

# Pathways

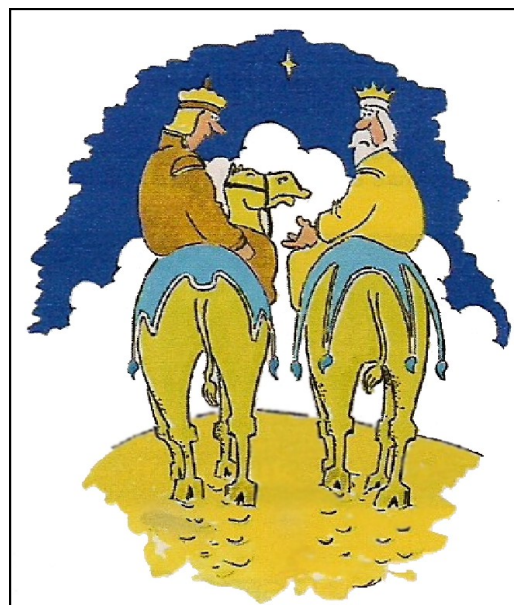
Price £ 2.50 (Free to members)

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.

## Welcome to Pathways no 34.

In this issue in the News from Upper Weston, Sarah Myhill has sent a press release about her third research paper entitled *"Targeting mitochondrial dysfunction in the treatment of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) – a clinical audit"*. This and the previous paper develops the original research she carried out. Whether it carries any weight with the medical establishment will only reveal itself with time. I've reproduced it, as received, on page 12.

I've also covered more information about PIP received from the DWP and how this may affect Leger ME members. I've also included a copy of the claimant journey as received from the DWP. There is one certainty; from past experience —when a major benefit change is introduced there will be many unintended outcomes, and it may take as long as two years before they are rectified. More details from page 7 onwards.



*Hang on a minute,  
Where's the guy with the gold?*



There has been an unexpected dialogue on the internet about the health hazards of grapefruit and drugs. I've included a short feature on page 5.

Following an unexpected telephone call from a member, I've included a feature on Electrosensitivity from page 17. This is an issue which doesn't seem to do away and seems to get worse year by year as increasing numbers of electromagnetic gadgets enter our lives.



I've included a dialogue between Dr. Simon Wessely and the Countess of Mar from page 19, mainly because it has been widely circulated around

various ME/CFS forums, and so that members can form their own views.

Finally I've added a feature about the Yorkshire air ambulance on pages 4 and feature about a well known Christmas Carol on page 15



*I'm not just for Christmas, I'm for keeps  
from Roo, the newest resident at no 10.*

Happy Christmas to everyone from the Pathways team.

## You Write

**Kathryn Writes:** Further to your advice about obtaining medical evidence from the DWP ESA examination to support a DLA. I have contacted the DWP; there have been promises, and I have been passed between the departments—but nothing has turned up. When I ring up I get excuses and so on. Nothing seems to be happening. What can I do?

*The reason we request an ESA 50 medical report from the DWP is to support a DLA application. Although the report is for ESA, a lot of aspects are covered which would apply to DLA. When assessing a DLA form the DWP will refer to this document and basically will take it as evidence. You never see the ESA 85 medical report unless you ask for it. In the past, in a lot of cases, although the ESA has been awarded comments made by the examiner have been detrimental to a DLA application. Obtaining these documents has two functions: firstly to correct a wrong assertion and secondly to provide supporting evidence for a DLA application.*

*I suspect that there is some sort of unofficial directive somewhere that these documents should not readily be released. In principle, any request for your documents, in writing, should come under the Data Protection Act, and if the documents are withheld, you can make a complaint to the Information Commissioner. However, it is not clear from your post whether the DWP are acknowledging receipt of your request, which of course would be a requirement for any further action. Make an appointment to see me at the next benefits clinic with all your documents, and we'll take it from there.*

**Paul Writes;** I'm returning to full time work as I have had a brilliant job offer, which pays far more than the state benefits that I'm receiving. I'm certain that my ME/CFS has gone away as I have been OK over the summer. I'm cured. Thanks very much for your help and support.

*Hold on a minute. Hold on a minute.— I've had this one before, and you could be on a loser. People of your age don't recover from ME/CFS. You have been well over the summer during the warm weather. I would prefer to think that you are in remission i.e. you still have the condition but it is so mild it does not significantly affect your life. It also means that it could hit you again when you least expect it. From your history, you've got a type of ME known as relapsing/remitting. Remission can sometimes last for years—so let's hope this happens in your case. There is another scenario something called 'masking' where the ME/CFS is turned off for a while—e.g. by a bee's sting or viral cold or some other undiagnosed condition. My advice is that you proceed with caution and take the following steps to help your rehabilitation and optimise your chances of staying in remission.*

*1) Before starting work, you need to be certain that you are fit to do so. See your doctor and ask him to do the usual health tests & screening. It will possibly mean seeing the practice nurse and having blood sent off. I would suggest that this be repeated periodically, especially as you have blood relatives with a family history of later life diseases e.g. diabetes or heart conditions.*

*2) You need a mentor or someone professional to supervise your pacing and well being and to help & advise you keep as fit and healthy as possible. I would suggest using one of the occupational therapist-run private clinics so that you can see the staff of the Leeds or Sheffield ME/CFS services privately.*

*3) Give yourself a lifestyle where you can balance diet, work and play. If necessary, join a sports club or whatever you would like to do. You would need to tell the instructors of your past history, and they will be able to recommend a suitable activity programme for you.*

*4) Don't take on any new financial commitments or loans, and don't spend beyond your means.*

*5) Give yourself a year before you make any further decisions. You may find that over the winter months or in stressful times the occasional symptom will re-appear. Hopefully the support network you've set up should enable you to take action to stop your ME/CFS from going high grade again.*

*Good luck !*

**Sally Writes:** . Can you put Clouds' contact details in Pathways? We wish a happy Christmas to all past and present clients. Could you please remind everyone that the client line will be checked once per day for emergencies. Details are: <http://www.cloudscounselling.com> Phone: 07962 907053 (leave your name and contact number and someone will ring back within 24 hours). Thanks.

### ***ME Humour with thanks to Hans-Michael Sobetzko (Germany)***

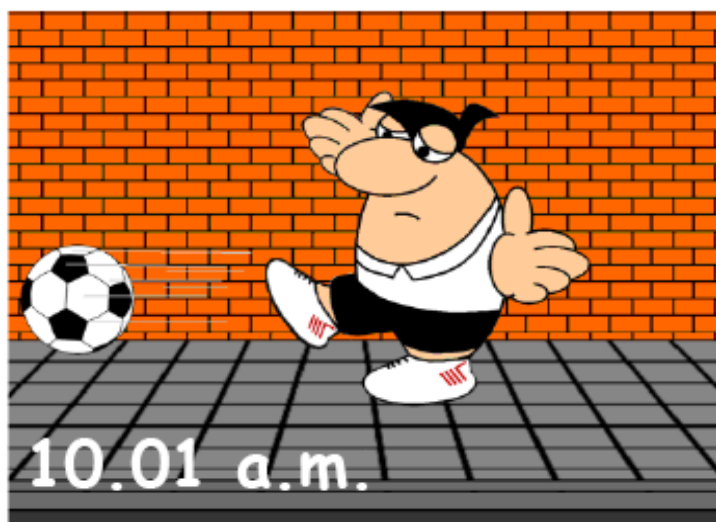


No, he hasn't got MCS. It's your overpowering perfume that's completely knocked him out.

(MCS = Multiple Chemical Sensitivity)



I HAD HOPED HE'D FINISH DECORATING THE TREE BEFORE YOUR ARRIVAL, AFTER ALL, HE STARTED IT IN AUGUST!!



It often takes many hours before the effects of any activity finally hit you.



## ***The Yorkshire Air Ambulance***

Yorkshire Air Ambulance is a dedicated helicopter emergency service for the Yorkshire and the Humber region of England. It was introduced on 1st April 2000, and currently operates two aircraft. The helicopters provide a swift response time and access to isolated locations, such as beaches, cliff-tops and moorland areas which are inaccessible by road. The original aircraft is based at Leeds Bradford Airport and has landing pads at various major hospitals around the region including Leeds General Infirmary and James Cook University Hospital in Middlesbrough. In October 2007 a second helicopter based at Sheffield City Airport entered service. The airport closed at the end of April 2008 but a heliport facility was still provided for the use of the Air Ambulance and the South Yorkshire Police helicopter. In November 2010 the operational base for the Sheffield-based aircraft was moved to Bagby Airport near Thirsk. The second aircraft made another move in March 2012 to RAF Topcliffe.

The Yorkshire Air Ambulance is maintained by the Yorkshire Air Ambulance Trust, a registered charity and is not part of the National Health Service or any local authority. It relies on the generosity of individuals and organisations to help save lives across Yorkshire.

In fact as a Charity we receive help only through secondment of paramedics from the NHS, through Yorkshire Ambulance Service. To keep both of Yorkshire's air ambulances in the air we need to raise £7200 per day. This is equivalent to £2.65 million per year which comes from you the public. You can donate to the Yorkshire Air Ambulance via : <http://www.yorkshireairambulance.org.uk> Or via 01422 237900, or shops and banks.

### **G-SASH in Derbyshire**

One helicopter (Helimed 99, registration G-SASH) is based at a hangar at Leeds Bradford Airport (EGNM), which enables servicing and maintenance to be carried out overnight, leading to even quicker response times in many parts of the county. It can be airborne in two minutes of a 999 call and flies at 140 mph (230 km/h) enabling fast paramedic support to the patient.

In September 2006 the original helicopter was involved in transporting the Top Gear presenter Richard Hammond following his high-speed accident at the former-RAF Elvington airfield near York. Following this operation a high profile charity appeal was launched and by 16th October 2006, contributions to the appeal amounted to £185,770.

**G-CEMS at Leeds Bradford Airport**  
The second YAA helicopter (Helimed 98, registration G-CEMS) was originally based at Sheffield City Airport but moved in March 2012 to RAF Topcliffe near Thirsk.

A spokesman for the charity commented: "What we're looking to do is provide the very best coverage for the whole of Yorkshire.



## ***Grapefruit versus Medicines***

*from the BBC, British National Formulary and Wikipedia*

Doctors have warned of a "lack of knowledge" about the dangers of mixing some medications with grapefruit. The fruit can cause overdoses of some drugs by stopping the medicines being broken down in the intestines and the liver. The researchers who first identified the link said the number of drugs that become dangerous with grapefruit was increasing rapidly. They were writing in the Canadian Medical Association Journal. The team at the Lawson Health Research Institute in Canada said the number of drugs which had serious side effects with grapefruit had gone from 17 in 2008 to 43 in 2012. They include some drugs for a range of conditions including blood pressure, cancer and cholesterol-lowering statins and those taken to suppress the immune system after an organ transplant.

Chemicals in grapefruit, furanocoumarins, wipe out an enzyme which breaks the drugs down. It means much more of the drug escapes the digestive system than the body can handle. For example, one blood pressure drug, felodipine, was reported as inadequately metabolised leading to an excessive blood level after a patient had a glass of grapefruit juice compared with a patient who took a glass of water. The side effects are varied depending on the drug, but include stomach bleeds, altered heart beat, kidney damage and sudden death. Other citrus fruits such as Seville oranges, often used in marmalade, and limes, have the same effect.

**Words of wisdom.** Neal Patel, from the Royal Pharmaceutical Society said: "Grapefruit isn't the only food that can cause issues, for example milk can stop the absorption of some antibiotics if taken at the same time. "Although some of these interactions may not be clinically significant, some may lead to more serious outcomes. "Pharmacists are the best port of call for anyone concerned about how their diet may affect their medication. Information about any interactions would always be included in the patient information leaflet that comes with the medicine."

### ***The Reputed Health Benefits of Grapefruit***

When eating or juicing grapefruit, peel off the skin but leave as much of the pith intact as possible as it contains the highest amount of valuable bioflavonoids and other antioxidants:

**Acidity:** Although grapefruit has a sub-acid taste, its juice actually has an alkaline reaction after digestion. This has a profound effect in the treatment of acidity in the digestive system that causes a host of other health problems.

**Atherosclerosis:** Pectin in this fruit has been found to be effective in reducing the accumulation of arterial deposits, and the vitamin C helps to strengthen and maintain the elasticity of arteries.

**Common cold:** A common cold is usually your body telling you that you are overworked. A regular drink of grapefruit during a stressful period gives your immune system the boost needed to prevent it coming on.

**Cholesterol:** A certain compound found in grapefruit helps reduce the excessive production of cholesterol from the liver.

**Fatigue:** At the end of a long and tiring day, drink a glass of grapefruit juice with lemon juice in equal parts with a little honey, to dispel all fatigue and tiredness.

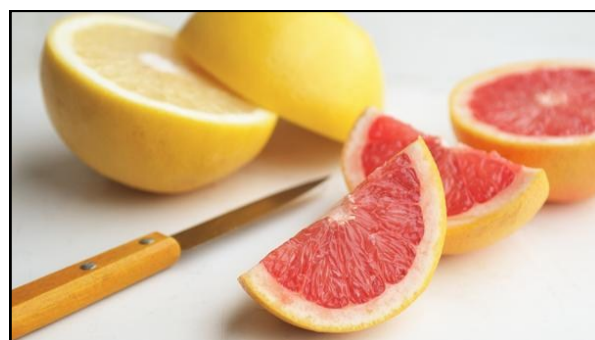
**Insomnia:** A drink of grapefruit juice before bedtime, helps to promote sleep and alleviates insomnia.

**Sore throat:** Drinking a freshly-squeezed grapefruit juice helps relieve sore throats and soothes coughs.

One tablet with a glass of grapefruit juice can be like taking five or 10 tablets with a glass of water. So you can unintentionally go from a therapeutic level to a toxic level just by consuming grapefruit juice.

here remains a lack of knowledge about this interaction in the general health care community. Unless health care professionals are aware of the possibility that the adverse event they are seeing might have an origin in the recent addition of grapefruit to the patient's diet, it is very unlikely that they will investigate it."

*Dr David Bailey, Researcher*



## ***Grapefruit Juice Interaction with some commonly used medicines***

Here is some information which has been checked against the current British National Formulary (December 2012). This information is not definitive and may change with time, and is only intended as a alert, and does not include everything. Specifically excluded are non UK medicines and those obtained covertly via the internet. In case of doubt refer to a pharmacist, prescriber or product literature enclosed with the medicine. Surprisingly two medicines that react with many medicines, warfarin & St. John's Wort don't seem to be listed anywhere as being affected by Grapefruit.

Aliskiren			X			? Indicates that there may be an uncertainty issue.
Amiodarone	+			May occur may weeks after stopping		- reduces blood plasma concentration and may make medicines less effective.
Amlodipine	+	?				
Atorvastatin	+	?		*		
Bilastine	-					+ increases blood plasma concentration and may increase the effect of the medicine and also toxic and undesirable side effect.
Buspirone	+			*		
Ciclosporin	+			increased risk of toxicity		
Colchicine		?		increased risk of toxicity		
Dronedarone	+		X			X avoidance advised.
Efavirenz	+	?				
Everolimus			XM			XM avoidance advised by manufacturer.
Felodipine	+			*		
Fexofenadine	-		X	Telfast		* Known to be used by some people with ME/CFS.
Isradipine	+					
Ivabradine	+					
Lacidipine	+					
Lapatinib			XM			
Lercanidipine	+					
Midazolam	+	?		*	Buccolam	
Nicardipine	+			*		
Nifedipine	+			*		
Nilotinib			XM			
Nimodipine	+			*		
Pazopanib			XM			
Quetiapine	+	?	X			
Ranolazine	+	?	XM			
Rupatadine	+		X			
Sertraline	+	?		*	Lustral	
Sildenafil	+	?		*	Viagra	
Simvastatin	+		X	*		
Sirolimus	+		X			
Tacrolimus	+			When used to treat skin		
Tadalafil	+	?		Cialis		
Tolvaptan	+		X			
Vardenafil	+	?	X	Levitra		
Verapamil	+			*		
Vinflunine	+	?	XM			

### ***Grapefruit Seed Extract***

Grapefruit seed extract (GSE) is sold as a food supplement and is a claimed natural antimicrobial. This extract is claimed to be safe, as it is a natural product. The extract has been used by some alternative practitioners to treat fungal infections associated with ME/CFS e.g. gut fermentation.

GSE has been recommended by some nutritionists for the treatment of candidiasis, earache, throat infections, and diarrhoea. It is promoted at health food shops and on the internet.

The safe assumption is that GSE reacts with conventional medicines in the same way as grapefruit juice and err on the side of caution.



## **Changes to State Benefits Coming in 2013**

### **Personal Independence Payment**

Earlier this year I published in Pathways what we knew about Personal Independence Payment (PIP) at the time. We know that it will replace DLA, and we are concerned that a number of people with ME/CFS will lose out. What follows are two documents received from the DWP, the first being a 'claimant journey', and the second being a 'mythbuster'. (DWP's own words). From previous experiences with the DWP, there are statements that I just don't believe. I've marked these up with a salt pot to the right.



### **Replacing DLA with PIP is intended to save the government 30% of the DLA bill.**

For quite a while, where people have been receiving DLA high rate, we've advised them NOT to take out a mobility car lease. This is simply because the case can be reviewed any time and you could lose it. The DWP say that ESA and DLA are not linked, but this has proven wrong in the cases of an number of members of Leger ME. An adverse report from a medical is all it takes to lose DLA.

### **Some disability forums think at 45,000 claimants will lose their mobility cars.**

Ok, you could get it reinstated on appeal, but with the experience of recent cases that could take up to a year. If you receive low rate care there is no PIP equivalent. DLA received should not be relied on for things like rent, other long term financial commitments or loans, for the above reasons. What is quite clear is that when PIP does come in there are going to be a load of mistakes made by the people who administer it, and bugs within the system as has happened with ESA. And it is still is going on.

The timetable for the introduction of Personal Independence Payment (PIP), the benefit set to replace Disability Living Allowance (DLA) has now been set out in detail in the DWP's Frequently Asked Questions document:

- From April 2013 a few thousand new PIP claims will be taken from people aged 16-64 in Merseyside, North West England, Cumbria, Cheshire and North East England. All other new claimants will continue to make claims for DLA.
- From June 2013 all new claims from people aged 16-64 will be for PIP rather than DLA.
- From October 2013 the DWP will begin reassessing all existing DLA claimants aged between 16-64. However, between October and December 2013 they intend to reassess just 30,000 existing DLA claimants to check that the systems work.
- Full scale national reassessment will begin in January 2014.
- The DWP says that all existing DLA claimants "will have been contacted about reassessment by March 2016", suggesting that by that stage everyone will have received a letter warning them that they are to be reassessed but that not everyone will have completed the reassessment process.

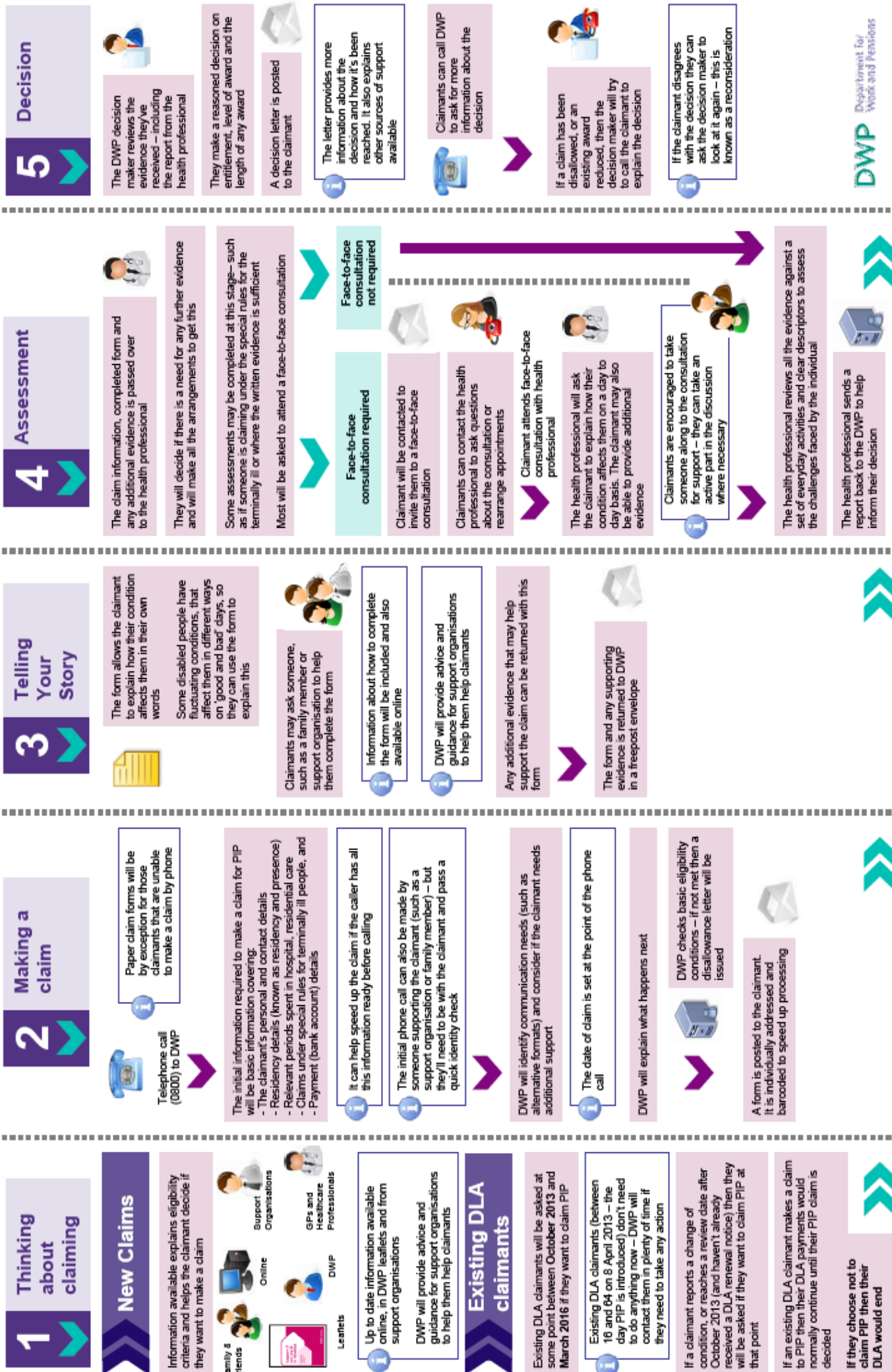
### **Universal Credit**

This new benefit is due to come into place in October 2013. In the report, Baroness Grey-Thompson and the three supporting organisations make recommendations to ensure that some of the most vulnerable people are protected. The fear is that these changes will leave gaping holes in the safety net for many disabled people. Disabled people and their families have warned that cuts to the child disability additions and to the Severe Disability Premium are likely to result in their struggling to pay for basic essentials such as food and heating. Many disabled people, who are already finding it difficult to make ends meet, face further hardship under the new benefit system, leading to potentially disastrous consequences. Despite the intention of Universal Credit to make work pay, evidence in the inquiry shows that the changes could make it harder for disabled people to remain in work. *Pathways* will include features on this subject when more is known.

# Personal Independence Payment: The Claimant Journey

UPDATED 31 August 2012

This claimant journey explains how the claim process for Personal Independence Payment is expected to work. This uses the latest available information but please note that some of the detail may change over time as processes and ways of working are confirmed. You should always check the PIP website at [www.dwp.gov.uk/PIP](http://www.dwp.gov.uk/PIP) for the latest version – this version was issued on 31 August 2012. The site also features a range of supporting information including a quick guide to PIP (including eligibility and implementation timetable) and frequently asked questions.





## ***Commonly asked questions about Personal Independence Payment***

*From the DWP website.*

*Will People will be discouraged from claiming Personal Independence Payment to save money?*

No. We want to simplify the claims process to ensure that everyone who might be entitled is able to apply. We are committed to working with disabled people and their representatives to develop delivery arrangements for Personal Independence Payment to ensure we get it right and this includes the claims process.



*I've heard that the Mobility component is going to be removed?*

No. Personal Independence Payment will continue to have a Mobility component, paid at either a standard or enhanced rate. The assessment criteria will assess a person's ability to plan and follow a journey as well as their ability to move around physically.

*I've heard that the Motability scheme is going to be scrapped?*

No. We want this scheme to continue and are working with Motability, the charity that runs the scheme, to decide the best way to do this under Personal Independence Payment.

*Will older people on Personal Independence Payment lose their entitlement at age 65.?*

No. If someone is in receipt of Personal Independence Payment before they reach their 65th birthday they will continue to receive the benefit so long as they continue to satisfy the eligibility criteria.

*I've been told that Personal Independence Payment will not be paid to people who are working?*

No that's incorrect. Personal Independence Payment can be paid to people who are in work or out of work.



*Will going into work affect the amount of Personal Independence Payment or stop it altogether ?*

No, this is not true. Personal Independence Payment will be available to disabled people whether they are in work or not. Being in work or returning to work will not be a relevant change of circumstances unless someone's needs have increased or decreased as a result of employment. Personal Independence Payment will be a non-taxable benefit. Personal Independence Payment will be non-means-tested, so earnings and other sources of income will not affect the amount of Personal Independence Payment.

*I understand all assessments will be conducted annually and review checks could be as frequently as weekly or monthly ?*

No. Following the assessment we will decide on the length of the benefit award. This will be based on individual circumstances and the likelihood of changes occurring. Some people will get shorter awards (up to two years), others will get longer ones (such as five or ten years) and some will get indefinite awards (which will be subject to review). To ensure that people continue to receive the right level of benefit we may reassess a claimants needs within an award period to ensure that it is still correct. This will also be based on individual circumstances and the likelihood of changes occurring.

*Will disabled people will have to attend face to face consultations by themselves.*

No. Individuals attending face to face consultations will be able to take a family member, carer or someone else with them.

*Will awards will be decided by the trained health professional and no other evidence considered. ?*

No. The benefit decision maker will make the decision as is the case with DLA. We want them to use the widest range of evidence to ensure awards are made correctly. We will be asking disabled people to tell us who would be best placed to provide this evidence. That might include information given by the individual, or a relevant professional who supports the individual on a regular basis. Information gathered during face to face consultations will form part of the evidence considered. We want to ensure that individuals are given the opportunity to tell us how their condition affects them. Decision makers will not understand the range of barriers disabled people face. Assessors and decision makers will be given all the necessary specialist training and guidance to carry out their roles and will be able to draw on specialised support where needed. We will work with disability organisations to help develop this.



*I've heard that individuals with fluctuating conditions will lose out.?*

No. We will take in to account that people's conditions fluctuate and their level of ability may be changeable. The assessment will not be a 'snapshot' of any one day. We will consider an individual's ability to carry out activities over a period of time - we are thinking a year. We will consider the impact of an impairment where it applies on over 50 per cent of the days in this period. We have recently concluded a consultation on the second draft of the assessment criteria for Personal Independence Payment and in particular on the changes that have been made since the first draft, the proposed descriptor weightings and entitlement thresholds and the draft regulations. We are considering the replies and the Government will publish its response in due course.



*Will terminally ill people will have to go through a face to face consultation?*

Individuals with a terminal illness and who are not expected to live for six months will be fast-tracked on to a guaranteed payment of the enhanced rate of the Daily Living component of Personal Independence Payment. They will also be able to apply for the Mobility component without having to wait for a payment. We expect that most people who are terminally ill would not have a face to face consultation. In all circumstances we would look at what is in the best interest of the claimant and would consider the evidence they provide with their application and that from their hospital consultant or GP.

*Will the Employment & Support Allowance (ESA) Work Capability Assessment (WCA) and Personal Independence Payment (PIP) assessment be the same?*

ESA, WCA and PIP are very different things. The Personal Independence Payment assessment will focus on an individual's ability to carry out key everyday activities and participate in society, rather than their capability to work. We are, however, learning from the experience of the ESA Work Capability Assessment and the reviews by Professor Harrington as we develop the assessment for Personal Independence Payment.



*Will everyone currently getting lowest rate DLA care component lose out?*

The new benefit will have different entitlement criteria to those for DLA. Entitlement will depend on the person's circumstances and the impact of their health condition or disability on their everyday lives. Some people will receive more support, others less, and some will leave the benefit altogether. Those who will not get Personal Independence Payment are most likely to be people with conditions that have a low impact on their day to day lives and who have a high level of participation in society without needing expensive aids and appliances or a lot of help from others. They will come from across the full range of disabilities.



## Recipe Corner by Carolyn

### **Lemon, Haddock and Herbs with Pasta**

*This is a 20 minute recipe which takes inspiration from a Delia Smith recipe and is well tried and tested at home. Serves 4*

#### **Method**

Begin by preheating the oven with a baking tray in it, to 190c.

When the oven has reached the temperature put in the 4 haddocks and leave to cook for 20 minutes. (You can see when they are done because they will have risen and the sauce inside will be bubbling). Just watch that they don't overcook as that can ruin the taste.

While waiting for the haddock to cook, in a large saucepan, heat up 8 pints (4.7 liters) water with 1 level tablespoon sea salt and bring it up to a good, fierce boil. Add the pasta to the boiling water and stir once, then let it boil briskly for 10 minutes.

While the pasta and fish are cooking, the rest of the ingredients are piled into a food processor with a teaspoon of salt, then one big whiz till the herbs are chopped and that's it.

Now drain the pasta and return it quickly to the saucepan with the sauce and toss the two together.

Take the cooked fish out of the packets, being careful to cut a small corner in each packet first in order to separate the Lemon and Chive Sauce into a jug, so people can add the extra sauce to taste as they wish. Chop the fish up and toss into the pasta.

Serve in the warm bowls with a little extra zest sprinkled over each one.

#### **You need**

- 1 lb (450 g) dried pasta
- 2 Packs( 2 haddock in each pack) of frozen Birds Eye 'Bake to Perfection' Haddock fillets with a Lemon and Chive Sauce.
- 2 tablespoons fresh lemon juice
- 2 level tablespoons fresh lemon zest, plus a little extra to sprinkle at the end
- 12 whole peppercorns, lightly crushed in a pestle and mortar
- 1½ oz (40 g) fresh basil
- 1 oz (25 g) fresh mint
- 2 oz (50 g) fresh rocket leaves
- 6 spring onions, trimmed
- 2 cloves garlic, peeled
- 4 tablespoons extra virgin olive oil
- sea salt



### **Mulled Wine as made by my Danish Friend's Mum**

*Those Danes know a thing or two. Makes 2 litres (3½ pints)*

#### **Method**

Pour the vodka into a small glass jar. Add the cinnamon, cloves, ginger, orange peel and cardamom.

Cover and leave to stand at room temperature for a week.

Taste after a few days and remove the ginger if the flavour is strong enough.

Dissolve the sugar in a little wine in a pan over a low heat.

#### **You need**

- ¼ pint of Vodka
- 6 cinnamon stick
- 30 cloves
- 2 large pieces of ginger
- Handful of bitter (Seville) orange zest
- 2tsp cardamom pods
- 1lb granulated sugar
- 1.5 litres (2½ pints) red wine
- Raisins and almonds to garnish (if you wish)



Sieve the vodka to remove the spices.

Mix the vodka and sugared wine with the rest of the wine.

Pour into clean sterilized bottles – it keeps for several weeks. Heat gently before serving but don't let it boil.

Please send us your favorite recipes for this page.—Carolyn



**News from Upper Weston**

by Dr. Sarah Myhill. (Upper Weston Llangunllo Knighton Powys Wales LD7 1SL 01547 550 331  
<http://www.drmyhill.co.uk> )

We are pleased to announce our third publication which looks at targeting mitochondrial dysfunction in the treatment of ME/CFS. Our first two papers established that mitochondrial dysfunction is a central pathophysiological lesion in ME/CFS. ([www.ijcem.com/files/IJCEM812001.pdf](http://www.ijcem.com/files/IJCEM812001.pdf) and [www.ijcem.com/files/IJCEM1204005.pdf](http://www.ijcem.com/files/IJCEM1204005.pdf)). Those papers demonstrated that the patients with the worst levels of fatigue had the worst levels of mitochondrial (energy) function and vice versa. There was a very strong relationship between mitochondrial energy scores and patient fatigue scores and these studies clearly place ME/CFS as a physical disorder.

Mitochondrial (energy) function scores are calculated from the ATP profile test. This is a test that measures how efficiently mitochondria can make ATP, how well they move ATP from the mitochondria into the cell where it is needed and recycled back and also how efficiently energy can be released from ATP once in the cell. These are important measurements because from them one can further deduce whether the mitochondria are “going slow” either because they are lacking the “raw materials” to “do the job”, or because they are “blocked” from doing their “job”. This “blockage” could result either from an external source [a toxin] or from an internal source notably the fermenting gut.

Knowing and understanding what the biochemical lesions are, and whether they derive from “internal” or “external” sources, means that treatment packages can be tailored to individual patients. The aim of this third study was, therefore, to see how well patients respond to this tailored package of treatments and what impact, if any, did those treatment packages have on both the ATP profile test results and also on the patient fatigue scores.

The nature of this study was an audit – that is to say clinical decisions were made for the benefit of the patient, not for the doctor or researchers. However, the information that this audit yields is very encouraging. Essentially what is shown is that those patients who are able stick to the demanding treatment packages, involving a “stone age” low carbohydrate diet, discipline about sleep and pacing, together with a package of nutritional supplements, do indeed improve biochemically reliably well. That is to say their ATP Profile test results improve consequentially with their treatment package compliance. Moreover, most of these biochemical improvements were accompanied by clinical improvements, as measured by patient fatigue scores. It was also notable that four patients who did not adhere to the treatment packages either saw no improvement or indeed worsened. In a clinical setting, therefore, it is incumbent upon the physician both to understand the difficulties that patients face with such a wide ranging treatment package and also to support fully the patient with the challenges they face.

It is clear from these studies that mitochondrial function is not the only factor in ME/CFS, but it is an important one and correcting mitochondrial function is an essential part of improving functionality and therefore of recovery. Indeed it is my personal view that to put a patient on a graded exercise programme without first checking these essential biochemical parameters is not good medicine. One risks making the patient much more ill because the underlying cause of their disease has not been addressed. Conversely if the improvement in mitochondrial function, consequent upon compliance with the treatment package, is not paralleled by clinical improvement then there must be a further reason for fatigue. We discuss reasons why correcting the mitochondrial function is not paralleled by clinical improvement and treatment options in these cases.

The symptom of fatigue arises when energy demand exceeds energy delivery. The way I think about ME/CFS is that we all have a certain “bucketful” of energy available to us everyday. Fatigue is the symptom we all experience at the end of every day which prevents us from FULLY emptying that bucket of energy. Of course part of my job is to make that bucket of energy as full as possible through addressing mitochondrial function, sleep, thyroid function, diet and so on. This third study demonstrates that patient compliance with the tailored treatment packages will help to achieve this ‘filling’ of the bucket.

However, we, (myself and the patient) also have to look at how that energy is spent (i.e. how the bucket is emptied) and essentially it can be spent in four different ways: mentally, physically, emotionally, or immunologically. Patients quickly work this out for themselves (it's called "survival") and the careful spending of mental and physical energy is what we call pacing.

The spending of emotional energy can be helped by a variety of means and again patients often work this out for themselves via methods such as meditation, deep relaxation methods or perhaps talking therapies. However, the most difficult problem to address is the immunological hole in our energy bucket. We all know this exists – take a "normal" person and give them a dose of 'flu and they will develop a very acute fatigue. This is because the immune system is enormously demanding of energy.

Therefore there is a two pronged approach – firstly to look at energy delivery systems and secondly to look at how energy is being spent. A very useful analogy is to think of the body as a car which means that the mitochondria constitute the engine of the car, the diet the fuel, the antioxidants the cooling system, the thyroid gland the accelerator pedal, the adrenal gland the gear box and so on. Once the expenditure on physical, mental and emotional energy has been addressed, along with putting in place the treatment packages as tailored via the ATP Profile test results, the most common reason therefore for a failure to improve is an immunological hole in the energy bucket. A common cause of failure to respond within this bracket of "immunological hole issues" is a problem with the upper fermenting gut.

In addition, I have seen success using pure T3 where there is evidence of hypothyroidism. The idea here is that there is thyroid hormone resistance - there are clear parallels here with type II diabetes in which we have essentially the same problem. In type II diabetes there are high levels of insulin, but insulin hormone receptor resistance. There is now good evidence to suggest that this resistance results from toxic stress. Indeed this issue was flagged up in a paper published in the Lancet which looked at the levels of persistent organic pollutants (POPS) in the general population. What was found is that those with the highest levels of POPS, compared with those with the lowest level, were 38 times more likely to be diabetic.

### **Targeting mitochondrial dysfunction in the treatment of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome/ (ME/CFS) – a clinical audit**

Sarah Myhill<sup>1</sup>, Norman E. Booth<sup>2</sup>, and John McLaren-Howard<sup>3</sup>

<sup>1</sup> Sarah Myhill Ltd, Llangunllo, Powys UK; <sup>2</sup> Department of Physics and Mansfield College, University of Oxford, Oxford UK; <sup>3</sup> Acumen, Tiverton, Devon UK

**Abstract:** We report on an audit of 138 ME/CFS patients who attended a private practice and took the ATP Profile biomedical test. The results revealed that all of these patients had measureable mitochondrial dysfunction. A basic treatment regime, based on 1) eating the evolutionary correct stone-age diet, 2) ensuring optimum hours of good quality sleep, 3) taking a standard package of nutritional supplements, and 4) getting the right balance between work and rest, was recommended for all patients. Additions to the basic regime were tailored for each patient according to the results of the ATP Profile and additional nutritional tests and clues from the clinical history. Mitochondrial function is typically impaired in two ways: substrate or co-factor deficiency, and inhibition by chemicals, exogenous or endogenous. For the former, additional nutrients are recommended where there is a deficiency, and for the latter, improvement of anti-oxidant status and selective chelation therapy or far-infrared saunas are appropriate. We show case histories of nine patients who have taken the ATP Profile on three or four occasions, and a before-and-after treatment summary of the 34 patients who have had at least two ATP Profile tests separated by some months. Finally, we summarize the results for the 30 patients who followed all aspects of the treatment regime and compare them with the 4 patients who were lax on two or more aspects of the treatment regime. All patients who followed the treatment regime improved in mitochondrial function by on average a factor of 4.

**Keywords:** Myalgic encephalomyelitis, chronic fatigue syndrome, mitochondrial dysfunction, adenosine triphosphate (ATP), oxidative phosphorylation, cellular energetics, nutrition

## Sheffield ME Group Conference : 24th October

A Personal Report by Ute Elliott, Sheffield ME Group Chairperson.

Julia Newton, Professor of Ageing and Medicine & Consultant Physician, Fatigue Interest Group / Falls and Syncope Service at University of Newcastle gave a lively and most informative presentation of the work she and her team have done as well as the work they are planning to do in the next two years. For the first time I felt that there is hope at last for a definite biomarker of the illness of ME/CFS.

This research is funded by the MRC (Medical Research Council), ME Research UK and the MEA (ME Association) among others. The MRC has contributed the most funding and has stipulated that Fukuda criteria are to be used in selecting the 81 people with ME/CFS and they have given Julia and her team 20 months to do the research. The volunteers will be mildly to moderately affected as the team will not have the time to go to the homes of severely affected, nor could this group cope with the barrage of tests which can only be done in the laboratory environment; but the team hopes to extrapolate parts of their research to the severely affected group making their work helpful to that group too.

They will address the following points:

1. Understanding the autonomic dysfunction in ME/CFS and the relationship to cognitive impairment
2. Identify biological fingerprints of fatigue
3. Understand muscle dysfunction in ME/CFS
4. Explore qualitative experience of sleep

So, needless to say, we hope that Julia will agree to come back to Sheffield in about two year's time and inform us of their findings, fingers crossed! Julia and team have looked into fatigue associated diseases like MS (Multiple

Sclerosis) and Rheumatoid Arthritis which can be diagnosed by a definite test – but ME/CFS presents a big problem as there is a definite lack of diagnosis, as we all know. In a range of diseases characterised by fatigue, they discovered a strong association between fatigue and autonomic dysfunction; they came to the conclusion that fatigue is characterised by abnormalities of blood pressure control. Hence people with ME/CFS experience light-headedness or even black-outs when standing up. In tests 89% of people with ME/CFS experience this Orthostatic Intolerance (OI) and in all cases fatigue severity associates with increased OI. (This was established via the tilt-table test). They found that low blood pressure also leads to memory problems.

Dysfunction of the autonomic nervous system (ANS) is known as dysautonomia. The autonomic nervous system regulates unconscious body functions, including heart rate, blood pressure, temperature regulation, gastrointestinal secretion, and metabolic and endocrine response. As regulating these functions involves various and multiple organ systems, dysfunctions of the autonomic nervous system encompasses various and multiple disorders. The team also took muscle biopsies and grew them in culture media then tested them for fatigue. They found that after exercise people with ME/CFS produced lactic acid in their muscles which was difficult to disperse. *(This is something that had been strongly suspected about ME for many years but now here is proof –ed ).*

They also found indications of cardiomyopathy as hearts of people with ME/CFS had to work much harder in response to the stress of standing up compared to the control group. They also detected a twist of the heart in the pumping action meaning that the heart is working less efficiently. *(See the Pathways 33 for more details)*



### Conclusion

- Symptoms suggestive of autonomic dysfunction are common in fatigue.
- Autonomic dysfunction is associated with fatigue severity.
- Central and peripheral abnormalities are detectable in those with fatigue using state of the art techniques.
- Cardiovascular response to standing may have potential as a diagnostic biomarker in fatigue.



## ***Publication Review of received publication.***

### **MYALGIC ENCEPHALOMYELITIS – Adult & Paediatric: International Consensus Primer for Medical Practitioners.**

The first comprehensive publication about ME/CFS I came across was Charles Shepherd's 'Living with ME'. The next landmark was the Chief Medical Officers report of around 2000. The next significant publication was the NICE Guides of 2004—what as we all know was a great disappointment mainly advocating GET & CBT. This latest publication contains a lot of medical level information which should have been in the NICE guidelines, but was politically excluded because it is non-UK or non-NHS based.

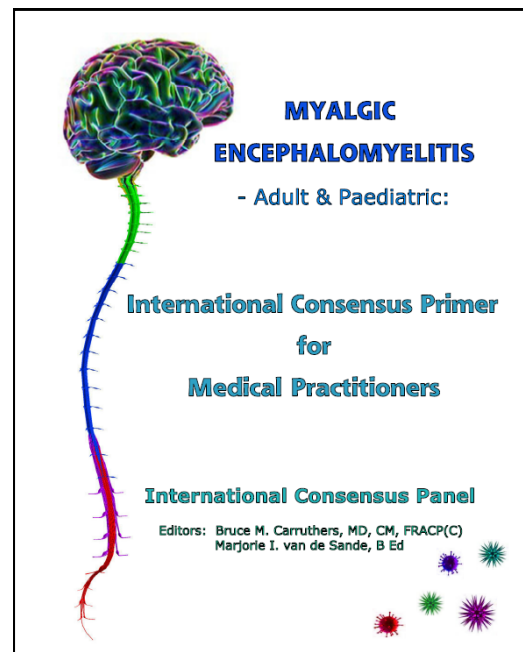
As a health professional and chairman of the Leger ME community group I frequently come across cases where there are welfare rights and medical care disputes. Frustratingly if I were able to use this publication authoritatively it would be very useful, and would go a long way to providing the necessary evidence that is lacking.

If you look at the authorship you see impressive international names from the ME/CFS world names like Betty Dowsett, Nigel Speight and David Bell, plus many of the international names from the ME/CFS world. What is notably absent is are the well known names in the ME/CFS world the from the UK and NHS. From my point of view this is possibly is greatest failing and weakness because it lacks the credibility needed to make it authoritative. However, most of the text is backed up by academic references, but in practical terms how many doctors would actually bother to follow these up?

The publication is the result of a International Consensus Panel, consisting of clinicians, research investigators, teaching faculty, and an independent educator, representing diverse backgrounds, medical specialities and geographical regions. Collectively, the members have more than 50,000 patient-years of ME/CFS, more than 500 years of clinical experience, approximately 500 years of teaching experience, have authored hundreds of peer-reviewed publications, as well as written chapters and medical books; and several members have co-authored previous criteria.

Where it does score is that it includes patients' reporting charts, checklists and systems (backed by research references) for reporting symptoms. In particular it does focus on cardiovascular issues, which within the UK are relatively new—but appear to have been known to the rest of the world for quite a while.

So how do you get a copy ? Well its in the public domain, and anyone who would like a copy can obtain it via the normal Leger ME channels. Enquiries regarding reprinting the primer to should go to: Marj van de Sande: [mvandes@shaw.ca](mailto:mvandes@shaw.ca) 151 Arbour Ridge Circle NW, Calgary, Alberta T3G 3V9, Canada -Mike.





## The Wenceslas Legend

The Carol 'Good King Wenceslas' is possibly not heard as often now as it was in the past. Rather than telling the religious side of the Charismas story, the narrative of the carol describes an act of piety or charity to someone less well off, an act advocated by many religions. As a result it popularized Christian and Victorian ideals of social benevolence and practical almsgiving. The plot was used in a Tom and Jerry cartoon entitled 'The Night Before Christmas'. The words were written by Mason Neale, an English hymn writer, in 1853. The melody was from a 13th century spring carol "Tempus adest floridum" ("The time is near for flowering") first published in the 1582 A Finnish song collection Piaie Cantiones was used. Good King Wenceslas was actually Wenceslas (Wenzel) (907–929), Duke of Bohemia. His feast was celebrated from 985, and about thirty years later he became Bohemia's patron saint. His picture was engraved on the coins and the Crown of Wenceslas was regarded as a symbol of Czech nationalism and independence.



Good King Wenceslas on a biscuit tin, made by Hudson, Scott & Sons for Huntley & Palmers, 1913, on display at the Victoria & Albert Museum. At that time many people would have had access to a piano, so the music script was included much as I-player files are used these days.



Above : A status of King Wenceslas in Wenceslas Square in Prague.

Right : The first page of "Tempus adest floridum" in the original version of the 1582 Piaie Cantiones. The carol melody is now better known as "Good King Wenceslas" after the added Victorian text by J M Neale. When I tried out the music it sounded a bit off – then I realised the music script is written in the old alto clef – only used these days in symphony orchestras for viola parts.



## What is the difference between Christmas Songs, Hymns & Carols ?

These days Christmas carols seems to imply any Christmas music, but there are differences. The history of Christmas hymns goes back much further than the history of Christmas carols. Christmas hymns are typically a solemn religious song, most frequently heard in a Church or in the context of a religious Christmas play or presentation, some which have been dated to the 4th century. Christmas carols are typically a song that celebrates the Christmas season in a joyous manner, originally accompanied by dance. The carol, as an art form, arose about the 13th century. The Melody for the Wenceslas Legend was actually a dance tune with the last three notes played slower to enhance the words when sung –Mike.

## ***Electrosensitivity - Is it Real or Imaginary ?.***

*Following a conversation on the topic I was sent a leaflet from ES-UK by a group member. We have reproduced part of the text of the leaflet here.*

**Electrosensitivity— What's is it?** Electrosensitivity (ES) is a condition which can develop when people are exposed to things like mobile phones, mobile phone masts, power lines, substations, computers, WiFi wireless networks, domestic wiring, DECT cordless phones and other household appliances.

**What are the symptoms of ES?** Electromagnetic fields (EMFs) are produced by electrical and wireless appliances in homes and workplaces and outside in our everyday environment. These EMFs are what can provoke ES. The most common symptoms are head/ear pain when using a mobile phone, redness and burning on the face or arms when using a computer or headaches and sleep disruption when living near a mobile phone mast, sleeplessness, lethargy, even miscarriages and depression living near power lines. Other symptoms include skin tingling, burning sensations, concentration and memory problems, muscle and joint pains, cardiac palpitations, fatigue, irritability and erratic high blood pressure. Unfortunately, ES is usually progressive and over time the sufferer may become sensitive to a wider range of frequencies and/or their reactions may become more severe, or they may begin to react to chemicals or develop food allergies. When, because of EMFs around you, you can no longer go to work, use a computer, watch television, go to the shops, go out in a car, or even use a telephone, your lifestyle becomes very restricted. Often family, friends, GPs do not believe your symptoms can be caused by the modern technology we all take for granted. They suggest it is 'all in the mind' and your GP may even refer you to a psychiatrist. It is hard for the sufferer not to believe they are indeed going mad.

**Who develops ES and what happens to them?** Anyone can develop electrical sensitivity, at any age, it is impossible to predict. We estimate that about 5% of the UK population suffer quite badly from electrical sensitivity. That is more than 2,000,000 people. Increasingly, it is our children who are being made to suffer. Many adults lose their jobs when they can no longer tolerate modern work environments. Some have to move home, though getting away from substations and mobile phone masts is not an easy task. A few become so sensitive that they have to live without electricity altogether. Social isolation and lack of access to basic services can become a major problem. GPs and other medical professionals have no training in recognising or treating ES. So many schools have installed WiFi that many of our children are developing behavioural and learning problems that are robbing them of their education, and may be disrupting the education of others. Internet access can easily be achieved with wired networks. Our children can have modern technology without the health side effects of WiFi.

**Are power lines, substations, mobile and cordless phones, phone masts and WiFi networks safe?** Hundreds of scientific studies show increased risk of cancer, depression, Alzheimer's disease, leukaemia, brain tumours, fertility problems, miscarriages and damage to DNA as a result of exposure to EMFs from power lines, masts, mobile and DECT phones.

**Why doesn't the government do something?** The government follows outdated advice that only protects the general public from acute effects such as electric shocks and being cooked. The exposure guidelines are not meant to protect us from the chronic effects such as those listed above. The government advised by the HPA, seems to be influenced more by commercial interests and tax revenues than the wellbeing of those who are sensitive to environmental pollutants.

**What is being done about ES?** In Sweden, ES is treated as a disability. People with ES can get grants to adapt and shield their homes. Employers make changes to the work environment for employees with ES. Mobile phone-free zones have been introduced on the Stockholm and Salzburg public transport systems. In America houses cannot be built close to power lines. There is unfortunately widespread ignorance of ES among GPs and public bodies in the UK, despite the evidence, because of influential commercial interests and the reluctance to question official policy.



**Where does ES-UK come in?** The aims of the ES-UK charity are:

- To promote and protect the physical and mental health of sufferers of electrosensitivity in the United Kingdom through the provision of support, education and practical advice.
- To advance the education of the general public in all areas relating to electrosensitivity.

ES-UK is independent of Government and commercial interests. The Trustees are people who have experienced the problems of living with electrical hypersensitivity or who have supported people suffering from this disability for many years.

For more information about ES-UK, write to:

BM Box ES-UK, London, WC1N 3XX tel. 0845 643 9748 web. [www.es-uk.info](http://www.es-uk.info)

ES-UK is an independent charity, Registered No. 1103018.

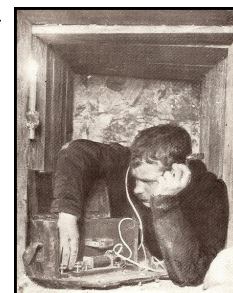
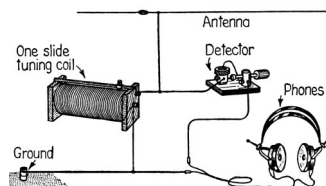
## ***Electricity in the air.***

All the suspect gadgets produce radio waves—they are a type of electromagnetic radiation like x-rays and light, but of much longer wavelength. There are basically two sources. Firstly the wireless gadgets we all use e.g. mobile phones, internet routers, microwave ovens & radios where they are deliberate producers. The second group is unintentional radiators, petrol engine ignition coils, some electrical lighting equipment, all alternating current lighting power circuits. They all pump electricity into the air and it has to go somewhere. There are two distinct types 'near field' & 'far field'. The near field effect is mostly lost as heat e.g. in a microwave oven, RF therapy machine in hospitals, MRI scanners (although very weak), or eddy currents (e.g. induction hobs or car speedometer).

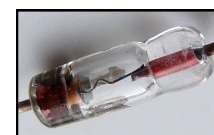
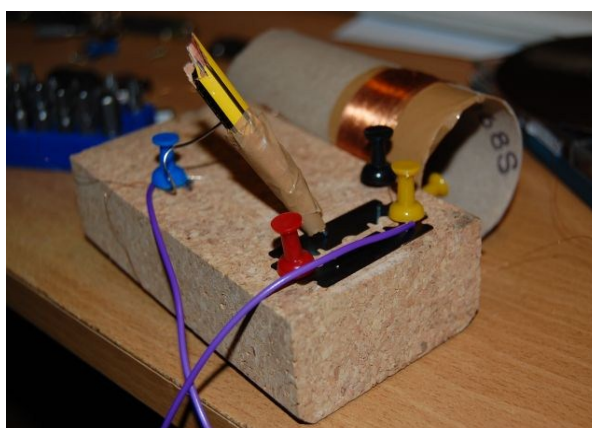
Far Field effects are far weaker. Here the mechanism is a little bit more sophisticated. The first condition is two electrical conductors of different materials to detect the wave. Almost any two materials that will pass electricity one way better than the other will do. Perhaps this was better known to our great grandfathers in a crystal radio. Any old bit of wire to collect the waves, followed by a coil to 'tune', or select the wavelength. The 'detector' is a 'cats whisker' of fine wire which had to be adjusted to find a sensitive spot on the crystal (usually a mineral called galena, lead ore). Just by connecting a telephone earphone and adjusting the frequency, the radio signal could be heard. Crystal radio sets were used in both world wars. They were a main means of communication in the first and used in the second in covert radios in prison camps or occupied territories. In past years making a crystal radio was part of a schoolboy's 'must do' things. The illustration shows how one could be made from office material. The detector or diode is formed by the pencil lead touching the edge of the razor blade.

The first question to ask is where is the battery and where does the power come from? The power is created by the diode rectifying the radio wave—the radio wave itself powers the radio and here is the key to electrosensitivity. One well known effect seen by some dentists is for patients in the dentist's chair to hear a local radio station. The dentist becomes the aerial and the waves are detected when dissimilar metals touch (e.g. steel & dental amalgam) - the rest is due to the small current being picked up by a nerve in the inner ear. Something similar could happen with pierced rings, or other metal jewellery.

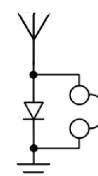
So what about the health effects? Well maybe there are the biological equivalent of diodes in the cell protein structures which behave as biological semiconductors. Certainly the cytochrome or NAD electron transport chains that produce energy could be, and are most likely to be affected. After that it's a matter of research—Mike



*Soldier listening to a crystal radio during World War I, 1914.*



*A modern diode, about the size of a pin head is the basis of detecting radio waves. If a sensitive meter is put in place of the headphones then we have a means to measure the power, and this is the basis of all the field strength meters sold to detect radio*



**North of Doncaster. Pathways ME Politics Feature****An overdue exchange of views:****Countess of Mar v. Dr Simon Wessely***From correspondence received, dated 4th December 2012 .*

Dear Professor Wessely,



I note from recent correspondence arising from the report in the Independent on Sunday on 25 November 2012, that you believe me as guilty of harassing you. Perhaps it is not surprising that I regard this belief with something less than amusement.

I wonder whether you recall the time when you were just getting your initial research into Gulf War Illnesses off the ground in mid-1998? I had given evidence to the Royal College of Physicians and Royal College of Psychiatrists Inquiry on Low Level Exposure to Organophosphate Sheep Dip which was published in November 1998. Your colleague, Professor Anthony David, was a member of the inquiry. I recall receiving a letter from you both to the effect that you were sorry that I had had reason to criticise your Gulf War research in the course of my evidence when, in fact I had not mentioned Gulf War research. You also asked to meet me. I recall correcting you on the facts and stated that I had no desire to meet you. I then received a number of telephone calls and letters, both to my office and my home, demanding that I meet you. I have to say that I regarded this as harassment at the time, though I did not see the need to contact the police. Eventually I agreed to accept your invitation to lunch at Gordon's Wine Bar behind Charing Cross Station.

I brought with me Ms Emily Green, an eminent scientific journalist, with your agreement. I shall never forget being astounded to find that, when we arrived at the appointed time, 12.30 pm, you had arrived early; bought your own lunch, and presented us with a bottle of water. Prior to the meeting you were very firm about the time, as you had patients to see at 2.00 pm. We discussed a number of topics, including whether you knew Elaine Showalter and whether you had ever advised the Department of Social Security on subjects such as ME. Some of your responses we found were economical with the truth to put it mildly. It was very shortly before 3.00 pm that you finally got to the point – you wanted me to help persuade the Gulf War Veterans to complete your questionnaire!

I think you need to understand that this encounter left a rather enduring and nasty taste in my mouth, not least because I had to buy my own lunch when you had invited me to lunch. Neither was I impressed by your deviousness in response to straightforward questions. This caused me to look more deeply into what you were doing and into your associations, most of which are now public knowledge. This, in part, helps to explain why I have reason to criticise some of your work.

*This crest came with on the mail received. It is used on House of Lords note paper.*



I have also attended some of your lectures and have read reports of others. I have heard and read the extraordinary way in which you and some of your colleagues have denigrated people with ME and have tried (and to some extent succeeded) to persuade others that people with ME are not really ill at all; they merely have 'aberrant illness beliefs'. You have deliberately obfuscated the terminology surrounding ME by linking it with chronic fatigue and attempting surreptitiously to reclassify it as a psychological condition under the WHO ICD classifications.

In doing this you appear to have totally ignored the first exhortation to doctors – "First do no harm". Yet when this beleaguered population has reason to look at your work critically you deny what you have said and written and plead persecution and harassment from the very people you purport to be helping. I would have thought that any thinking person would ask themselves why this is happening; would ask the individuals who are clearly angry what is angering them, and try to put things right. You are in an exalted position – a Professor of Psychiatry with all sorts of awards.

Why on earth do you need to play the victim?

My personal experience with organophosphate poisoning taught me that there are members of the medical profession who are not prepared to “listen to the patient for they will probably tell you the diagnosis”. I am fortunate in that I am articulate and determined and I have been put into a position where I can speak for others less fortunate than I am. If that means offering honest criticism of individuals who, I believe, are hurting others who are not in a position to speak for themselves, I am prepared to take any brickbats that come my way.

So much of the friction comes from people not knowing what you think because you are so inconsistent. For example, in your presentation to the full Board Meeting of the DLAAB on 2 November 1993 which was considering those with ME/CFS you said: “Benefits can often make people worse”, yet in your letter to Dr Mansell Aylward at the DSS you wrote: “CFS sufferers should be entitled to the full range of benefits”. Given that, in 1990 you had written: “A number of patients diagnosed as having myalgic encephalomyelitis ..... were examined .....in many of them, the usual findings of simulated muscle weakness were present” (Recent advances in Clinical Neurology, 1990, pp 85 – 131), I am wondering how a genuine condition can also be simulated and am curious to know what your position is regarding benefits for people with ME. I note that you do not hesitate to condemn statements from your critics as “the same old stuff that they have been saying about me for years”. People with ME could be equally justified in their belief that you perpetuate the beliefs that you have long held that ME is a psychosocial behavioural problem and that you have totally failed to embrace the vast body of peer reviewed scientific literature that demonstrates damage to neurological, cardiac, endocrine and other systems in people with ME. I believe it was you who recommended that GPs should not indulge patients with too many investigations. This has meant that people with conditions that could have been treated have been misdiagnosed and neglected.

I have spoken strongly in defence of people with ME who have been traduced by you and your colleagues who have embraced the psychosocial behavioural model. I am not ashamed of having done so for they have few who will defend them publicly. The scientific evidence is heavily weighted against ME being ‘all in the mind’ so, by deduction it must be the economic argument that prevails, to the disadvantage of the estimated 250,000 people who have ME. have you ever considered the savings to the exchequer and to the insurance industry if people with ME were properly investigated and treated so that they could return to work or education?

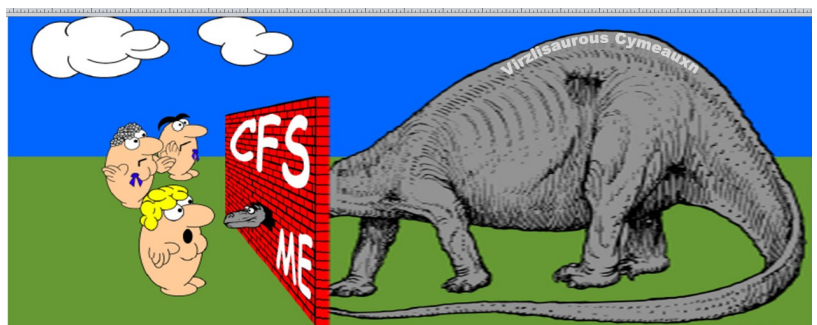
I take no pleasure in asking “bogus” questions and making speeches in the Lords. I would very much sooner your profession got its act together and spent some time studying the real effects of ME on patients and looking for solutions. We all recognise that chronic illness, whatever it may be, presents with psychological aspects. CBT can only be a management tool and GET reportedly does more harm than good for patients with ME/CFS as opposed to chronic fatigue.

Patients must be able to trust doctors and scientists. You have betrayed this trust. A scientist should be able to accept honest criticism. You have misconstrued criticism and turned it into harassment. You have much to answer for, so it ill behoves you to employ diversionary tactics in an attempt to portray yourself as the injured party.

I have written this as an open letter because so much of this debate has been in the open. It would be helpful if you would make your position with regard to people with ME/CFS utterly clear. Do you still believe the ME/CFS is “perpetuated by dysfunctional beliefs and coping behaviours” as you wrote in your 2002 CBT Manual for Therapists? If you do, please will you explain why no one got better with your model. If you do not, would it not be sensible for you to withdraw it instead of continuing to make the facts fit your theories as they appear to have been in the PACE statistics where you were in charge of the Clinical Trial Unit. I look forward to hearing from you.

Yours sincerely

Countess of Mar





**The Reply**

From: Wessely, Simon

Sent: 4th December 2012 17:23 send to: MAR, Countess Subject: your letter

Dear Lady Mar

I received your letter. You state that "I note from recent correspondence arising from the report in the Independent on Sunday on 25 November 2012, that you believe me as guilty of harassing you".

You are referring to the letter published in the Independent on Sunday on Dec 2nd from 25 leading clinicians and academics that was a response to the article of 25th November. I am not an author of that letter, and did not have sight of it before it was sent. I am however informed today by one of the authors that the letter published in the newspaper was not the same as the letter submitted, and that some editorial changes were made. I can see that you might make the inference that you do from the published version, but I am told that was not in the original. I understand that a correction may be requested. It is anyway a little harsh to blame me for a letter that I neither saw nor signed.

I think we will have to differ on our recollections of our lunch engagement over ten years ago. What I am certain about however is that I have never written to you at your home address, and never called you on the telephone. I have no idea where you live, and no record of your phone number. I do however have the letter that I did write to you before the meeting, which are addressed to the House of Lords. If you are interested I am happy to forward a copy, but I think that anyone reading it would conclude that it was written in a polite and respectful manner. If it was otherwise, I doubt that you would have agreed to meet me. I am afraid that I have not the slightest memory of what we ate or drank, nor who picked up the bill – oddly enough I usually have the reputation of being a rather generous host, but if my manners failed me back then, then I apologise.

If we are going over history, then I wonder what you now think of your speeches in the Upper House reported in Hansard 16 April 2002, and 22 Jan 2004. I attach the transcripts to refresh your memory. By now I hope you realize that you were seriously misquoting and misrepresenting me, although I suspect this was on the basis of inaccurate material provided to you by a third party, and that you would not have access to the relevant sources to be able to check for yourself. If you are still in doubt, then you will find many of these highlighted in a statement on my website in which I point out just some of the significant distortions and misrepresentations in the material you were supplied with.

<http://www.simonwessely.com/misund.html>

Some of your language about me in that debate was also distinctly un-parliamentary, and again I suspect was not your voice. I note that Lord Addington speaking after you remarked that that the debate "would make libel lawyers feel like dieters looking in a cake shop window". I wonder if you in turn regret some of what you said that day, looking back in time as we are.

Yours sincerely

Professor Simon Wessely,  
Vice Dean, Institute of Psychiatry  
Head, Department of Psychological Medicine,  
Director, King's Centre for Military Health Research  
King's College London



*According to his website he is a clinical academic at King's College London. He is the Professor of Psychological Medicine there and Vice Dean at the Institute of Psychiatry, which is a School within King's. He is a Consultant Psychiatrist at King's College Hospital and the Maudsley Hospital.*

## The Reply to the Reply

From: MAR, Countess,  
Sent: 05 December 2012 18:40,  
To: 'Wessely, Simon',  
Subject: RE: your letter

Dear Professor Wessely

Thank you for replying to my letter of December 2012.

I found your response unsatisfactory in that you chose not to answer my questions and instead made derogatory comments about me, about which I will simply say that I am sorry your long-term memory is so selective. However, I can tell you that regarding the letter in the Independent on Sunday signed by 27 of your colleagues, I have received a very gracious apology from Professor White for any inference that may be drawn from it, which I have accepted.

I have no wish to enter into an unproductive and personalised correspondence with you because the issue of how people with ME are treated is far too important to be side-tracked by such diversions.

Instead I will ask you again: the data from the FINE and PACE trials strongly suggest that the psychosocial model of ME/CFS, which you first proposed, **is wrong**. These were large trials involving several hundred people and which cost the UK taxpayer several million pounds. In the light of these results, do you still believe that ME/CFS is “perpetuated predominantly by dysfunctional beliefs and coping behaviours”?

If not, do you not have a duty to say this clearly, in plain language, so that other, more productive lines of research can be pursued?

When data suggest a model is wrong it must either be amended or discarded and the data is clear, so what is your intention? The harm that may result from pursuing wrong ideas in medicine cannot be overstated.

In your reply you ask if I regret some of the things I said about you. I have seen and heard nothing that alters what I said in my speech of 16 April 2002 and anything I might have said on the subject subsequently.

What I said does not hold a candle to the scorn and derision that you have poured on people with ME and on the doctors who do not subscribe to the psychosocial model.

Yours sincerely,

Mar



*Margaret of Mar, 31st Countess of Mar and 24th Lady Garioch (born 19 September 1940) is a crossbench member of the House of Lords, an elected hereditary peer, and the holder of the original Earldom of Mar, the oldest peerage title in the United Kingdom. She is a farmer and specialist cheese maker in Worcestershire. She is the only 'suo jure' (in her own right) Countess in the House of Lords.*

### Please Note

As far as we can tell, each piece of correspondence is that of the author. *Pathways'* editorial policy is always to give balanced content so that *Pathways* readers can decide for themselves about an issue. Normally we wouldn't print anything of this sort or this type of dialogue but we think members will be very interested to read this.

**WATCH THIS SPACE!**

**19/12/12**

**Editors Note:**

*After the this edition was published compiled, the debate continued and there were many postings on this topic around the web forums.*

See [www.meactionuk.org.uk](http://www.meactionuk.org.uk) and [www.meassociation.org.uk/](http://www.meassociation.org.uk/)

*Pathways found the most recent update that pathways found was on:*

<http://www.meactionuk.org.uk/Mar-Wessely-correspondence-update-171212.pd>