy & ME/CFS Compared.***

Epilepsy is a 'respectable' neurological condition, whereas CFS/ME is not. However when both are compared there is a strong degree of overlap. The ancient Greek, Hippocrates (460 to 377 BC), was the first person to suggest that epilepsy was an affliction of the brain. However, it was Thomas Wilks (1622-75), regarded as the founder of modern neurology, who re-established the view that epilepsy arose from a disorder of the brain. Epilepsy has been described as: 'A transient uncontrolled discharge of nerve tissue in the brain leading to a brief stereotyped event in which the individual's awareness of his surroundings may be impaired and/or in which his behaviour is altered'. A single event cannot be described as epilepsy. There must be more than one event of the same type before we can describe it as such. These events are usually called 'seizures'. While most attacks occur spontaneously they may occasionally be triggered by flickering lights e.g. disco lights and poor quality television, emotional states (fear, anger, stress, boredom), menstruation (before or during the menstrual period - (catmenial epilepsy), sleep (seizures are often triggered by a lack of sleep), and drugs (alcohol and medication). Attacks almost always stop spontaneously but rarely attack will follow attack with the patient not recovering in between. This is Status Epilepticus, and is a clinical emergency. It is particularly dangerous if the seizure stops a person breathing normally.

### ***Diagnosis***

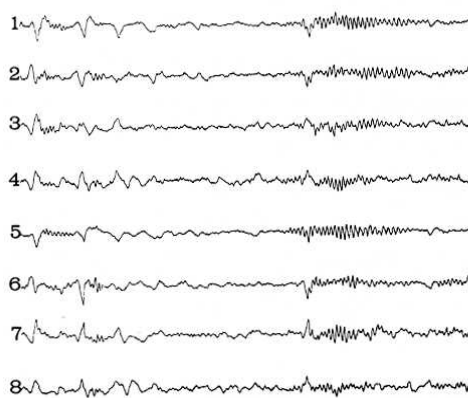
In a similar way to ME/CFS the diagnosis of epilepsy is based entirely on the history or story of events from the patient and from an eyewitness. However, one seizure cannot be regarded as epilepsy, which is a tendency to have recurrent spontaneous seizures. The distinguishing features of epilepsy are that it is periodic and recurrent and, in between seizures, the majority of patients are perfectly normal. Many people diagnosed with epilepsy subsequently are found not to have the condition. One study showed that up to 30% of children referred for uncontrolled seizures did not have epilepsy. The opposite also applies - many people thought to have similar conditions subsequently are found to have epilepsy. If a person is having blackouts, dizzy spells or 'funny turns', then referral to a neurological specialist is required. The diagnosis is essentially clinical and an accurate description of the episodes by an eye witness, if any, is a great help in distinguishing the condition from other similar but unrelated conditions. There are a number of conditions which are also characterised by an impairment of consciousness, these include:

Vaso-vagal attacks (fainting fits or syncope), migraine, stroke, temper tantrums, panic attacks. .  
 abreactive attacks (part of post traumatic stress disorder), psychogenic attack (pseudo seizures or hysterical fits).

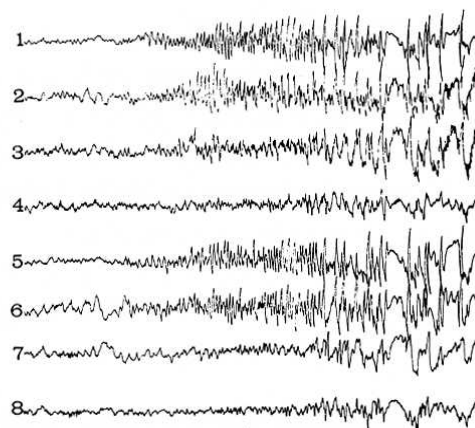
While the Electro Encephalogram (EEG) can be used to establish the type of epilepsy and thus will influence initial treatment, the vast majority of patients with epilepsy have a normal EEG between seizures. Accepting these limitations, an EEG can help to distinguish between generalised epilepsy and partial epilepsy. It

may also locate the area of a focus for abnormal electrical activity.

Computerised Tomography (CT scan) may help detect scar tissue, cysts, abnormal blood-vessels and tumours, while Nuclear Magnetic Resonance (NMR) scanners are also used to obtain a more detailed picture than that obtained by the CT scan.



Typical EEGs. Left— normal.



Right—during an epileptic seizure.

## Types of Epilepsy

<b>Generalised</b>	<i>In generalised seizures both sides of the brain are affected at the same time.</i>	M.E.-related issues.
<b>Tonic-clonic seizure</b> (grand mal)	Most common seizure type. The patient becomes rigid and falls to the ground, often emitting a cry. May become cyanosed as breathing is interrupted. This is followed by a rhythmic jerking of the body. The patient may make grunting sounds as air is forced through the larynx. Saliva may froth from the mouth which may be tinged with blood if the tongue or cheek has been bitten. Occasionally the patient is incontinent. As the seizure passes, the patient is left drowsy and confused and may sleep. This can vary from minutes to hours, although patients may be conscious almost immediately. There is no recollection of the seizure but they may experience pains in the muscles and/or feel disorientated. Some patients experience seizures at night, the condition may only be recognised by a partner.	This can happen in patients with high fever especially children.  Can happen with diabetics with a hypo (Insulin-overdose or lack of food).
<b>Absence seizure</b> (petit mal)	This pattern affects mainly children. The patient becomes unaware for a brief time and recovers quickly. The seizure may pass unnoticed and may occur many times a day. In children of school age, absence seizures may be mistakenly attributed to lack of attention.	Something similar can affect ME/CFS sufferers, especially, if chronic and uncontrolled.
<b>Myoclonus</b> (myoclonic Jerks).	In this type of seizure the limbs periodically jerk uncontrollably. The patient may occasionally be thrown to the ground by the severity of the jerks. The most common type of myoclonic epilepsy is juvenile myoclonic epilepsy, which usually starts in adolescence. It is manifest by early morning jerks, usually just after rising. The epilepsy is often unrecognised until a tonic clonic seizure supervenes. Other rare seizure types are included under this general heading, but these account for less than 1% of all seizure types. They are usually very severe forms, are difficult to control and can often lead to injury.	The myoclonic jerk is a symptom of ME/CFS suffered by a high proportion of patients at sometime in their illness.
<b>Tonic seizure</b>	Here the muscles remain rigid for the duration of the attack and often the arms are held out in front of the patient in the salaam posture.	Not usually seen in ME/CFS
<b>Atonic seizure</b> (or drop attack).	In contrast to the tonic seizure, the patient loses all tone to the muscles and can fall heavily.	This can happen in some ME/CFS patients, who are undiagnosed or unpaired.
<b><u>Partial Seizures</u></b>	<i>The electrical disturbance starts in a localised area. The nature depends on the position of the focus and on the passage that the electrical disturbance takes through surrounding brain tissue. There may be an aura experienced that will allow the patient to place themselves in a safe position. The aura may be a feeling in a limb, a sound, smell, déjà-vu phenomena or it may not be describable by the patient. The patient may retain awareness throughout and symptoms may persist for some time afterwards.</i>	This depends on the type of partial seizure—see below.
<b>Simple partial seizure</b> (Jacksonian).	The symptoms depend on the area of the focus but will remain consistent for any one patient. Usually an abnormal sensation is felt such as a rising in the pit of the stomach, unusual smells (often sulphurous) or sounds, such as a snatch of conversation or music. Visual disturbances may also be experienced. These symptoms can seldom be seen by observers and therefore health professionals often rely on the patient to describe their own simple partial seizures. Normally the seizure will progress from a simple (consciousness unimpaired) to a complex partial (consciousness impaired).	Some ME/CFS patients experience false sensations like auras. These are usually a symptom of poor pacing or treatment.
<b>Complex partial seizure.</b>	The presentation of complex partial seizures shows great variation. For example, patients may appear to be agitated, perhaps displaying the typical plucking and smoothing of the clothes with the hands (automation). Patients may remove clothing, smack their lips, wander about and even perform tasks such as making a pot of tea without realising. They can respond to questions or when their name is called, even during the seizure, demonstrating that there is an impairment of consciousness rather than unconsciousness. Other behaviour may include the patient apparently attempting to open a window and these actions can be misinterpreted. In the past epilepsy has been misinterpreted as criminal intent or confused with psychiatric disorders.	Sometimes similar problems may be experienced by ME/CFS patients. These are usually attributed to short term memory problems, concentration or nominal aphasia (problem with speech).
<b>Unclassifiable</b>	There remains a small number of seizure types which defy classification, usually because of inadequate information regarding the description of the seizure.	I often wonder if some of these cases are misdiagnosed ME/CFS!.

## Treatment of Epilepsy

Preventing exposure to contributory factors or triggers is applicable in most epilepsies. Surgery to remove a focus from the brain can help a small number, while a few will find an element of control in various relaxation techniques. However, for the majority of patients, drug therapy is the mainstay of treatment. Some of the neuroleptic drugs have uses in treating ME/CFS

**Phenytoin** was introduced in 1939. It is effective, but however is a hepatic enzyme inducer and the ability of the liver to metabolise it becomes saturated at around its therapeutic concentration. It is effective only within a narrow therapeutic window. Adverse effects are common in about 50% of patients with 10% requiring withdrawal. It is no longer used as a first line drug. Fosphenytoin This recently introduced pro-drug is converted to phenytoin in the body. It has advantages when injected in emergency use.



*A vagal nerve stimulator. This is an implanted device that helps control epilepsy in some cases.*

**Primidone** is a precursor of phenobarbitone. The main problem as with phenobarbitone is sedation. It can be used to control tics and tremors.

**Carbamazepine** (Tegretol) Since its introduction in 1962, carbamazepine has become one of the most widely prescribed anti-epileptic agents. It is related structurally to tricyclic antidepressants and, because it has some psychotropic action, may also be used in some bipolar affective disorders. Trigeminal (facial pain) neuralgia will also respond, and the drug is often used for this condition. Some ME/CFS patients have been prescribed it to try and control the disease and also for pain control. The people with ME/CFS who are prescribed it usually say it works, so I am surprised it's not more widely used. Oxcarbazepine is a functionally related pro-drug activated by liver metabolism. It has advantages over carbamazepine in certain cases.

**Valproates** (e.g. Epilim) were used in the rest of Europe before their introduction in the UK, as the sodium salt, in 1974. They have been tried in the Greater Manchester area to treat ME/CFS. One patient told me that all it did was sedate her. It did however stop the tinnitus associated with her ME/CFS.

**Benzodiazepines** Diazepam is used to treat febrile convulsions and Status Epilepticus. It has been used to control absences and myoclonic jerks. It is also an effective muscle relaxant in certain cases of pain and has been prescribed for ME patients. The benzodiazepines are limited by their sedative properties and the development of tolerance, so doctors are reluctant to prescribe them.

**Gabapentin** is used to treat epilepsy, and trigeminal neuralgia. It is used in ME/CFS patients to control neuropathic pain.

**Other drugs include** Vigabatrin Piracetam, Levetiracetam Lamotrigine Topiramate Tiagabine Felbamate Ramecamide Acetazolamide AGH Methosuximide, Sulthamine and Paraldehyde.

Some ME/CFS patients may show similar symptoms to the epilepsy types. Please bear in mind that any concerns should be raised with your G.P. Happily, most cases of epilepsy can be controlled, which is a far better outlook than in the case of ME/CFS.

## ***Summer Boat Trips Aboard the 'Ethel'***

As with past years we decided to run another boat trip around the canals at Thorne using the 'Ethel'. This year we had two trips, the first going eastbound then the second westbound. As usual the skipper for the day was Phil Harrison with a crew member volunteer from the *Ethel Trust* team.

For the first trip we went eastbound towards the river Trent. The sky was overcast and the weather dull. On the way out from Thorne we passed a number of private moorings where the owners had made their patch more homely by adding garden features. The land is flat, and the canal is crossed by many road bridges. The bridges are the equivalent of the railways' level crossings, with the road having right of way. There were two sorts of bridges we passed, one type being a lift bridge and another a swing bridge, both of which are 'do it yourself'. On approaching the bridge the *Ethel* had to stop and tie up at a temporary mooring for that purpose. Several of the crew members then had to jump off and work the bridge. The first thing to do is erect in the road barriers to stop road traffic. Then the bridge has to be moved away from the canal. In the case of the lift bridge, this was done electrically whereas the swing bridge has to be moved by manual force. In several instances we went through with another boat sharing the work. The canal people are very friendly and co-operative. When we passed through the bridge we had to berth again to retrieve our bridge-operators. We did pass a number of fisherman and a guy walking his dogs. I've heard of people taking their dog for a walk in the car, but on a narrow boat was the limit!. Throughout the trip, skipper Phil gave us a running commentary about the various features we saw. We passed a section heavily overgrown with aquatic plants. Phil explained that this section was like a nature reserve with several rare species being seen there. We passed an overhead power line, where, because at one time tall barges had been expected to use this route commercially, the lines had been raised over two tall towers. After that, we did a three point turn on the canal and headed for home.

The second trip went westbound from Thorne. The weather was brighter. After negotiating Thorne lock which is a jump off and do it yourself affair, we proceeded towards Stainforth. We had provided a buffet, and Margaret kindly acted as Mum, keeping the tea flowing. We passed a number of features not normally seen from the road. We heard a shout of glee from a young fisherman who proudly showed us his first catch. We passed what must be the worst garden on the canal the remnants of the Christmas tree being in the canal bank. This part of the canal passed through woodland, and is isolated with no towpath. Phil explained all the various features of the flora and fauna, and very often they had seen red deer on previous trips. However we were not that lucky this time. He explained how this area of woodland had been planted after a local man had campaigned for the marsh to be drained. As we approached Stainforth we saw a family of swans. We did a three-point-turn and headed back. On the way back we saw a group of people testing their riding skills on their four wheeled motor cycles on a isolated dusty part of the canal bank. Although I had planned to run a raffle for LME, Phil as last year beat me to it and started selling tickets for the *Ethel Trust*. It was on the way back I noticed the ride was a little rougher than usual. When I looked, Margaret's daughter was at the helm, trying her boating skills supervised by Phil. Throughout the day she had been enthusiastically helping with the locks and bridges. I'm sure that she will have something to tell her school friends about the day out on the canal.

By having a day out on the canal with friends and family of members, it does allow people to talk freely about their problems. This trip was no different to the previous ones. Most of my time was spent talking to group members and family of members on various ME related issues. Certainly from my point of view, issues were raised which were not discussed elsewhere. So from my point of view, the trip had achieved its two objectives. It had helped a number of people with ME, and provided enjoyable day out for family and friends. Will we have another boat trip? Certainly. As the time coincided with the school holidays, a number of members who would have liked to be on the trips could not do so. So we will take this into account when planning the trip next year. *Mike*





**Sights from  
our Summer  
Boat Trip  
on board the  
'Ethel'**





## ***ME 50 YEARS ON A vigil outside the Royal Free***

Although the bombs of 7/7 hit London the Thursday before, we decided to carry out the Vigil. After arriving in Kings Cross, we made our way to the Royal Free Hospital, setting up in the grounds. We had to promise silence. There were many old campaigners there. Priority was given to the lighting and setting up of the candle, then it was into the Convict Suit and get the slogan ready. Once tied between two posts, it was to work. The flyers were handed out as were both BRAME info and MERSC Carers' Guides, the latter with e-mail links to certain groups. One young sufferer who was a patient at the hospital asked about the difference between ME and CFS, and the current PACE trials.

At midday came the command "silence everyone". After the silence ended we had a conversation with two of the Royal Free Security Staff. Due to a breakdown in communications we would have to move. The Met found us an equally good position, outside the hospital grounds, which gave even greater exposure to the slogan. I did take the chance to ask the Press Officer to accept the Tymes Trust Study on young people, 'Our Needs, Our lives' she willingly did so and I could not help but think, had she not come out, who would I have handed it to?

So to our new spot where it was business as usual. In fact it was even better, as we were joined by a patient in a wheelchair, quite happy to chat with us. People passing seemed to have more time and were curious as to why we were there, some even having friends and family with the illness and coming to us. We, the ordinary rank and file, were there to give them advice. I was still amazed at the number of people that did not know of the main ME support groups, something is desperately wrong there, what are those who are getting paid for running the groups, getting paid for?

Then the appearance of a legend, Russ Basset himself turned up. It was great to put a face to the name of one of the great campaigners. There was a bomb-scare while we were there but this turned out to be little more than a water engineer putting a cylinder down a drain to check for faults. The afternoon went on with one interested party; a woman who with a different illness had endured the problems of disbelief.

The Prison Suit again attracted attention with people asking why I was wearing it. I answered "I see a diagnosis of ME as a prison sentence without a release date".

Our slogan had been placed so as to be seen by the passing traffic, one passenger even winding the window down to ask what it was about, while the traffic lights were at red. She was hastily given some info and a quick explanation before the lights changed. Yes it was a great spot. In asking us to move on, the Press Officer had done us a great favour.

As with many events I have been involved with I decided to take some time out and look at it from the outside in. I was not disappointed. Not only were those attending talking to each other but ordinary interested people were coming up and joining the conversations. Yes, I thought, we were right to go ahead with the Vigil.

It got to 3:30 in the afternoon, it was getting quiet, and the candle had almost burnt down to its limit, so we decided that it was time to call it a day. But what to do with the Petunia? I took it to the reception, handing it to a member of staff. The man smiled and said "I will see it goes to a good home".

As we walked back to Kings Cross we saw a grim reminder of 7/7, pictures on the railings of the still missing. I thought of those who were missing a life through ME. We boarded the train and it left on time. It had been said during the Vigil, despite my reluctance to do it for a fourth time, that I was the best person to organise May 12 next year. Others had offered to form a committee, so at last there was rhyme and reason. "Are you going to do it?" someone asked, "Yeah, you bet I am" I replied, looking at the passing scenery as the train rumbled northwards towards our beloved Yorkshire and home.

## ***The Sheffield ME/CFS Clinic: Progress and Frustration***

First there was chaos, then the Chief Medical Officers Report, then six million pounds to solve the problem nationally. Over the past twelve months Elizabeth McDonagh and I (Mike Valentine) have been attending various consultative meetings held to assist the setting up of the Sheffield Clinic. At the very first meeting it was clear that there was no consensus. Ute Elliot, the chairperson of the Sheffield group had submitted quite a comprehensive document listing various issues about support and treatment in the private and NHS sectors. To the frustration of myself and many other group representatives, most of what we submitted has been side lined in favour of 'evidence-based' strategies. This 'evidence-based' approach is the way the NHS works, and as expected there is some degree of muddle when evidence contradicts other evidence.

For example we were given copies of an extract from the British Medical Journal based on clinical evidence listing interventions which went something along these lines:-

*"We have searched the evidence for systematic and rigorous answers to the clinical questions and situations below, focusing on the outcomes that matter most to patients and clinicians. We have then categorised each treatment or intervention according to its harms and benefits in those situations.*

*Treatments Beneficial:* Graded Exercise & Cognitive Behavioural Therapy

*Unknown effectiveness:* Antidepressants, Corticosteroids, Oral NAD, Magnesium injections  
Evening Primrose Oil.

*Likely to be ineffective or harmful:* immunotherapy."

This contradicts my experience and that of many other people. With this sort of rubbish being presented to health professionals, you can understand our frustration. Our inclination was to walk out of the meetings, but that would not be constructive and we would lose out eventually. The various teams are aware of this, and so have decided to formulate their own approach based on an evolutionary concept. In layman's words this is 'suck it and see' strategy.

The clinic saw their first patient on the 4th February this year, and with experience under their belt they called a meeting on Wednesday, 6th July 2005 for South Yorkshire and North Derbyshire Stakeholders. We were asked to consider progress mapping the patients' expected journeys. As well as staff from the NHS clinic, there were doctors in General Practice, hospital nurses, occupational therapists and other NHS workers. Conspicuously absent were people from the private sector. At the meeting we were split up into groups. One group considered ME in adults, another group looked at issues surrounding children and so on. The group I was with was asked to develop a process map. This is very similar to the drawing of a flow chart.

The process mapping allows the development group to see the 'whole picture' of the care process with all the major steps identified. It highlights the order in which things are completed or when specialists have input. It also makes it easy to identify the standards of care which may be monitored at the various stages of care. We were given a brief to answer four questions:-

What are the interventions?

When should interventions be completed?

Who should complete them?

Where should they be completed?

Having done that, we had to consider the patient's journey through the various stages and consider what should happen in terms of:- Medical Information, Rehabilitation, Patient Information, Patient Support and Carer Support.

The table I've produced is my own interpretation from experience and is an example of what was discussed. My contributions will be considered and compared alongside the other groups' responses. I expect certain aspects will be accepted. We'll have to wait and see.



***Example of Stages of ME/CFS Used To Identify Opportunities For Care.***

<b><u>Stage</u></b>	<b><u>Patient experience</u></b>	<b><u>Intervention</u></b>	<b><u>Typical Timescale</u></b>
<b>Presymptoms</b>	Minor abnormalities at the time not attributable to ME/CFS, but only in retrospect. May not happen in some cases.	G.P. may intervene, but nothing specific identified.	A few days to several years
<b>Symptoms</b>	Onset of major symptoms may follow what in retrospect is a triggering event. May be sudden and severe. Others may experience insidious onset.	G.P. may advise abstain from work or school. Symptomatic treatment.	Around 4-6 weeks
<b>Prediagnosis</b>	Symptoms do not resolve within expected time-frame. G.P. considers a preliminary diagnosis, and adopts a wait and see strategy.	G.P. arranges tests and a hospital appointment for second opinion. Counselling considered.	3-6 months
<b>Diagnosis</b>	Patient seen by consultant team, and usually told of diagnosis in hospital setting after many routine tests have turned out negative.	Issues of work and school have to be dealt with. Various health professionals' support is needed.	Date zero
<b>Early Phase</b>	Patient referred to speciality team for assessment and treatment including mental health assessment.	Given information about condition. May include various treatments.	First few months
<b>Acute Phase</b>	Patient experiences a cluster of erratic symptoms varying in presentation from day to day.	Work & school issues. Intense mental health support may be needed.	3–18 months
<b>Chronic Phase</b>	The patient experiences stable and predictable symptoms. They are usually more intense than in early phase. About 1% of patients remain at this stage for life.	Consideration of patient's long term care and welfare needs. School and work issues need to be resolved.	12 months to 3-5 years
<b>Recovery Phase</b>	The symptoms tend to be less intense and restricting, but are still present. 20-25% of patients will recover, but not to complete health. About 50-60% will alternate between recovery and chronic phase indefinitely.	There are long term issues of rehabilitation and welfare.	12 months onwards.
<b>Resolution</b>	Patient devoid of all symptoms. Only about 25% of patients reach this stage.	Back to normality	12 months onwards

***Oddments*** We were talking about vitamin and mineral treatment when a G.P. in my group who said “Aha! The placebo effect”. Little does he know about nutritional treatment, I thought. There was intense interest in the NE ME Group's ME sheets based on the CMO's report which I distributed. We talked of cyclic referral where patients are bounced between doctors. We talked of the NICE guidance (a subject on it's own, yet to come, which will be very controversial when published). Nothing concrete was resolved about DWP issues i.e. Incapacity Benefit and Disability Living Allowance. Then, private sector treatments were labelled of as ‘*Holy Grail*’. I received an apology about that at a subsequent meeting.

So what has been achieved? We'll have to wait and see -Mike (*More waiting and seeing-Liz*)

## **General Medical Council Place Restrictions on Dr. Skinner's Right to Practice.**

Current medical dogma decrees that if the blood levels of thyroid hormones (TH) are within the normal range, then the patient does not have a thyroid problem. What Dr. Skinner claims to have found is that patients with M.E. as a whole tend have lower TH four levels than the general population. He is among a group of doctors who prescribed TH to ME/CFS patients with 'normal' levels of TH.

There is an argument that there is TH resistance in some patients (analogous to insulin resistance in type 2 diabetes), therefore these patients should be given TH as treatment above normal levels. However there are dangers with this practice, for example one of our members has acquired a heart arrhythmia because of this practice. Some other private doctors take this approach, but only in conjunction with the patients G.P. and regular monitoring by means of blood tests. While thyroid hormones are cheap, costing pence per tablet, private thyroid blood tests cost about £100 a go. There is a tendency for M.E. patients not to visit their G.P.s and to rely on these private doctors. Hence a potential for short cuts and trouble.

The GMC Panel said:

*'Information ... suggests that your fitness to practise may be impaired as a result of the allegations made against you. These include, irregularities surrounding your prescribing practice which may have potentially harmful consequences and a failure to notify some of your patient's General Practitioners following treatment. ... the Panel considers that if your registration was to remain unrestricted you may pose a risk to patients and the confidence that the public are entitled to place in the medical profession and its practitioners would be undermined ... The Panel has noted the circumstances surrounding the complaints made against you by patients and other professional colleagues. The Panel has concluded that these are serious allegations which indicate that your professional practice and conduct may have fallen short of the standard expected of a medical practitioner. The Panel is therefore satisfied that in all the circumstances it is necessary to impose an order restricting your registration. ... The Panel is satisfied that the period of eighteen months is necessary and appropriate. In reaching this decision the Panel has taken into account not only the uncertainty of the time needed to resolve all the issues in this case but also the fact that whilst the total length of the order is eighteen months you are entitled at any time to make an application for an early review under section 41A(2) of the Act should circumstances surrounding your case change. Notwithstanding this, the order will be reviewed at a further meeting of the Panel to be held within six months unless matters have been resolved by that time.'*

As a result of the hearing of 29th June 2005, the Interim Orders Panel stipulated that for 18 months:

- a) He will accept new patients for endocrinological treatment only if they have been referred to him by a fully registered medical practitioner. i.e. he cannot accept self referral.
- b) Prior to starting or varying any treatment he has to ensure that he has liaised with the person's G.P. about any diagnosis and provisional care plan.
- c) He has to keep a detailed logbook of all patients seen in relation to work carried out as a registered medical practitioner and this will be reviewed at a later date.
- d) He has to keep clear, contemporaneous and accurate records, and record reasons for prescribing outside of recommended guidelines.
- e) He has to provide references from other doctors with whom he works and patient's G.Ps.
- f) He has to notify anyone he works for about these issues.
- g) He has to notify the GMC before starting any new job.

In other words this is something like the doctors equivalent of a ASBO (Anti Social Behaviour Order). There is an organisation called Thyroid Patient Advocacy -UK (TPA-UK) which disputes current medical dogma. They believe that there are thyroid problems in at least 25% of the population. They can be telephoned directly on 01865 310073. Their website is [www.tpa-uk.org.uk](http://www.tpa-uk.org.uk) The website covers the issues and describes Dr. Skinner's 'trial' in depth.



## ***European Court Tighten Rules On The Sale of Vitamins and Minerals.***

*(From the BBC NEWS)*

It is estimated that around 10 million Britons take vitamin supplements. The vitamin control proposals backed by Europe could ban around 200 supplements from sale and put restrictions on the upper limits of vitamin doses. Some health experts wanted to see vitamins and minerals controlled in the same way as conventional medicines. But critics argued the new rules were unnecessarily restrictive, and would deny consumers choice. Under the EU Food Supplements Directive, now in effect, supplements will only be able to include vitamins and minerals taken from an approved list. Minerals not currently on the approved list include tin, silicon, nickel, boron, cobalt and vanadium. However, manufacturers of products already on the market will have until the end of December 2009 to change any of the banned ingredients to ensure that their product can continue to be sold in the future. It is expected that the vast majority of products will not be affected.

The Alliance for Natural Health (ANH) said it interpreted the ban as applying only to synthetically produced supplements, and not to vitamins and minerals normally found in or consumed as part of the diet. The ban had been challenged by the ANH, the Health Food Manufacturers' Association (HFMA) and the National Association of Health Stores (NAHS). They argued the legislation would be too restrictive, and would threaten thousands of perfectly safe products. The directive was first approved by EU governments in 2002 and was designed to tighten controls on the growing market in products sold under the health food heading viz. natural remedies, vitamin supplements and mineral plant extracts. The HFMA and the ANH argued the directive was an unlawful restriction on freedom to trade, that implementation would impose an unnecessary burden on British business and there are no reasons to believe it is necessary to protect consumers' welfare.

After reviewing the evidence presented by both sides, European Court of Justice Advocate General Leendert Geelhoed said in April that the directive infringed legal guidelines in his opinion. However, the court pointed out that certain restrictions could be justified by the protection of public health and considered the measures in question to be necessary and appropriate for the purpose of achieving that objective. It is concerned about patients admitted to hospital suffering liver failure and severe stomach problems after taking high doses of vitamins. It said in some cases the supplements are preventing people getting the correct treatment for other chronic illness.

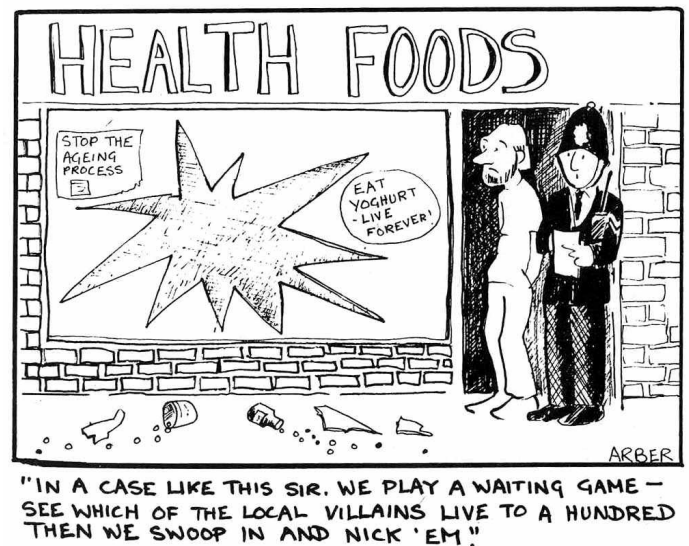
The ruling was also welcomed by Sue Davies, of the consumer magazine Which?. She said: "It will ensure that products are safe, that they contain forms of vitamins and minerals that offer some benefit, and that they are clearly labelled." Peter Aldiss, managing director of Holland and Barrett, said he was very disappointed by the decision. "There are hundreds of nutrients which are already very safely on sale with very strict laws in the UK. "This directive purely takes those nutrients out of the reckoning - they're perfectly safe and they've been on sale for decades." David Adams, director of HFMA, said the Prime Minister, who currently holds the EU Presidency, should get the legislation rewritten to allow the UK to include products on the market which would otherwise lie outside the list - a call echoed by the Conservative Party. The ANH said its lawyers had interpreted the directive's restrictions to apply only to minerals and vitamins from synthetic sources.

Public Health Minister Caroline Flint said Government was concerned that some of the provisions in the Directive could be "unduly burdensome", particularly for small companies making these products. "We have provided resources to help industry and small businesses supply the evidence necessary to allow their products to continue to stay on the market for the time being. This doesn't require them to do any new testing or provide new data at this stage. "The directive will also set maximum levels of vitamins and minerals in food supplements. We believe that any maximum dosage level should be based on scientific evidence. We will work with other member states and the European Commission on this basis." It will be possible to add products to the approved list and none will be removed unless they are proved to be unsafe.

The Food Supplements Directive 2002/46/EC came into force in July 2002 and was implemented in England by the Food Supplements (England) Regulations 2003. Separate, equivalent legislation has been made in Scotland, Wales and Northern Ireland. The directive and these regulations apply from 1 August 2005.

<u>Nutrient</u>	<u>Observed range</u>	<u>Most common daily intake</u>	<u>Possible effects of overdose</u>
Vitamin B6	10-80mg/day	10mg/day for 60kg adult	Peripheral neuropathy
Beta carotene	1.35-15mg/day	7mg/day	Promotion of lung cancer in smokers
Zinc	30mg/day	25mg/day	Gastrointestinal effects

As a result, safe upper levels of consumption have only been set for nine of the vitamins and minerals investigated — vitamin B6, beta-carotene, vitamin E, boron, copper, nickel, selenium, zinc and silicon. Guidance on safe levels, not to be confused with safe upper levels, was suggested for a further 22, and statements were issued for the remaining three, germanium, vanadium and sodium chloride because the data were inadequate to inform either safe upper limits or guidance. These three, the report says, are not suitable for use in food supplements even though they are still used in some instances. Specifically it notes that vanadium supplements aimed at body-builders and dietary supplements containing germanium, which were voluntarily withdrawn in the UK, are available over the internet. Don't ask us the difference between safe levels and safe upper levels 'cos we haven't a clue but, on your behalf, we're going to ask the DOH. Watch this space!



### ***Goodmornin', I'm from British Gas***

I wonder if you recall? What I'm on about is, before you had M.E., when decision making was easy? You needed a job done, you picked up the 'phone to chose the firm and how you wanted the job done. Completely decisive; you knew exactly what you wanted, and who you wanted to do the work.

We recently needed a job doing on our central heating system, nothing difficult, in fact very routine. The system needed to be flushed out and then an anti-corrosion fluid put through in order to prolong the life of the system. All we had to do was wait for the man to arrive, which he did, very cheerfully, at the allotted time on the correct day. I was already worn out by the time he was due to arrive having got up too early, chivvied the family into tidying up rooms and generally had my routine thoroughly messed up. John had been busy since the early hours moving furniture and general clutter away from radiators. Colin duly arrived and set about looking around all the radiators after which he set up the equipment. By this time I was 'completely exhausted' having done not a thing! I beat a fast retreat across to the neighbours for a while while John looked after Colin's brews. By the time I got back I was so wiped out I couldn't hold a conversation with them. Thankfully, Colin had nearly finished and was packing up his stuff while nattering cheerily with John. John then cleared up and put everything back in its place and then made tea, which I simply couldn't face by then.

Is this a dream, or a story from Fawlty Towers? No, this is the devastation of this debilitating illness we know as M.E. I am not writing this article to complain because this is what the illness does to me, but rather to let you know that this is a boat we are all in, you are not alone, you are not stupid, or foolish or deranged; we all understand that these are the kind of difficulties you face every single day.

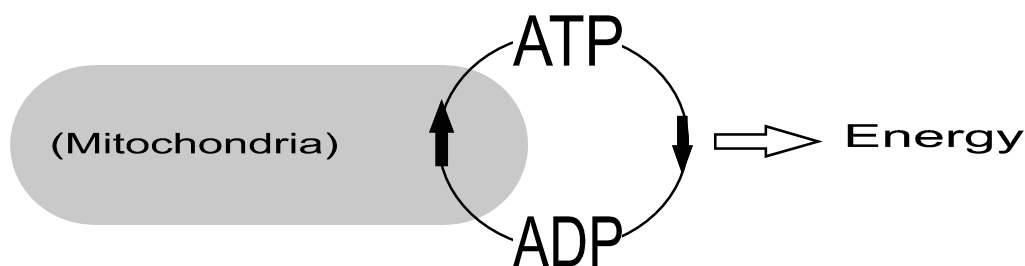


## Refining the Mitochondrial Model of Chronic Fatigue Syndrome

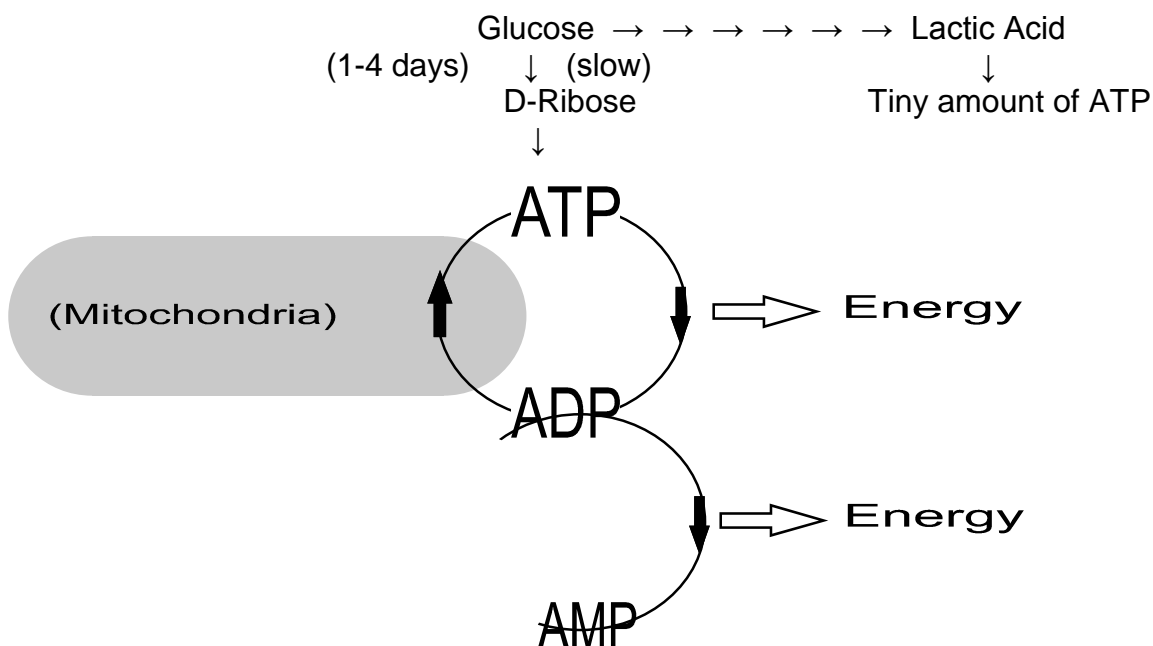
In Pathways No. 3, we explained what a mitochondrion is and featured a model of mitochondrial issues in ME/CFS based on Dr. Myhill's theories. Since then Dr. Myhill has further refined the model to a point where research indicates that definitive tests are available for ME/CFS, and the same tests can point the way to possible treatments.

### Is CFS/ME a symptom of Mitochondrial Failure?

Mitochondria are organelles situated in body cells. They are the power-houses of the cells, producing Adenosine Triphosphate (ATP) which is the energy source of the body. ATP is converted to Adenosine Diphosphate (ADP) releasing the energy for life processes. The ADP is recycled to ATP, and the whole process is repeated.



The whole cycle takes about 10 seconds, however if it slows down, the body goes slow. If the CFS sufferer really pushes himself he can get some energy by converting Adenosine Diphosphate (Adenosine+2 phosphates) to Adenosine Monophosphate (Adenosine+1 phosphate, AMP), but AMP cannot be recycled and is lost in urine. The body then has to wait for new ATP to be made. It can be made quickly from the sugar D-ribose, but D-ribose is only slowly made from glucose. If the body is short of ATP it can make a very small amount directly from glucose by converting the glucose into lactic acid. Two problems here, firstly lactic acid quickly builds up especially in muscles to cause pain, heaviness, aching and soreness ("lactic acid burn"), secondly no ATP is available to make D-ribose. So new ATP cannot be made when you are really run down. Recovery takes days.



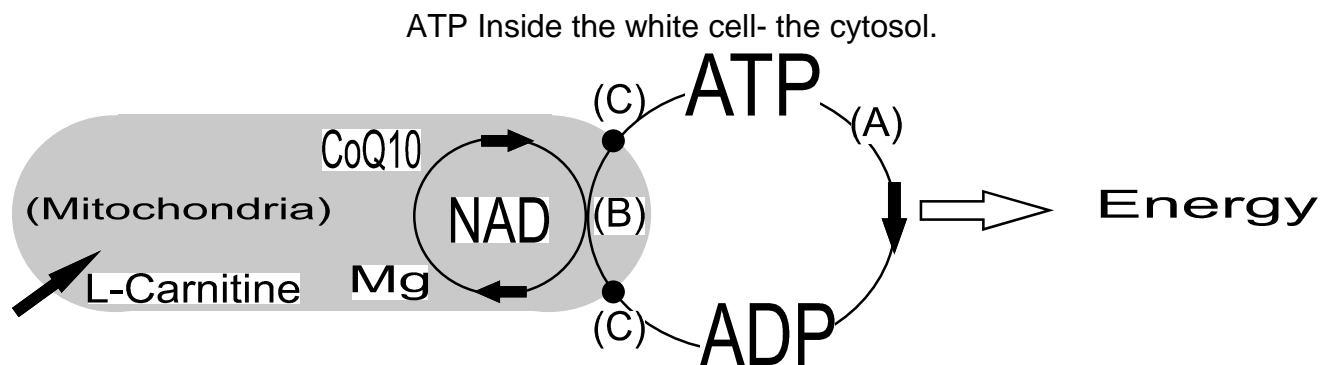
AMP cannot be recycled and is lost to the body via uric acid.

Treatment of CFS therefore is a two pronged approach. Firstly feed the mitochondria the raw material necessary to heal themselves and work efficiently. This means feeding the mitochondria correctly so they can heal and repair. Secondly address the underlying causes as to why

mitochondria have been damaged. This must also be put in place to prevent ongoing damage to mitochondria. In order of importance this involves:- Pacing activities to avoid undue stress to mitochondria, getting excellent sleep so mitochondria can repair, excellent nutrition with respect to taking a good range of micronutrient supplements, stabilising blood sugar levels identifying allergies to foods, detoxifying to unload heavy metals, pesticides, drugs, social poisons (alcohol, tobacco etc) and volatile organic compounds all of which poison mitochondria.

### ***A Test For Chronic Fatigue Syndrome ?***

The only difference between a normal person and a CFS sufferer is this speed of conversion of ADP to ATP. This depends on the amount of ATP available, how well it moves across mitochondrial membranes and how quickly the mitochondria can remake it from ADP. After resting (during when ATP levels are partially restored) the CFS sufferer therefore has normal energy for a few seconds, then he/she has to go slow. This means we have a test for CFS which has been developed by John McLaren Howard at Biolab. He can look at how much ATP there is and how it cycles through the cell and mitochondria. So we have not just the test for CFS, he can also identify where in the mitochondria things are going wrong. This test is done on white cells which, at the time of the test, are alive and kicking. Normally, the mitochondria inside white cells make ATP which pass through the mitochondrial membrane, outside the mitochondria and into the white cell cytosol where it is converted in the white cell cytosol into ADP with the release of energy. This conversion requires magnesium. Then ADP is moved back into the mitochondria where it is converted back into ATP again.



There are three parts to the test.

A) the speed at which ATP is converted to ADP is measured. This depends on magnesium, so the reaction is looked at normally, then again with addition of excess magnesium. This measures the rate of reaction and also picks up a magnesium deficiency. It also measures the amount of ATP in cells.

B) the speed at which mitochondria make ATP from ADP.

C) how well ADP and ATP move across the mitochondrial membrane.

From this test we can tell how disabled a sufferer is from the amount of ATP, how well it converts to ADP, how well they move it through mitochondrial membranes and how quickly they re-create ATP from ADP. Furthermore all these things can be treated.

A) Poor conversion of ATP to ADP is magnesium-dependent and may require magnesium supplements by mouth or by injection. Low levels of ATP can be improved by supplementing with D-ribose.

B) this is dependent largely on levels of magnesium, co-enzyme Q10 and vitamin B3.

C) this also is dependent on magnesium and pH. L-carnitine is necessary to bring fuel across the mitochondrial membrane as an energy source for mitochondria to recycle ATP. All these actions are dependent on enzymes which can be blocked by toxins such as pesticides, heavy metals, drugs etc. All enzymes need vitamins, minerals, EFAs and amino acids to work!

*The test costs £105 and requires a blood sample. It has to be arranged through Dr Myhill or your G.P. Although early trials are promising, more work is needed to refine the procedures and verify its accuracy before it will gain general credibility.*