



Pathways

Price £ 2.50 (Free to members)

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

Seasonal Greetings from the Pathways Team

Dealing with the Winter

Today is the first day of December, there is about 9" of snow on the ground. Winter is a testing time for people with chronic conditions like ME/CFS. The cold weather means people's bodies have to burn more energy, and have less available for the normal every day things, so pacing becomes more important. We are more susceptible to winter health problems. Flu and pneumonia vaccinations are offered to other people with chronic conditions, and should be to those with ME/CFS. However many people with ME/CFS are reluctant to accept vaccinations because of past adverse effects. So this means we have to be more vigilant than ever about chest disease. One case I've come across this week is a severe ME case, with severe health problems. It turns out that the member is also suffering from Chronic Obstructive Pulmonary Disease (COPD) as well as ME/CFS and this is contributing to the overall disability, but has been missed by the GP and more worryingly by the DWP in their medical examination. There has been a local epidemic of chest infections. Anyone with a cough or coughing up yellow green phlegm needs to urgently see their doctor as soon as possible as this is an ALARM symptom, and it is a sure sign of a serious chest infection, it is not part of the cluster of problems associated with ME/CFS.

This month there is a mixture of good and bad news. Dr Myhill has been suspended for 3 months after a low key second hearing. The cuts and changes to benefits have been revealed, and the result of the Work Capability Assessment review is has been published. As it is getting near Christmas we've put in a Christmas recipe and Trevor tells us of the background to a well known Christmas Carol.



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Tony Writes: *Hi mike, I have been watching the BBC news this morning there is a feature about Vitamin B delaying onset of Alzheimer's in people with mild cognitive impairment (MCI). We get that in ME/CFS. Would vitamin B help?*

There is no definitive answer to this, but many of the private doctors who deal with ME/CFS push this strategy. In the early days of the Sheffield ME/CFS clinic there was a strategy planning meeting with various healthcare professionals, and they were firmly placed into two camps. Those for and against. Those against won, mainly because of lack of evidence, and that strategies including vitamins did not appear in the NICE guidelines.

Personally I think that they were wrong. We had a local South African NHS consultant in Doncaster who regularly prescribed vitamin B compound tablets for many of his ME/CFS patients. Although these were supplied from DRI, the Doncaster Primary Care Trust (PCT) refused to allow G.P.'s to prescribe them on NHS repeat prescription because of the lack of proof that they worked. (There was a similar scenario with VegEPA as many members will remember). I asked Dr. Swinbourne, a retired ME/CFS specialist about this, she wrote:

"Even in the early days of ME, Dr Melvyn Ramsey and his colleague Betty Scott discovered that many people with ME were deficient in some B vitamins, especially B1 and B6. Some improved dramatically after only a few days' treatment although longer treatment was advisable. Many of the visual symptoms such as slow accommodation, muscle pain, mental glitches and memory problems of ME are very similar to those occurring in thiamine (Vitamin B1) deficiency and are correctable with adequate doses.

What's new? These things just get forgotten or overlooked. My colleagues in the geriatric unit demonstrated long ago that many old people were very deficient in B vitamins and other nutrients and improved mentally and memory-wise when treated or properly fed. I expect a lot of people are wrongly diagnosed as having Alzheimer's syndrome when they are suffering from forms of malnutrition."

Vitamins and minerals sold as food supplements are openly available on supermarket shelves, in health shops, and pharmacies. Some are not expensive. Certainly the B vitamin group (sometimes sold as B complex or compound) are the ones to go for rather than individual vitamins because the B vitamins have to be all taken together as a group to be effective. Personally, I suggest that if you want to try this route you go for an A-Z type multivitamin and mineral supplement because this kind of product contains all the B group vitamins as well as others, plus minerals. Those containing iron may need to be avoided.

There are dangers in taking high doses of single vitamins, and really that is to be avoided, except on medical advice. For example a dose of B6 200mg was commonly recommended for ME/CFS. This was found to produce nerve damage (neuropathy) - so the maximum daily amount was reduced, and currently most multivitamin products I see contain about 25mg.

Does vitamin supplementation work with ME/CFS? Well I think it does. It does make a detectable difference with some people with ME/CFS that I know when they stop taking them, particularly the multivitamins. Could it be the placebo effect? Possibly no. Could it be that people with ME are not receiving an ideal diet and have nutrient deficiencies? Well, I would strongly bet on this option. Could it be that vitamins somehow ease the ME/CFS disease process? I would strongly bet on this option as well. You can have specific tests done privately to establish this - but really that is not necessary. You can insure yourself vitamin-wise by taking a multivitamin which is far, far, far, cheaper.

So the message is that if you want to try this option, don't mega dose, stick to A-Z multivitamins with minerals and shop around. One particular brand costs about £30 a month, whereas you should pay about £1 per month—Mike.

Marie Writes: *I have suffered 25 years with this disabling illness. I have now slowly regained nearly full health. I too believe that nutrition plays a big part in recovery. In early years I suffered a lot of stress and worked to exhaustion, so I think over-using the body's reserves which it needs to supply the brain and organs and still pushing to carry on with young children to look after, you go on a downward spiral, to a state where you have not a clue what is the matter, you cannot think straight, every bone in your body is in severe pain, it affects every part of your body as I think every organ's demand is not met. I was not eating properly as I did not find time. I had the biggest challenge of my life as I had to let go mentally of all the chores that I could not do and start eating healthily. It took me about 10 years to do this by myself I had to tell myself I only had one life and I did not want to waste it like this, but at first I had to mentally sort myself out which was the hardest thing I have ever experienced as I had no clue what was a matter. My doctor said it was osteoarthritis and I did not have the mental or the physical energy to challenge this. Sorry for boring you with all 'my', but what I wanted to explain was my insight. I have looking back to what my experiences were and if they could help anyone at all on the road to recovery that would be great. Best wishes and thank you for all the work you are doing, I do hope you can find a conclusion to this horrific condition.*

Carolyn Writes: *You may already know that the Government has scrapped the 50p monthly broadband tax which was due to begin on fixed-line phone bills in October, 2010. But two of the major operators, BT and TalkTalk have decided to increase their landline rental by the same amount from the same date – and keep the money. BT line rental will rise from £11.54 a month to £12.04 from October 1st (add £1.25 to this if you receive paper bills). The only way to avoid the charge is to pay for your line rental in advance for a full year, rather than the normal three months. Paying in advance for the year would bring the cost down to £10.99 a month BUT, you then cannot move to another telecom supplier within that period without losing the payment you have made, so you are tied in for the year. BT is also raising the cost of calls outside your monthly pricing package by up to 10%.*

A spokesman for BT told a well respected magazine, "We review our charges from time to time and rebalance prices. There is absolutely no connection at all with the Government cancelling its broadband tax." The fact that Talk Talk's planned increase also takes effect from October is no doubt no more than a coincidence too.

DMBC Welfare Rights Service Outreach Sessions

(Thanks to John Church for the information)

Monday

Stainforth Opportunity Centre Hope Centre, Church Road, Stainforth - 9.00am to 1.00pm.

Redmond Centre High Street, Carcroft 10am - 12.30pm

Bentley Customer Service Centre, Chapel Street, Bentley 2.30pm - 4.30pm

Tuesday

Woodlands Customer Service Centre, Windmill Balk Lane, Woodlands 9.30am - 12.30pm.

Town Centre Library, Waterdale, Doncaster 9.30am - 12.30pm

Balby Customer Service Centre, High Street, Balby 2.30pm - 4.30pm

Askern Opportunity Centre, Houlsby Resource Centre, Sutton Road, Askern 2.30pm - 4.30pm

Wednesday

Central Library Waterdale, Doncaster 9.30am - 12.00pm

Edlington Library, Martin Wells Centre, Thompson Avenue, Edlington 2.00pm - 4.30pm.

East Doncaster Development Trust, Station Road, Dunscroft 2.00pm - 4.00pm

Thursday

Consibrough Customer Service Centre, Old Road, Conisbrough 9.30am - 12.30

Hyde Park Opportunity Centre, 153 Carr House, Hyde Park 9.30am - 12.30

Mexborough Customer Service Centre, John Street, Mexborough 2.00pm - 4.00pm

Friday

Stainforth Opportunity Centre, Hope Centre, Church Road Stainforth 9.00am-1.00pm 2.00 - 4.30pm

Rossington Miners' Welfare, Station Road, Rossington 9.30am - 12.30pm

Denaby Main Opportunity Centre, 9 Grays Court, Denaby Main 9.30am - 12.30

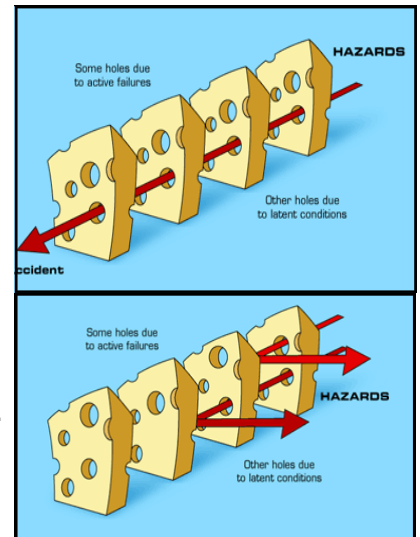
Intake Opportunity Centre, Montrose Avenue, Intake 2.30pm - 4.30pm

Betty Writes: *I am my family have been blood donors for many years. After I got ME/CFS two years ago, I stopped. Now I am feeling better, I would like to start giving blood again, but have been told I can't. Why ?*

The following letter was written by Clara Swenson, Director of Health Protection, Department of Health, regarding ME/CFS and Blood Donation:

As of 1st November 2010, blood donors who report that they have had ME/CFS will be permanently excluded from giving blood in the UK. This change is being made on the grounds of donor safety, as ME/CFS is a relapsing condition. It brings practice for ME/CFS into line with other relapsing conditions or neurological conditions of unknown origin. The change to donor selection criteria is being made following a recommendation by the UK Blood Services Standing Advisory Committee on the Care and Selection of Donors, and Joint Professional Advisory Committee (JPAC).

The thinking behind this is based on the Swiss Cheese Model of Undesirable Outcome theory. Any system, be it a bank security system, medical screening or just a health and safety issue can be thought about in something called the "Swiss Cheese Model" of system failure. Every step in a process or process has flaws in it, and the possibility of an undesirable outcome. The ideal system is like a stack of slices of Swiss cheese. The holes are opportunities for something to go wrong or fail. An adverse outcome occurs when error may allow a problem to pass through a hole in one layer, but it also passes through a hole that lines up in the next in the next layer(s). Good design will ensure that the holes are in different places. Each slice is a defence or filter against potential error creating an adverse outcome. The better a system, the fewer holes there are in each slice, and the more slices there are.



The most common example is with PIN codes. A four digit pin code has the option of 0-9 for each digit. Hence there could be a hole in any of 10 position places in the slice. So, the chances of someone guessing are the chance of a correct guess (1 in 10) of options (0-9) multiplied by the number of digits (4). For a four figure pin is it 1; 10,000, a six figure pin is 1:1000, 000. However, if people use a birthday as a pin, for example you use the date and month, you get more holes, and the security levels drop to about 1:800 because dates are from 1-13 and months are 0-12. It is possible that banks will have a five or six figure pin in future. One example of this is in the national lottery as most people tend to use birthdays as numbers. Choosing a number above 32 will increase your chances of winning more money by about one and a half times. It is fine if the problems can be quantified. In the case of bus driving for example the driving test is one layer, the periodic medical is another, and each training event adds a further layer. If there were an accident, the investigation, apart from establishing blame on the driver, is to establish if there are system errors. E.g. does the bus driver check his tyres before leaving the depot?

In medicine, the number of layers is unknown, and you don't know for definite how many holes there are in any one layer, or where they might be. With blood transfusion, for example, before the 1930s the chance of an adverse outcome was 50:50. Adding the ABO and rhesus layers improved the outcome but there was still a small proportion of adverse events. Further subtyping (e.g. B1, B2) reduced this. Donor screening for blood-borne diseases reduced these events further. Unknown infections like the HIV virus and prions (e.g. CJD) are further holes in the slice, with a variable number of holes anywhere. The cheapest way to avoid these is to screen only healthy individuals. There is no doubt there are consistent and detectable changes in blood of people with ME/CFS. What is not known for definite is why. Previously, when the persistent virus theory of ME/CFS was abandoned and the illness became 'a psychiatric condition', provided the person was well enough to give blood, their offer was accepted. However some doctors did not accept this. Certainly Charles Shepherd, the Medical director of the ME Association had an intuitive guess that blood donation for MEs was not a good idea. With the only spin off of the XMLV research is that while an effective treatment is still over the horizon, banning ME/CFS patients from giving blood just reinforces the acceptance that ME/CFS is an organic disease, not a psychiatric one.

This Months Health Promotion: Lung Cancer

Lung cancer is the second most common cancer in men and the third most common in women. There were 38,598 cases of lung cancer registered in 2005, with 80 percent occurring in patients over the age of 60.3. However, the incidence is currently dropping in men, but is stable in women. Overall, one year after diagnosis, around 25 percent of patients will still be alive, and the five-year survival rate is seven percent, but much depends on the stage the cancer had reached when diagnosed - earlier diagnosis leads to improved survival. A couple of years ago in the Sheffield area there were two avoidable deaths from lung cancer. Both cases had been classed as 'ME'. What had really happened was that screening tests as recommended in the NICE guidelines had not been carried out for one reason or another. Had this been done, there would have been abnormalities found and followed up. The early stages of lung cancer are indistinguishable from ME/CFS.

If you have any of the symptoms, it is important to have them checked by your doctor. It's important to remember that all of these symptoms may also be caused by illnesses other than cancer, which is why you need to talk. The golden rule is 'if in any doubt, you should go to see your GP'. Sometimes he/she will send you for a chest X-ray. At a minimum, the GP should listen to you and ask about your smoking habits. Do not think that you are wasting their time. Several people report that they hesitate to go to the GP because they feel the doctor has 'better things to do'. It is the doctor's role to look after the health of the patients registered with his/her practice.

Lung cancer can be divided into three main types, based on appearance under microscopy. Mesothelioma (asbestos related), small-cell lung cancer (SCLC) and non-small-cell lung cancer (NSCLC). Generally, the SCLC variant has a better initial response to treatment, but returns rapidly, and is often associated with a worse outcome. Around 90 percent of lung cancer is associated with smoking.

Lung cancer was rare up until the early years of the twentieth century, when the impact of the wider availability of mass-produced, cheap cigarettes was felt. Other possible causes of lung cancer include asbestos exposure and radon gas exposure.

Alarm Symptoms

The symptoms of lung cancer may include any of the following:

- a continuing cough for three weeks, or change in a long-standing cough
- a chest infection that does not get better
- increasing breathlessness
- coughing up blood-stained phlegm (sputum)
- a hoarse voice
- a dull ache, or a sharp pain, when you cough or take a deep breath
- loss of appetite and loss of weight
- difficulty swallowing
- excessive tiredness (fatigue) and lethargy.

Dr Doris Lister, Abbey Medical Centre, Camden, London said:

"Patients worry too much about wasting the doctor's time. If a symptom turns out to be nothing, I am as happy as the patient. So don't hold back!"

The Department of Health has given the following guidelines to GPs to help them know when to arrange an urgent referral. They should arrange an urgent referral with a chest specialist

- For anyone over 40 who smokes or previously done so and has coughed up blood more than once, they should arrange an urgent chest x-ray
- for anyone who comes with chest pain without any other obvious cause (such as an infection)
- for anyone who has any of the following symptoms for more than three weeks: chest pain; breathing difficulties; weight loss; hoarseness; enlargement of the ends of the fingers (called clubbing) ; swelling of the lymph nodes (glands) in the neck area; cough

If the x-ray shows something suspicious then the GP will arrange an urgent referral to a chest specialist. Usually you should see the specialist within 2 weeks of this referral being made. Once you are under the care of the hospital, you will get regular communication from health professionals involved in your treatment. It's always worth asking lots of questions, so you understand the process. Make a note of anything you want to ask, possibly in a notebook and you will then remember. And, if it makes life easier, ask a friend or family member to go with you so they can hear the answers you are given.

See Cancer Research UK. www.cruk.org

Dr Sarah Myhill: Interim Orders Panel (IOP) - 14th October 2010

You can read the judgement in full on Sarah's website, and is quite a complex document which can be daunting for anyone with ME/CFS. Here is a précis, cutting out a lot of the medico-legal jargon. (Normal print is a quotation whereas *italics* are my précised interpretation).

Preamble, reference to previous hearings, decisions and legal justification. There are repeated and significant concerns raised by former patients, medical practitioners and other members of the public. It would not be practicable to list each individual concern raised. *In addition to two complaints dealt with in April 2010, we have concerns* regarding your:

- 1) Website *that recommends* that patients obtain prescription only medication (PoM) from untested, unmonitored and unapproved overseas sources, bypassing (*qualified doctors*) NHS or private.
- 2) *Treating patients remotely without face to face contact, consultation, examination or history taking*
- 3) *You took no notice of the Formal warning* given to you by the GMC in 2005;
- 4) Your promotion of clinically unsubstantiated treatments to vulnerable patients;
- 5) Your promotion of personal opinions in relation to nutrition, use of oral contraceptive medicines, patient investigation specifically breast biopsy, and advice in relation to vaccinations;
- 6) Your failure to engage with approved medical practice and appropriate continuing medical education;
- 7) Using your status as a *doctor* to reinforce your personal beliefs and to promote private treatments.
- 8) Your potential failure to recognise and work within the limits of your competence.
- 9) Your disregard for the conditions imposed by this Panel.
- 10) *Your possible serious limitation of your insight* into fitness to practise and the consequences of your actions: especially in light of your correspondence with and behaviour towards *us*
- 11) *Your breaching our conditions, in that that you did not inform others about your limitations*
- 12) Your attempts apparently to circumvent, or having the effect of circumventing, the conditions restricting prescribing practice and restricting the information you were allowed to publish on your website;
- 13) Your lack of familiarity with the principles of Good Medical Practice and *up to date treatments*;
- 14) Your ability to practise safely;
- 15) *You are not aware and do not understand* the effect your attitude, behaviour, and conduct has on others and on the Profession.
- 16) Your understanding and perception as to the consequences of your actions in relation not only to *fellow doctors, patients* the general public; and
- 17) The provision by you of medical care which *doesn't meet our standards*.

Do not use personal beliefs with patients *these are likely to exploit vulnerability or cause distress*. If you publish information about your services, *make sure that it can be checked out, and do not make* unjustifiable claims about the quality or outcome of your services;
You should Not provide information which might exploit any vulnerability or lack of patient knowledge;
You should Not *frighten* people to use a service for example by arousing ill-founded fears.
You should take/verify information in documents, and not leave out *anything important*.
You should keep your professional knowledge and skills up to date, *recognise and work within the limits of your competence*.
You should adequately assess your patient's condition.
You should only prescribe drugs or treatment *if* you have adequate knowledge of patient's health.

This panel is not to check what is true, or check out the information submitted, expert or otherwise, or your comments. *It is our job to decide what is important and appropriate.* *You have not helped* by your submissions or your unsubstantiated reference to outdated medical Journals and reports. *Although you have been previously advised, then warned, you have not tried to reform yourself.* *In April we put a mild restriction on your ability to practise, which you have tried to get around or circumvent.* *You do not have respect for us, and we don't think you would follow our guidance.* *We don't think that if we imposed any further conditions on your doctoring practice you would comply with them, so we will suspend, ban your registration from now, and review the position in 3 months.*

Pathways Comment

The General Medical Council effectively has done quite a good character assassination of Sarah Myhill. This is *'the iron fist within the velvet glove'* approach of many professional bodies. If it looks like a school report reprimand, it is. It is also reminiscent of a visit to a headmasters study by a delinquent child, and barring or exclusion from school. But really doctors have to be, and are expected to be, more than an ideal member of Society, with the responsible positions that they hold, and it is the GMC's responsibility to enforce this and protect the reputation of the medical profession.

The GMC were not impressed by Sarah's supporters and the demonstrations in April outside GMC HQ for the first hearing. The GMC would take a dim view this, as it is reminiscent of a delinquent's badge of honour, and this definitely would not help her case. The 'out of date' references are mainly the early work in ME/CFS which has sadly not been followed up, and has mainly been swamped in this country by current NICE guidelines. There are laws which prevent promotion of medicines directly to the public for serious and incurable diseases. This would have been a British contention, as within the USA medicines are promoted, apparently without restriction.

Sarah would have taken six years to qualify as a doctor, something which takes a lot of dedication and hard work and is beyond many. She then would have done further training in hospitals, before being allowed to practice as a GP. If you read her website, you find that she became dissatisfied with NHS practice and went mainly private due to NHS restrictions and professional dissatisfaction. At that point all of the NHS peer mentoring, education and guidance would have stopped as would all the checks and balances from colleagues to keep her within the guidelines. Because she is a one person practice, the GMC is really the only source of Clinical Governance. It is almost impossible to keep up to date without NHS networking. And as the judgement shows, whereas with the NHS there would have been several levels of higher management, for Sarah, the GMC is the next tier up. These people are of course NHS centred.

The Way Forward ? I don't think legal challenge is a viable or credible option. Sarah can relinquish being a doctor, but at that point I would say she would not be giving her best to her patients. Yes, she could make money as a nutritionist—but that title is unregulated and there are many charlatans around, and once that route is taken, the way back to being a practising doctor becomes more difficult, if not impossible. Alternatively, she could make a decision to reform and become new Dr. Myhill, follow the guidance of the GMC and get her licence to practice back. If she takes the reform route, things would have to change. Firstly she would have to become more up to date, with maybe a Return to Practise course. The GMC are more concerned with attitudes, and really she may choose to have a go and work in a NHS practice for a while as these days best practice changes so quickly. Gone are the days like it used to be, that if someone qualified professionally fifty years ago, they qualified for life. Now, if you are out of the system, after five years you're out of date.

If you look at the photograph of Sarah's staff on the website—there is really only Sarah that is medically qualified, and to the best of my knowledge the rest don't carry any high level health qualifications. If that is compared to a typical GP's practice, there are other health professionals involved including practice nurses and receptionists. Maybe the way forward is a multi-disciplinary ME Centre. Certainly the countryside around Knighton is ideal for that.

Part of the GMC's *'iron fist within the velvet glove'* approach to give every opportunity for the doctor to reform and comply with the high standards of the profession. Sarah has not been struck off yet!

The General Medical Council is like a private police force for doctors.

It has the power to reprimand, restrict, suspend or strike off a doctors right to practice.

It has the backing of the Medical Act, and is a law unto itself. Only a court of law can overturn it's judgements.

Despite this, they did not take action on the most notorious doctor Harold Shipman.



Spending review 03.11.10: Benefits Cuts and Changes Timetable.

(Thanks to Work and Benefits)

OCTOBER 2010

Incapacity Benefit. Pilot trial of transfer of IB claimants to ESA begins in Burnley and Aberdeen areas involving 700 claimants. The DWP estimate that 23% of IB claimants will fail the work capability assessment and will not be eligible for ESA.

Mortgage Interest Payments. Rate of mortgage interest support reduced from 6.08% to Bank of England average, currently 3.67%. Many claimants of income support, jobseekers allowance, employment and support allowance and pension credit now face a shortfall in their mortgage interest payments, meaning they must either meet the difference out of their benefits or face losing their home.

JANUARY 2011

VAT. Not a benefit at all except to the Government, but on 4 January 2011, the standard rate of VAT will rise to 20%. The cost of many staple items will increase, affecting people on low incomes disproportionately and meaning benefits will not stretch as far.

MARCH 2011

Employment and support allowance. A new harsher work capability assessment (ESA2) is to be introduced. The DWP estimate that the number of people being found fit for work will increase by 5% and the number being placed in the support group will increase by 0.5%.

Incapacity Benefit. Transfer of IB claimants to ESA begins. This is due for completion in March 2014. The DWP estimate that 23% of incapacity benefit claimants will 'fail' the work capability assessment and will not be eligible for ESA.

APRIL 2011

Disability living allowance. Higher rate mobility component will be payable to people with a severe visual impairment. The DWP say that it will allow around 22,000 blind people to claim higher rate mobility.

Local housing allowance. Maximum weekly allowance payable limited to: £250 for a 1 bedroom property, £290 for a 2 bedroom property, £340 for a 3, and £400 for a 4 bed property. Property size limit will drop from five bedrooms to four. Many private sector tenants, especially in London, are likely to face a shortfall between the amount of their benefit and the rent they have to pay. Claimants with large families are also likely to suffer.

Various. Benefits such as disability living allowance that has until now been up-rated based on increases in the retail price index will be up-rated in line with the less generous consumer price index. This will mean that benefits will increase by less each year and claimant's incomes will fall further and further behind those of the rest of the population.



OCTOBER 2011

Local housing allowance. Rents will be based on the cheapest 30% of properties in an area, rather than the cheapest 50%. This will affect many private sector tenants who are likely to face a shortfall between the amount of their benefit and the rent they have to pay.

APRIL 2012

Employment and Support Allowance. Contribution-based ESA will be time-limited to one year. The start date for this is not yet clear, but it appears that legislation may be enacted in 2012 with immediate effect on those who have been in receipt of contribution-based ESA for 12 months or more. People in receipt of contribution-based ESA who have savings or a partner who works may no longer be able to receive ESA or JSA.

Local housing allowance. The shared room rate will apply to single people aged under 35 years old, rather than 25 years old. Under this rule, claimants cannot get more than the rate for a room in a shared house rather than the rate for a one bedroom flat. This means that private rented tenants under 35 years old will be more likely to face a shortfall between the amount of their benefit and the rent they have to pay.

OCTOBER 2012

Disability Living allowance. DLA mobility component will no longer be payable to people in residential care, affecting around 58,000 people in residential care who will lose the mobility component and have their lives made considerably poorer as a result

APRIL 2013

Housing benefit. This will be limited to the size of property a claimant's household requires. Social housing tenants who are judged to have too many rooms, perhaps because their partner has died or left or their children have left home, will have their housing benefit reduced or they will have to move to a smaller property. There is likely to be a shortage of such smaller properties in the social housing sector.

Jobseekers Allowance. Claimants who receive JSA for more than 12 months will have their housing benefit or local housing allowance reduced by 10%. Many claimants in high unemployment areas or who have physical or mental health conditions which mean they are discriminated against in the jobs market will have to meet the shortfall in their rent payments out of their benefits. Some will undoubtedly become homeless. Combined with the harsher ESA medical this will mean that, for example, deaf claimants who can read 16 point type will be forced onto JSA and then have their HB or LHA cut by 10% because they are so heavily discriminated against by employers and thus less likely to find employment. In effect it will be a punishment for being disabled.

SOMETIME IN 2013

Benefit cap: The maximum amount a household can receive in benefits will be limited to the average take-home pay for working households, estimated to be £500 a week in 2013. The cap will apply to combined income from:

- a) The main income replacement benefits (Jobseekers Allowance, Income Support, Employment Support Allowance);
- b) Other means-tested benefits (including Housing Benefit and Council Tax Benefit);
- c) Child Benefit and Child Tax Credit;
- d) Other benefits (including Carers Allowance and Industrial Injuries Disablement Benefit).

The cap will not apply to claimants of DLA, working tax credit or war widows benefit. This is most likely to affect larger households with high housing costs.

SOMETIME IN 2013-2014

Disability Living Allowance.

Medical and eligibility rules for DLA for claimants of working age will change. All existing claimants will be reassessed using the new system. The intention is to reduce the number of DLA claimants by at least one fifth.



Daleks loose Incapacity Benefit

Davros, leader of the Daleks, has reacted angrily to news that he and his creations will no longer be eligible for Incapacity Benefit. Despite being confined to a wheelchair, having the use of only one hand and monocular vision, the brilliant but twisted scientist was informed that he would still be capable of undertaking basic clerical or catering-centric roles.

Davros, who is originally from the planet Skaro, but has been living in Hammersmith since 2008, is said to have screeched at benefit clerks: 'You dare to defy me. I am Davros! I am the creator of the Daleks, the supreme power of the cosmos!! You must, you will, OBEY ME!!! 'I'm still getting the housing benefit though, right?'

Simon Woodburn, the benefits officer in charge of Davros' case, said: 'We got him a job right here in our Benefit's Call Centre where his distinctive rasping electronic voice was perfect for directing callers to the Claimants' Helpline. Then we found out he was telling them that as well as recording their calls for training and quality purposes, benefit claimants would be sought out and exterminated. Just because that is what the government are thinking, it doesn't mean we are allowed to say it out loud...' *Fin Robertson*

Working age benefits. Universal credit will replace: Employment and Support Allowance, Jobseekers Allowance, Income Support, Housing Benefit, Council Tax Benefit, Working Tax Credit, Child Tax Credit. Initially this will only apply to the long-term unemployed, but the intention is to move all claimants of the above benefits onto universal credit over the course of two parliaments. There are not yet enough details to know who might be better off and who will be worse off under the new system.

The Review of the Work Capability Assessment

From Steve Donnison, Benefits & Work

You may have heard on the UK news that the work capability assessment (WCA) – the medical test for Employment and Support Allowance – is to be made fairer and more just. It isn't. It's actually going to be made very much more harsh and unjust. Because although the Coalition have said they accept all of the recommendations made by Professor Harrington in his report on the WCA, they have also said they are still going ahead with changes to the WCA which they set out earlier this year. We've written before about the plans to remove almost half the mental health descriptors, dock points from amputees who can lift with their stumps and assess claimants with walking problems using imaginary wheelchairs. Nothing has changed in those plans according to the Government response to Harrington. So don't give the claims of a new, fairer world for claimants too much credibility until you've read the small print. Citizens Advice is a member of the Disability Benefits Consortium fronted by Disability Alliance. The best that the Consortium seems to be able to manage by way of campaigning, however, seems to be a really stiff letter to Iain Duncan Smith. Though, just as we were writing this, we got news of a more promising campaign by Mind to postpone the migration of incapacity benefit claimants to ESA until all of Harrington's recommendations have been implemented.

Extracts Professor Malcolm Harrington Review of the Work Capability Assessment

The review has considered a wide range of evidence to reach its conclusions. Over 400 responses were received to a Call for Evidence and the review met with around 100 key organisations including disability organisations, providers, representative groups, unions and employers. Data was also gathered from DWP/Jobcentre Plus, Atos and the First-tier Tribunal to assist with the review. This evidence has consistently and regularly highlighted problems with each stage of the WCA process, which limit both the assessment's fairness and effectiveness.

The key findings are:

- Claimants' interactions with both Jobcentre Plus and Atos are often impersonal, mechanistic and lack clarity. As a consequence, many people who are found fit for work feel an injustice has been done and are more likely to appeal, rather than being receptive to other support available.
- The Jobcentre Plus Decision Makers do not in practice make decisions, but instead they typically 'rubber stamp' the advice provided through the Atos assessment. They often do not have or do not appropriately consider additional evidence submitted to support a claim for Employment and Support Allowance (ESA). This results in the Atos assessment driving the whole process, rather than being seen in its proper context as part of the process.
- Some conditions are more difficult to assess than others. This appears to be the case with more subjective conditions such as mental health or other fluctuating conditions. As a result, some of the descriptors used in the assessment may not adequately measure or reflect the full impact of such conditions on the individual's capability for work.
- Communication and feedback between the different agencies and organisations involved is often fragmented and in some cases non-existent. For example, if a claim goes to appeal, Jobcentre Plus and Atos are not provided with the reasons for the subsequent decision.

Key recommendations

The review has set out a substantial series of recommendations to improve the fairness and effectiveness of the WCA. They are based on evidence that just procedures and processes lead to a fairer overall assessment. They aim to reposition the WCA as a positive first step towards work for most people and ensure people who cannot work are given support. To do this they will ensure that individuals going through the WCA are treated with respect, are listened to, are able to get their case across and are able to understand and recognise the reasons behind the decision that is reached.

The review's key recommendations include:

- Building more empathy into the process with Jobcentre Plus managing and supporting the claimant. This includes speaking to them to explain the process, to explain their result and to explain the support that is available after the WCA.
- Improving transparency of the Atos assessment by ensuring each report contains a personalised summary of the Atos healthcare professional's recommendations; sending this summary to all claimants; and piloting the audio recording of Atos assessments.
- Accounting for the particular difficulties in assessing mental, intellectual and cognitive impairments by ensuring Atos employ "mental, intellectual and cognitive champions" in each Medical Examination Centre to spread best practice and build understanding of these disabilities.
- Empowering and investing in Decision Makers so that they are able to take the right decision, can gather and use additional information appropriately and speak to claimants to explain their decision.
- Better communication and feedback between Jobcentre Plus, Atos and the First-tier Tribunal to improve the quality of decision making on all sides.

A programme of work for year two

This review is the first of five annual Independent Reviews into the WCA. It has examined the whole WCA process from end-to-end in a short timescale. As a result, some questions have remained unanswered and some pieces of work have remained uncompleted. The review has set out a proposed programme of work to look in more detail at these issues during the second review. This programme focuses on: the descriptors, particularly in assessing fluctuating conditions; what happens to people who go through the WCA; and assessing whether the WCA could also provide a more rounded picture of a person's readiness to work. The review has already set up a task group to look at the mental, intellectual and cognitive descriptors and they will report back in late-November. The Independent Reviewer will assess this report and after consulting with a wide range of experts will make recommendations to Ministers. In year two the review should also monitor the implementation of those recommendations in the year one report which have been adopted by the Government.

Homeopathic Medicines v Herbal Medicines

What are Herbal Preparations? Herbal preparations contain plant-derived materials, either as raw or processed ingredients and may be from one or more plants.

What are the differences between Homeopathic and Herbal products? This can be confusing because homeopathic products may be derived from herbs (not always) and called by their botanical names, e.g. aloe, and also because one manufacturer may produce both homeopathic and herbal products. Homeopathy uses minute quantities of the active ingredient on the basis that the substance causing the symptoms in a healthy person is used as a remedy against those symptoms in a patient.

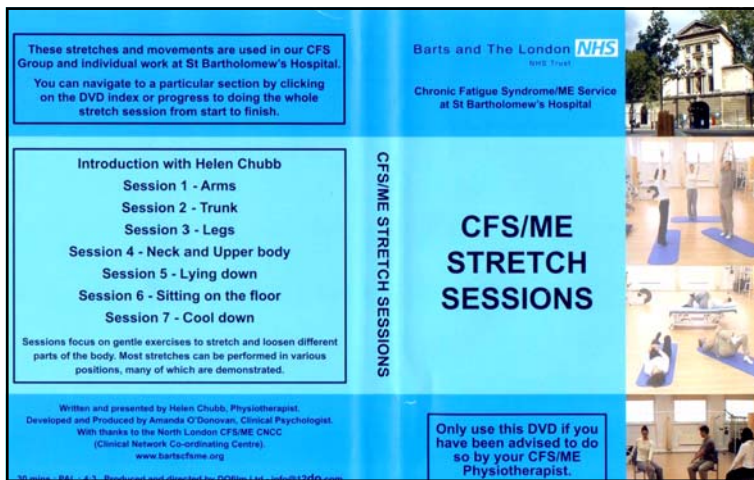
What is the evidence for homeopathy? There is no scientific or clinical evidence to support the efficacy of homeopathic products, although anecdotal reports of their effectiveness have been published, particularly when used as part of individualised homeopathic treatment by a homeopathic practitioner. Given the lack of clinical and scientific evidence to support homeopathy, many health professionals do not endorse homeopathy as a form of treatment. Some health professionals advise on the lack of evidence of the efficacy of homeopathic products, discuss the formulation and composition of the product, and provide advice relevant to the patient's condition.

Should patients stop taking their prescribed medication if they take a homeopathic product. No
Are there dangers in taking a homeopathic product? Yes, taking the product may delay investigation of a serious, underlying undiagnosed medical condition requiring the patient to be referred to another healthcare professional. Homeopathic tablets often contain lactose to which some people are sensitive.

What conditions should homeopathic products be used to treat? Homeopathic products should only be used for the treatment of minor, self-limiting conditions, and must never be used for the treatment of serious medical conditions.

How are homeopathic products licensed? For the purpose of licensing, the Medicines & Health care Regulatory Authority does not currently require homeopathic products to demonstrate efficacy (i.e. whether they work), but only quality and safety.

The Barts and the London NHS CFS/ME Stretch Exercise Session DVD



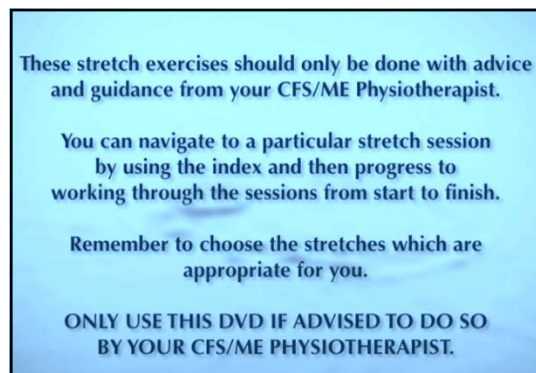
Recently, I had a case where I came across this DVD. It is one of the tools that the Sheffield ME/CFS clinic uses to help people manage their ME/CFS. Although this disk is available on loan from the clinic, patients can choose to purchase the disk.

I am always interested in anything to do with ME/CFS for many reasons. This was of particular interest to me, because I used to be a member of a local Karate club, and as with anyone who practises martial arts, a big part of the workout

session is related to stretch type exercises as part of the warm up. The disk itself comes with a typical CD package. It runs on either a DVD player or a more recently manufactured computer. You can go into the menu and select the session. I've attached a copy of the cover, which gives a lot of information about the content. The programme is introduced by Helen Chubb, a Physiotherapist. There are a series of sessions, the last being a cool down session. More of the content is Helen instructing two ME/CFS patients in a gym through the various activities.

Ross, one of our members, wrote: *"The Stretching Exercise DVD, well I've watched it. It is only gentle stretches, nothing hard (for non ME's), with enough warnings not to do it if you don't feel OK with doing the stretches. If you only do two minutes a day, if you feel happy with that that's OK, but as we know if you over do you will crash and burn and go into relapse. So, all in all it's up to each individual to work out what is best. If you can't do them or don't want to do them, don't. We all know that pacing is supposed to help, but sticking to it is very hard to do in the real world. It's like saying you can put the cloths into the washer and wash them, but you can't hang them out till the next day or you can only wash half the dishes in the sink or only Hoover half a room. These things in the real world are not realistic. So remember, you have to work out for yourself what you can and can't do, so enjoy. But, remember only do what you want to do - do not overdo it."*

Personally, I think this DVD would be suitable with Grade 1 cases or those who have recovered. There are a number of ME Yoga groups around the country, which seem popular. It works for some people, and is disastrous for others. As members would have to travel a considerable distance to Sheffield, I am keen to see something like this offered at the Redmond Centre. It may be possible to get funding from somewhere, or it may be economical for people to pay a small fee for a session. I can have a word with possibly SYCIL who promote this sort of activity.



Obviously we would have to have guidance from OT's Anne and Mark from the Sheffield clinic for health safety, and clinical governance. Please let me know if you would be interested—Mike.



News from Fairlawns.

(The South Yorkshire and North Derbyshire Chronic Fatigue Syndrome/ME Service)



I represent the Leger ME group, along with Michèle Young, from Derbyshire ME Support Group and Ute Elliott from Sheffield ME Support Group. I can't really report everything that goes on at the Sheffield CFS/ME clinic's Local Patient Involvement Group (LPIG) Meetings. For this edition of Pathways we are including a resume of the CFS/ME Team for Children & Young People in South Yorkshire & North Derbyshire, given by Dr. Allison Wray at the meeting of 10/9/2010 which gives an insight into ME/CFS in children & young people and the services they are providing.

Who we are?

The CFS/ME Team for Children & Young People in South Yorkshire & North Derbyshire is a specialist regional tier 3 service provided by Sheffield Children's Hospital NHS Foundation Trust. They provide a high quality, effective service to children up to the age of 18 suffering with CFS/ME and to their families.

The Team

They are a small, part-time team made up of a Consultant Paediatrician - 1 hour per week: 2 Occupational Therapists - 3 days per week: 1 Clinical Psychologist - 2 days per week: and one newly recruited Clinical Psychologist - 2 days per week:

Who we see?

Children & Young people and their families up to the age of 18. Young people under 16 are referred by a Paediatrician and those aged 16 - 18 years referred by their GP.

Who do they see?

The children's clinic sees just over 30 cases a year. About one third is in the age range 16-18. About two thirds are girls. About half the people they see are from Sheffield, and around 7% are from Doncaster.

What do they do?

They offer a range of treatments to help young people & their families manage CFS/ME. The most popular are activity management and CBT for problems with anxiety or mood. They also liaise regularly with education and attend meetings to negotiate plans for schooling. The average length of treatment is about 18 months varying from 3 - 4 months (4 - 6 sessions) to 24 months. In September 2010 they reported having 54 open cases.

How effective are we?

At discharge the majority of our patients show significant improvement as measured by improvement in symptoms and attendance at school, college and university. Since the service started in 2005 we have transferred 3 patients to the adult team and one person sought a referral 18 months after discharge. Of the young people unable to attend school 99% obtain GCSE's as a result of our close partnership with Hospital and Home Education Services.

Planned Future Developments

Further developments include: Staffing and Staff Training, Patient Groups, Patient Resources, and training of other professionals.

Leger ME Group Meeting 19/10/11: My Understanding of Pacing by Anne Fisher

If we are having a meeting at the Redmond Centre, I have to try and find a speaker, or at least have something of interest otherwise it would not be worthwhile for people to attend. The past few meetings have been about the DWP benefits system and the budget cuts, so I thought it would be good to try a change. Coincidentally, Anne offer to do a talk on Pacing based on her experience of the Sheffield ME/ CFS clinic, so I thought it would be a good idea to give the meeting over to Anne and take a back seat for a change. Anne prepared her very first ever PowerPoint presentation a PowerPoint presentation, and presented it at the meeting. The slides are reproduced unedited, as seen on the screen.

MY UNDERSTANDING OF PACING

ANN FISHER

Me and ME

- I have 20 years experience of the illness
 - During the first year I was very ill
 - Followed by 3 years of slow recovery
 - After this I gradually returned to part time work, and was able to do most of the housework and the family activities for 13 years.
- 3 years ago I suffered a moderate/severe relapse which has meant I have been unable again to do most activities.
- Approximately 1 year ago I noticed small improvements and began to look forward again to having a future with less symptoms.
- Pacing has helped form part of this recovery.

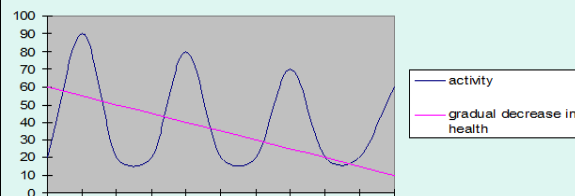
Introduction to pacing

- Pacing is a way that can help us balance our daily activities between doing things and resting.

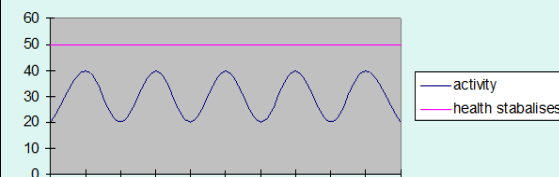


Reproduced from CFS/ME Service for Sheffield and N Derbyshire

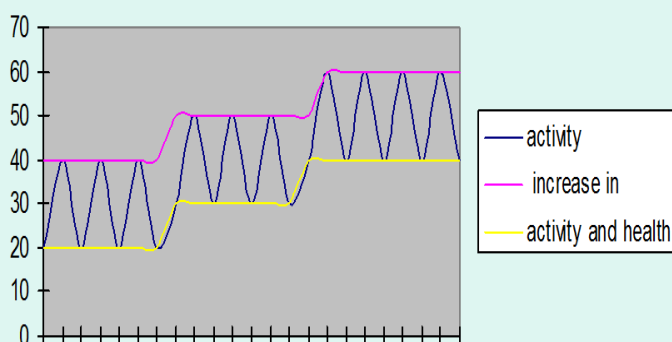
- People with ME tend to do too much on good days, tire themselves out and then have to rest for long periods.
- This is called 'Boom and bust' as shown below



- The idea of pacing is to stop the swinging from one extreme to the other and to start the process towards recovery.



- By having frequent small rests and balancing activity with rest over a period of time your levels of activity and symptoms should improve.



Energy use

- Re-chargeable batteries.** If you use all the energy from the battery it will take a long time to recharge, if small amounts are used then the recharging time isn't as long.
- As with our energy, use a small amount and take a rest, don't try to use all your available energy as this will take longer to recover from.



- Bank account.** Likewise it is important to budget our money so that we have enough to last us though the week, spending a little each day and not using it all at one time.
- We also should spread out the energy we have and not use it all up with one burst of activity.

How I Pace

- I began with only being able to do 10-15 minutes activity with a rest that lasted from 10 minutes to 1 hour. So I would shower and then have a short rest followed by dressing and another short rest then dry my hair and have a longer rest, this continued throughout day.
- After living with this very restricted amount of activity for many months I noticed small improvements in my symptoms and so began to gradually increase the amount of activity by a few minutes each time up to 20-30 minutes activity with 30 to 60 minute rests.
- I can now do 30mins – 1 hours activity and rests have reduced to 30mins.
- These changes have been built up over many months and are adapted to daily changes in symptoms that are brought on by circumstances that are out of my control.
- If doing a long activity – up to or over one hour I try to break it up with short 5-10min rest every 20-30mins.
- The longer the activity the more short rests I try to include.
- *This is the routine I have developed for my symptoms they will be different for each ME/CFS sufferer*

- When I am having a bad day I tend to rest for too long and I can then start to feel worse. To prevent this I try to move around, take a walk around the house and garden, make a drink, just do a short simple non energetic task.



Rest periods

- Ideally these should be taken without any stimulation so that the mind and body can rest and recover.
- However I find this very difficult as I am always wanting to be busy so I use tv or music for longer rests and silence in the form of a relaxation technique for short rests.
- I also use complementary Therapies such as Massage (not suitable for fibromyalgia sufferers) and Reflexology to help with symptom control and relaxation.
- Relaxation techniques have been useful for me to help take quick rests but also for during the night to help relax or return to sleep.

Saving energy

- Whenever possible I simplify tasks as this saves energy, I try to
 - Soak pots and allow them to dry
 - Never go upstairs empty handed
 - Try not to do all the cleaning at once
 - Break up mental, physical and emotional tasks
 - Allow others to help
- I also use my DLA to help with my care so making life at home easier, I have a Cleaner once a week for a couple of hours to do all the heavy work, a Gardner occasionally and my Food delivered. This helps to keep some of my symptoms away and enables me to have time and energy for more pleasurable activities.
- I try not to go 'mad' on good days but I find this very difficult and have to be very strong willed to control my urge to be busy.

- Accepting my illness and that it's prescribed treatment is rest, instead of fighting against it, has given me a certain amount of contentment. I still get frustrated and low at times but generally looking for the improvements and staying positive helps.
- Trying to keep the balance between rest and activity isn't easy and very often I fail and start to feel a return of my symptoms so I know then that it is important to return to pacing and eventually enjoy the reduction in symptoms once again.



Questions and Discussion

Pacing is the only real management tool we have. OK, so most of us with ME/CFS find out about pacing by default, i.e. we do things and learn the consequences, and so learn by default. But there are still those who don't understand how to pace, and find it difficult to accept the realities of ME/CFS. These sorts of people usually experience the consequential denial and anxiety problems, which need careful management. Fortunately, this is one problem that the Sheffield ME/CFS clinic handles well. After they opened their doors about five years ago, there was a definite drop in the number of people with management problems contacting Leger ME – so the Team at Fairlawns are doing some great work. Anne was asked if she got it right all the time; really the answer was "mostly". 100% effective pacing is not always possible due to pressures where family and life commitments are concerned.

I was asked if there was a biological basis to explain why pacing works. One theory suggests that the last point in the mitochondrial energy chain involved conversion to ATP to ADP, then ADP is then recycled back to ATP. The theory then says it is that the fatigue with ME/CFS is caused by this recycling process being slowed down by the disease process, and as a consequence ADP is converted to AMP to release further energy. The catch is that the ADP/ATP recycling is very quick, done in a matter of minutes, whereas the AMP/ADP takes 2-3 days, and it is this timing that explains the rebound/recovery period. It's a nice theory, but doesn't explain everything.

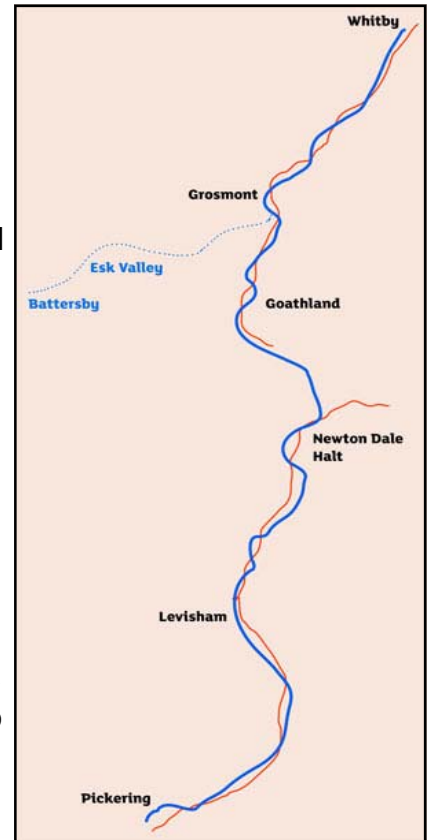
One of Anne's concerns was her lack of expertise in the subject. Really, while Anne, Mark and their colleagues at Fairlawns are very good, what they can't do is encounter the experience of ME/CFS – and really the really experts are those who have to apply it in real life – not those who teach it.

Well done Anne, and thank you for your contribution. - Mike

Travel Diary: A Visit to Whitby

Images thanks to North Yorkshire Moors Railway

Since having ME/CFS, one of the biggest frustrations has been the limitations of what you can enjoy. Anyone with ME/CFS will understand these limitations and frustrations, and realise that even a day trip has to be carefully planned and thought through carefully to make the trip worthwhile. I have been to Scarborough, Filey and Bridlington many times, but never to Whitby. Also of interest was the North Yorkshire Moors Railway. Having been a child in the days when steam engines on the railway were the norm – there is always some sort of reassuring reminiscence attraction. One of the images from childhood is the blue A4 Pacific locomotives, which were used to haul the predecessors of the intercity services along the East coast main line through Doncaster. A number of these are preserved and run on the NYMR which was an additional attraction. The NYMR railway line is a preserved railway about 18 miles long with the attraction that it is connected to the National Rail network on the Esk Valley line which runs into Whitby. So the adventure was set: a drive to Pickering via the A1 and A64, ride a train via Grosmont to Whitby, avoiding the drive, spend a couple of hours in Whitby and return via the same route.



So, having rested on the days before, one mid morning in late August we arrived at the Pickering Station Car Park. We drove around and found the car park full, the disabled car spaces were occupied by cars not displaying blue badges. We met someone else trying their luck for a parking space on the way out, but then spotted a notice 'overflow parking 200 yards left'. Obediently we drove to the car park, and ended up parking up in front of someone's bungalow on a fish farm. On the gate post was padlocked a cash box with a notice asking for a donation to NYMR. Next came the '200 yards' walk to the station, (or as I found out later more like 700 yards!). At that point I made a decision that basically I've blown the pacing, and as with people who had suffered from ME/CFS many years I knew a rebound was coming on the following days. But we had come a long way, and in spite of knowing I would pay the price later the thing to do was enjoy the day.

We boarded the train, a 1960's style corridor coach with compartments. This type of coach is interesting, because unlike on modern trains you can open the window, and lean out to see what is going on. Off we went—quite a 'pull-you-back-in-the-seat' kangaroo start, reminiscent of a first driving lesson start, then sudden deceleration, then a puff and then the sudden lurch forward like a botched 1st to 2nd gear change. This repeated itself many times until the running speed limit of 25 mph for preserved railways was achieved. This was part of the 'steam experience' like the dada-dada of the coaches as they cross over the fishplates connecting the different rails. After every surge forward, there was a puff from the engine. Along came the guard to punch the tickets. Unlike the guards of the National Rail services, this guy was very chatty, and explained that the engine being used today was originally built in the late 1900s, and was a slow very powerful engine, formerly being used to haul goods around the mineral lines in the area.

The NYMR route has many steep hills or in railway jargon 'gradients', as it crosses the North Yorkshire Moors. Unlike modern motor vehicles, old steam engines don't have a gearbox. The design strategy for that type of engine is a high pressure boiler about 180 psi, big cylinders, and eight driving wheels. Every school child knows that in a steam engine, a fire boils water to produce steam, the steam is then allowed into a cylinder. The steam pressure, then pushes the piston, providing mechanical power, a bit like blowing back into a pedal-cycle type pump. The mechanics have further bicycle parallels too to transfer the back and forth motion to the circular motion. When you set off, you set the pedal to just below the top dead centre, and push down hard. As the pedal travels down, the maximum pulling power occurs about halfway down. By the time you get to the bottom, you can't

push any further, with any power from the leg, the bicycle coasts, until the opposite pedal has just gone past top and then that takes over. In a steam engine, a similar thing happens, except steam is blown in alternately from opposite ends of the cylinder. What happens if the engine stops at the bottom of the stroke? We'll, if some early engines stopped with the piston in the wrong place they were stuck and had to be moved manually. Stopping part way along the stroke was the usually practice. The later engines had two cylinders, the second was arranged to turn a quarter and was always a turn of the wheel later on, so is always stopped with a cylinder in a pulling position. A further complication is that steam engines only produce useful power at a maximum of 70% of the stroke—so the power delivered to the wheels varies as they rotate. At low speed and a full throttle, this produces the surge of acceleration that ends with every puff of smoke. If you have ever been in the driving cab of a steam engine, you know that the engine sways from side to side, as a result of the wheels and frame distorting as uneven power is delivered to the rails. It also explains why older type carriages were heavily padded. This along with smell and sounds contributes to the 'smelly old railways' experience.

We eventually arrived at the first stop, Levisham, an isolated station in the middle of nowhere, then past Newton Dale Halt, a single platform in the middle of nowhere. These are within the North Yorkshire Moors National Park, and these days are really targeted to walkers. Just before Goathland, the next station on

the line, we got a glance across Goathland Moor to the RAF Fylingdales early warning station. The infamous golf balls of the cold war have been replaced by pyramid type structures, reminiscent of 'Dr Who'. A further less infamous celebrity status is claimed by the station itself, because it was the filming location of 'Adensfield' in Heartbeat, and 'Hogsmeade' in the first Harry Potter film. We then proceeded through the tunnel to Grosmont station where the train stopped.

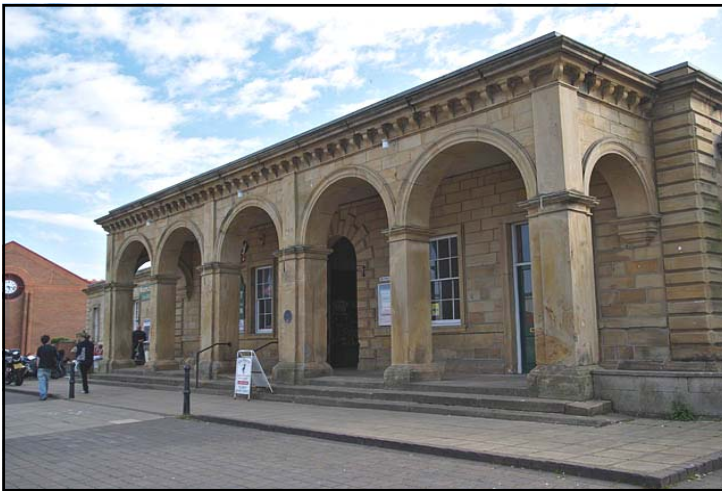
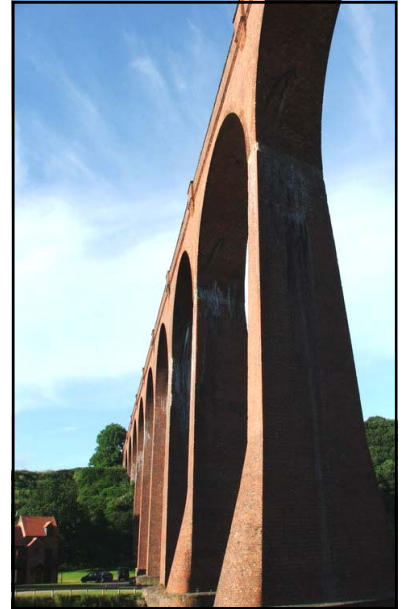


I got worried, because nothing happened for a while. I then saw a man in a BR overall walking along the track along the side of the train. National rail are always finicky about who drives trains along their track. Ah, I thought –this is an inspection before we go over the border between the NYMR track and the national network. Peering through the window, I watched him, and realised that the old steam engine had disappeared, and been replaced by a BR era green diesel. At that point a lady with three children appeared in our carriage compartment. She carried a comprehensive selection of camera and other photography paraphernalia. This was a surprise, a female railway anorak, she surprised me even more with her depth of knowledge about the railway operation. Apparently, there are many sharp curves in the next part of the line and as steam engines have a fixed frame and the wheel cannot pivot with solid axles, this causes excessive wear on the rails, so access to steam engines is limited to occasional special events. A useless unrelated fact I learned was that most of the wear to channel tunnel trains and tracks occurs at the loop around at either end.

Finally we were on our way again. The Diesel accelerated smoothly out of the station, a bit like the 3 cylinder for passenger service Blue A4 Pacifics we had expected to see. The train meandered along side the river Esk very quickly. I learned that this line was earmarked for closure by Dr. Beeching in the 1960s, and that it had only been saved because it was the only viable route for children to get to school and consequently has been nicknamed 'The School Line'. I also learned that this section of the line was shared alternately with Northern Rail services that ran between Middlesbrough and Whitby. The further we went the wider the river Esk became. We passed under Rusworth Viaduct, which formally carried a long dismantled railway across the Esk. Very shortly after that, we saw more railway lines, a sure sign that we were approaching Whitby station. The train slowed down and eventually, stopped. The guard appeared, and in a loud voice said his piece. The train was to form the 1400 back to Pickering. Even those who had just come for the ride had had to leave the train. There is now only one track and platform. They have to reverse further up the line where the train can be diverted into a siding, and the engine can run around the train to the other end. The train would then reverse back into the station and be taken back to collect the waiting passengers. We were recommended not to get the 1605 train, as this was a Northern Rail service to Middlesbrough. Although it would call at Grosmont, and they would accept NYMR tickets, it only consisted of two rail



Above, a picture from NYMR literature of a train leaving Whitby on a gala day. What you actually see are the river Esk (middle) and the impressive Rusworth Viaduct



Whitby Station entrance: Designed to impress by the railway companies before the age of the motor car.



On the wall of Whitby Station there is a ceramic tile map showing the North Yorkshire railways network pre-war.

Recipe Corner

Christmas Mini-Muffins

Ingredients for 24 mini-muffins:-

- 200g/7oz Golden Caster Sugar
- 100ml/3½fl oz Sunflower Oil
- 75ml/2½fl oz Milk
- 1 large free-range egg
- 50g/1¾ oz Good quality dark chocolate, chopped
- 1 heaped tablespoon quality mincemeat
- 50g/1¾ oz good quality white chocolate, chopped
- 50g/1¾ oz dried (or fresh) cranberries

Preparation:-

Preheat the oven to 190C/375F/Gas5, and put 24 mini-muffin cases inside a mini-muffin tin.

Mix the flour and sugar in a bowl, then make a well in the centre. Whisk together the oil, milk and egg and slowly pour into the bowl, stirring gently.

Divide this mixture between two bowls. In one bowl add the dark chocolate and mincemeat.

Add the white chocolate and cranberries to the other bowl. Stir very gently.

Divide the two mixtures among the 24 muffin cases and bake for 20 minutes or until golden brown and risen. Remove the muffins to a wire rack and eat warm.



cars, as opposed to the 8-coach train we had arrived on, and quickly overcrowded. He also said that to avoid this, NYMR usually lays on a bus to get people to Grosmont to pick up a train. He strongly recommended that we use their 1800 service as there was plenty of space it, and it was last train of the day, and it would be a long walk home.

On leaving the train, we walked down the platform. The train staff were busy closing all the windows, ejecting all the passengers, and locking up. By the time we got to the front of the train, the guard had made himself comfortable in the drivers cab, and the train reversed and vanished. The track actually finished short of platform—possible to reduce damage in the event of overrunning the buffers? In the wall of the station there is an historical feature, it is a map on tiles of the old local railways many years ago. The majestic entrances to stations just show the prominence and prestige imparted to the pre-nationalisation railways companies. The front is now a car part and bus station. Next thing toilets. Toilets? No, there weren't any in the station. Nearest were in the Co-op supermarket, next to the station. Grr. Next—food. Strolling along the harbour with its usual seaside attractions, across the harbour we could see the bridge and church with the 199 steps up to St. Mary's Abbey. 'Not for us', I thought. Eventually we found an open air café and decided to settle for lunch. It was a warm sunny day. While we were waiting for our order, I watched people wondering past. From their clothes, they looked mainly like day trippers, and their accents indicated they were possibly from Middlesbrough. The same people who walked past us, walked back about 6 minutes later—so it is was quite clear they were exploring—and had found nothing of interest.

The sandwiches appeared. Not long after, the sky darkened, and it started spotting with rain. The weather turned cold and at that point the ME kicked in, and rather than enjoying the days, the place became irritable and hostile. Finishing the meal, the next thing was to find somewhere sheltered and sit down and make plans. So we made our way nearer to the railway station. There was no refuge like a car to get out of there. There were only two options for exit trains, the unwelcome 1600 or the 1800. After several moments reconsidering—we decided to go for the 1600 crowded or not, so we went back to the railway station. At least there it was sheltered, and there were seats alongside the platform. Shortly, a uniformed lady turned up, wearing a prominent NYMR tie. NYMR had laid on several coaches to get its passengers to Grosmont in time to catch the next train, so we proceeded to the bus stop outside the station and queued. Eventually, a coach did turn up, which we boarded. Unusually the coach had an asymmetrical central gangway; with a 2/3 rows arrangement of seats, packed like sardines I thought, a bit like budget airlines!

The bus departed, and made its way through Whitby town, and climbed up to the Moors. The scenery! We got a panoramic view of Whitby, the sea and the area for miles around. We were just enjoying the ride when suddenly I heard the bus engine rev up. The driver dropped down several gears—and the bus lunged at 45 degrees downwards, engine roaring. We were on a very steep hill, and at the bottom was Grosmont station. The bus stopped on the level crossing, blocking the path of the train. We all piled out and breathed a sigh of relief. The journey back to Pickering took just over an hour, when we arrived on the station—I thought I'd better have a photograph of the engine 63395, then get to the car. By the time I was organised, the train was reversing out of the station—it was, I guess, just after 1930. After a stroll to the car park, it was back home by the same route we came. We were home just after 9 p.m. During the following days, there was of course rebound, it took about a week for the effect of the day to fully settle.

So was it worth it? Well, just because you have ME/CFS, it doesn't mean life has got to be on hold, but you have to plan around it and be prepared for its consequences. Would I go back—definitely yes, there is a lot I didn't see, but maybe the strategy is to hire a cottage, and explore the area a bit at a time. Disappointingly except for the last few miles just before Whitby, unless you are a railway anorak, there is not much to see as the line meanders down the bottom of the valleys. I still think it was an adventure, and the best bit, the unexpected journey over the North Yorkshire Moors. Perhaps stopping at several of the stations on route, and exploring the villages would be more interesting.



63395, our motive power for the day on the NYMR

Experiences of Pain

'From 'ME Research UK, Breakthrough, Autumn 2010'

Muscle pain is reported in more than two thirds of patients with ME/CFS. Pain is a very common symptom in ME/CFS; it tends to be experienced in the muscles and/or joints, but it can often be widespread and changeable in location and intensity. In one survey, quoted in the Chief Medical Officer's report, 79% of patients said that they had severe pain sometimes, much of the time, or all of the time, and between 84 and 94% of patients in formal research studies report some degree of muscle or joint pain. Importantly, 53% of unemployed people surveyed recently by the campaigning charity Action for ME said that chronic muscle pain was one of the greatest reported barriers to their obtaining paid employment.

Despite this, there is very little scientific information about the specific pain characteristics of ME/CFS patients. What kind of pain is it? Where is it localised? What strength is it? To explore such questions, ME Research UK provided part-funding for a PhD studentship, under the supervision of Prof. Lorna Paul and Dr Les Wood (pictured on page 13), at Glasgow Caledonian University. The student, Rebecca Marshall, has now submitted her thesis, and the first scientific paper from her work has just been published in the journal of Musculoskeletal Pain.

For the investigation, 50 people with ME/CFS and painful symptoms were recruited from support groups across Scotland; all had previously been diagnosed by a consultant or general practitioner, and all met the CDC-1994 and Canadian Guideline symptom criteria. No participants had any psychiatric illness or any other serious conditions such as cancer, rheumatoid arthritis or multiple sclerosis (which would have affected their experience of pain).

The investigators visited the patients in their own homes to conduct their interviews, which allowed the participation of those who were so severely affected that they would not have been able to make a trip to the hospital. This was particularly important in this study since the researchers wanted to ensure that the findings represented the full spectrum of ME/CFS. Between 10% and 25% of ME/CFS sufferers fall into the "severe" category, so 10 of the 50 patients interviewed by Dr Paul's team were either housebound or bed bound and had been recruited via the national charity, the "25% ME Group" which caters for severely ill patients.

Overall, the 50 patients had been ill for an average of 12.6 years (range 1.3 to 27.4). Only one was working full time, and two part-time. A number of tools and questionnaires were used to evaluate participants' experiences of pain, and these consisted of a visual analogue scale, the Margolis Body Chart, the McGill Pain Questionnaire, the Pain Anxiety Symptoms Scale-20 and the Medical Outcome Survey Short Form-36 (see above box for more detailed descriptions of each of these).

The results revealed that pain is indeed an important symptom of patients with ME/CFS. The most common painful symptom was muscle pain, which was reported by more than two-thirds of patients.

Methods of pain reporting

VISUAL ANALOGUE SCALE

Participants are asked to indicate their current pain intensity on a visual scale from 0 (representing "no pain"), to 100, (representing "most pain ever experienced").

MARGOLIS BODY CHART

Participants use a diagram of the human body to indicate the areas in which they experience the most pain. This is then matched to a chart which divides the body into 45 sections, in order to identify the locations of most pain.

MCGILL PAIN QUESTIONNAIRE

Participants are asked to describe their pain using words from a standard list of 78, grouped into 20 subcategories. Numerical values are assigned to each word, and a Pain Rating Index is calculated as the total of the values for each word chosen. This provides a measurement of the pain itself (sensory component), as well as unpleasant feelings and emotions (affective component), and how it is judged by the sufferer (evaluative component).

PAIN ANXIETY SYMPTOMS SCALE-20

Participants are asked to score their experience of 20 psychological aspects of experience of 20 psychological aspects of pain, such as anxiety, fearful thinking, feelings of wanting to escape or avoid a situation, and physiological responses. Each item is scored from 0 (never) to 5 (always), and the total is calculated out of a maximum of 100.

MEDICAL OUTCOME SURVEY SHORT FORM-36

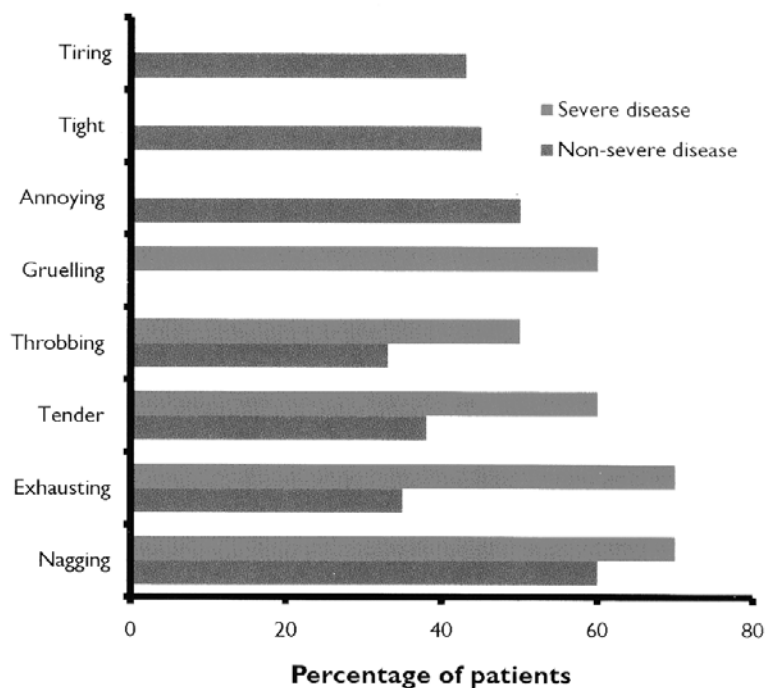
A questionnaire consisting of 36 questions examining physical functioning, physical role, bodily pain, general health, vitality, social functioning, emotional role and mental health. The participant's answers to each question are translated into a total score from 0, representing poor health, to 100, representing good health.

The average intensity of pain at the time of the interview was reported to be around 43 out of a maximum of 100 on the visual analogue scale, while the average intensity over the previous 24 hours was higher at around 58. The investigators suggest that this latter value may be a more accurate reflection of patients' experiences, particularly if pain fluctuates. Significantly, ME/CFS patients reported worse pain than did patients with rheumatoid arthritis or multiple sclerosis in previous studies, both conditions in which pain is recognised as a major symptom.

Patients used words such as "throbbing", "aching", "tender", "gnawing" and "burning" to describe the pain they experienced, while those with more severe illness also used "exhausting" and "nagging". In fact, as the chart opposite shows, only the severe patients chose the word "gruelling" while, none chose the less emotive words "tight" or "annoying" - indicating more severe pain, and intensity, in the most severely affected group.

These descriptions may give clues as to the mechanisms causing pain in ME/CFS; in particular, "burning" pain is often associated with neuropathic conditions in which the nerves have been damaged. Also, they may help in assessing any change in the quality of pain over time, such as after treatment, as Dr Paul's group suggests. Despite this burden of pain, most participants described their mood as generally positive, although those with more intense pain tended to describe a lower mood.

The most common locations of pain were the cervical spine (in 66% of patients), the anterior thighs (44 to 46%), the lumbar spine (42%) and the posterior calves (38%), and most participants had pain in more than one location. Nearly a third of patients said they experienced their most severe pain in the area of the cervical spine/upper trapezius muscle, while 20% reported the scapular/upper thoracic area and another 20% reported the right lumbar spine as the most painful regions. Twenty-eight participants said they experienced the worst pain in the morning, while it was the afternoon for four individuals, the evening for ten and the night for eight.



The results of the Pain Anxiety Symptoms questionnaire suggest that the study participants were not overly anxious or fearful because of their pain, although the most severely affected were more susceptible. When considering quality of life, Dr Paul's findings were similar to those of Dr Gwen Kennedy's study from 2004 (published in the *Annals of Epidemiology*). Patients tended to have reduced physical functioning and vitality (but not reduced emotional or mental health), and again this was more pronounced in those with more severe illness.

This is the first major study to document and categorise the pain experienced by people with ME/CFS, and to provide sound, objective, scientific support to their anecdotal and clinical reports of painful symptoms. As the authors say, *"This study has emphasised that the problem of chronic pain... needs to be treated as seriously as the pain experienced in other conditions such as rheumatoid arthritis and multiple sclerosis."*

Abnormalities in Muscle 'From 'ME Research UK, Breakthrough, Autumn 2010'

Findings point to a significant impairment of proton excretion following exercise

The autonomic nervous system has a range of important functions, so the consequences can be severe when it goes wrong. Since ME/CFS patients experience symptoms such as dizziness, altered vision, nausea and fatigue when they are standing, particularly when they are standing still, the possibility exists that the autonomic nervous system could be at fault.

Since 2006, with the financial help of ME Research UK, Professors Julia Newton and David Jones (pictured) of the School of Clinical Medical Sciences, University of Newcastle, have examined a large group of patients using a battery of tests of autonomic function, including heart rate and blood pressure. In a series of fascinating scientific papers, they have reported finding autonomic dysfunction in three-quarters of ME/CFS patients, a most unexpected result; they have shown that the heart rate response to standing is abnormal in a significant proportion of patients; and they have confirmed that blood pressure is lower, and blood pressure regulation abnormal, in this clinical group compared with healthy people.



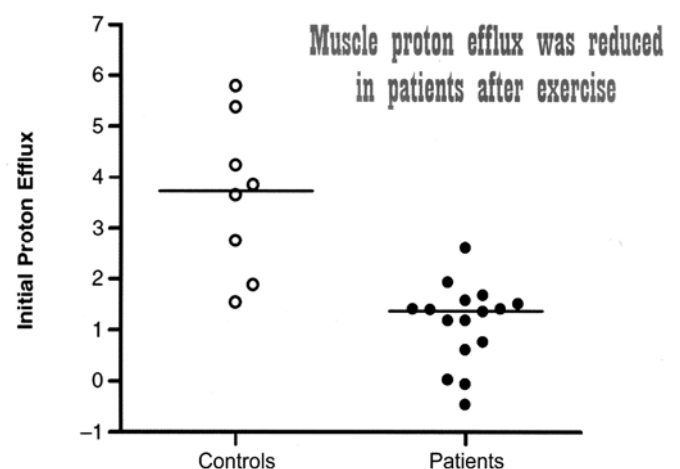
Prof Julia Newton and Prof David Jones

The autonomic nervous system also plays a part in regulating events in exercising muscle, however, and the researchers hypothesised that it might be involved in the exercise-induced symptoms so characteristic of ME/CFS. To examine this, they enlisted the help of phosphorus magnetic resonance spectroscopy (MRS), a marvellous tool which allows assessment of acid (pH) handling inside the muscle where the problems might lie.

Sixteen ME/CFS patients and healthy controls matched for age and sex underwent MRS to examine acid-handling in their soleus and gastrocnemius muscles during exercise, which involved rising and lowering the foot under very controlled conditions. Measures of autonomic function were also assessed. Prof. Jones and Newtons' results have just been published in the Journal of Internal Medicine (2010).

Compared with normal controls, the patients' proton efflux (a measure of acid-handling) was reduced immediately after exercise (see the figure opposite), while their time taken to reach maximum proton efflux was significantly prolonged, and the magnitude of maximum proton efflux was reduced compared with the controls. Taken together, these findings point to a significant impairment of proton excretion in the recovery phase following exercise - in simple terms, ME/CFS patients recovered substantially more slowly than controls.

Could simple deconditioning be the cause? Probably not, since both maximum voluntary contraction measurements and muscle volume were similar in patients and in the inactive controls. Rather, the researchers think, it more likely that impaired acid-handling could be one of the mechanisms through which autonomic abnormalities act to produce post-exercise symptoms and fatigue, given the role played by the autonomic nervous system in the regulation of acid transporter pathways and vascular flow in muscle.



Despite the key role of post-exercise symptoms in the illness, there has actually been very little scientific investigation into muscle physiology during exercise in ME/CFS—a fact that makes these novel findings so important. Based on these results, ME Research UK has now organised funding for the next step: an examination of the function of an energy-generating enzyme which might be under-performing in people with ME/CFS.

Focusing on muscle: Next steps in Newcastle 'From 'ME Research UK, Breakthrough, Autumn 2010'

In the historical literature, the hallmark of myalgic encephalomyelitis (ME) has been marked muscle fatigability often in response to minor degrees of exercise. Muscle cramps, twitching and extreme muscle tenderness were also common findings. And today, patients diagnosed with ME/CF5 frequently highlight the importance of peripheral "fatigue", such as impairment of muscle power, in their experience of illness. So it makes sense for researchers to focus on muscle.

Given their results published this year in the journal of Internal Medicine, the next step for Prof. Jones and his colleagues is to see whether a problem with muscle "bioenergetics" might be at the root of the slower recovery from exercise seen in ME/CF5 patients. For instance, it might be that acid build-up during exercise is the result of an under-performing energy-generating enzyme within the mitochondria (the "batteries of the cell"). To investigate this, the researchers will undertake a range of in-vitro studies, all based on primary assay and culture of muscle cells (myocytes) in the laboratory, using cells harvested from ME/CF5 patients and from matched normal and chronic disease controls.

The first phase of the investigative strategy has already been funded by the Northern Clinical Network in Newcastle, and involves an examination of the function of ME/CF5 patients' cultured muscle cells; the muscle biopsies taken during this phase represent a unique opportunity to study the pathways of metabolism within muscle, exploring the expression of the key energy-generating enzymes and cell proteins which help to control acid build up within the cell.

The second phase has been funded by ME Research UK and involves array studies to look at metabolic gene expression in muscle. The aim is to show whether cultured muscle cells from patients with ME/CF5 have altered gene expression, and whether the response of gene expression to "exercise in vitro" is impaired in patients' muscle cultures.

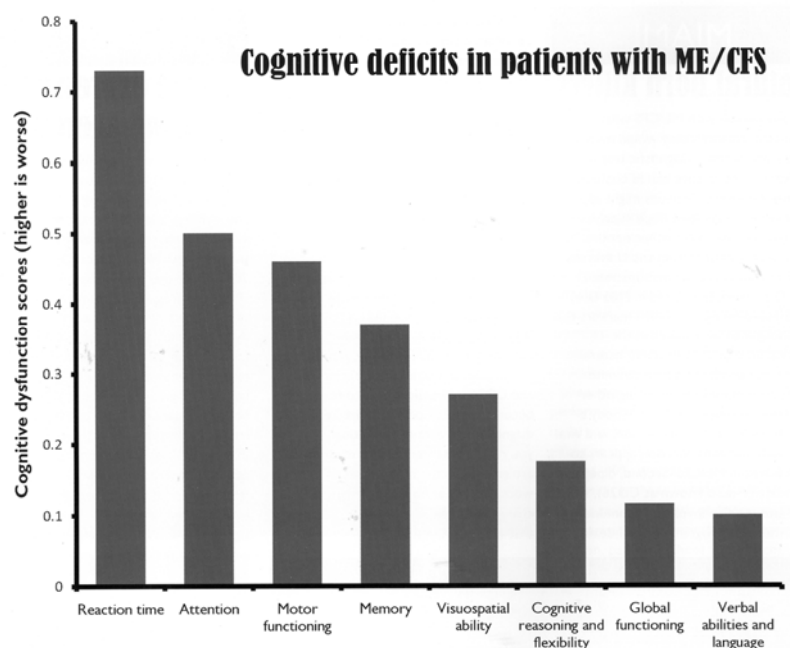
The exciting thing is that this series of interlinked studies brings together investigators from diverse academic backgrounds (muscle energetics, muscle cell culture and nanotechnology development), all members of the Institute of Cellular Medicine within Newcastle University, and all applying their skills to the illness ME/CF5 for the first time.

Australia: Memory and attention problems.

Neurocognitive problems are one of the most frequent and disabling symptoms associated with ME/CF5. In one investigation, 89% of patients reported memory/concentration problems, while in another large study memory/attention deficit problems were reported by approximately 90% of 2,073 consecutive patients. Crucially, patients often report that their cognitive problems can be made worse by physical or mental exertion. But do such self-reported anecdotes about cognitive symptoms also show up as measurable deficits on objective cognitive testing in a clinical setting?

Meta-analysis is a method of combining results from a range of studies to obtain an overall estimate of the "true" effect of a treatment. Researchers at the University of Adelaide, South Australia have just published (in Psychological Medicine) a meta-analysis of all relevant clinical trials examining cognitive functioning in people with ME/CF5, with the aim of identifying the pattern and magnitude of these deficits. Overall, they found a very mixed bag of 50 studies (made up of 1,577 patients and 1,487 controls) published between 1988 and 2008 from which, nevertheless, a clear and very revealing pattern emerged on detailed examination.

The most significant cognitive deficits (see the chart above) were found in "attention" (encompassing attention span and working memory), "memory" (examined from verbal and visual memory tests, mostly memory for word lists) and reaction time (assessed as responses to both simple and complex choice stimuli). These results were consistent with the memory and concentration problems that patients themselves complain about. In contrast, there were no apparent deficits on tests of "fine motor speed", "vocabulary", "reasoning" or "global functioning", suggesting that the "higher order" cognitive abilities such as language, reasoning and intelligence remain unimpaired. Importantly, most studies that examined the impact of self-reported depression on cognitive functioning failed to find a relationship, indicating that depression was not responsible for most cognitive impairments. The range of these studies and the clarity of the findings leave no doubt that people with ME/CF5 have moderate to large impairments in simple and complex information processing speed, and in tasks requiring working memory over a sustained period of time. As the authors point out, the deficits in performance are around 0.5 to 1.0 standard deviations below that of healthy people, a fact which explains the significant impact cognitive problems have on patients' day-to-day activities and quality of life.



North of Doncaster

Personal Comment by Trevor Wainwright

Christians, Awake! An interesting story behind an old well known Christmas Carol.

We all know many Carols. Many have an interesting story behind them. Originally called 'Christmas day for Dolly', Christians Awake was written by John Byrom of Stockport, inventor of shorthand, at the whim of his daughter Dorothy who when asked what she wanted for Christmas said "please write me a poem". On Christmas morning 1745 she found of all her presents it was the first she opened and was complete with crossings out and amendments; her father had laboured well into Christmas Eve night to complete it.

It was first published in Harrop's Manchester Mercury in 1746 from where it came to the attention of John Wainwright organist at Manchester Parish Church, now its Cathedral, who composed for it the tune 'Yorkshire', and on Christmas morning 1746 Byrom and Dolly were awoken by the sound of Wainwright and his choir singing the carol 'Christians Awake' outside their bedroom windows. Published in 1750 as a carol, there are two versions, one only six verses long compared to eight verses in the second version.

The original poem was discovered by accident when during an examination of a box of books, a folded piece of paper used as a bookmark dropped out of a book. Curiously, the finder opened it and one can only wonder what the person thought when they realised they had found a very important piece of English Literary History. The poem is now preserved in its original state complete with creases and other signs of wear in a glass frame in the library of Chetham's Music School Manchester, formerly Chetham's Hospital for poor boys, next door to Manchester Cathedral.

Part of the original manuscript of words of Christians Awake!, This is now held at Chetham's Library in Manchester. It is the oldest free public library in England



It is perhaps interesting to note that the original poem is in fact 52 lines long, 4 lines have been taken out and 6 changed. Another aspect is the use of the old English long 's' like 'f' much like using the letter f, for instance cross appears to be written as *crofs*. Following a recent visit to Chetham's, I found myself wondering what it would have been like had Wainwright simply put a tune to the original poem and scored it for the instruments of the day, a point to ponder indeed.

A happy Christmas to you all – Trev

80 Christians, awake!

YORKSHIRE 10 10 10 10 10 10

Words: John Byrom (1692–1763) altd.
Music: John Wainwright (1723–68)

C G C G C F C Dm7

Christ-ians, a - wake! sa - lute the hap-py morn, where - on the

The top line from a modern hymn book. 'Yorkshire'; is the name of the tune. Hymn tunes are musical entities within themselves, and are separate from the words. They were usually given names of places, but not always. The series of 10s are what is known as a metrical index, which is a measure of the words. It was common church practice at the time to substitute different sets of words. While the tune stays the same, the sets of words very often change with time, and even with the different editions of hymn books used by the various churches. A good example is 'Cranbrook', which was originally a hymn, but is the tune of 'On Ilkla Moor Baht 'at'. Likewise, Cwm Rhondda has been adopted and is sung at football matches with various set of words depending on the nationality of the football team!