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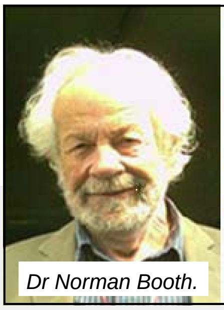
Pathways

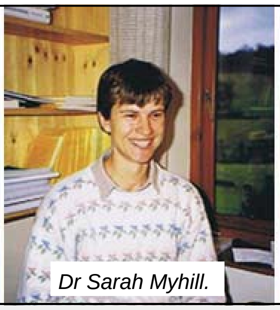
The newsletter of Leger M.E. Supporting Myalgic Encephalopathy or Encephalomyelitis (ME), Chronic Fatigue Syndrome (CFS), Post Viral Fatigue Syndrome (PVFS), Fibromyalgia Syndrome (FMS), Patients & Carers.

Research Breakthrough: A Test for M.E./C.F.S.

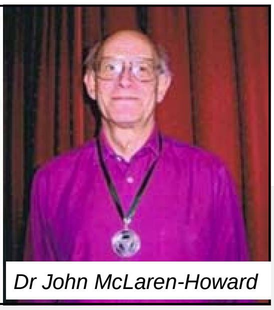
For more information see page 6



Dr Norman Booth.



Dr Sarah Myhill.



Dr John McLaren-Howard

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Original Article

Chronic fatigue syndrome and mitochondrial dysfunction

Sarah Myhill[1], Norman E. Booth[2], John McLaren-Howard[3]

[1]Sarah Myhill Limited, Llangunllo, Knighton, Powys, Wales LD7 1SL, UK; [2]Department of Physics and Mansfield College, University of Oxford, Oxford OX1 3RH, UK; [3]Acumen, PO Box 129, Tiverton, Devon EX16 0AJ, UK

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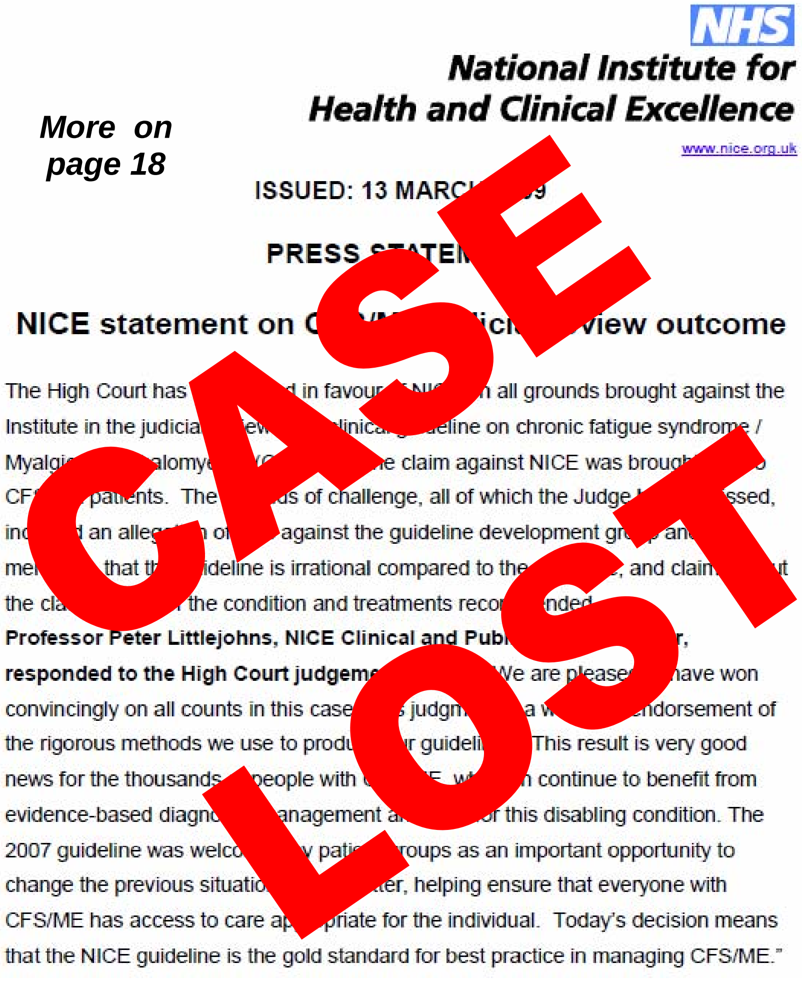
Nice guidelines legal challenge.

On 11th February two ME patients launched a High Court appeal against what they say is an "unfair and irrational" approach by the NHS to their condition. The judicial review has been brought by Kevin Short, from Norwich, and London-based Douglas Fraser. They argue the NHS was wrong to place so much emphasis on psychological rather than on medical therapies. But the National Institute for Health and Clinical Excellence said its August 2007 guidance was "robust". And he added the court case was "diverting resources away" from NICE's core work., AND ….*the case was lost - see right*

More on page 18



NHS
National Institute for Health and Clinical Excellence
www.nice.org.uk

ISSUED: 13 MARC[illegible]9

PRESS S[illegible]TE[illegible]

NICE statement on C[illegible]ici[illegible]view outcome

The High Court has [illegible]d in favour [illegible] NI[illegible]n all grounds brought against the Institute in the judicia[illegible]ew[illegible]linica[illegible]eline on chronic fatigue syndrome / Myalgi[illegible]alomye[illegible](C[illegible]e claim against NICE was brough[illegible] CF[illegible] patients. The [illegible]s of challenge, all of which the Judge [illegible]ssed, inc[illegible]d an alleg[illegible]n of [illegible] against the guideline development gr[illegible] an[illegible] me[illegible] that th[illegible]ideline is irrational compared to the[illegible], and claim[illegible]t the cla[illegible] the condition and treatments recom[illegible]nded.

Professor Peter Littlejohns, NICE Clinical and Publ[illegible]r, responded to the High Court judgeme[illegible] [illegible]We are please[illegible] have won convincingly on all counts in this case[illegible]s judgm[illegible]a w[illegible]ndorsement of the rigorous methods we use to produ[illegible]r guideli[illegible] This result is very good news for the thousands [illegible]people with [illegible]E, w[illegible]n continue to benefit from evidence-based diagno[illegible]anagement a[illegible]or this disabling condition. The 2007 guideline was welco[illegible]y pati[illegible]roups as an important opportunity to change the previous situatio[illegible]ter, helping ensure that everyone with CFS/ME has access to care ap[illegible]priate for the individual. Today's decision means that the NICE guideline is the gold standard for best practice in managing CFS/ME."

You Write

Bill Writes: I've just had an electric bill for £1500 for the winter quarter, and I'm having difficulty in paying it. I've been told that if I have gas central heating installed it will be cheaper to run. My neighbour tells me that the electric heaters I use are not efficient, and I would really be better of using gas. Because I am disabled I have been offered a 'Warm Front Grant' to have central heating put in, but I am frightened the hassle of the work will upset my ME. As ideas ???

I think you should put up with a couple of days of hassle, for peace on mind. There is nothing worse for ME than stress, whether it be cold, or anxiety about paying bills. Although electric heaters are convenient, and can be easily plugged in they are very expensive to run. To install gas central heating would cost about £3000 for the average house in our area.

I use British Gas for Electricity and Gas. For the same quarter as yourself I paid £162 for gas and £107 for electricity, a total of £269 which is around £30 per week. I am in a large detached bungalow, and do not economize - in fact am frivolous with energy use. The cost of a semi-detached house should be less, and even less for a terraced. So with a bill for £1500, something is not right. The first thing to do is contact your electricity supplier, get the meter checked, then you obviously need to work out what it is really costing. If you are using plug-in electric heaters, you are paying about three times more than you need. My gas costs 2.01p per kwh, and electricity 6.73p per kwh so if I used electric heaters for heating, it would cost me 3.5 times as much. So, using electric heaters alone my bill would be £1048. I would be absolutely stupid to change.

I think you really have two options, firstly get the central heating installed or use electric storage heaters. The latter use off peak electricity supplied at certain times which is far cheaper however, it requires separate wiring and a separate meter. Its disadvantage is that is it not instant and controllable - this type of heater takes at least a day to warm up. They are only really suitable for background heating or where there is no gas supply. Gas central heating is the cheapest to run, and since you have been offered it free anyway, you should take the offer - put up with the few days of inconvenience. Warm Front will also check for heat loss, and draught proofing may be offered along with loft insulation. I have not spoken about fireplace heaters. You have to consider your need. Electric and gas ones are around the same price, BUT gas appliances need to be regularly maintained at least once a year. There are various deals going with different companies. Expect to pay about £250 for central heating servicing and about £100 for any other gas appliance. This has to be considered against any fuel used. Personally I have two electric heaters, one fan, and one oil-filled. They are only for emergency use in the house if the central heating fails or for use in the ga+rage or shed. Don't even consider portable paraffin or gas heaters - they are expensive to run and dangerous. The fumes will make ME even worse. - Mike.

Donald writes: I have been prescribed simvastatin by my doctor, however I understand that it can cause serious side-effects especially in people with ME/CFS. What are my options?

Pathways asked Dr. Myhill her view:
People are becoming increasingly aware of raised cholesterol levels because they have been brainwashed by the pharmaceutical companies into believing that this is a serious risk factor for arterial disease, so they can sell expensive drugs in order to lower cholesterol levels. The main class of drugs currently used are the statins, but they have problems which are not generally voiced by the drug companies for obvious reasons. Whilst statins reduce mortality from cardiovascular disease, they do not reduce overall mortality - that is to say, more people die for other reasons, such as cancer, suicide and accidents. Secondly, statins have never been trialed in women. Thirdly statins work by inhibiting the enzyme that creates cholesterol, but it also incidentally inhibits the enzyme responsible for creation of selenium-dependent proteins, e.g. the glutathione essential as for heart function. Many statin-takers have died as a result of the muscle damage induced by statins and they are absolutely contraindicated in any patient with a history of muscle disorders, which includes sufferers with chronic fatigue syndrome. Statins are particularly bad for CFS sufferers because of their malign effects on muscle metabolism.

A raised cholesterol level is a bio-chemical symptom, it is indicative of a problem elsewhere in the body. 80% of cholesterol in the blood is manufactured in the liver, only 20% comes from diet, so it is difficult to affect levels simply through eating cholesterol. Secondly there are good cholesterols and bad cholesterols and it is a case of getting the right balance between the two. Every laboratory has their own normal range, but for a true reading you need to know your levels of HDL cholesterol, LDL cholesterol and triglycerides. However, if it has been ascertained that your cholesterol is unacceptably high (and for me that is 7 or above) with a low HDL, then this is symptomatic of something else going wrong. The common causes of raised cholesterol are as follows:

1) Borderline hypothyroidism. Indeed, thirty years ago a raised cholesterol was almost routinely treated with thyroid hormones.
2). Vitamin D3 deficiency. Cholesterol is the raw material, which through the action of sunshine on the skin, is converted into vitamin D. If the body perceives a deficiency in D3 and this is almost universal in our sunless climate, then the liver pushes out more cholesterol so that when ultraviolet radiation does land upon the skin, there is plenty of substrate for vitamin D3 to be made. Vitamin D3 deficiency itself is a major risk factor for arterial disease.
3) Vitamin B3 deficiency. A small study of six patients with chronic fatigue syndrome have shown them all to be deficient in vitamin B3 (niacinamide). Before the advent of statins vitamin B3 was widely used for the treatment of high cholesterol and is available on NHS prescription.
4) Copper deficiency.
5) Vanadium may be implicated but is unproven.
My (SM) view is that all the above mechanisms should be carefully explored before considering anti-cholesterol drugs, which have potentially serious side effects.

I agree with Dr.Myhill. We have 86 members with ME/CFS, 4 of which have been prescribed statins, with the resultant muscle damage, rhabdomyolysis. The claimed risk level is 0.001% (about the same level as being killed by a car when crossing the road), but with the people I see, it is more like 5%. The problem is that high cholesterol often occurs with high blood pressure, type 2 diabetes, overweight, increase risk of heart attack and stroke, and so on. Very often statins are prescribed with a basket of other drugs. The simplest precaution is a 75mg aspirin tablet daily - but is not appropriate for everyone, and very often missed.

My recommendations are that prior to any treatment the following blood tests should be done: Creatinine Phosphokinase, (if raised, indicates muscle damage), liver function tests, and a full thyroid function test (TSH, T4 and T3). Firstly fish oil (maxEPA) or nicotininc acid should be considered. Some members have been treated with bezafibrate (a fibrate, not a statin) and atorvastatin without side effects. I have had one case of rhabdomyolysis following a prescription of ezetimibe and bezafibrate combined. Once treatment is established, monitor CPK, LFT, thyroid and lipids frequently. If any new unexplained muscle pain develops, stop taking the antilipid, and immediately report this to the doctor as a matter of urgency. Over the years I have covered these issues in past issues of Pathways. These are available on the group's website.

Mike writes I wrote the following open letter to DRI, after receiving a complaint about the Doncaster ME/CFS clinic. Many people know that Dr. Odes at DRI is sympathetic to ME/CFS, and many of our members have been seen by him at DRI. Dr. Odes' interest in ME/CFS is welcomed, and from Leger ME point of view he supplements the Sheffield ME/CFS service, prescribing treatments via DRI that are normally only available to private patients. I have received various reports from around ten members of problems associated with Dr. Odes' Clinic at DRI. These appear to be mainly because the service he provides is not a planned mainstream NHS service, but only a personal specialisation. It would appear that DRI see this service as an anomaly outside their service remit, and are administratively discouraging the clinic. On many occasions, appointments have been issued by DRI when Dr Odes is not in the country. Several reports I have received indicate that Dr Odes will not be accepting any further NHS ME/CFS patients. I have written to DRI on behalf of the members about what I think are the most important issues and the text of the letter follows*:*

24/02/2009

Attention of:
Nigel Clifton, Chairman, D.R.I.
Armthorpe Road,
Doncaster,
DN2 5LT.

Dr. R.A. Odes' Clinic and ME/CFS Patients

As you are aware, I am chairman of the Leger ME, and I also represent the Doncaster area on behalf of the Sheffield ME/CFS Clinic. I have received reports from a number of our members, regarding the clinic Dr. Odes holds in D.R.I. (General Medicines), which gives me cause for concern. They are as follows:

1) Patients given an appointment with Dr. Odes, rarely ever see him, very often seeing someone they describe at a 'locum'. Although the 'locum' will provide repeat prescriptions on request, he/she does not appear to have any working knowledge of ME/CFS. This is causing frustration and stress among my members.

2) There are difficulties with Dr. Odes' medical secretary. They describe an officious, off hand, unsympathetic, patronising, 'take it or leave it' attitude. Many ME/CFS patients have issues with morning stiffness, and travelling. This fact alone stops many grade 2 and 3 patients attending the Sheffield ME/CFS clinic. The also complain of stress and rebound issues, which as you are aware of, are detrimental with ME/CFS and the general well being of patients.

3) Following discharge to the G.P., repeat prescriptions are declined by local G.P.s on the advice of Doncaster PCT. The drugs concerned are Ubiquinone(Q10), VegEPA (GLA & EPA), Melatonin, Vitamin B complex and Ascorbic acid. These usually have to be obtained privately.

As you are aware there is a Sheffield ME/CFS clinic, BUT this is mainly for grade 1 cases, and is OT-led dealing with CBT, Pacing and GET. There are NICE guidelines, but they are disputed in a similar way to many other conditions. Dr Odes is providing an NHS service only available from private doctors, and those who can afford to pay.

What can I do to help resolve these issues?

Yours sincerely, etc.

THERE IS NO ISSUE WITH DR ODES OR THE WAY HE TREATS PATIENTS AND PRACTICES

Shaun writes I experienced similar situations, the b****y secretary is incredibly rude, I phoned to cancel an appointment she said she would do it and didn't bother, I then received an abrupt letter telling me how naughty I was missing my appointment. She said she would ask Dr. Odes if he would see me but has never bothered to date. Dr. Odes said he would ring me at least four months ago but has never bothered, he got me there for nothing on one other appointment, by then I was stressed to the point of tears. My last appointment was attended by a black doctor God knows who he was no knowledge of ME/CFS. He asked me to cut down on my alcohol intake, me, haven't drank for 15 years and then asked me why I wasn't better, I could have done a far better job, p****t!! and the parking attendant had me in tears again another p****t.

Carolyn writes I'm in the Bolton and Bury groups, as well as Leger ME. Locally, their ME friendly specialist was dropped for a psychiatrist.

Lawrence writes I am a patient of Dr Odes and I agree with everything you have put in your letter. I had two appointments a few months apart where I saw a different consultant to Dr Odes who was

no help whatsoever and told me I had to see Dr Odes; however I was given an appointment by the hospital for a day when he didn't even work. The second time we went and saw a different consultant I was told that Dr Odes only holds his clinic on Mondays and that they would squeeze me in. They did say however that sometimes he will be needed on the wards and if that is the case he wouldn't be available for the clinic and it would be worth ringing on the day to see if he was there. My last appointment was in December and I am supposed to have another in June but I have not yet received a letter. I also agree that his secretary is less than helpful - I had one instance where she insinuated that I was lying about something Dr Odes had said to me regarding my next appointment and she put the phone down on me. My mother ended up complaining to the hospital about my treatment over this. I always struggle to get an earlier appointment than the one booked if I am bad and feel I need it. I have to say that although I feel I haven't had the best support or help Dr Odes does seem to be the only doctor in this area who firstly believes you have a genuine illness, secondly will do tests and thirdly rule things out and he will at least try to help. I do think it would be a shame to lose his service.
Gwen Writes Herefordshire & Worcestershire have had referrals stopped. 'Lack of secretarial and admin support' was the reason given. That isn't all. The consultant is a post-polio specialist with interest in ME.

Pathways will follow the story and keep you up to date

Sharon writes People who look after ill or disabled relatives often find it difficult to balance work with caring responsibilities. In some cases, this may cause problems in the workplace, and although some basic legal protection is available to carers, specific information is not widely known by either carers or employers. Doncaster Council has commissioned a pilot help line, which will be serviced by the Pay and Employment Rights Service (PERS). Advisers will be available to offer guidance to Doncaster carers (and their advisers in the voluntary sector and the council) who have queries about their employment rights. There will be a trial period from April 1 until June 30 2009 during which the help line will be available to Doncaster carers. IF there are any queries relating to employment rights, please telephone 01924 42803 and a PERS adviser will be able to discuss any problems you are facing at work. They will be able to provide information about your rights and talk through strategies for dealing with issues. The hotline will initially operate on a pilot basis and will be open during the following hours: • Monday and Friday 10am- 1pm, Tuesday, Wednesday and Thursday 10am - 4pm and Tuesday 5.30- 7.30pm. PERS has also produced a series of easy-to-understand leaflets on different aspects of employment rights which can be downloaded from www.pers.org.uk. Information leaflets can be posted out to carers upon request. Please telephone the help line to request a copy. For more information contact: Write to: Doncaster Council, Floor Ten, Council House, DN1 3DA, Telephone: 01302 862342, Email: sharon.gillott@doncaster.gov.uk. Website: www.doncaster.gov.uk

Carol writes I've just heard a report on the BBC Radio 4's Money Box programme that banks are leaving people unable to pay mortgages by taking money from their current accounts to cover credit card and loan debts. A charity has claimed this and the Citizens Advice Bureau is calling on banks to scrap the practice, which allows them to transfer funds without permission. It says it has seen a 25% rise in the number of such cases in each of the past two years. However, The British Bankers' Association says the onus is on customers to talk to their banks if they are in difficulty. In most cases, companies can only force someone to pay a debt by taking them to court. The Right of Set Off allows banks to legally transfer cash to pay credit card or loan arrears without account-holders' permission. The Citizens Advice says there have been cases of people having benefit payments removed from accounts, leaving them unable to meet "priority debts" like mortgages and council tax. The British Bankers' Association says cases where money has been removed "inappropriately" are regrettable but that banks take their responsibilities under the banking code seriously.

The ‘Right to Set Off’ debits by banks is a well known banking practice, and is quite openly set out on customer agreements. In some ways they are doing a favour by reducing the sky high interest rate of credit cards, and transferring the debit to a lower interest account. This is usually a communication problem, and people not keeping track of their money matters. The get-around is to open another account with a different bank, and seek expert advice before things get out of hand. - Mike.

A TEST FOR CHRONIC FATIGUE SYNDROME CFS/ME.

Until recently the diagnosis of ME/CFS has been based on clinical observation and exclusion of other causes of fatigue. Essentially, it is a diagnosis of negative factors, without any positive features contributing. Many health disorders e.g. diabetes have a simple test that can point to a diagnosis and quantify (put into numbers) the severity of the disorder. Up until recently, no similar test has been available for ME/CFS. Now things are different. On the 20th January 2009 the International Journal of Clinical and Experimental Medicine published on line details of a biochemical test which measures energy supply to body cells and therefore fatigue levels in people with Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME). The scientific paper entitled ‘Chronic Fatigue Syndrome and Mitochondrial Dysfunction’ is available here http://www.ijcem.com/files/IJCEM812001.pdf, Int J Clin Exp Med (2009) 2, 1-16. Here is an extract of the press release.

For treating the fatigue of CFS/ME, doctors have been hampered by the lack of a good test. This scientific paper clearly shows that the fatigue of CFS/ME is a symptom of mitochondrial dysfunction. Mitochondria are the biochemical engines within every cell in the body, which supply energy to that cell. What is shown by this paper demonstrates that the more fatigued the patient, the worse is the mitochondrial dysfunction and vice versa. This means that we now have an objective measure of energy supply and therefore a test for one immediate cause of CFS/ME

This test has resulted from the pioneering work of the internationally recognised Dr John McLaren-Howard of Acumen laboratories. He has taken cutting edge research in biochemistry and applied it to the clinical conundrums thrown up by the illness known as CFS/ME. This test can help distinguish between those people fatigued because of a biochemical problem in their mitochondria and those who are fatigued for other reasons. Other reasons include dietary causes (allergy and carbohydrate intolerance), hormonal reasons (such as borderline thyroid and adrenal function), poor antioxidant status, chronic insomnia, psycho-social causes such as anxiety and other causes.

Many doctors are already using this test and hundreds of patients are already taking the necessary nutritional supplements to support mitochondria. Many of these doctors and patients have observed significant clinical improvements. For some, their health is so much improved that they have been able to lead normal lives and return to the workplace. Dr Myhill, one of the authors of the paper, says “This test represents a huge breakthrough in the diagnosis and management of Chronic Fatigue Syndrome/Myalgic Encephalomyelitis.

THE AUTHORS OF THE STUDY

From left: Dr Norman Booth, Dr Sarah Myhill and Dr John McLaren-Howard

Dr John McLaren-Howard is seen here receiving the Maberley Medal from the British Society for Ecological Medicine for his outstanding laboratory work in the field of Nutritional and Environmental Medicine. It is his brilliant work and skills which have made this research possible. He has developed many known biochemical research techniques and pioneered new tests for investigation of patients with fatigue syndromes and related disorders. These have proved vital in ascertaining the cause of disease. The ATP profile featured in this scientific paper is just one example of many cutting edge research tools which he has applied to establishing disease causation.

Dr Norman Booth is a retired physicist from Mansfield College, Oxford University. Dr Booth has been responsible for ensuring the necessary academic rigor to ensure publication in this scientific journal. He prepared all the necessary graphs and illustrations which clearly show the relationship between mitochondrial function and levels of fatigue

Dr Sarah Myhill is a clinical doctor with a special interest in the treatment of Chronic Fatigue Syndrome/ME. She was responsible for collecting the original data from her patients, and from the biochemical tests, and noticing a relationship between the two.

ME/CFS has already been classified as a neurological disease by the World Health Organisation under ICD 10 G93.3, but many doctors continue to treat CFS/ME as if it were a psychological condition. This has been enshrined in NICE Guidelines for treating CFS/ME because their recommendations are for psychological treatments including antidepressants, Cognitive Behavioural Therapy and Graded Exercise Therapy. This is completely inappropriate for patients who have mitochondrial pathology and indeed is likely to make the mitochondrial pathology even worse.

“A useful analogy is to compare your body with your car. The mitochondria represent the engine of that car, the diet represents the fuel that goes in the tank, the thyroid gland represents the accelerator pedal and the adrenal gland the gearbox of that car. Using Cognitive Behaviour Therapy or Graded Exercise to treat a patient with CFS/ME is akin to beating up the driver of the car when actually the car needs a re-conditioned engine, suitable fuel in the tank, resetting of the accelerator pedal, a new gear box or whatever. This test invalidates the psychological model of CFS/ME and clearly establishes this illness as having a physical basis. Sufferers of CFS/ME have known this for many years but now we have the biochemical basis to prove this. “This study clearly shows that CFS/ME has a physical basis with the potential for correction through physical and biochemical interventions. Clinical experience has shown that the package of supplements to support mitochondrial dysfunction is effective and this will be the subject of further studies.” We are all especially grateful to those CFS/ME patients and non-patients who all co-operated fully without whom none of this would have been possible.

More details from Dr Sarah Myhill MB BS, Upper Weston, Llangunllo, Knighton, Powys, LD7 1SL
Tel: 01547550331 Fax: 01547550339 E-mail: office@doctormyhill.co.uk
Website: www.doctormyhill.co.uk

Opinion …..

Many of our members have had this test through a private Practitioner, and have benefited in several ways

a) At last there is a biochemical test which says 'something' is wrong.
b) The test is a yard stick which links the result a number to the degree of fatigue to the observed.
c) There an indication for treatment options.
d) With medico legal issues, it is supporting evidence.

So the question is 'why is it not available on the NHS'. There are a number of reasons, here are some:

a) There is no published reliability data. No test is 100% accurate, but as far as I am aware, it is about 95% accurate.
b) There is an issue in how the fatigue was assessed and scored.
c) This pre-dates the Kerr subtype research, and so these have not been taken into account. This will explain the low resolution, spread of results as being a flattened peak, rather than sharp spike.
d) Certain physiological assumptions are made e.g. that the neutrophil (white blood cells) mitochondria used in the tests reflect the biochemical parameters within the rest of the body.
e) The funding is private, and is reputed to promote a non NHS service or product, and not ‘*independent*’, e.g. through a University or The Medical Research Council.
f) It does not put into context the ME/CFS relationship with Mitochondrial Myopathies (MM). Similar observations have been made with similar results in diabetics and other diseases. MM's are usually genetic diseases, but may be acquired and have similar problems to ME/CFS.

However, I believe that the NHS and/or MRC should :

a) Acknowledge this research is a pathfinder project or research scout, and support or fund research into repeating the study at a second centre to confirm or refute the results.
b) Acknowledge that Mitochondrial dysfunctions may be a cause of CFS/ME in some cases.
c) Put into context the role of Mitochondrial Myopathies - are they a separate condition or part of the ME/CFS spectrum?

Locally, Sarah's paper was raised at a meeting with the Sheffield ME clinic they have decided to refer the matter to Prof. Gundwald - neurologist in Sheffield.

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Original Article

Chronic fatigue syndrome and mitochondrial dysfunction

Sarah Myhill[1], Norman E. Booth[2], John McLaren-Howard[3]

[1]Sarah Myhill Limited, Llangunllo, Knighton, Powys, Wales LD7 1SL, UK; [2]Department of Physics and Mansfield College, University of Oxford, Oxford OX1 3RH, UK; [3]Acumen, PO Box 129, Tiverton, Devon EX16 0AJ, UK

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

Key Words: Chronic fatigue syndrome; myalgic encephalomyelitis; mitochondria; neutrophils, oxidative phosphorylation.

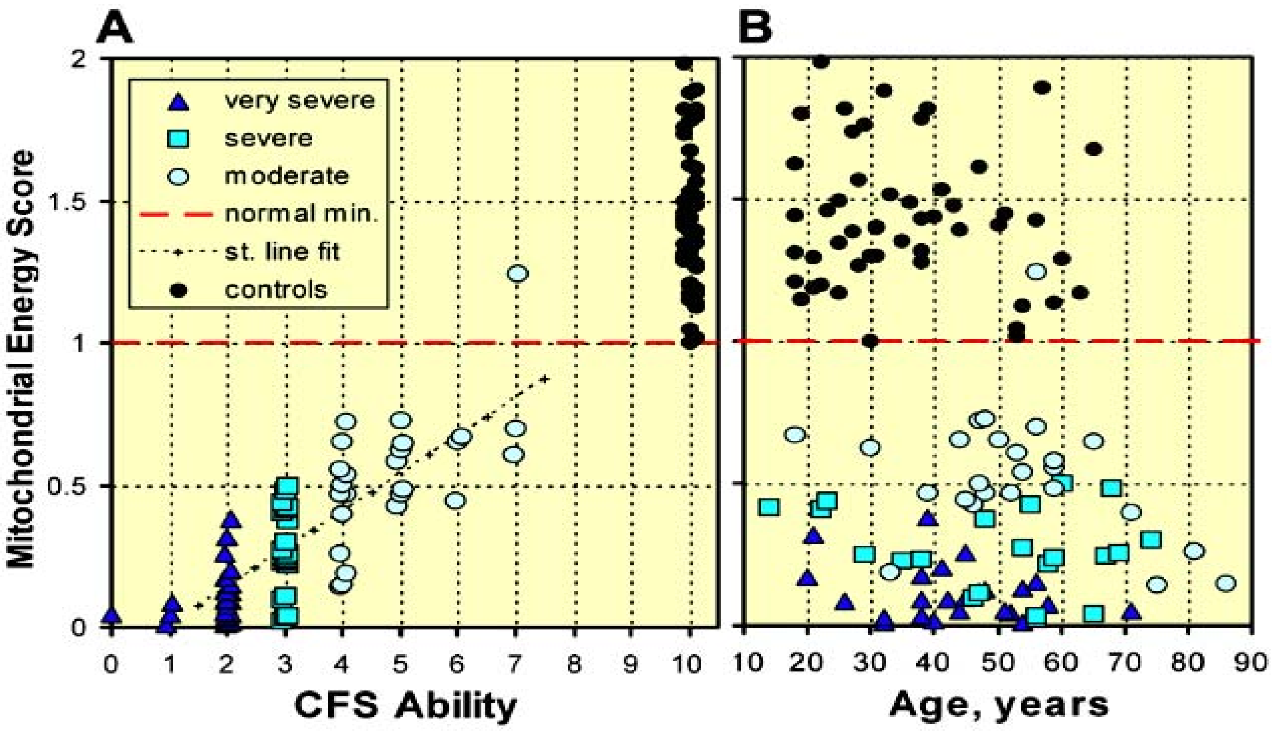


Figure 4. The Mitochondrial Energy Score. A. The Energy Score plotted against CFS Ability with a point for each patient. A point for each control is plotted at CFS Ability = 10. The horizontal dashed line at Energy Score = 1.00 is our normalisation at the minimum Energy Score for controls. Also shown is the best straight line fit to the patient data. B. The Energy Score plotted vs. Age of patients and controls.

Here are two frames from the paper. The frame above is a abstract, a summary of the study and results, the actual paper is 22 pages long. The bottom frame is a graphic plot of the results which is a 'bottom line' or summary of the whole study. ('Controls are normal non-MEs subjected to the same test for comparison.)

Go, Go, Go, for Bananas

A professor at CCNY for a physiological psychology class told his class about bananas. He said the expression "going bananas" is from the effects of bananas on the brain. Never put your banana in the refrigerator!!! This is interesting.

Banana is the common name for a fruit and also the herbaceous plants of the genus Musa which produce this commonly eaten fruit. They are native to the tropical region of Southeast Asia. Bananas are likely to have been first domesticated in Papua New Guinea. Today, they are cultivated throughout the tropics. Banana plants are of the family Musaceae. They are cultivated primarily for their fruit, and to a lesser extent for the production of fibre and as ornamental plants. As the banana plants are normally tall and fairly sturdy they are often mistaken for trees, but their main or upright stem is actually a pseudostem (literally "fake stem"). For some species this pseudostem can reach a height of up to 2–8 m, with leaves of up to 3.5 m in length. Each pseudostem can produce a bunch of yellow, green or even red bananas before dying back and being replaced by another pseudostem.

The banana fruit grows in hanging clusters, with up to 20 fruit to a tier (called a hand), and 3-20 tiers to a bunch. The total of the hanging clusters is known as a bunch, or commercially as a "banana stem", and can weigh from 30–50 kg. The fruit averages 125 g, of which approximately 75% is water and 25% dry matter content. Each individual fruit (known as a banana or 'finger') has a protective outer layer (a peel or skin) with a fleshy edible inner portion. Both skin and inner part can be eaten raw or cooked. Western cultures generally eat the inside raw and throw away the skin while some Asian cultures generally eat both the skin and inside cooked. Typically, the fruit has numerous strings (called 'phloem bundles') which run between the skin and the inner part. Bananas are a valuable source of vitamin B6, vitamin C, and potassium.

Bananas are grown in at least 107 countries. In popular culture and commerce, "banana" usually refers to soft, sweet "dessert" bananas. The bananas from a group of cultivars with firmer, starchier fruit are called plantains. Bananas may also be cut and dried and eaten as a type of chip. Dried bananas are also ground into banana flour. Although the wild species have fruits with numerous large, hard seeds, virtually all culinary bananas have seedless fruits. Bananas are classified either as dessert bananas (meaning they are yellow and fully ripe when eaten) or as green cooking bananas. Almost all export bananas are of the dessert types; however, only about 10-15% of all production is for export, with the United States and European Union being the dominant buyers.

After reading this, you'll never look at a banana in the same way again. Bananas contain three natural sugars - sucrose, fructose and glucose combined with fibre. A banana gives an instant, sustained and substantial boost of energy. Research has proven that just two bananas provide enough energy for a strenuous 90-minute workout. No wonder the banana is the number one fruit with the world's leading athletes. But energy isn't the only way a banana can help us keep fit. It can also help overcome or prevent a substantial number of illnesses and conditions, making it a must to add to our daily diet.

Anaemia: High in iron, bananas can stimulate the production of haemoglobin in the blood and so helps in cases of anaemia.

Blood Pressure: This unique tropical fruit is extremely high in potassium yet low in salt, making it perfect to beat blood pressure. So much so, the FDA has just allowed the banana industry to make official claims for the fruit's ability to reduce the risk of blood pressure and stroke.

Brain Power: 200 students at a Twickenham (Middlesex) school (England) were helped through their exams this year by eating bananas at breakfast, break, and lunch in a bid to boost their brain power. Research has shown that the potassium-packed fruit can assist learning by making pupils more alert.

Constipation: Because they are high in fibre, including bananas in the diet can help restore normal bowel action, helping to overcome the problem without resorting to laxatives.

Depression: According to a recent survey undertaken by MIND amongst people suffering from depression, many felt much better after eating a banana. They contain tryptophan, a precursor of serotonin, known to make you relax, improve your mood and generally make you feel happier.

Hangovers: One of the quickest ways of curing a hangover is to make a banana milkshake, sweetened with honey. The banana calms the stomach and, with the help of the honey, builds up depleted blood sugar levels, while the milk soothes and re-hydrates your system.

Heartburn: Bananas have a natural antacid effect in the body, so if you suffer from heartburn, try eating a banana for soothing relief.

Morning Sickness: Snacking on bananas between meals helps to keep blood sugar levels up and avoids morning sickness.

Mosquito bites: Before reaching for the insect bite cream, try rubbing the affected area with the inside of a banana skin. Many people find it amazingly successful at reducing swelling and irritation.

Nerves: Bananas are high in B vitamins that help calm the nervous system.

Overweight and at work? Studies at the Institute of Psychology in Austria found pressure at work leads to gorging on comfort food like chocolate and chips. Looking at 5,000 hospital patients, researchers found the most obese were more likely to be in high-pressure jobs. The report concluded that, to avoid panic-induced food cravings, we need to control our blood sugar levels by snacking on high carbohydrate foods every two hours to keep levels steady.

PMS Forget the pills - eat a banana. The vitamin B6 it contains regulates blood glucose levels, which can affect your mood.

Seasonal Affective Disorder (SAD): Bananas can help SAD sufferers because they contain the natural mood enhancer tryptophan.

Smoking & Tobacco Use: Bananas can also help people trying to give up smoking. The B6 and B12 they contain, as well as the potassium and magnesium found in them, help the body recover from the effects of nicotine withdrawal.

Stress: Potassium is a vital mineral, which helps normalize the heartbeat, sends oxygen to the brain and regulates your body's water balance. When we are stressed, our metabolic rate rises, thereby reducing our potassium levels. These can be rebalanced with the help of a high-potassium banana snack.

Strokes: According to research in The New England Journal of Medicine, eating bananas as part of a regular diet can cut the risk of death by strokes by as much as 40%!

Temperature control: Many other cultures see bananas as a "cooling" fruit that can lower both the physical and emotional temperature of expectant mothers. In Thailand , for example, pregnant women eat bananas to ensure their baby is born with a cool temperature.

Ulcers: The banana is used as the dietary food against intestinal disorders because of its soft texture and smoothness. It is the only raw fruit that can be eaten without distress in people with sensitive digestive systems. It also neutralizes over-acidity and reduces irritation by coating the lining of the stomach

Warts: Those keen on natural alternatives swear that if you want to kill off a wart, take a piece of banana skin and place it on the wart, with the yellow side out. Carefully hold the skin in place with a plaster or surgical tape!

So, a banana really is a natural remedy for many ills. When you compare it to an apple, it has four times the protein, twice the carbohydrate, three times the phosphorus, five times the vitamin A and iron, and twice the other vitamins and minerals. It is also rich in potassium and is one of the best value foods around. So maybe its time to change that well-known phrase so that we say, "A banana a day keeps the doctor away!"

Recipe Corner

<u>Hunter's Chicken</u>

4 large chicken breasts with the skin taken off
1 large onion
Olive oil
2 cloves of garlic, diced
1 tin of chopped tomatoes
1 tin of peeled plum tomatoes
1 tbsp tomato purée
100g mascarpone cheese
125g mushrooms, sliced
12 olives, halved and stoned
A good handful of fresh basil, washed and torn
Salt and pepper to taste

Heat the oven to 190 degrees C (fan oven) or gas mark 5.

Fry the onion and garlic in 2 tbsp oil over a low heat for a minute or two, but don't let them brown.

Tip the tins of tomatoes into the pan and stir in the tomato purée and a dash of salt and pepper.

Simmer on a low heat for around 10 minutes until the sauce has thickened, then add the olives and mushrooms and simmer for a further 5 minutes.

Remove the pan from the heat and stir in the mascarpone and basil leaves.

In another pan, heat a little oil and fry the chicken until it begins to brown on both sides, then place the breasts side by side in a baking dish.

Pour over the sauce and pop the dish into the middle shelf of the oven for around 30 minutes.

Serve with green beans and crusty bread. Or, cook some sliced potatoes and serve them dotted with butter and topped with cheese together with with broccoli or any other green vegetable.

Petition to no 10 Downing Street

Would it not a great leveller if representatives from HM Government's Ministers Of Health, Medical Research Council and NICE and The Chief Medical Office attended the INVEST in ME Conference 29th May? Now is your chance. Log onto:
http://petitions.number10.gov.uk/ttendIiME2009/
And fill out the form. Thanks to Irene for bringing this to Pathways' attention. - *Mike*

The I.C.E. Campaign

Most people carry a mobile phone with many names and numbers stored in its memory but nobody, other than the owner, knows which of these numbers belong to our closest family and friends.
If we were taken ill or involved in an accident, the people attending us would have our mobile phone but wouldn't know whom to call. The phone has many stored numbers, but which one is the contact person to call in an emergency? Hence, this "ICE", in case of emergency campaign. The concept of' ICE" is catching on very quickly. It is a method of contact during emergency situations. As mobile phones are carried by the majority of the population, all you need to do is store the number of a contact person or persons who should be contacted during emergencies under the name "ICE" (In case of emergency).

This idea was thought up by a paramedic who realised that when he went to the scene of an accident, there were usually mobile phones with patients, but he didn't know which numbers to call. He therefore thought that it would be a good idea if there was a nationally recognised name for this purpose. In an emergency situation, ~emergency Service personnel and Hospital Staff would be able to quickly contact the right person by simply dialling the number you Have stored as "ICE". For more than one contact name simply enter ICE 1, ICE 2, ICE 3, etc. A great idea that will make a huge difference! Let's spread the concept of ICE by storing an ICE number on our mobile phones today.
ICE can speak for you when you are not able to!

We the undersigned petition the Prime Minister to Petition forMinisters Of Health, MRC and CMO to attend the INVEST in MEConference 29th May 2009. More details

Submitted by David Loomes – **Deadline to sign up by:** 01 May 2009 – **Signatures:** 329

You must be a British citizen or resident to sign the petition. Please enter your name only; signatures containing other text may be removed by the petitions team.

I, ________ , sign up to the petition.

Your email:

Confirm email:

Your address (will not be published):

UK postcode:

Or, if you're an expatriate, you're in an overseas territory, a Crown dependency or in the Armed Forces without a postcode, please select from this list:

Children and M.E

by Jane Colby, The Young ME Sufferers Trust

ME (Myalgic Encephalomyelitis) is a serious neurological condition also known as Post Viral Fatigue Syndrome (PVFS). It was formerly known as Atypical Polio. The term Chronic Fatigue Syndrome (CFS) is also used but may include other fatigue states. Viral infections are known triggers of ME. An estimated 25,000 of the 300,000 UK sufferers are children. ME is the biggest cause of long-term sickness absence in schools; a study of 333,000 pupils revealed that 51 % of those on long-term sick leave had ME. This is the biggest category of pupils with medical needs requiring home tuition or distance learning on a long-term basis. Clusters of ME occur in schools, families and communities.

Tymes Trust Executive Director Jane Colby is a former head teacher, member of the National Association of Educational Inspectors, Advisers and Consultants (now ASPECT), the National Association of Head Teachers, the Society of Authors, and the UK Government Chief Medical Officer's Working Group on CFS/ME. Jane is a medical educator and professional author who writes for children as well as for adults. She edits the Trust's publications and co-authored the largest ever epidemiological study of ME.

Symptoms of ME

Brain and central nervous system.

Loss of memory, concentration, balance, coordination and fine motor skills.

Difficulty sequencing words and numbers, speaking, thinking and absorbing information. Abnormalities of sensation (e.g. pins and needles, numbness), vision, hearing, sleep rhythm, appetite, temperature control, digestion, blood pressure, circulation, hormone production, response to stress.

Development of sensitivities (e.g. to light, sound, touch, certain foods, chemical substances such as perfume, paint, medication and anaesthesia).

Bouts of racing pulse (tachycardia) and breathlessness.

Mood swings, panic, anxiety or depression may result from brain dysfunction and the distress of misunderstood illness

Generalised pain and weakness.

Pain in muscles, joints, head, back, limbs, chest and stomach.

Muscular weakness and twitching is common

Exhaustion, up to 72 hours after effort.

Even minimal exertion (cognitive or physical) can trigger exhaustion; the delayed effect is a classic sign of ME, differentiating it from other types of fatigue. Temporary hyperactivity may be experienced due to brain dysfunction, resulting in exhaustion.

***Management*.**

There is no known cure. The body needs energy to heal, so personal energy management is a safe way to live with ME without provoking side-effects. Pacing life carefully, using physical aids and finding alternatives to energy-sapping activities are often effective in promoting recovery.

Studies claiming the effectiveness of 'graded exercise' have generally been restricted to the less sick or the partially recovered and to those without classic ME symptoms.

- Some treatments may be harmful, such as overzealous physiotherapy. The condition naturally fluctuates, and may improve despite, rather than because of, treatments.
- GPs may be able to assist with symptomatic relief but medication can cause side effects and may not always be of benefit e.g. for inducing sleep or relieving pain. .
- The illness tends to resolve over an extended period but relapses can occur.
- If treated inappropriately, the patient can become much worse. In extreme cases, children can suffer fits or collapse. Some go through periods of partial paralysis and may have to be tube-fed. .

Good old-fashioned convalescence is a good start, followed by careful management of the young person's life and education to avoid the downturns associated with trying to force recovery.

Education in Young People.

Inappropriate educational demands impede recovery and are a key cause of relapse in children. Energy Efficient Education (home tuition, distance or virtual learning) can maximise achievement whilst protecting health. Social contact can be preserved through visits from school and friends and through making new friends who understand the limitations imposed by the illness, for example, through the Trust. Children with ME are legally entitled to education suited to their medical and special educational needs.

The Young ME Sufferers Trust

The Trust is a national ME charity specialising in children and young people. We played a major role in the Government Chief Medical Officer's Working Group on CFS/ME, focusing on compiling the children's chapter of the report published by the Department of Health in 2002. We are the longest running national organisation supporting children with ME, inaugurated in 1989 by two young people with ME. We realise that much distress is experienced when a young person is diagnosed with a serious and disabling illness. Members tell us that our friendly, personal approach, coupled with the provision of reputable information supplied by a professional and experienced team, makes us a 'lifeline' and a 'port in the storm' of controversy surrounding ME. We hope that we shall be able to help you too.

The Trust provides an Advice Line manned by our own trained and experienced Advice Line Team, all of them with personal experience of ME. Most are parents of children with the condition and some have also had ME themselves. Advice Line hours are Monday to Friday, from 11.00am to 1.00pm and 5.00pm to 7.00pm. Outside Advice Line hours or when the line is busy you may leave a message and one of our Team will call you back.

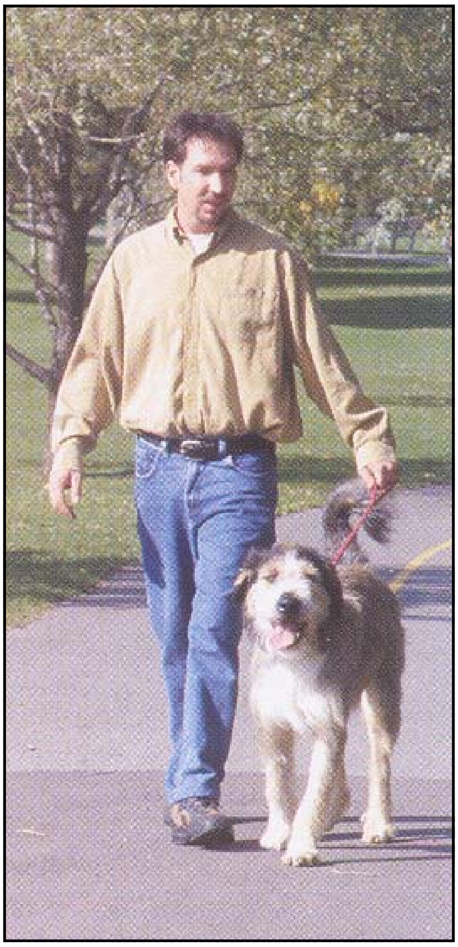
Members receive our magazine, Vision, which includes medical and educational articles, activities for and contributions from children, young people and their families. Each issue has an information pullout, ‘The Brief’, for parents and older readers.

Professionals Referral Service: We can refer doctors, teachers, social workers and other professionals to an appropriate ME expert from our panel. So your GP could talk with an ME specialist GP, your consultant could talk with an ME specialist consultant, your teacher could talk with an ME specialist teacher and so on. www.tymestrust.org. Much more information (including this leaflet) is available free from the Trust's website, from a single sheet to give your friends to show them how to help, to detailed guides for your doctor or your school. You can find out about the Young Hearts book of poetry, watch the ITV Central News interview with Jane Colby which was aired when the book was launched by Terry Waite at Warwick Castle, and download ‘Vision’ and ‘The Brief’.

The Trustcard Carry the Young ME Sufferer's Trustcard at school or college to make sure you get the help you need. It is endorsed by the Association of School and College Leaders and by Lord Adonis, Parliamentary Under-Secretary of State for Schools.

Become a Friend of the Trust Let us together support this excellent charity that is providing so much practical help to children with ME. As you consider whether to become a Friend, I urge you to remember that everyone at the Trust works free of charge. This is a cause they believe in. You may donate £15 or more at www.tymestrust.orgidonations.htm and register as a Friend using our website Contact Form. Or just write in with your cheque. Lady Elizabeth Anson, Cousin to the Queen ME sufferer, is Patron of the Trust
The Young ME Sufferers Trust, PO Box 4347, Stock, Ingatestone,
CM4 9TE. Registered Charity 1080985
Thank you and welcome. *Jane*

Group Meeting 20/1/2009 : Pacing with Mark Adams MCSP .



Mark is currently working as a private practitioner at Hallamshire Physiotherapy Ltd as well as being a senior NHS physiotherapist with the Chronic Fatigue Syndrome/Myalgic Encephalomyelitis service for South Yorkshire and North Derbyshire. He teaches on the post graduate pain management module at Sheffield Hallam University. He qualified as a physiotherapist in 1990 and his main area of interest is the management of long term conditions including Chronic Fatigue Syndrome/Myalgic Encephalomyelitis, fibromyalgia and chronic pain. Mark is a keen cyclist and enjoys family life especially walking his dogs.

Mark's Presentation

CFS/ ME is a relatively common illness. The physical symptoms can be as disabling as other chronic medical conditions. This illness involves a complex range of symptoms that includes fatigue, malaise, headaches, sleep disturbance, difficulties with concentration and muscle pain. A diagnosis of CFS/ME can be made if someone has been experiencing some of these characteristic symptoms for at least 4 months (3 months in children and young people) and their activity levels are substantially reduced. Changes in activity levels are normally associated with post-exertional malaise and/or fatigue. A diagnosis should be made after other possible diagnoses have been excluded. In most circumstances the medical tests required to do this can be done by a General Medical Practioner (GP). The pattern and intensity of symptoms vary between people, and during the course of each person's illness. People often have symptoms for many years before CFS/ME is diagnosed. There is some evidence to suggest that a common trigger for the onset of the illness is a viral infection. However it is recognised that other triggers do exist. The causes and disease processes of CFS/ ME are still not understood, but there is good evidence that with the right treatment it is possible for people to be helped to manage their condition.

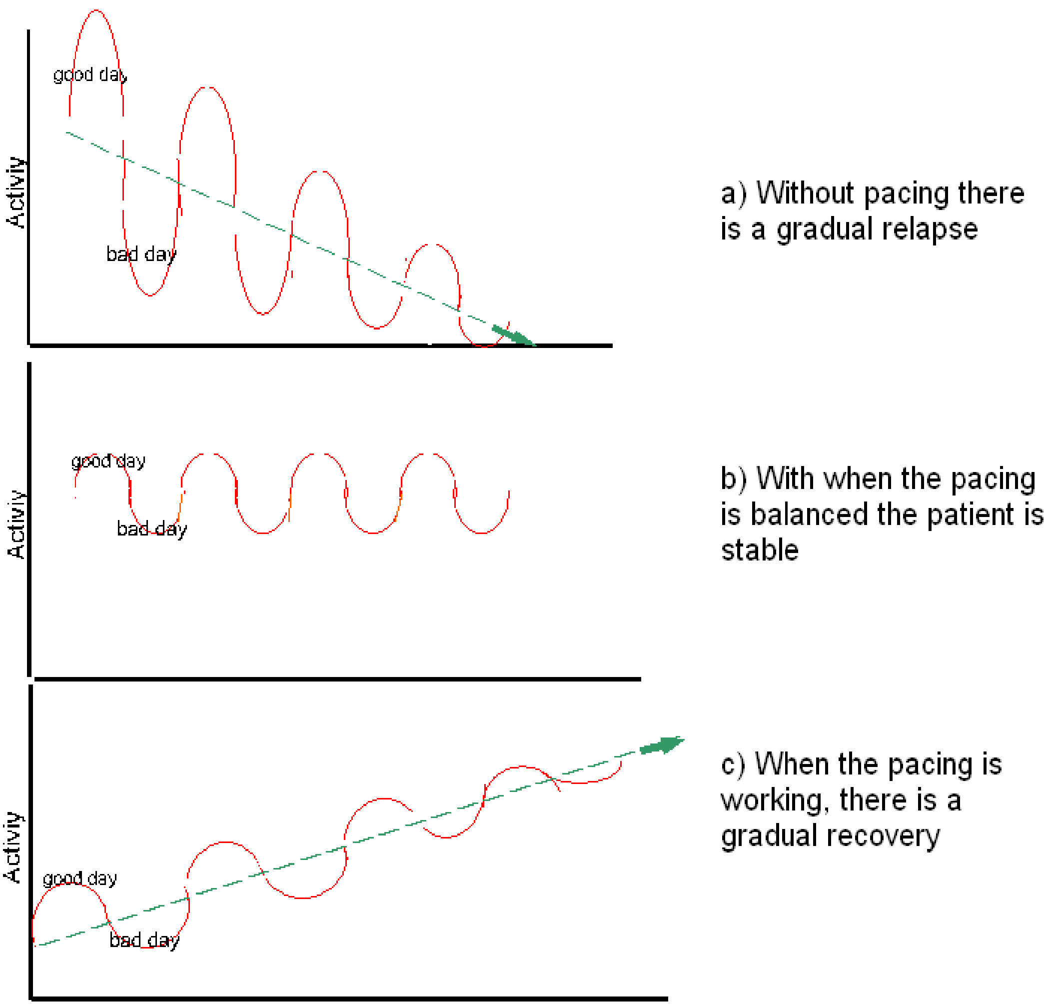
What can a specialist Physiotherapist do to help you? A specialist physiotherapist with experience in the treatment of CFS/ ME will offer you an individualised, person centred programme that aims to;

- **Sustain or gradually extend if possible your physical capacity.**
- **Manage the physical impact of your condition, including better control of your symptoms.**

This approach is known as graded exercise/activity therapy (GET), this is one of the treatments for which there is the clearest research evidence of benefit. Together you and the physiotherapist will set the goals on which your treatment will be based and the content of the treatment and its progression. GET will be provided on a one to one basis and will be based on your current level of activities, frequency of set backs/ relapses, emotional factors, vocational or educational factors and your goals.

When planning GET the Physiotherapist will do an activity analysis to ensure that you are not in a 'boom and bust' cycle of activity and rest*. We will discuss your ultimate goals, for example a twice daily short walk to the shop, a return to cycling or gardening, or for people with severe CFS/

ME sitting up in bed for a short while. You should take into account that it can take some time to achieve your realistic goals. When starting GET the physiotherapist will assess your current daily activities to help you to determine your activity baseline. You will then agree on a level of additional low intensity exercise that is sustainable, independent of daily fluctuations in symptoms, and does not lead to boom and bust. *'Boom and bust' is a cycle of fluctuating activity levels and symptoms which are a common feature of CFS/ME.*



Pacing Strategy as explained by Ann Nichol in a lecture at D.R.I several years ago

You will be encouraged to undertake this exercise for at least five days out of seven, or gradually build up to this level. Symptoms such as stiffness and fatigue may increase slightly for a few days when you first start your exercise. This is the body's normal response to starting a new physical activity and will be short lived. You will be offered advice about managing flare ups/relapses in the condition. When you can sustain the low intensity exercise on a regular basis the physiotherapist will review the duration and encourage you to increase it. For example a five minute walk becomes 6 minutes. If you meet your goals and want to progress further then, with your agreement, exercise duration and intensity may be increased further if other daily activities can be sustained. The physiotherapist will work with you to develop and build strategies to maintain your exercise and support you to continue with GET beyond the completion of treatment.

Will exercise make me worse? Research evidence demonstrates that individuals participating in GET are not harmed by exercise. However it is important that your exercise programme is provided by a physiotherapist with experience in CFS/ ME. Your physiotherapist will help to tailor an exercise programme to your needs so that it is sustainable and does not result in symptoms that are so severe that you need to rest to recover from them. You may have already tried to do exercises and found that they have made your symptoms worse and you may well have had to stop. Your physiotherapist will be able to help you to design an exercise programme that will prevent this from happening. If you have GET, it should be given by a trained professional with experience of using it to help people with CFS/ME, and given one to one if possible (CFS/ME NICE Guidelines 2007).

How Can I Access Mark's Expertise?

NHS. Through the Sheffield NHS Clinic. You have to be referred by your doctor to Fairlawns, through the NHS referral system. You then are put on a waiting list and take your place in the queue for a consultation. You may get Mark. You may get someone or something else.

Privately A doctor's referral is not necessary to make an appointment but the clinic will often refer you back to your doctor if they think you require further examination or tests. Contact Hallamshire Physiotherapy, 2 Newbould Lane, Broomhill, Sheffield, S10 2PL, Tel. 0114 267 1223. First assessment is about £50, and follow up is about £40 at the time of writing.

The ME Association Position on Graded Exercise Therapy (GET)

The ME Association have concerns about both the effectiveness and safety of this controversial approach to management. GET makes a significant proportion of people with ME/CFS worse. One can argue about the percentage of people whose condition becomes worse as a result of GET (ie 30% to 50% in patient questionnaires) but this not just due to a problem with the way in which GET is being delivered. The fact is that a progressive and sometimes rather inflexible increase in physical activity, the key component to a treatment that is based on the scientifically flawed deconditioning model of ME/CFS, is just not appropriate for a significant proportion of people with ME/CFS. Any treatment that causes an adverse reaction in 33 - 50% of those using it cannot be recommended as a blanket form of treatment - though this is exactly what the guideline for treatment of ME/CFS that has been produced by the National Institute for Health and Clinical Excellence (NICE) does. (But if it worked for some, would it not have been better to try in identify who it could help ? Ed) *If a drug treatment were causing this level of adverse reactions, then serious questions would have to be asked about its use - certainly by non-specialists. The MEA is therefore calling for an urgent review of the NICE recommendation relating to GET - which recommends that everyone with mild or moderate ME/CFS should be automatically offered a course of GET. The only form of activity management that the MEA endorses and recommends is pacing - a process whereby people make very flexible and, where appropriate, gradual increases in both mental and physical activity levels depending on stage, severity and variability of their illness.*

We asked Mark about the his thoughts on MEA position, and basically this was not consistent with his experience. He told us that the MEA information is based on patients self reported experiences, while the NICE accepted studies have been subject to rigorous checking and double checking. Most of the NICE accredited studies have taken place prior to creation of the National Collaborative and present national network of ME/CFS clinics. So they could be thought of as 'early' research studies. Since then a lot of practical experience has been gained, and strategies modified accordingly. The Sheffield clinic has its own way of dealing with GET strategies, which have evolved through local experience. Mark has started up his own private practice using GET/pacing for ME/CFS, which I believe is a good indicator of his self confidence and belief in his skills. In other words it's not the therapy itself, but how it is used in practice by individual therapists. Think of it this way: A car in a expert hands is relatively safe. but in wrong hands is a dangerous and lethal weapon.

The Bottom line.

Physiotherapy does not have the complete answer, and is not a cure, only a means of condition management. A physiotherapist like Mark would be most helpful early on ME/CFS, and certainly could help with early pacing strategies. As to the chronic and later stages I'm not so clear. Where rehabilitation is concerned in the recovery phase, GET will definitely be of value. It is interesting to note that we have received reports that in Sheffield, that applicants for Blue Badge without DLA high Mobility award are being asked to attend an appointment with a physiotherapist. This begs the question would a physiotherapist report support a DLA application or help in a benefits dispute? Maybe, but that remains to be clarified with experience. *-Mike*

Managing Energy Levels In CFS - A systems analysis approach. *Dr S Myhill & Lindsey Adams*

I am very aware that one of the hardest aspects of having CFS is knowing how to manage your time so that in each day you have enough complete rest. Without this, the healing process does not have the chance to begin its work and the illness goes from bad to worse. I am grateful to one of my patients, Andy Stephens, for the theory behind this handout. He has a background in systems analysis, which is a tool used to ensure a consistent output from a system. Lost already? Don't panic. Andy tells me this can be applied to any system, including the body. He has used his experience to devise a system to help him pace his activities and predict the level of activity at which he is going to be well. This is very helpful for CFS patients. It is vital that they pace all their activities, but most sufferers are driven by guilt because they feel they are not doing enough. Working out this system for each sufferer means that how much they are or are not allowed to do in a day is dictated by a few simple guidelines. Many thanks also to Lindsey Adams, who supplied the figures for our example and made this handout patient- friendly.

Day	Hours of Daily Activity	Difference
1	8.50	-
2	8.25	0.25
3	10.50	2.25
4	9.50	1.00
5	8.00	1.50
6	8.75	0.75
7	10.50	1.75
8	9.50	1.00
9	11.50	2.00
10	8.75	2.75
11	12.50	3.00
12	12.50	3.00
TOTAL	115.75	17.00

EXAMPLE
This is how you do it for yourself:

1. You keep a daily record of all your activities, which you log on an hourly chart (not shown here). You do it for a month paying careful attention to record the periods of rest when you are either sleeping, lying down without the TV or radio on, or are in the bath. Gentle yoga, relaxation or meditation can also be logged into this category.

2. You add up the hours of activity for each day,
i.e. day 1 - 8.5 hours(8 hrs 30 mins),
day 2 - 8.25 hours (8 hr 15 mins) etc.

3. Now you work out the difference between each day's hours of activity and the next. In our example the difference between day 1 and day 2 is 1/4 hour (recorded as 0.25), between day 2 and day 3 is 2 1/4 hours (2.25) and so on.

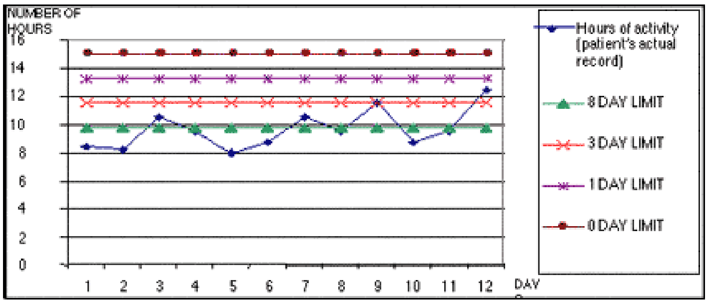
4. Add up all the differences: 0.25 + 2.25 + 1 + 1.5 + 0.75 + 1.75 + 1 + 2 + 2.75 + 0.75 + 3 = 17.

5. To find the average of this sum you divide 17 by the number of differences (the number of differences in our example is 11), i.e. 17:11=1.54).

6. Use this average and multiply it by 1.128 = 1.73(Don't ask where 1.128 comes from – it is just a number that works for this system!) This figure 1.73 (rounded up to 1.75 hours) is called a standard deviation from the average.

7. Total up the daily hours of activity - in our example the sum is 115.75 hours. When divided by the number of days it gives you your average hours of activity per day;

AVERAGE HOURS: 115.75 : 12 days = 9.64; rounded up to nearest 1/4 hour = 9.75 hours
STANDARD DEVIATION: 17 : 11 = 1.54; 1.54 X 1.128 = 1.73; rounded up to nearest 0.25 hour = 1.75 hours
Using these figures we can draw a graph



RULES
8 Day limit: Keeping your daily amount of activity at or below 9.75 hours (9 hours 45 mins) results in wellness (unless something unexpected happens, i.e. extra stress you did not budget for); exceeding the average (9.75 hours a day) for more than 8 days in a row results in relapse.
3 Day limit (Average hours + 1 standard deviation = 11.5 hours): Exceeding 11.5 hours (11 hour 30 mins) of activity a day on more than 3 out of 4 days results in relapse.
1 Day limit (Average hours + 2 standard deviations = 13.75 hours): Exceeding 13.75 hours (13 hours 45 mins) of activity a day on more than 1 in 4 days results in relapse.
0 Day limit (Average hours + 3 standard deviations = 15 hours): Exceeding 15 hours of activity ALWAYS results in relapse.
This does make sense. What it means is that to work most efficiently you should never do more than 11 hours 15 minutes of activity and never less than 7 hours 45 minutes. Working outside these limits mean you become inefficient and waste energy needlessly. This is comparable to a marathon runner. If he is to succeed he must pace himself carefully and always run within certain limits - not too fast, not too slow. The runner who sprints 100 metres, then walks 100 metres is not going to manage a marathon. The runner who jogs along at comfortable running speed will make it!

I would be interested to know if anyone else has tried it. Mike.

Judicial Review: ME Sufferers take on N.I.C.E., *Dr. Charles Shepherd, MEA (14/2/09)*

The Judicial Review of the NICE guideline on ME/CFS took place on Wednesday and Thursday, 11th and 12th February, at the Royal Courts of Justice in London. The hearing was held in Court 76 - a large modernised courtroom tucked away on the third floor of this historic maze of legal activity. Unlike the preliminary hearing in June last year, there was plenty of room to move around along with comfortable non-squeaking seats and wheelchair access - although it was difficult at times for those at the back to hear precisely what was being said by barristers representing the two sides. Around 50 members of the public, along with occasional brief visits from journalists, packed Court 76 to witness the proceedings. At times, a 'Court Full' sign had to be posted up. Not surprisingly, there did not appear to be a single person with ME/CFS who had come up to London to support the NICE guideline. Outside the main entrance in The Strand, where all the TV news bulletin shots of the High Court are taken, a small peaceful demonstration against the NICE guideline took place over lunch. This managed to attract quite a lot of legal and public interest.
Almost all of Wednesday was taken up with a legal presentation from barrister Jeremy Hyam on behalf of the two claimants who suffer from ME - Kevin Short from Norfolk and Douglas Fraser from London.

In relation to the effects of the NICE guideline on practical patient care, two key issues were examined:
Firstly, the procedures by which the NICE guideline development group (GDG) had come to the conclusion that the only treatments worth recommending for people with ME/CFS were two behavioural interventions, namely cognitive behaviour therapy (CBT) and graded exercise therapy (GET), and this was to the exclusion of all others.
Secondly, the fact that a number of medical/drug and supplement interventions, which may be helpful in selected cases, were not therefore being recommended by NICE. As a result of not being recommended, doctors would not be willing to consider using them, and healthcare providers (ie PCTs) would not be willing to pay for them. Some people with ME/CFS would therefore be denied forms of treatment that could be of benefit.

In relation to the way in which a judicial review is there to examine procedures rather than actual decisions, it was argued that the decision making process had been based on a foundation of insufficient evidence of clear benefit being available to recommend the widespread use of CBT and GET. In particular, was the way in which a systematic review of results from randomised controlled trials involving CBT and GET (ie the York Review) had failed to demonstrate the sort of robust consistent evidence that could stand alone and satisfy the requirements for this type of recommendation to be made in a NICE guideline. Counsel for the claimants also argued that insufficient weight had then been given to certain other key sources of evidence further down the hierarchy of evidence that were made available to the guideline development group (GDG) - in particular the results of patient questionnaires and stakeholder feedback which had reported that in a significant proportion of people with ME/CFS these treatments were either ineffective or even harmful.

When it came to the final analysis it was argued that with several members of the GDG being involved in clinical trails involving these two treatments, or expressing support for their use, there was an appearance of bias in the way that the GDG decided to recommend CBT and GET as the only forms of effective treatment. To support the appearance of bias reference was made to comments contained in a letter from a patient representative on the GDG (Tanya Harrison) who had resigned from the group as a result of what she believed was bias towards the psychosocial model. It was also argued that the appearance of bias towards CBT and GET was compounded by the absence of any health professionals on the GDG who were known to be in favour of the biomedical model of ME/CFS

The final part of the first day's hearing, and almost all of Thursday morning, was taken up by counter arguments being presented by the barrister representing NICE, namely that the research evidence in favour of CBT and GET was sufficiently robust; that the process of collecting and analysing other types of evidence from clinical trials, stakeholders, experience of clinicians etc was thorough and transparent; and that no evidence of bias towards the psychosocial model had been shown by individual members of the GDG. Neither was there any bias in the way in which the members of the GDG were selected by nomination of the relevant Royal Colleges or professional bodies, and some of the accusations relating to bias, conflict of interest, or disclosure of interest were based on factual inaccuracies. In other words, the procedures that were followed by NICE were as robust and fair as could be achieved in the circumstances and that the decision to only recommend CBT and GET was not the result of any bias on the part of individual members of the GDG, or the group as a whole. Legal arguments on behalf of the defendants (ie NICE) went on till early afternoon on Thursday.

Thursday afternoon produced a further legal argument involving the cost effectiveness of both treatments. This was given by a barrister acting for an 'interested party' in the case against NICE. Evidence was put forward on behalf of this interested party to show that the cost effective analysis for CBT was seriously flawed and that no proper cost effectiveness analysis for GET had even been undertaken. In other words, it was claimed that NICE was recommending two forms of treatment that had not yet been properly shown to be cost effective. Again, this position was vigorously challenged by the barrister representing NICE.

A great deal of time was spent in discussing the points that are summarised above, along with legal technicalities. However, some of the other aspects of the case against the NICE guideline, which have surfaced in public discussion on the internet prior to the case being heard in Court, were not referred to or left very much out on the periphery (eg neurological classification of the illness). Legal arguments and discussion went on till almost 5pm on Thursday and there is still some unfinished business for the Judge, Mr Justice Simon, to deal with. So it looks as though the Judge's decision on the case will be delayed for at least a week, possibly even longer. The ME Association has fully supported the case for Judicial Review that has been made by the two claimants

For anyone involved with insurance companies referred to during the hearing - Exeter Friendly Society and Liverpool Victoria - some interesting and useful statements regarding their positions on recognition and classification of ME/CFS were made during the hearing.

Newspaper coverage:

The Herald, Glasgow - February 12th : *‘A former violinist for the Scottish Philharmonic Orchestra launched a High Court battle yesterday to change the "perverse and irrational" guidance given to doctors who treat ME sufferers.’ I*
FT Adviser (Financial Times) – February 12th: *Insurers are set to come under fire at a High Court case today (12 February) over their treatment of myalgic encephalomyelitis (ME) and chronic fatigue syndrome suffers, who are often unsuccessful in claiming on their insurance policies.*
Fenland Citizen – February 11th: *Two ME sufferers, including one from Norfolk, have launched a High Court battle over the “perverse and irrational” guidance they say has been issued to doctors for the treatment of their condition.*
The Herald, Glasgow - February 12th: *A former violinist for the Scottish Philharmonic Orchestra launched a High Court battle yesterday to change the "perverse and irrational" guidance given to doctors who treat ME sufferers.*

Comment:

The judgement found in favour of NICE. However, this session sends NICE a clear message. NICE may revise the guidelines eventually. Who knows ? Mike.
NICE = National Institute of Health and Clinical Economics???

North of Doncaster *Personal Comment by Trevor Wainwright*
(Meanwhile Outside the Court)

It felt great to be doing something again. Annette, a campaigner, had organised accommodation near to the Courts, a short tube ride away. I was billeted with John and Phillida, whose daughter lived in New Zealand and suffered from ME. The following morning Phillida and I travelled together and met with other campaigners for coffee in the Knights Templar pub, some familiar faces from the 90's and the first ever May 12 Demo were there. Then it was to the Courts, I had decided to stand with my banner "The NICE GUIDELINES ARE A HEALTH HAZARD FOR ME", during this I was approached by Dewi Bermingham who had been handing leaflets outside Kings College.

Day 1. I was invited to swell the numbers in the court room. I was surprised to see at least 50 there; this was not counting the plaintiffs, defendants' and legal staff. The first session started at 10:30; people still came in. by 11:00 I met co campaigners for coffee in the Knights Templar, some familiar faces from the 90's and the first ever May 12th Demos were there. By 11:20 the court was full. I was of the opinion that the Solicitor for Kev and Doug seemed somewhat overawed by the interruptions from the Judge, seemingly unable to manoeuvre, however he doggedly carried on. After an hour I headed for one of three rest rooms put aside for us. Meeting a young man at the top of the stairs, I made conversation. He was a member of the public who had seen the agenda and decided to come and listen. He was interested, which meant an opportunity to educate someone else. As we talked and I explained the symptoms and my daughters experience, a young woman came out of the courtroom drip white and shaking. The heat had proved too much for her. She was helped into one of the rest rooms where she was able to lie down and rest. Eventually, with her colour returning, I returned to the young man and explained further. If we didn't win the Review at least another person was going to go home educated. I went to check on the young woman again and when I came back he had gone back into the court room apparently wanting to learn more. We listened to the case our Solicitor presented; the evidence; the York Review which came in for criticism. Soon it was lunch time, which saw the convict suit donned as we took to The Strand at the front of the RCJ with our banners, and educated many of the public who enquired what it was about. Charles Shepherd was being interviewed by Grace Productions; later others would be interviewed all telling why they were here and in my case why I was wearing the convict suit and naming Wessely, White and Sharpe as wanting sidelining. I was later joined by a guy from Sheffield who introduced himself as Barry, and more photos followed. Eventually we went back inside and a brief word with someone coming out for a break gave a bit of hope. I noticed that there were different faces as the morning people had gone replaced by the afternoon people. I hoped the Judge noticed also. The Barrister from NICE seemed to have a better way of handling the judge, even though he seemed to be quoting comparisons with other cases as to why the case should not have been brought to court. There was a third Barrister in attendance who was representing One Click 'pro bono', he made a brief statement saying he would have some information for the judge the following day.

Day 2. A young woman asked if I would help the Northern Ireland contingent who had flown over that very morning. I readily agreed. They were outside the main entrance with a banner stretching the full length of one of the pens. I would spend the morning with them and so would Barry. People still kept coming and asking what it was about, amongst which was a woman who had a child with ME and was totally at a loss. She was advised to get in touch with Tymes Trust (see earlier pages). Two young men whose mothers had ME were also given advice. They too had been at a loss; it was obvious someone was not doing their job. In the afternoon the girls from Northern Ireland went into the court. Barry and I stopped outside. Barry eventually went in mid afternoon; I went in for the last hour in time to hear the NICE Barrister close his case. The three Barristers then stood as if to end the proceedings, then the One Click barrister spoke, a short but relevant interjection with the Judge who actually smiled during it. Then, all rise, exit Judge, goodbyes said and home.

The Judge would give his verdict on the 13th February, which was in favour of NICE. So, it is now a case of commiseration. The fight will go on. *-Trev*