



Pathways

Price £ 2.50 (Free to members)

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



ESA. Here We Go Again ...

I've written a feature on Employment and Support Allowance experience (ESA) to date. The carrot and stick approach is certainly with us. Prudence and caution apply more than ever when dealing with the DWP. See page 21.



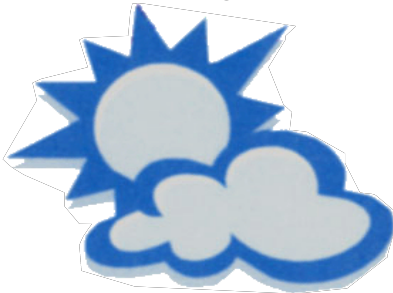
Research Features

From time to time we receive enough copies of **Breakthrough** to distribute to members who attend the Redmond Centre meetings. We've adapted a couple of features for Pathways.

See page 17

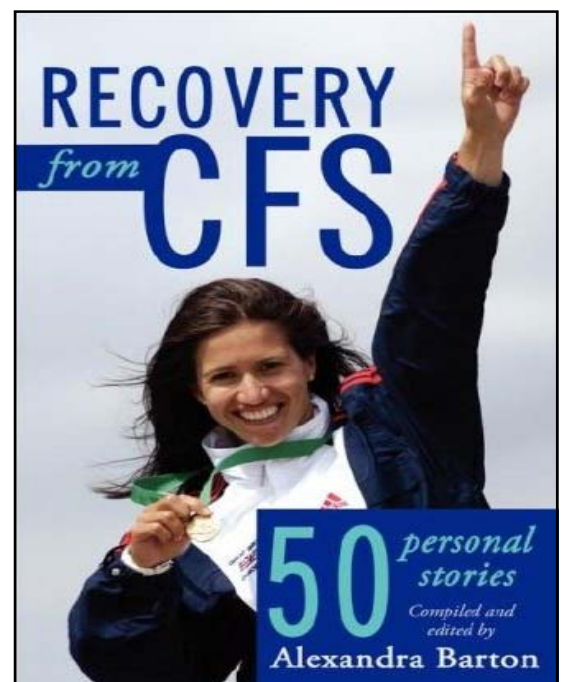
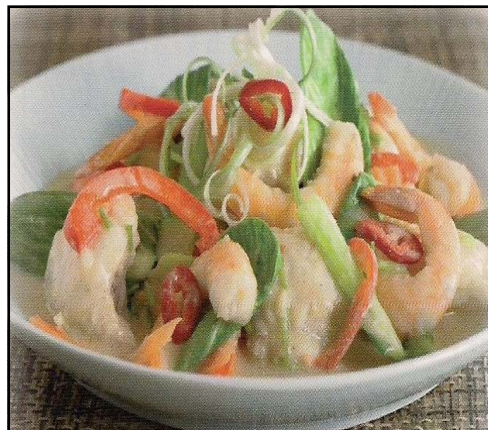
Clouds Community Counselling Service

See page 12



Thai Seafood Curry

See page 17



Book Review Recovery from CFS, 50 personal stories

See page 11

Meet the Sodas

see page 9



The world of ASTHMA and its association with ME/CFS

see page 6



You write:

Gillian Writes: I found a recent feature in the paper on Tonsil stones. I have told my doctor about them as I suffer with them myself, in fact I have a large white stone on my left tonsil and it's causing me to have a lot of ear pain, sore throat and it feels like I have a peanut stuck in my throat. Now I have gone to my local Herbalist in Mexborough and bought a second lot of Echinacea throat spray. The lady got me the first lot when she asked a second opinion on my tonsil stones and she was told to tell me to try this as it was my immune system. I have used it as soon as the stone came it's eased it very good stuff. Is this another part of having CFS/ME or am I just unlucky as one of the statistics to get these Tonsil Stones?

This is something new to me. For Pathways readers, Tonsilloliths (Tonsil Stones) are small white/or cream coloured pieces of tissue or debris that accumulate in the fold of the tonsil. Anatomically tonsils by their nature have a very convoluted surface which allows the build up of debris in the 'cracks'. Normally the lining of the tonsil (mucosa) should shed like the external skin is shed. The problem is that large colonies of bacteria may form which often make the tonsilloliths smell unpleasant, and as such that they can cause bad breath. Typically people producing tonsilloliths give a history of regularly coughing up these small smelly white fragments from their throat. Tonsilloliths are often completely benign and often require no treatment. In recurrent cases, or in people who cannot tolerate the symptoms, excision, or tonsillectomy is the only surgical cure.



Tonsilloliths (Wikipedia)

I've checked locally, and Tonsilloliths don't seem to be that common in our population, and I wonder if they are an indication of poor oral hygiene, or as a result of a dry mouth produced by chronic conditions like ME or people taking drugs like tricyclics which reduce saliva production. More common issues of this nature are dental scale and tartar with teeth, and I do think that tonsilloliths share a similar cause. I think that your throat sprays are a good first aid solution, but you really need to be looking towards getting your tonsilloliths properly excised (taken out) as soon as possible. The reason I say that is that it is capable of acting as a septic focus, and underneath there may be an abscess or other abnormality which needs attention. As your tonsils are part of the immune system, it is possible that they may aggravate ME/CFS, if irritated by tonsilloliths. As to who treats them it, I'm not clear. I think that your doctor or dentist should have a look at it, and if they think it's a problem they will pass you on to an orofacial or ENT unit. The nearest local unit is situated at Mexborough Montague hospital.

Matthew Writes Do you know if it is possible for sensitive ME's to be sensitive to:

a) Wi-Fi, communications towers.

Communications towers are deemed safe next to schools. In Wi-Fi equipment, the power is not high enough to cause a heating effect and there is more danger from a mobile phone.

b) The electromagnetic field on a computer?

This is usually contained within the metal cabinet. Electro Magnetic Compatibility (EMC) regulations say that computers have to be screened and have to have filters on the leads, e.g. ferrite beads because they can jam mobile radios, especially of emergency services like the police or fire brigade.

c) How far does the EMF (electromotive force) of a laptop extend?

The electrostatic field from the plastic on a laptop is about the same as when you stroke a cat or comb your hair, usually a matter of inches at best. The magnetic component is shielded by metal foil.

Have you had much feedback yet from members who have had swine 'flu and taken Tamiflu?

Swine 'flu seems to be not as vicious as expected. A recent news feature suggested that majority of school children may have had swine 'flu and not been aware of it. The level of serious cases is about the same level as would be expected in normal seasonal 'flu. If someone with ME/CFS got swine 'flu, I don't think that they would no know the difference between that and ME. I've heard reports that Tamiflu causes diarrhoea in about 8% of people who take it, and I wouldn't expect ME/CFS people to be any different in that respect.

Ian Writes: I've just received what I think is a DLA renewal form. I've renewed DLA before, and it's always been like applying, the form being the forty-odd page job, like the original claim form. I've also received a covering letter saying that if they don't receive it back within one month they will assume I don't want to claim again and my money will stop. Is this something new?

Most Leger ME members get DLA in addition to ESA, ICB and/or Income Support. DLA is usually awarded for 1-3 years for ME/CFS case. Usually, about 6 months before expiry of the claim, a new form is sent to be filled out. Recent awards have had no expiry date on them; which is an indication that something is changing. A quick survey of the internet ME chat rooms reports that the DWP have recently started sending out a new-style 4-page DLA renewal form, with, astonishingly, only two pages asking for information about your health condition and how it affects you. I have some concern that it seems too simple, just to tick a box saying there has been no change in your condition or circumstances, signing it and sending it off to get your DLA renewed. Most people I see with ME/CFS have ongoing tests and treatments that change so there is always something to report. But really, as well, I don't think that it could be as simple as that. The Benefits and Work website have mentioned this and are urging caution, and I expect that they will issue their own guidance in due course. Make an appointment to see me for case review at the monthly mentoring clinic, and we'll look at it further. Anyone else with further information, please contact me on the usual number.

Ross writes: To all at Leger ME, thank you for the help and guidance with my applications for ESA and DLA. This has now been going on since February of 2009. Following a medical examination at home I have now been awarded DLA. Just this week following a second medical, I have been put into the ESA Limited Capability For Work group. I would also like to thank Helen from SYCIL for acting as an advocate for the medical, and prompting me when my mind went blank. I have obtained a copy of my ESA medical report form and it starts off with a lot of writing and, guess what, the government computer system crashed again and poor Doc had to hand write it all out in longhand. So, towards the end of the medical he had writer's cramp or maybe ME/CFS block like me, and missed out a load of things I told him. But as you know, he had no understanding nor any compassion towards ME/CFS - also the point. It was interesting that this doctor only works part time and is in his 70s. The same doctor was a pain in the *** as of 20 years ago when he was the one that did Diving Medicals and HGV medicals. I am told I will have to attend a third medical putting me under even greater stress for a Work Focused Health Related Assessment (WFHRA). When will it stop?

I will agree that three medicals in a year are excessive, and really could be argued as being harassment. Based on the information available to me, it is the right procedure that the DWP have asked you to do. Do you think you are entitled to the ESA Support group? I say this because if the DWP agree to that, then you will have no further harassment. You mention that the doctor missed out a load of things on his report. Would your G.P. be prepared to back you up?

If someone is placed in the Limited Capability For Work for work group, this is roughly the equivalent of the Incapacity Benefit, but then they are expected to take steps to control their condition and prepare for a return to work-related activity, with the ultimate aim of returning to paid work. The Work Focused Health Related Assessment (WFHRA) is a formal interview to produce a massive form/report, planning the process and looking at the options. This is intended to be followed up by a series of monthly interviews just to make sure you comply with the scheme. As previously detailed in Pathways 18, if you do not comply your ESA will be cut by about £25 per week. That is why I use the carrot and stick logo for ESA in Pathways.

Later in this issue you will read about other members' experiences with ESA and the outrageous way that several group members have been treated. If the same standard of assessment that you have experienced is applied to this part of the ESA scheme, there will be trouble ahead. I will arrange a group meeting about WFHRA in the new year. My advice is that you see someone like an occupational therapist and take their advice before discussing anything with the DWP. I've not been able to contact anyone in other areas who have already gone through the WFHRA system.

Helen writes: I have recently received a report concerning a company that claims to help people with DLA claims and as it is an obvious cause for concern, I thought that Pathways readers would want to know about it: Here is part of it.

“.....who stated that they had contacted a company offering free benefits advice. The company visited, completed DLA, Incapacity Benefit and Carers' Allowance forms on behalf of the client. The company works on the basis that it is paid 45% of any back pay that the client receives from the DWP. My client ended up paying the company £1500! The company has no official address, just a PO Box in Preston. Although I am not sure about the legality of this and intend to raise it with our Welfare Rights service and the DWP, I think all members should be aware of the company. They have a website www.benefitanswers.co.uk. Their website also asks for contact from clients going through the benefits appeals procedure which would indicate that they are likely to receive a high amount of back pay and are therefore vulnerable to end up giving almost half of it to this company. It does leave a rather uncomfortable feeling all round...”

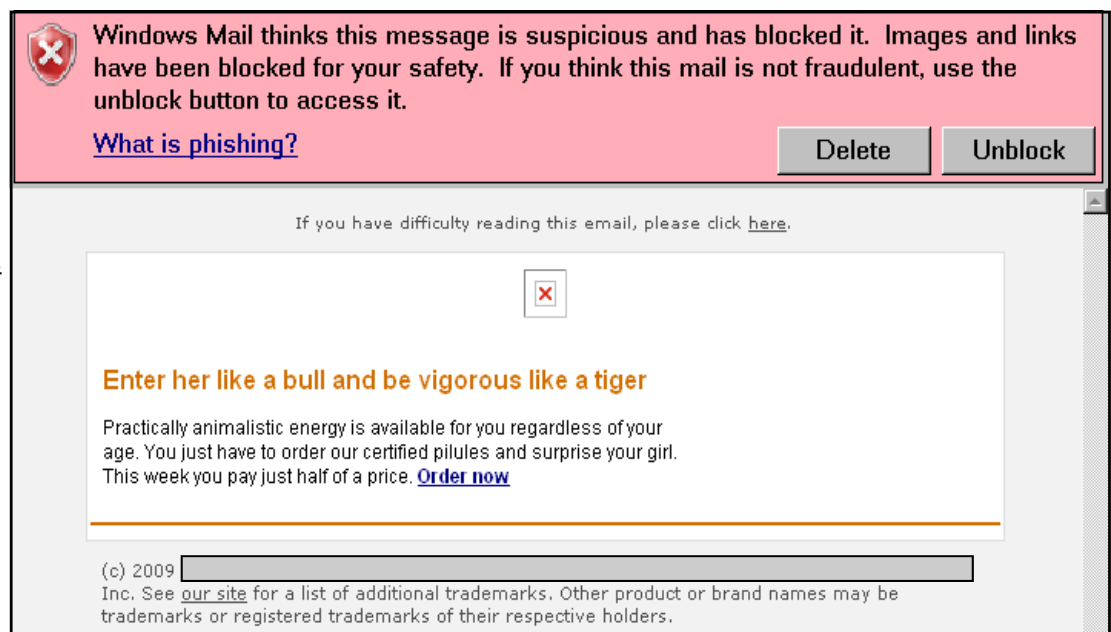
I must admit that I had thought that something like this might happen. I've checked the website and the report seems to be accurate. I'm just wondering if this is the thin end of the wedge, and we are going to get glut of organisations offering similar services. It just reminds me of the 'no win, no fee' solicitors and of course the local infamous solicitors in Doncaster who fleeced some of the former mineworkers locally. I don't think that they are competition for local organisations like DiAL, SYCIL, M25, CAB, Welfare Rights, & DPFC who offer similar services free in Doncaster, without taking a cut of the back pay!

John Writes (by email): I've received information about a postal scam. Can you circulate this around especially as Christmas..... "

Hold it! Hold it! I've seen that one before. The story goes something like:

You receive an email from a friend warning you that “you may receive a post card through you door saying you were not in, and to ring a telephone number beginning 09xxxxxxx to rearrange delivery. It's a delivery scam, and if you ring that 'phone number you will be charged about £100.00 on your telephone bill.

It's not the postal delivery that a scam, it's the email. The temptation is to click the forward button and send it to everyone on your mailing list as a favour. Don't, because that is what it wants you to do. The email contains a very clever computer virus, activated by clicking on the blue ICS link. Our system security picked it up straight away. If your anti virus software hasn't kicked in and warned you about it, your computer is not secure and you need to do something about it. It means no security is installed or it is not working. If you have sent something similar to your friends I would suggest you contact them by phone and warn them. On the right is the sort of warning the office system security produces if a suspect email is received, and your computer should do the same. If you want further information please email me on the group helpline.*



Money matters

Identity theft

Identity theft is one of the UK's fastest growing crimes with over a quarter of the population either directly affected or aware of someone who has been a victim. The primary reason identity theft is committed is to obtain unauthorised access to your bank account and/or take out credit in your name. In its early stages, it is difficult to discover and, even when it is clear that your identity has been stolen, it can be very inconvenient and stressful to unravel. In the short-term, it can also affect your personal credit rating.

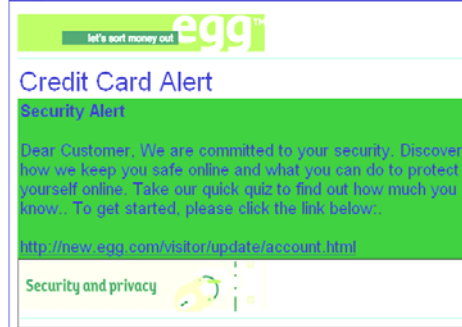
- Keep track of when your bank, credit card and club statements are due so you can quickly identify if you haven't received one.
- If you receive bills or statements addressed to you but you know they don't belong to you, inform the sender straight away.
- Make plans to keep your post safe whilst on holiday.
- If you move, make sure your post is redirected to your new address.
- Restrict what personal information you carry around in your handbag or wallet.
- Consider the use of a domestic safe or lockable cabinet to secure personal documents.
- Shred all confidential waste including receipts, statements and any official forms before you throw them away.
- Be vigilant regarding e-mail or telephone requests for personal information.
- Memorise PINs and passwords, never share them with anyone else and don't choose passwords that can easily be guessed by a fraudster.
- Make regular checks on your credit file. If you are unexpectedly declined check your credit file is correct.

Online shopping

More and more consumers each year opt to shop online, and, with the busiest shopping week of the year upon us (mid December), we all need to take a proactive approach to protecting our personal and sensitive data such as card numbers and PINs. Top tips to follow include:

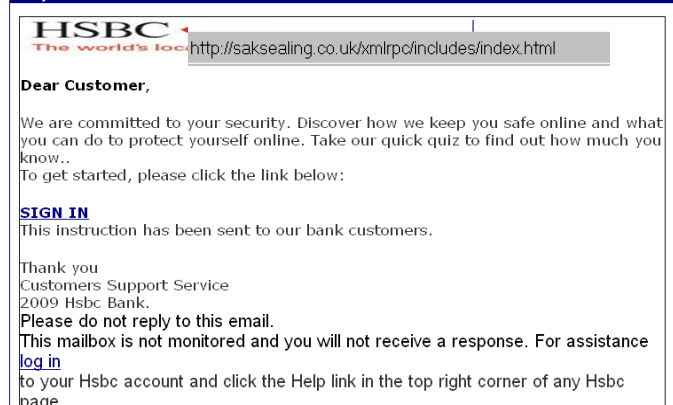
- Keep your PC protected by ensuring you have the latest operating system, firewall, browser, and up-to-date anti virus software.
- Look for the padlock symbol, especially if you are buying from someone for the first time. It's a good indication that they are reputable, but is no guarantee.
- Register your cards with Verified by Visa or MasterCard Secure as soon as you are asked to and then use them wherever you can.
- Always log out properly after shopping and save the confirmation email as a record of your order in case there's a problem.

From: Egg Bank Alert <customerservice@online-egg.com> To: mike@danum.me.uk <mike@danum.me.uk>
Subject: Notification message From Customer Service



Email messages are not always what they seem. Here are two attempts to gain Leger ME's bank access details that were recently received in the office. The top one purports to be from Egg bank. That's easy to spot because we don't have an Egg account. Click on the 'http://...' bit sends you to false lookalike website designed to extract your full security details. The lower one is a little more difficult to spot. The sign in link is the key or the log in link is the key. We've put in the actual address on the side of that bank's logo. The real HSBC site starts off with 'http://www.hsbc.co.uk'. At Leger ME we don't use email for banking. The Leger ME accounts are protected by a password, pin and access code. The access code comes from a small electronic device issued by the bank which gives us a number that changes every time. It is more secure than many personal accounts

From: Hsbc Bank Uk <i-banking@hsbc.co.uk> To: mike@danum.me.uk <mike@danum.me.uk>
Subject: Online Alert



The world of Asthma and its association with ME/CFS

What is asthma? About 40% of people I see are asthmatic. Asthma is a condition that affects the airways – the small tubes that carry air in and out of the lungs. Inflammation causes an associated increase in airway hyper-responsiveness that leads to recurrent episodes of wheezing, breathlessness, chest tightness and coughing, particularly at night or in the early morning. These episodes are usually variable, but often resolve spontaneously or with treatment. If untreated the airways become acutely and chronically inflamed, blood vessels in them become engorged causing inflammation and tissue-fluid leakage into the lining of the airway. Mucus-secreting goblet cells are increased in number and stimulated, generating plugs of mucus. Long term poorly-controlled asthma leads to permanent harmful changes in the lung when the reversibility is lost, in a similar way to what happens in chronic obstructive pulmonary disease (COPD), most of which is caused by smoking.

What causes asthma? A type of white blood cell known as an eosinophil is associated with the disease process but the process is not well understood. We know that people are more likely to develop asthma if they have an atopic family history e.g. asthma, eczema or allergies. These problems are associated with certain environmental factors, aspects of modern lifestyles, which influence whether or not someone develops asthma. As with ME/CFS, the onset of asthma may develop after a viral infection.

Who suffers? About 10% of UK children are asthmatic, with increased prevalence as they grow into adults. In 2002, around 1400 people died as a result of their asthma, 66% of these being over 65.

Diagnosis There is no single satisfactory diagnostic test. Diagnosis requires careful medical history, physical examination and lung function tests. The symptoms of asthma tend to be variable, intermittent, worse at night and provoked by triggers. Wheezing is caused by airflow limitation, resulting in a high-pitched whistling sound that is usually heard on expiration but may also be heard on inspiration. Chest tightness, or dyspnoea, is the sensation that patients often feel is caused by the increased work needed to breathe when the airways are constricted. Any coughing probably results from the stimulation of sensory nerves in the airways by inflammatory mediators that are released by various cells involved in asthma. It is essential that a careful history is taken, to identify trigger factors that may exacerbate asthma. Ideally in hospital, a spirometer can be used to demonstrate airflow restriction and reversibility after giving a reliever inhaler. In the doctor's surgery blowing into a peak expiratory flow (PEF) meter can help with diagnosis and monitoring of treatment.

Management. Emergency exacerbations of asthma (asthma attacks) can range from mild to life-threatening. In the worst cases failure to recognise the severity of an asthma attack is a major factor contributing to death. Firstly treatment lines are oxygen, short-acting beta2 agonists drugs via an inhaler or nebuliser, anticholinergic drugs like ipratropium is given in urgent cases. Systemic corticosteroids are given in the following days. Magnesium and aminophyllines are held in reserve. For chronic asthma, a ladder-like strategy is used. The British asthma guideline recommends a stepwise approach to the treatment, which is started at a particular level, according to the severity of the patient's symptoms. The aim is to achieve early control and maintain this by stepping up treatment as necessary and stepping down when control is good. Once asthma is controlled, stepping down the treatment is an important part of therapy to ensure maximum benefit with minimum adverse effects. Patients should be maintained on the lowest dose of inhaled corticosteroid at which effective control is achieved.

Work-aggravated asthma is pre-existing asthma that is made worse by dust and fumes at work.

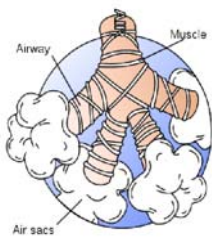
Occupational asthma is due to exposure to specific substances at work. Often these substances are specific to certain occupations. For example, some nurses develop occupational asthma as a response to prolonged exposure to latex, and some workers in the food processing industry develop occupational asthma as a response to prolonged exposure to flour.

Exercise-induced asthma is pre-existing asthma brought on by physical exercise. However, for most people, it is an indication of poorly controlled asthma.

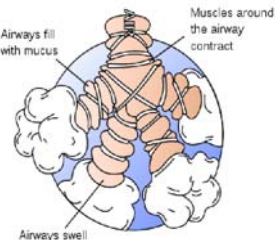
Seasonal Asthma is triggered by sensitivity to pollen or fungal spores, and is usually specific to a certain time of the year. Most ME's with Asthma fall into this category.

Anatomy of Lungs and Asthma

Before an asthma episode



After an asthma episode



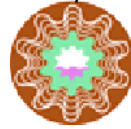
The trachea branches about 23 times, and each branch ends in a alveolus. This is lined with capillaries, and is where gas-exchange takes place. When an asthma attack is triggered, the muscles around the alveoli duct tighten narrowing the air way, restricting the airflow and causing wheezing. In the simple cases a LABA spray can relax these muscles to give relief. In more complicated cases the lining of the airways starts to swell and become inflamed. Mucus or phlegm can build up, further narrowing the airways and even plugging it in the severest cases.



normal



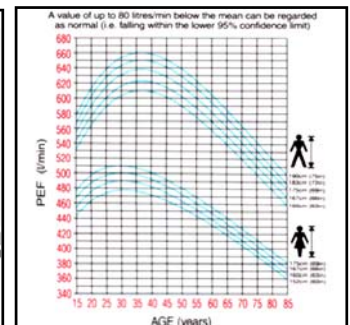
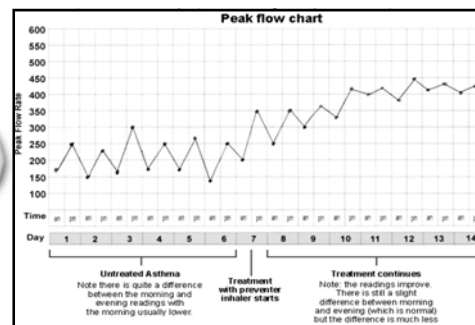
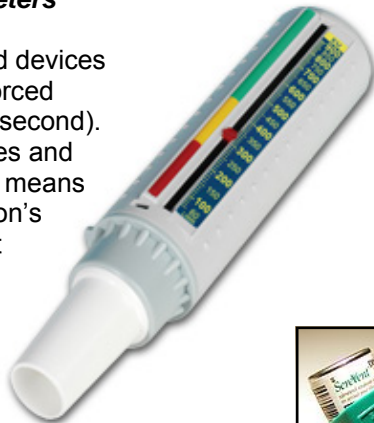
simple



complex

Peak expiratory flow meters

These are small handheld devices which measure FEV1 (Forced expiratory volume in one second). Using one of these devices and keeping a diary is a good means of monitoring how a person's asthma reacts to different circumstances and medications. It is useful if the symptoms of one's asthma are different from the norm. The device can detect chronic obstructive pulmonary disease (COPD) (a lung condition that is similar to asthma), bronchiectasis or neoplastic changes.



The actual numbers change according to sex, body mass and age, but more important is how the numbers change.



The cornerstone of asthma treatment are inhalers. There are many different types. Spacer devices help people who have difficulty synchronising their breath to get the full dose of medication. Oral drugs or injections are used for more resistant cases.



Inhalers. There are different delivery systems; dry powder, sprays, nebulisers etc, but really they all fall into the following



Blue
Reliever

Fist of all there is the Blue inhaler, which is a reliever, for use occasionally or when required. The drug inside is usually a short acting Beta 2 agonist (SABA) for example salbutamol



Brown
preventer

Next comes the brown inhaler, which is a preventer, which has to use used continuously. The drug inside is usually an insoluble locally-acting corticosteroid like budesonide



Green
Long acting reliever

Add on is a green inhaler, which is a long acting reliever to be used alongside a brown preventer. The drug inside is a long acting beta 2 agonist (LABA) for example formoterol. A blue inhaler is usually needed for emergencies.



Combined
Preventer/ reliever

These inhalers have a combined preventer and reliever, and have to be used on a regular daily basis. Usually a blue reliever is need for emergencies, but at least one manufacturer claims their combined product is just as effective in an extra dose.

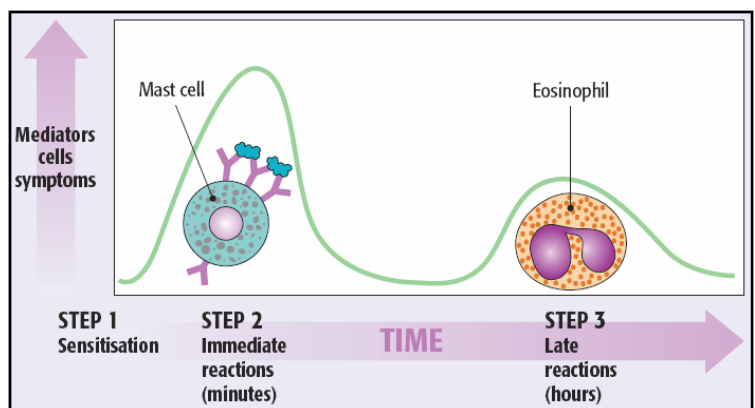
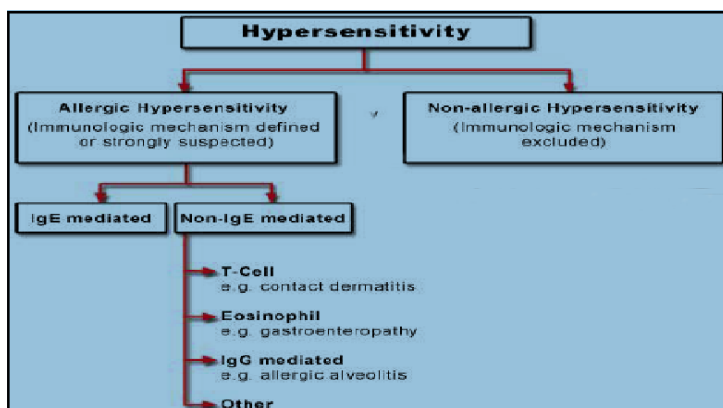
Others

Examples are ipratropium and chromoglycates which are use-specific.

NHS Asthma Treatment Stepwise Strategies as of June 2009

Step	Stage	Strategy	Notes
1	Occasional asthma	Inhaled short-acting beta ₂ agonist as required (up to once daily)	Move to step 2 if needed more than twice a week, or if night-time symptoms more than once a week, or if exacerbation in the last 2 years
2	Introduction of regular preventer	Inhaled short-acting beta ₂ agonist as required plus Regular standard-dose inhaled corticosteroid Guideline recommends that patients with persistent mild, moderate or severe asthma receive daily long-term preventer medicine. The most effective preventer medicines are the inhaled corticosteroids because they diminish chronic airway inflammation and airway hyper-responsiveness.	They should be considered for people: who have had exacerbations of asthma in the last two years, who use inhaled beta ₂ agonists three times a week or more, who are symptomatic three times a week or more, or are woken by their condition one night a week or more.
3	Add-on therapy	Step 3: inhaled corticosteroid + long-acting inhaled beta₂ agonist Inhaled short-acting beta ₂ agonist as required plus Regular standard-dose(1) inhaled corticosteroid plus Regular inhaled long-acting beta ₂ agonist (salmeterol or formoterol) If asthma not controlled Increase dose of inhaled corticosteroid to upper end of standard dose range(1) and Either stop long-acting beta ₂ agonist if of no benefit Or continue long-acting beta ₂ agonist if of some benefit <i>If asthma still not controlled and long-acting beta₂ agonist stopped, add one of</i> Leukotriene receptor antagonist Modified-release oral theophylline Modified-release oral beta ₂ agonist	At Step 3, increasing the dose of inhaled corticosteroids above 800 micrograms/day beclometasone or equivalent is not recommended; there is little increase in benefit and there is an increased risk of adverse effects. A trial of other treatments should be initiated before the dose of inhaled corticosteroids is increased.
4	Persistent poor control	Step 4: high-dose inhaled corticosteroid + regular bronchodilators Inhaled short-acting beta ₂ agonist as required with Regular high-dose(3) inhaled corticosteroid plus Inhaled long-acting beta ₂ agonist plus In adults 6-week sequential therapeutic trial of one or more of Leukotriene receptor antagonist Modified-release oral theophylline Modified-release oral beta ₂ agonist	At Step 4, for adults, a trial of increasing inhaled corticosteroids to the maximum recommended daily dose is recommended. For beclometasone this is 2000 micrograms/day in adults and 800 micrograms/day for children.
5	Severe persistent asthma	Step 5: regular corticosteroid tablets Inhaled short-acting beta ₂ agonist as required with Regular high-dose inhaled corticosteroid and One or more long-acting bronchodilators plus Regular prednisolone tablets (as single daily dose)	Refer to a respiratory specialist
		Stepping down Review treatment every 3 months; if control achieved, stepwise reduction may be possible; reduce dose of <i>inhaled</i> corticosteroid slowly (consider reduction every 3 months, halving dose 50% each time)	Combined inhaler

The Atopic Relationship Because of the strong link between a large proportion of ME/CFS patients and asthma, this suggests some sort of relationship. A very high proportion of ME's have multiple allergies, and sensitivities so there must be common ground



Meet the Sodas

Daddy Soda. If you go out at night, and look at a street lamp, you will see his work. He is very energy-efficient at producing the strong yellow/orange used in many of our street lamps. He colours flames & fireworks with the same hue, and his light can be found in the outer surface of the sun. Most of use won't see ever meet him in person.



Sodium, yes, that's him, at 11 in the periodic table and weighing in at 23. His nickname is Natrium, and he uses the monogram Na. He floats on water and melts just below the temperature of boiling water. He doesn't like water, producing hydrogen on contact, resulting in a violent explosion. If you ever meet him, he will be kept out of mischief, bottled up in mineral oil. In his marriage to chlorine, he produces salt, and his children are all around us every day and part of us. Salt is about 1.3% of the ocean, and 0.9% of our blood plasma. All his children are the alkalis.



Caustic Soda is the nastiest of his offspring. This child is conceived by the electrolysis of sea water. Otherwise known as lye or sodium hydroxide, he signs in as NaOH, being capable of causing chemical burns and dissolving flesh. He is very useful in the home and industry. We see him in the home in a drain or oven cleaner. He helps with making paper, and textiles, and even with drinking water. He is also very good at removing some of the

sulphur-based nasties from crude oil and bio diesel. His offspring are a housewife's best friend. Boil him up with fats or oils and he makes soap. He is used in washing or chemical peeling of fruits and vegetables, chocolate and cocoa processing, caramel colouring production, soft drink processing, and for thickening ice cream!



Washing Soda is not as nasty as his bigger brother. He is conceived in the ashes of many plants or made from sea water by the Solvay process. We commonly see him as ICI Soda crystals, he is known as sodium carbonate, and signs in as Na_2CO_3 . For help with washing and cleaning, being inorganic, he is green and inexpensive. We most often see through his children, as when mixed with sand and limestone and heated to very high temperatures he produces glass. In a purified form, he is known as E500, used as an acidity regulator, anti-caking agent, raising agent and stabilizer. He also appears in toothpastes, acting as a foaming agent, and abrasive.



Baking Soda is the nicest of the family. This sibling brother is conceived from his older brother by adding carbon dioxide or mined or extracted from the mineral nahcolite. Worldwide, in excess of 100,000 tonnes are produced annually. Chemically we know him as sodium bicarbonate, and he signs in as NaHCO_3 . We most often see him as a white powder. We have known him for many years, have known him as baking soda, bread soda, cooking soda, bicarbonate of soda, or just sodium bicarb, bicarb soda, or simply bicarb.

His main use is in cooking (in baking powder) where it reacts with other components to release carbon dioxide, that helps dough "rise". Anything acid e.g. cream of tartar, lemon juice, yogurt, buttermilk, cocoa, vinegar, etc. will cause him to fizz releasing carbon dioxide used in seltzers. He may also be used for softening vegetable e.g. peas ($\frac{1}{8}$ tsp. per pint of water and bring to boil for one hour), but by doing so he also destroys the vitamin content. He is also good at neutralising acids (e.g. battery acid) safely and has found his way into many medicines. However, in these uses he has gone out of favour because he is a sodium compound, and can produce high blood pressure. A paste from baking soda can be very effective when used in cleaning and scrubbing. Because it can be used to absorb odours, it is a tried-and-true method of used booksellers. The baking soda will absorb the musty smell, leaving the books less odorous.



So when you wash, eat ice cream or even travel at night - it's all with the help of the useful SODAS!

News From Fairlawns.

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



I can't really report everything that goes on at the Sheffield CFS/ME clinic Local Patient Involvement Group (LPIG) Meetings, but I can give a digest of what is happening in that part of the world. I represent the Leger ME group, along with Michèle Young, from Derbyshire ME Support Group and Ute Elliott from Sheffield ME Support Group. Mark Adams, a CFS/ME Service Physiotherapist, chaired the last meeting. Also present were Anne Nichol CFS/ME Service Manager, Maggie Campbell Commissioner (from Sheffield SW PCT), Cheryl Harper and Jonathan Battersby, who are 'Service user representatives', (people with ME who have used the clinic's services).

In recent meetings, I raised the issue about Dr. Odes in Doncaster offering a ME/CFS service at DRI, and offering similar alternative treatment for sufferers of ME as would be given by the private doctors. This is of particular concern because Dr. Odes is not working with the co-operation of the Sheffield clinic and may be diverting funding from the Sheffield ME/CFS service. Much of this treatment was speculative, and not based in the NICE guidelines, although some did have a foundation. Doncaster ME Support Group has taken a neutral stance as far as Dr. Odes service goes. A feature had appeared in a local newspaper concerning a complaint made against Dr Odes at D.R.I. unrelated to the ME/CFS service he had been providing. I had received complaints from Doncaster group members that they were being sidelined to other doctors from his appointments. There was concern that people were not being referred to the Sheffield clinic. Many DRI doctors do not appear to have been told about the CFS/ME Service, and do not refer people into the service. The Doncaster group has supported the Sheffield clinic from first conception over five years ago. I have more recently been told that Sheffield are now picking up referrals from former patients of Dr. Odes.

I also raised the issue that Sheffield Hallam University have carried out a research project about CFS/ME. The committee were disappointed that they hadn't been contacted for an input. Mark was delegated to contact the University to promote the clinic's and our services and to find out if in future they can be linked in to their research. This has subsequently taken place.

The more routine things included plans for more advanced training sessions on activity management which are being discussed. Plans are for introductory sessions for clients, and I suggested possibility of holding education sessions in Doncaster, but at this time the plan is to hold the sessions in Sheffield only, because of planning and funding issues. The clinic is looking for more volunteers to help around the clinic, and there has to be a formal interview and application including CRB checks. We have been asked to review the associated application forms. Feedback on advocacy service indicated that that has been received well by service users. The clinic is producing its own information sheets on pacing for use within the clinic and also information for relatives & carers. One of the issues raised was that pacing strategies are difficult to fit around a normal family life, but that's what ME is all about!

Griddled chicken salad

Serves 2

Place the chicken in a non-metallic bowl. Mix together the orange and mustard, pour over the chicken and leave to marinate for 20 minutes. Cook the potatoes in boiling water until tender. Drain.

Brush the griddle pan with the oil then heat until very hot, remove the chicken from the marinade, place on the griddle and cook for 6-7 minutes each side, until cooked through. Pour over the marinade and heat through. Slice the chicken then toss together with all the other ingredients. Serve with extra bread if desired. .

Ingredients

1 large boneless, skinless chicken breast
grated rind and juice of 1 orange
1 tablespoon wholegrain mustard
250g/90z new potatoes, halved'
1 teaspoon olive oil
large bunch watercress
3 spring onions, sliced
1 cucumber, chopped .

Book Review – Recovery from CFS. 50 personal stories

Michèle Young September 2009

It has taken me 2 months to read through the 50 personal stories and I think the key message this compilation book gives is that there is always hope and never give up the possibility that recovery from CFS/ME can happen. The route to recovery is, however, extremely variable just like the illness itself. When I was half way through the book I decided to summarise the recovery methods in a table to see if there was an overall best method - but unfortunately there wasn't.

The short stories were interesting to read and it is an ideal book for an ME/CFS sufferer as you can easily dip in & out of it and most stories are only 4 or 5 pages long. At the end of each account the author has offered helpful advice & given useful references and websites. There is also a glossary of terms and further details about each author at the back of the book. This book is definitely worth reading and you may even find a recovery route that is suitable for you. - *Michèle*

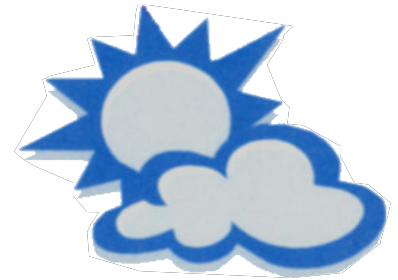


<u>Strategy</u>	<u>What the contributes ascribed to their Recovery</u>
Specific speciality or branded strategies	Mickel Therapy (4), The Lightning Process (2), Reverse Therapy (2), Orthomolecular Medicine & Integrated Medical Practice.
Practitioners or clinics	Dr David Smith (3), Dr Sarah Myhill, Dr Jacob Teitelbaum, Integrated approach, The Optimum Health Clinic, The Breakspear Hospital UK, Naturopathic medicine
Dietary	Raw food diet. cutting back sugar consumption, cutting out sugar, flour, caffeine & all processed food, anti-candida diet (3) , low carbohydrate, high good fat protein & diet, wheat & dairy-free diet, chemical-free diet and exercise, cayenne & drink your body weight in ounces of water/day & regular sleeping patterns
Philosophy	Hope that recovery is possible. people who believed in me & supported me, yoga, become your own expert, keep an open mind, get support & find what works for you keep breathing & being true to yourself taking control the Mossop philosophy, good nutrition & rest, the body in its wisdom takes over + listen to your body , positive thought & determination, a strong reason to get well & fierce determination to get back to full health whatever it costs & do whatever it takes, alternative medicine & take control of your life, acceptance, understand the causes of the illness
Medical treatment	ENT surgery, thyroid hormones. chinese herbs & regular exercise, Hanna Kroeger's homeopathic BE Kit
Lifestyle	A good bed, moving to a healthier environment. peace & quiet & someone to look after you. Regular ½ hour rest periods in bed with no TV, music/ radio, phone
Spiritual	Christian, faith healing, power of Jesus & forgiveness
Electro Magnetic	Magnetic watch & pendants

Clouds Community Counselling Service

by Sally Chamberlain

Clouds offers a free and confidential one-to-one professional counselling service offering a listening ear for people with problems, using a person-centred approach. The service is run by Diploma-trained counsellors who can offer support to those suffering from issues including anxiety, depression, low self esteem, relationship matters, anger-management, bereavement and loss, trauma, chronic illness, ME, addictions, self harm, abuse and eating disorders. Clouds is also planning to further expand the service to include group work; initially with regard to bereavement and loss and also to support grandparents who are the main carer for their grandchildren.



The clouds logo represents the sun rising from behind the clouds indicating how clients feel when low at the beginning and progress to feel better and happier at the end of the process. The sun shines again !

Clouds Community Counselling Service is a voluntary organisation which operates by appointment only from the Vermuyden Centre in Thorne and currently offers session on Mondays, Thursdays and Fridays. Although based in Thorne the Practice is able to accept referrals from other areas of Doncaster according to need and availability of appointments. To date Clouds has received over 100 referrals and has provided over 1000 counselling hours. Clouds Community Counselling Service Ltd has recently received a number of funding awards. A grant of £4990 has recently been awarded by 'Doncaster CDT Grassroots' which will be used to help cover counsellors' expenses as well as some admin, telephone and further training costs until June 2010. This funding will also enable Clouds to plan for the expansion of the service into Moorends and to include a further qualified counsellor within the team. Funding received from Hatfield Physiotherapy Service has been used to create a resource library for the Practice and the Doncaster Community Recycling Partnership Ltd has provided money for further books and a laptop computer.

What do the members think ?

Two Leger ME clients who are service users have given Pathways their feedback.

Member 1. I have attended Clouds counselling service now for a good many months. I was introduced to this service by Mike during a particularly stressful time in my life. I was trying to come to terms with changing my lifestyle to accommodate the symptoms of M.E, whilst supporting my teenage daughter and elderly mother coupled with being a single parent and the main breadwinner. There were many times when the emotions of this situation completely overwhelmed me, and it was at this time that Clouds and namely Sally was there to help me through. It has been long and fairly torturous pathway, but with the constant support of Sally and Clouds I have started to see the way out ahead of me, and a light at the end of the tunnel. I know that if short term counselling were to have been my only option, I would still have been in the same situation. From a financial point of view I could have never afforded to have paid for counselling on an ongoing basis. I think people in our situation with long term conditions need support on an ongoing basis, it is an integral part of feeling better and finding the strength to just keep on keeping on. Every person needs help at some time in their life, I am only so grateful that Sally and the wonderful Clouds Service was there for me when I needed help and emotional support so desperately. Thanks

Member 2. For the past year I have been receiving counselling from Sally at Clouds. The help I have had from Sally has been marvellous. When I first went along to see Sally I was feeling extremely low due to personal problems and my debilitating illness. I have come a long way since my first counselling session, as her advice to me regarding my situation has been invaluable. Sally has helped me to understand my strengths and abilities concerning my illness. I feel that I am now learning to control my condition, instead of it controlling me. I would wholeheartedly recommended anyone requiring counselling to make an appointment to see Sally, as without her I wouldn't be where I am today.

*To contact Clouds 'phone
07962 907053 and leave a
message. Your call will
normally be returned within 24
hours.*

*(Please call again if this does
not happen).*

Clouds Community Counselling Service Ltd



There is hope. Need to talk..... talk to us

A Free and confidential one-one counselling service offering a listening ear and support for people with problems in Thorne and Moorends and other areas according to need and availability of space.

This service is run by experienced trained counsellors.

Counselling can help with a wide variety of issues and no issue is excluded. The following list includes some issues that are frequently worked with:

Bereavement, Loss, Depression and anxiety, Stress, Anger, Guilt, Low self-esteem and loss of confidence, Abuse issues, Relationship issues, Addictions, obesity, Work related issues.

Appointments available At

Vermuyden Centre Thorne

Mondays 9-15am - 6pm

Thursday 9-15am - 2pm

Fridays 10 am - 2pm.

Hedgerows Moorends

Thursdays 10am – 2pm

Call the message line on 07962907053

Leave your name and contact number. You will be contacted within 24 hours.

(If not your telephone number may be inaudible so please ring again.)

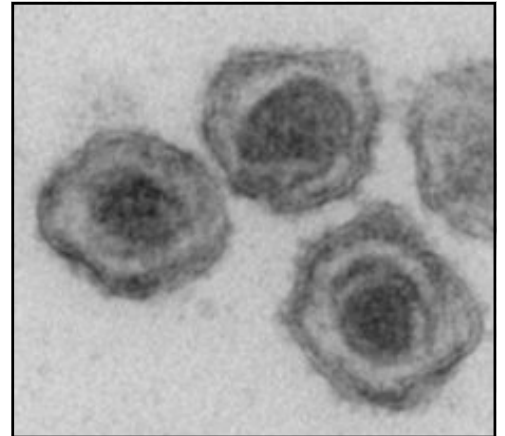
Opinion. The ME Virus?

Adapted from Nutrition Associates Update by Dr. Damien Downing. <http://naltd.co.uk/>

Breathless reports in the media last month that a virus known as XMRV was found in 67% of ME sufferers and only 4% of non-sufferers. Could this be the cause of ME at last?

Yeah, right. The same was found for Epstein-Barr virus years ago and that didn't work out; this one won't either. The numbers aren't that good; a much more impressive result, for example, was that obtained by Myhill and others in January this year when they looked at mitochondrial dysfunction in Chronic Fatigue. Only one out of 71 CFS/ME cases had a normal result. That's 98.6% positive (or sensitivity in statistical speak). Mitochondrial dysfunction is all about nutrition and toxicity, with maybe a touch of virus in the mix. That paper is available from the BSEM website (ecomед.org.uk, link below).

The same virus, with the X-Files name (it stands for Xenotropic Murine gamma-Retrovirus, more or less), has also been linked to a rare form of prostate cancer. But it's very early days for the technology involved in this study, which uses DNA micro-arrays, the same method as is used to test genomic profiles on humans. The research focus is still on proving that it works to identify viruses. Even if it does, the presence of a virus in of CFS/ME sufferers certainly doesn't prove that A causes B.



A far better explanation of the XMRV results would be that CFS sufferers have poorly-functioning immune systems and can't deal with viruses or bacteria or yeasts for that matter as well as they need to. Why? Due to Vitamin D deficiency for a start, then to too much sugar over the years, and also in most cases to toxic build-up; pesticides, flame retardants, dyes, & antibiotics.

I have to agree with Mike Adams here, who writes the Natural News website (link below). Science has discovered most of the big drugs, and they're running off patent; profits can only fall. The great hope for pharmaceutical profits lies with vaccines now. There are vaccines coming for everything; it will only be a few years until they announce the ME vaccine, and this is just to "soften us up" for it. Just look at the Swine Flu vaccine; introduced without proper safety checks – how can they have any idea how safe it is for pregnant women? – with an effectiveness, also unknown, that is unlikely to be very different from seasonal flu vaccines – poor. And to cap it all, they put thiomersal (a mercury containing preservative) in it.

Take this hyped-up virus "breakthrough" with a bucket of salt.

<http://www.ecomed.org.uk/publications/reports/cfs-and-mitochondrial-dysfunction>

<http://www.naturalnews.com>

DWP: Changes to frequency at which benefits are paid

Benefits affected are:

Income Support, Jobseeker's Allowance, Incapacity Benefit, Severe Disablement Allowance, Widow's Benefit, Widowed Parent's Allowance, Widowed Mother's Allowance, & Widow's Pension

Weekly payments are to stop, and during the next six months the listed benefits will be paid a minimum of fortnightly. It does mean you will have to rethink how you deal with your money, and how it will affect regular payments you make, such as direct debits, standing orders or loan repayments. You'll need to ensure there's enough money in your account on the day any payments are made. More information www.jobcentreplus.gov.uk/paydaychanges or call *Jobcentre Plus* now on 0845 604 0677 (textphone 0845 604 0363).

The Mitochondrial Function Test. Pathway Readers Feedback

In Pathways 19 we featured Dr. Myhill's mitochondria test. As well as Dr Myhill, we have received reports that Dr. Downing in York and Dr. Wright in Bolton have offered a similar service. We are informed that the Breakspear Hospital is also using the test for progress screening. We asked 'Pathways' readers about their experiences. Here is a digest of the feedback we received.

1) How much they paid

About £250, for the test and the report to my GP, plus about a further £200 or all the supplements recommended by Dr Myhill.

2) What they got back?

Most of Dr. Myhill's patients receive a long (9 - 11 pages) report sent to them and to their GP.

3) What did the report say? Did it show up any anomalies, if so, what were they ?

Everyone said that the results show a lot of very detailed information, usually suggesting that ME is a lack of energy production by the mitochondria. People have reported that Dr. Myhill is open about the fact that a lot of the report is formed from standard paragraphs, at bit like DWP letters. One member reported "There were several places where she said things like "...as can be seen from the problems xyz is having with abc, where abc was a problem symptom I didn't have!"

4) Did you receive counselling/consultation about the results.

Generally no. One member reported help from their GP, who was cooperative, but was not totally convinced, although he could see the logic in thinking that the mitochondria could well be implicated in ME. One chose not to contact Dr Myhill for further advice or guidance. There is lots of info available on www.drmyhill.co.uk which is free for anyone to access without charge. It was no surprise to learn that Dr. Myhill is very busy with enquiries and consultations.

5) Did it point the way to any interventions or treatments ?

One member said "My G.P. is very ME friendly and he agreed to prescribe the magnesium, B12 injections and the Q10". A friend had the test done, her GP ignored it because it was not done by the NHS. Another reported "We noticed that she recommended a number of treatments, mainly food supplements, which she could supply. On checking things out, all the treatments were intended to support mitochondrial function. The only thing that made a difference was Vitamin D, some of the others making me worse. Another experience was: "I went back to my GP wielding the report. We went through it together line by line, but he pooh-poohed every suggestion. Of particular note was the prescribing of vitamin B12 injections and so I am left without options. GP's who will recognise Dr M's findings are like hen's teeth, difficult to find. One reported that they had difficulty in following the 'stone-age diet', changing sleep patterns, and taking the recommended supplements and minerals. Another said "My GP could have prescribed some of these too to save me money, but would not". One member reported that some of the recommendations are also VERY difficult to fit around a normal family life, and could only really followed if you have a partner, selfless to the point of being a saint or if you lived alone. "Yes - but they didn't work for me", commented another member. "It shows up deficiencies in minerals for which supplements may work, but are not a cure. It is always hard to know as I have not actually improved but I think I have been more resilient after crashes. Another member said: "I found this did rather undermine my confidence in some of her recommendations as it was hard to work out which bits really applied to me and which didn't.

6) How did they feel about £200-400 being spent, and would they recommend it to anyone else.

One member said: "I'd advise anyone to be careful. As you say, it's a lot of money and certainly for me, it didn't help at all". Dr Myhill claims to have helped a large proportion of her patients but I haven't seen any evidence of that, although I have heard of a number of people who feel they have had some improvement since following her regime. For other people though, like me, it doesn't help at all and may make them worse. Another report was: "This is a lot of money, especially when any treatments can cost hundreds of pounds or more. If you can afford it, what have you got to lose? If you can't afford it, it isn't an option. This has to be it's one of those nasty "It's your decision" things. Another reports was "It's certainly accurate; I've always reckoned to be functioning at about 40% of full capacity and Dr. Myhill's report said, yep, 30%. By coincidence (at least I think it is) I had the most awful relapse in January this year and am still struggling to drag myself from the mire. I cannot honestly say I feel Dr. M's 'protocol' has done any more to help me progress from that than anything else I have tried though (in desperation) I continue to follow it. Another member said "Go for the mitochondria test if you like but be aware it's very expensive and you may end up holding a very interesting piece of information that you cannot use, UNLESS you live near enough to Dr. Myhill to see her yourself OR you can personally see one of the other doctors who follow her methods. Sadly I live miles away from any one of her colleagues so I'm stuck and a bit poorer too".

7) Welfare rights

A member reported "At the same time I paid for the mito test I was also going through a claim for permanent loss of health with my Critical Illness policy company. I sent them a copy of Dr M's report in support of my application, which was completely ignored. I was directed to a psychiatrist, resulting in a recommendation of CBT and GET. The claim would not be considered until I had undertaken their recommendations, BUT I've already been there and got the tee shirt. I won't do that again. Result stalemate. Someone else said "Yes, I've yet to try using it in support of a DLA application". We have had reports of people that have found it useful for benefit claims. It could be useful for DLA because having the test results could give evidence of physical abnormalities. It's hard to know how much credibility that the DWP actually gives them, but there is some anecdotal evidence that they help.

Summing up

- It could be useful for DLA, ESA or other welfare rights issues as it shows that ME is a real illness, but there is no easy way to assess how effective this is.
- Some members report that it doesn't fully deal with all the symptoms, there are cost implications of the test and follow up supplements. There is a concern that the implication is that any benefit is due to backing off the disease process rather than symptom relief.
- Ideally, G.P's would like a short report, no longer than a page. Probably a summary with clarification and an action plan would be a good idea.
- Some of her recommendations are also VERY difficult to fit around a normal family life.

With the feedback I obtained from members, I would estimate that the number of members experiencing a beneficial outcome from the money invested in the test is between 30% and 50%. Overall, an abnormality and a way of measuring ME/CFS is a good thing, but at present it is too expensive to do annually or frequently to test if treatments are working. The benefits I have seen are a 'new confidence' to deal with ME/CFS, and members being active in ME/CFS management. The best outcome I have heard is as a result of the test; one lady tried Ribose, and it enabled her to return to work part time, and worst; one member was found to be 'normal' from the point of view of the test, but definitely has ME.

For a final point we asked regular Pathways contributor Trevor for his thoughts. *Would any improvement or coming back quicker after relapses be attributed to the treatment, even if they were due to some other reason? Is it throwing good money after bad, and are these tests of use? Who knows? If it results in better health, it's a good thing; otherwise it's a waste of money! There's only one way to find out - sad to say. What a gamble !!!*

The Effect of Exercise on levels of Interleukin-6

From Autumn 2009 Breakthrough, ME Research UK

Muscle pain, fatigue and malaise after exercise - sometimes developing 24 to 48 hours later - are considered to be characteristic of ME/ CFS. There have been some suggestions that the "fatigue" in the illness could be associated with limitations in the use or supply of fuel by the tissues. If so, an understanding of interleukin-6 (IL-6) and its associated receptors could be important, since IL-6 is produced by working skeletal muscle and is also a key component of the body's response to the illness. Some studies have indicated that ME/CFS patients do not have raised levels of IL-6 and other cytokines in the blood at rest. However, IL-6 requires receptors to be biologically active, so it is important that both IL-6 and its receptors are investigated. As it is exercise that brings on symptoms in most people with ME/ CFS - at least in the early stages of the illness - perhaps researchers ought to be looking at changes during exercise rather than at rest?



The sort of equipment used in the research

It was this aspect that particularly interested Professor Myra Nimmo of the Strathclyde Institute of Pharmacy and Biomedical Sciences in Glasgow. Prof. Nimmo is a metabolic physiologist who is internationally renowned for work in exercise physiology and she says: "Exercise offers the opportunity to examine patients in an exacerbated state, yet many studies to date have not clearly categorised the exercise regimen and, since incremental maximal tests are essentially limited by cardiorespiratory fitness, metabolic limitations may be more clearly identified through the use of a sub-maximal exercise protocol."

To explore whether IL-6 and its receptors might be involved in the reduction in exercise performance and poor recovery from exercise seen in these patients, Prof. Nimmo and Mark Robinson conducted an ME Research UK-funded pilot study of six men with ME/CFS and six healthy control subjects matched for age, physical activity and body mass. Each participant undertook an exercise bout at 90% lactate threshold, allowing a "matching" of the metabolic load between controls and patients - a refinement missing from previous studies. All volunteers were required to visit the laboratory twice, the first visit for identification of the lactate threshold. On the second occasion, subjects were exercised at their identified exercise load in the morning before eating. Subjects were then given standardised meals for the following 24 hours (not very palatable, we're told!) and blood samples were taken before

Thai Seafood Curry

Made in less than 1 hour this quick and easy curry has a wonderful creamy coconut sauce flavoured with lime, coriander and chilli.

Serve with boiled noodles or Thai jasmine rice and crispy prawn crackers for an authentic Thai supper. Serves 4 ,Ready in 40 mins

1. Thinly slice the red pepper and carrots and cut the spring onions into short lengths. Chop the stalks of the pak choi and keep the leaves whole.

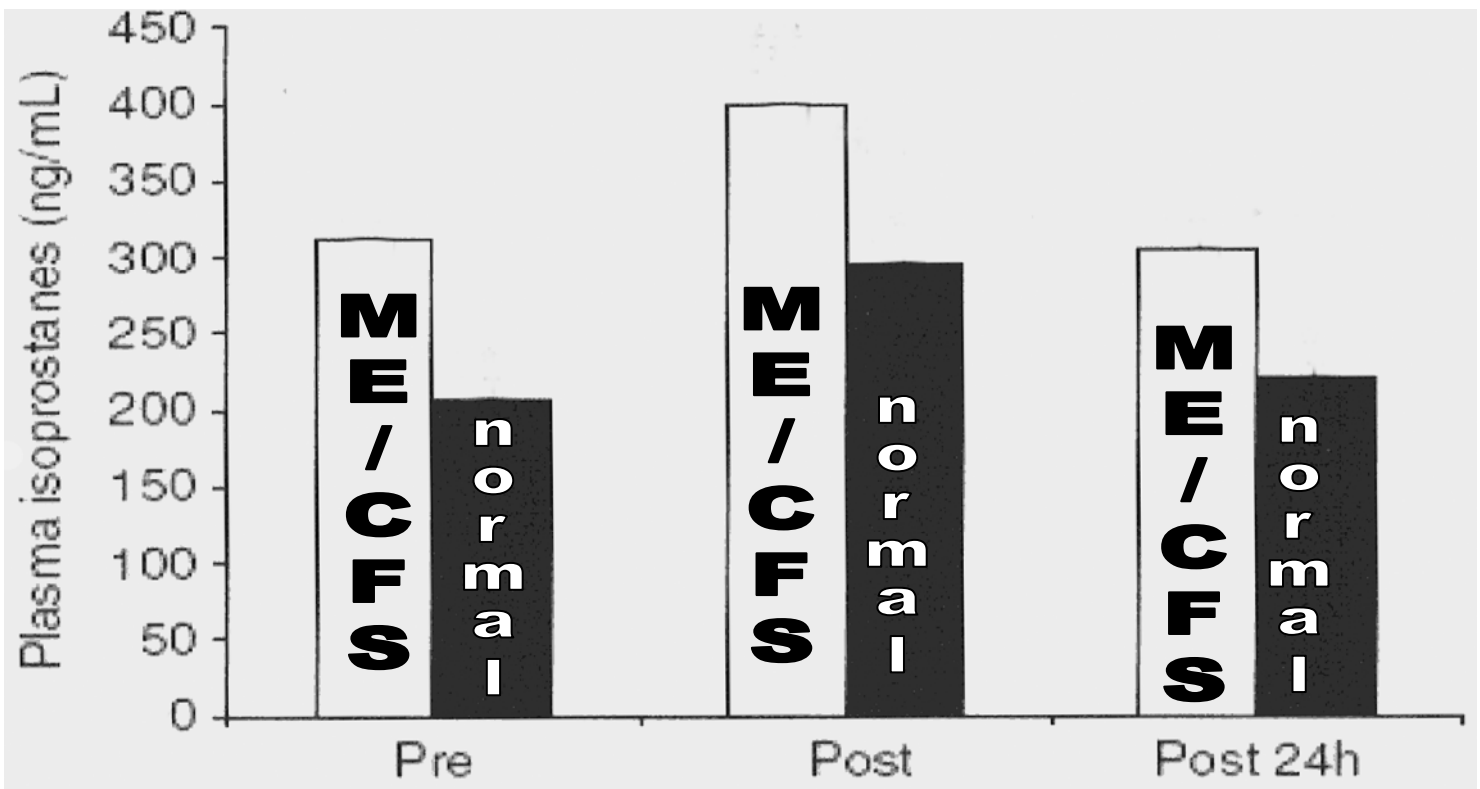
2. Heat the oil in a large wok or frying pan and fry the pepper, carrots and spring onions for 2-3mins. Stir in the curry paste and cook for 1 min then pour in the coconut milk. Bring slowly to the boil.

3. Add the cod or monkfish and pak choi stalks. Simmer 5-6 mins, stirring occasionally. Stir in the chopped coriander, lime juice and soy or fish sauce and season lightly with salt and freshly ground black pepper.

4. Add the prawns and pak choi leaves and simmer for a further 2-3 mins until the prawns are piping hot and the fish is cooked through. Divide between four serving bowls and garnish with shredded spring onion and chopped red chilli pepper.

You need

1 red pepper, deseeded
1 large carrot, peeled
6 spring onions, trimmed
2 heads of pak choi
1 tbsp sunflower oil
1 tbsp Thai red curry paste
400g can coconut milk
450g (1lb) cod loin or monkfish fillets, cut into chunks
2 tbsp fresh chopped coriander stalks
Juice from half a lime
1 tbsp light soy sauce
200g tail-on cooked king prawns
Shredded spring onion and chopped red chilli pepper, to garnish

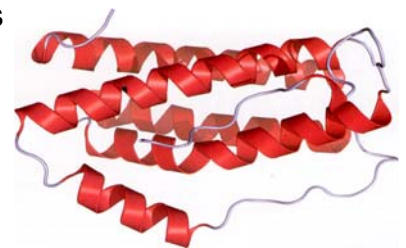


Oxidative Stress markers are higher in CFS/ME patients than in the controls (normal)

and after exercise, and at regular intervals throughout this period. A further 33 CFS and 33 healthy control participants gave a resting blood sample for measurement of IL-6 and soluble IL-6R levels. The results have just been published in the Scandinavian journal of Medicine and Science in Sports (2009). During the incremental exercise test, the physiological responses of both groups were closely similar, except that the power output at the lactate threshold was 28% lower in the ME/CFS group than in the matched controls ($p < 0.05$). In addition, F2-isoprostanes - which indicate oxidative stress - were higher in patients than in controls at rest ($p < 0.05$), as well as after exercise and after 24 hours (see the graph opposite). However, the study found no differences in IL-6 or its receptors between patients and controls at any time point, and in the larger study there were no differences in resting IL-6 levels or its receptors.

What are we to make of these findings? Well, the lack of a difference in either IL-6 or its soluble receptor at rest or during exercise suggests that "transignaling" is unlikely to be involved in the pathology of ME/CFS. This is a negative result yet an important one. However, the results do confirm previous ME Research UK-funded work (by Dr Kennedy in Dundee) showing raised levels of F2-isoprostanes in ME/CFS patients at rest, and Prof. Nimmo has now shown that these levels remain high during exercise and in the recovery period. Indeed, the level of isoprostanes in the "rested" ME/CFS patients was as great on average than that reached by the healthy controls after exercise! As isoprostanes also act as vasoconstrictors, their presence, accompanied by additional free radicals during exercise, may be responsible for some of the clinical symptoms seen in ME/CFS, such as joint pain and post-exercise illness.

Interleukins and their uses. The interleukins are naturally-occurring proteins important in the immune system, particularly in the activation of lymphocytes to ward off infection. The best-known interleukins are IL-1 and IL-2, which together ensure a plentiful supply of T-lymphocytes to fight specific infectious agents. Interleukin-6 (IL-6) is a fascinating member of the family which is secreted by T cells and macrophages to stimulate an immune response to trauma, especially burns or other tissue damage leading to inflammation. However, it also has an important part to play in exercise. IL-6 is produced from muscle and becomes significantly elevated with exercise. It can both stimulate inflammation (for example, when produced by blood vessels) and act as an anti-inflammatory through its inhibitory effects on cytokines such as tumour necrosis factor- α . Clinically, inhibitors of IL-6 (including oestrogen) have been used to treat postmenopausal osteoporosis, and blockade of IL-6 by its natural antagonist has been shown to inhibit the progression of arthritis, a disease expressing not dissimilar symptoms to those seen in ME/CFS patients.



Interleukin 6

Gene research the Quest continued.

From Autumn 2009 Breakthrough, ME Research UK

In a recent issue of the scientific journal BMC Medical Genomics (2009), Prof. John Gow and colleagues from Glasgow Caledonian University report the initial results of their efforts to identify genes involved in ME/CFS. Since 2005, with funding from Scottish Enterprise and ME Research UK among others, these researchers have been using DNA chip microarray technology to try to identify a specific gene expression "signature" that could become a diagnostic biomarker for ME/ CFS, a development that could revolutionise diagnosis and treatment.

The Glasgow team took blood from male patients who had developed ME/ CFS after an infection, as well as from matched healthy control subjects. Peripheral blood mononuclear cells were isolated so that levels of gene expression could be measured by genome-wide 'Affymetrix GeneChip' array technology. This allowed rapid comprehensive analysis of 39,000 transcripts derived from 33,000 gene sequences (see the box opposite). Significant differences in gene expression between patients and healthy people were observed for 366 genes. Closer analysis revealed a "gene signature" for ME/CFS that highlighted changes in gene expression in three main areas: oxidative stress, apoptosis and viral -like immune dysfunction (see the table below). Interestingly, previous ME Research UK-funded scientific studies have reported increased oxidative stress and neutrophil apoptosis in ME/CFS patients, and there are many reports in the literature of immune dysregulation being involved in the development of the illness. The team at Glasgow Caledonian University is just one of a number of research groups worldwide investigating gene expression in people with ME/CFS. The number of published scientific reports in this field has been steadily increasing in the past few years, a welcome development as few areas of biomedical research into ME/CFS can boast more than two or three separate research groups simultaneously engaged on a common quest.

In 2007, one group in the UK, led by Dr Jonathan Kerr at St George's London, reported their identification of a putative "gene signature" for ME/CFS consisting of 88 human genes, the top functional categories being haematological disease and function, immunological disease and

Oxidative stress genes	Prostaglandin Synthase: COX-I and 2 haemoglobin gamma A and gamma G	function, cancer, cell death, immune response, and infection. Notably, three of the commonly over-expressed genes identified in the most recent work by the Glasgow Caledonian group had also been identified previously by the St George's Group: CXCR4, upregulated in infection and reported to be high among patients with arthritis; EGR I, associated with infection; and PRKAR I A, a gene associated with a variety of disorders. While the putative
Apoptosis	Annexin-A3 Annexin-A5 Serine/threonine kinase 17b . Histones I and 2 Protein S (alpha) Serum deprivation response (Phosphatidylserine binding protein) Caspase I genes Transforming growth factor-f31 Death effector filament forming CED4-like apoptosis protein Complement 3a receptor I Early growth response I Tumour necrosis factor-A I P3 Tumour necrosis factor-RSF 17. Tumour necrosis factor-SF4	
Immune dysfunction genes	Decay accelerating factor (CDSS) and CD46 .Antigen processing via MHC class II (MHC II DP al and DR a) Interleukin-1213 and 6 biosynthesis	

"signature" identified in the current research seems promising as a potential biomarker for diagnosis and treatment, relating genetic findings in the laboratory to applications in the clinic can be a long and complicated process. Experience in the use of genome -wide scanning technologies for cancer screening has shown that discovery and validation of biomarkers requires multiple phases of research over many years. Nevertheless, work on gene expression by various groups across the world is one of the most exciting recent developments in ME/CFS, and could open the door to the development of pharmacological interventions. As Dr Russell Lane, a neurologist at Charing Cross Hospital in London has said of the work on genes, if the researchers succeed and identify "clear physical changes in people with CFS, the lingering opinion that it is 'all in the mind' could finally be laid to rest".

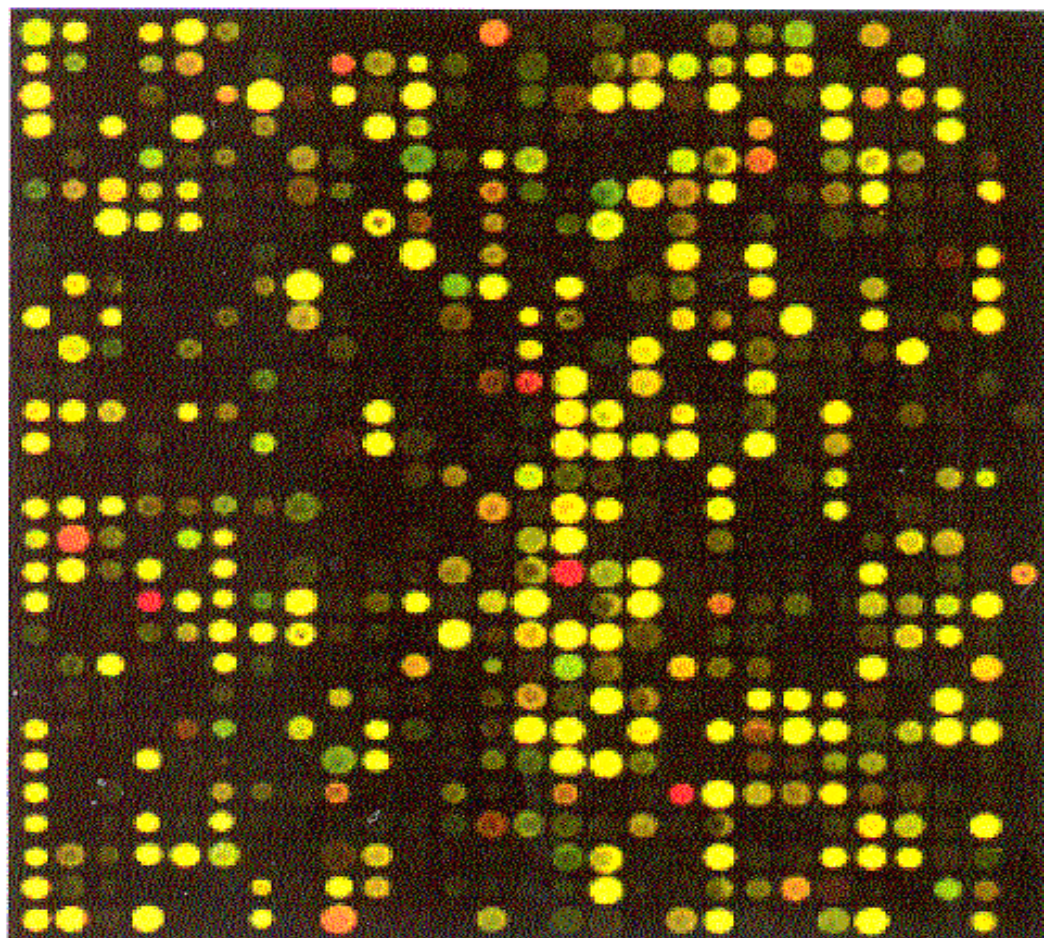
ME/CFS - the research problems

The same problems that confront all researchers in ME/CFS also apply to research groups using microarray technology. One is that "diagnosis" of the illness is most often based on a ragbag of common non-specific symptoms, resulting in a diverse group of patients. As Jason et al (2005) have pointed out in an excellent review of the subject. "Sub grouping is the key to understanding how CFS begins, how it is maintained and, in the best case, how it can be prevented, treated and cured," It is unlikely, therefore, that a single biomarker or gene cluster will be found able to detect ALL cases as currently defined, although microarray technology does have the potential to make diagnosis more precise. As Steinau et al (2004) have pointed out, "Biomarkers... could contribute to precision in case ascertainment, identify heterogeneity in the population to clarify contributing pathways to disease, suggest novel therapeutic targets, and provide indicators of disease progression and prognosis." The other major difficulty is obtaining and maintaining funding - a problem that haunts the efforts of all biomedical researchers in ME/CFS. and it is particularly acute in these gene biomarker studies which require major investment - millions of pounds over many years.

How is gene expression measured?

Gene expression is the way in which the information inherited from our parents (usually 'recorded' as a gene, a sequence of DNA) is translated into a product, such as a protein or an RNA molecule that can be used by the body. A

key component of gene research is the use of microarray technology to analyse the genetic material of an individual. Researchers take a sample of blood or tissue and apply it to a silicone slide, called a microarray, which contains more than 20,000 gene identifiers. From this, they are able to determine which genes in the sample are being expressed - that is, turned on or off, or turned up or down. If a particular gene is very active, it produces many molecules of messenger RNA which hybridise to the DNA on the microarray and generate a very bright fluorescent area (as seen in the picture below). Less active genes generate dimmer fluorescent spots, and inactive genes none. The gene expression profile generated provides a window into the disease process under examination.



Gene expression pattern on a microarray

Employment and Support Allowance Experience (ESA) to date.

Politics and History

Going back to the 1970's, I can remember the wife of a neighbour with MS having to go to the doctors every 12 weeks for a sick note in order to get sickness money. There was no such thing as long term sickness. Later on came Invalidity Benefit (IVB) which was payable after 6 months' sickness, there were a series of enhancements and one was Graduated Pensions, which could double sick pay. The case was if you had a low paid job, on the 'club' would give you just as much money for working as for being sick. As many of the miners suffered chest disease as a legacy of under ground conditions, it was not surprising the coalfields had more than their share of people of working age on sick pay, in fact locally Conisbrough has one of the densest populations of chest disease in the country. The politicians like Mrs Thatcher in the 1980's brought about mine closures. It was politically unacceptable to have many former mineworkers listed as unemployed so they were shunted onto IVB. However an audit revealed that in one of the Welsh valleys, the number of people claiming Invalidity Benefit was unacceptable, and more than expected. The gate holders to IVB were the local GP's, subject to supervision by the predecessors of the DWP. Something had to change.



Incapacity Benefit ICB replaced Sickness and Invalidity Benefit from 13th April 1995. The whole idea was that the system had to be transparent and accountable, taking the gate keeping away from the doctors, so the 15 points system was conceived, which of course is carried over to ESA. One issue was that someone on ICB could still get more than on Unemployment Benefit, Jobseekers Allowance and Income Support. So in recent times, the basic rates of Jobseekers and ESA have been made the same, about £65 per week, Income Support is being phased out. Those receiving the graduated pensions enhancement had the level frozen from 1995. All IVB benefit claimants were migrated to ICB eventually, over a period of time. After 1996 there was a glut of benefit refusals for ME/CFS which the new system bedded in. I'm afraid that now that ESA is being phased in, we will see the same situation, with all the associated anxiety and uncertainty as we did with the IVB/ICB changeover. There are still some group members receiving the Graduated Pensions component of IVB, which was frozen when carried to ICB in 1995. Whether to if it is carried over to ESA with its not-taxable status has yet to be clarified.

All new claimants for long term sick pay from 27th October 2008 are ESA. At the time of writing, the IB50 forms were still being issued and handled in the usual way to existing claimants. The new ESA50 system is a major problem. It is the stated intention of the government that the existing ICB claimants will be migrated to ESA possibly from 2012. So, we think that is prudent to take lessons from the IVB/ICB changeover. In Pathways18, starting on page 17, we speculatively published a strategy to deal with ESA for people with ME/CFS. From experience of group members, it is more than justified. With the cases I've seen over the past few weeks, there is no doubt that there are problems. The cases we have seen so far seem to have been based on snapshots, and do not take into account the longer term rebound issues of fatigue. The DWP also appear to be ignoring information from member's doctors and letters from specialist clinics like Sheffield. We've seen this situation before, and I suspect that many of the problems are to do with breaking in the new ESA system. I do know for example that there are delays in sorting decisions and sending letters. It looks like that they are dealing with new claimants first. Those on Incapacity Benefit will remain so for the time being, but at future point will be assessed under the ESA rules. I suspect that we will need to use the DLA type strategies when dealing with the ESA 50 and medicals. Here are some tips.

- a) You need the support of a consultant or NHS ME clinic. A G.P. does not seem to be enough.
- b) All conditions even if only minor need to be listed on the ESA 50, e.g. asthma, diabetes.
- c) You need the guidance of a welfare rights advisor - **DON'T FILL OUT THE FORM YOURSELF**, even if you have been successful before for DLA or Incapacity Benefit.
- d) When you are summoned to Crossgates House, you need to take a chaperone with you. Contact us for further information on how best to do this.
- e) You do not say anything to the DWP unless asked, and then you need to be very careful, as even a minor comment can be taken out of context. Contact us for further information.

Here are three scenarios based on local cases, all between 50 and 65. All have had medicals in Doncaster in the summer. Names have been changed.

Case 1 Tom is a ME/CFS case, consultant confirmed, with osteoarthritis, IBS, depressive tendency, partial deafness. The history of ill health is in excess of 4 years. DLA high rate mobility and low rate personal care have been recently awarded follow a medical examination. His IB50 was filled out by a welfare rights advisor, and examined for ESA by a well established English doctor. He has been awarded ESA at the limited capability of work rate, which is equivalent to the ICB benefit rate. The decision was based on walking-ability and mental health descriptors. Having had two medicals, he has been summoned for a third for a Work-Focused Health-Related Assessment (WFHRA). He first applied for ESA in February after struggling many years. He is now considering applying for the ESA Support group placing. Our main concern is that this is the third DWP medical he has been asked to attend. I feel that this is really unreasonable harassment because there is no way this guy could earn a living or get to the point where he could work. There is no cure or condition management for his health problems. There are also issues with the way his medical examination was carried out which are obvious on the ESA 85 doctor's report.

Case 2 Andrew is an ME/CFS patient, with a history of migraine. There is an ill health history is in excess of four years. Despite being a regular scooter user (even into Crossgate House) he has only been awarded DLA low care. He typed part of the form himself after telephone advice handwriting the rest. The medical examination was carried out by a registered nurse, resulting in zero points. There are issues with the way the nurse carried out the medical examination. The ESA 85 shows that the points awarded do not match the comments made by the examining nurse, suggesting maladministration on her part with the DWP computer (Lima ?) system. A supporting letter from the Sheffield ME/CFS clinic was totally ignored, not even being acknowledged. An appeal is in progress via DiAL.

How we arrived at the decision we sent you on [REDACTED] / 2009

To work out your points we used information from

- ☒ the questionnaire you filled in recently
- ☒ the report of the medical assessment you went to on [REDACTED] / 2009
- ☐ medical information from your own doctor
- ☐ other information you have provided.

It is quite clear that the DWP taking no notice of information sent or the members own doctor

Case 3 Harriet is a relative newcomer. Her history is PVFS dating from Feb 2009. She has a history of back trauma. Her PVFS is not yet stable. With her ESA 50 from, she chose all the 'no problems options', possibly because she did not take advice or misinterpreted the form. The result of the medical examination was zero points being awarded by an ethnic minority doctor. The ESA 85 shows basically that the examining doctor didn't take the time to properly carry out a medical examination, and missed an obvious back issue. The main issue with the case is that the consultant-based diagnosis of PVFS was three weeks after the DWP medical. In this case the DWP didn't consult the G.P. or the consultant. An Appeal is in progress.

Time Examination and Interview Started	14:40
Time Examination and Interview Ended	14:59
Time Report Complete	15:03

From the ESA Pathways calculates the time taken with the doctor is 19 minutes. It is later stated that the patient sat for 16 minutes.

Behaviour Observed During Assessment

Client was able to sit on a chair with a back for 16 minutes.
The client rose twice from sitting in an upright chair (with chair

Pathways calculates the time take for the medical examination was 3 minutes. Normally this should take ten times as long

Inferences

- 1) Firstly, it appears that the DWP are maladminstrating, not taking account of GP reports, specialist reports or even doing medical examinations properly.
- 2) There is no indication that the fatigue & effects of ME/CFS, as with other DWP benefits are being considered.
- 3) Even if you are awarded the WFHRA rate you face another medical examination.

Action

- 1) If you are refused, there is a long drawn out appeal process which has yet to happen with our members. This involves letters, doctor's reports and possible attendance at tribunal in a similar way to what happens with ICB and DLA.
- 2) Prevention is better that cure. Get the form right first. Use a welfare rights advisor. Get wise to the reality.



Can we trust DWP work openly and fairly ?

What the doctor or nurse sees on the computer screen is a series of questions to ask, and a series of options. Exactly what they are is a state secret. What we do know is that what appears on ESA 85 is mostly indirectly implied, indexed from a list of assumptions. Here are some examples which are from ESA 85s issued by the DWP how they work. Remedies are self explanatory.

Social History

The examination was carried out in an examination centre.
Came by bus here today, which took about 30 minutes.
Came to the examination centre alone.

In this member's ESA 50 it was implied from this statement that he could walk in excess of 400 yards without problems. This stopped any consideration of the walking descriptor, going out and coping with social situations.

This blows anything you have written about coping with social satiations, going out, listening and understanding how to do tasks It implies you are able to make a journey to work without difficulty.

Description of a Typical Day

Client states that:

Usually goes to bed at different times.
Usually gets up at different times.
Gets out of bed without difficulty.
Has no problems in the bathroom.
Has no problems with dressing.
The client can eat and drink everything they normally consume.
Usually able to do housework.
Can move around indoors on one level without difficulty.
Can climb and descend stairs independently.
Able to walk 400 metres at a normal pace most days.
Likes to watch television every day.
Can use a computer without difficulty.
Is usually able to use a mobile phone for chatting and making arrangements.
Has no difficulty communicating with others.
Completed ESA50 without difficulty.
Always able to begin and continue to complete getting washed and getting dressed without any help.
The client does not experience panic attacks.

This blows anything about morning stiffness, pacing, management variation of fatigue and coping strategies.

This blows anything about IBS, or dietary requirements

This blows anything about reading, concentration fatigue or eyesight.

This blows anything about reading, fatigue or eyesight IBS,

Harriet and Andrew both received identical pages on the ESA 65 notice. Normally we would expect to see the odd few points even in a refusal. Is there a system error or deliberate manipulation ?

About your limited capability for work assessment continued

Physical functions

On each line we have shown the points we have given you. The number of points given depends on how your illness or disability affects your everyday activities and your ability to work. The law states how many points we can give for each part of the assessment.

Functional area	Our assessment	Points
Walking	You can walk on level ground without difficulty	0
Standing and sitting	You can stand and sit without difficulty	0
Bending or kneeling	You can bend, kneel or squat without difficulty	0
Reaching and raising your arms	You can raise your arms without difficulty	0
Picking things up and moving things	You can pick things up and move things without difficulty	0
Using your hands	You can use your hands without difficulty	0
Speech	People can understand you when you speak to them	0
Hearing	You can hear without difficulty	0
Seeing	You can see without difficulty	0
Controlling you bladder and bowels	You can control your bowel and bladder without difficulty	0
Remaining conscious	You do not have problems staying conscious	0
Total points for physical functions		0

About your limited capability for work assessment continued

Mental, cognitive and intellectual functions

On each line we have shown the points we have given you. The number of points given depends on how your illness or disability affects your everyday activities and your ability to work. The law states how many points we can give for each part of the assessment.

Functional area	Our assessment	Points
Learning and understanding how to do tasks	You can learn how to do a task without any difficulty	0
Awareness of danger	You are fully aware of dangers and can manage your daily life safely	0
Memory and concentration	You can manage your daily routines without difficulty	0
Doing and finishing jobs	You can finish daily jobs without taking longer than a person who has no form of mental disablement	0
Starting jobs and keeping on with them	You can start and keep on with routine jobs	0
Coping with change	You have no problems coping with change	0
Going out	You are able to leave home on your own to get to a familiar place	0
Coping with social situations	You have no problems meeting and mixing with new people or going to new places	0
Behavior with other people	Your behaviour does not cause problems for you or other people	0
Getting on with other people	You have no problems getting on with other people, and they have no problems getting on with you	0
Total points for mental, cognitive and intellectual functions		0
Total points for physical functions		0
Total points		0

North of Doncaster Personal Sarcastic Comment by Trevor Wainwright

I wrote the following on impulse in **early 1999** it was immediately well received and I believe a copy was sent to the man himself.

THE WESSELEY

Greetings to you my Brothers and Sisters and peace be with you, for I am sent to tell you the story of the illness as it is wont to be told.

There came an illness, and there were noted epidemics in the two hemispheres of the known earth and in many countries, and it did cause great bodily problems of fatigue and pain and from this there came many other debilitating symptoms, and the medical people of the day sought to call the illness M. E. And many noted Physicians sought to learn more and to discern the bodily causes of the illness and didst labour hard and long to achieve this.

First there came the Beard and the McEvedy in the form of Psychiatrists who did claim it was all in the mind. This did cause much concern to those who knew of the illness and did seek to find a cure for the physical causes and did make their task much harder. For many of an organisation referred to as the media and of the medical profession did believe the two messengers, and did give their findings much publicity as was their wont, for it was in their own interests, to sell their items of information

Then there came The Wesseley and The Wesseley did, having the gift of speaking as if he understood the illness yet did not, saying it was not necessary, and many were taken in by this and became his followers. And they as his followers did believe everything that The Wesseley did say. And they that were at first doubtful of what the Wesseley did say, such was the powers of The Wesseley's speech that some those who questioned him, were soon to be in agreement. And so when The Wesseley said it is all in the mind, they marvelled at his brief knowledge and did believe him, as if forgetting all that had gone before. And so did The Wesseley take advantage of this and when he did speak, the misguided did listen and did say "truly this man speaketh the truth". And so did the willing be led by the unknowing in the belief that they were following the path of truth.

And there were those that disbelieved and questioned The Wesseley, and they were thus ignored by The Wesseley and his followers as if they were of no consequence. And The le Fanu who did at first doubt The Wesseley saying to The Wesseley "thy research would cause a wailing and gnashing of teeth" and The le Fanu was right but not in he way he meant, he too was soon won over to the side of The Wesseley. And The le Fanu didst write an article in which he did quote the paradox that those suffering the illness riseth and do more and this did provoke much anger amongst those that liveth with the illness and they did take up pen and didst write to The le Fanu saying thou hast got thy paradox wrong and they didst give examples, but as was his wont The le Fanu didst ignore those and chose to bestow on The Wesseley all honour and glory and so did The Wesseley continue being of no use to those that suffered under the physical side of the illness. For he was in good stead with many of his kind.

But I say unto you my Brothers and Sisters hold good your stead, for it is said that there is good work afoot and so shall come to fulfil the prophecy that all will be well and all manner of things will be well, that when the illness is defeated and is no more than a memory. One shall say unto the other dost thou remember The Wesseley? and the other shalt reply do I remember WHO?



Muriel felt it was important to work on the doctor-patient relationship.