



# 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.



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## Dr. Sarah Myhill appears before the General Medical Council (from BBC Wales)

Dr Myhill has been banned from prescribing POM drugs and told to take down part of her website after appearing before the General Medical Council. She will have to comply with the order for 18 months after two complaints were made against her—or else. Her supporters were outside the hearing in London and claimed she was the victim of a witch-hunt. There have been complaints against her on seven occasions since 2001, but this the first time Dr Myhill has appeared before a General Medical Council (GMC) panel. See page 6



**Moving Goalposts: The DWP plan to make ESA even harder to get see. See page 3**



**What is the future for claimants under coalition rule? See page 2**



**Recipe Corner**

**Asparagus and Pea Risotto See page 18**

## ***What future for claimants under coalition rule?*** ***(From Benefits and Work)***

Iain Duncan Smith (IDS), a former conservative party leader, has become the new Secretary of State for Work and Pensions. How will things change for sick and disabled claimants as a result? To get a clearer picture of how IDS views the benefits system, we've read the introduction – written by IDS himself – and the 20 page executive summary from a recent report entitled '*Dynamic Benefits: Towards welfare that works*'. We found some positive aspects to the report, but also some very negative ones.



*Iain Duncan Smith is Member of Parliament for Chingford and Woodford Green*

### **Possibly plus**

- IDS accepts that the current benefits system is irretrievably broken due to its sheer complexity. He probably has the personal will to dismantle it and start again.
- IDS believes that the very high proportion of benefits that are clawed back from claimants who start work is a massive disincentive and that claimants should be allowed to keep a much larger slice of their benefits when they enter employment.
- He believes that the current system unfairly penalises claimants who wish to live in a relationship with someone else rather than living alone.

### **Undoubtedly minus**

The report has a great deal to say about work and the importance of moving people into work, but very little to say about people who are unable to work because of a health condition or disability. IDS wants to see a very much simpler benefits system involving a Universal Credit Scheme with two components which would replace all current benefits. This would, however, involve doing away with Disability Living Allowance and replacing it with a means-tested award. The two components would be:

- **Universal Work Credit** – for those out of work and those on very low wages. This would combine Jobseekers Allowance, Income Support, Incapacity Benefit and Employment and Support Allowance.
- **Universal Life Credit** – which would cover 'additional living expenses' for those on low incomes. This would combine Housing Benefit, Council Tax Benefit, Disability Living Allowance, Working Tax Credit and Child Tax Credit.

The chair of the group that produced the report is the head of a multinational management consultancy firm. Other leading figures include the Wealth Director of Lloyds Bank, a private equity-backed businessman and the Senior Policy Director at the Institute of Directors—not necessarily the kind of people that most sick and disabled claimants would choose to decide their financial fate.

**Immediate future:** Whilst IDS' enthusiasm for the abolition of DLA will be a real concern for many people, any such plan will be a long-term one, possibly not even achievable within a single parliament. For most claimants, what will matter in the shorter term is the view that IDS takes of DWP proposals for issues such as making the medical test for Employment and Support Allowance much harder to pass. The plan was approved by the outgoing Secretary of State, Yvette Cooper, but will go nowhere unless IDS also endorses it. If pushing many thousands more sick and disabled people onto Job Seekers' Allowance does receive ministerial approval, claimants will have a very clear idea of what the coming months or years of coalition rule have in store for them.

### **Latest ESA figures**

*Long delays and high failure rates 29 April 2010*

Recent DWP statistic on how many people are getting awards of Employment and Support Allowance. An average of over 50,000 people a month are applying for ESA. Of these, around 20,000 close their claim before being medically assessed, many because they had a short-term condition which has improved. Of those who complete the assessment, an average of 9% per month are placed in the support group whilst 23% go into the work-related activity group. Around 68% of all those who are assessed are found to be capable of work. The percentage of claimants who app

real a decision that they are capable of work is uncertain because the DWP only lists appeals that have actually been heard, rather than including those lodged but not yet decided. But it appears that between one in three and one in four people found capable of work are challenging the decision via an appeal. The success rate for these appeals is currently running at 39% or almost one in four. The figures for assessments still in progress only cover claims made to August of 2009. These show that more than one in ten people who made a claim for ESA last August are still waiting for a decision, five months after their three month assessment phase should have ended. So, the overall picture is one of a stable, but very low, number of claimants being placed in the work-related activity group and the support group and an appeal success rate that has also remained stable at around four out of ten. The backlog of people whose claim is not dealt with in the supposed 13 week assessment phase is clearly growing ever larger.



## Even harsher new ESA medical approved from.

**Benefits and Work**  
Guides you can trust

Many claimants face losing their benefit on review or on being transferred from Incapacity Benefit, as plans to make the employment and support allowance (ESA) medical much harder to pass were approved by the then Secretary of State for Work and Pensions, Yvette Cooper. Ian Duncan Smith followed on.



The plans for 'simplifying' the Work Capability Assessment, drawn up by a DWP working group, include docking points from amputees who can lift and carry with their stumps. Claimants with speech problems who can write a sign saying, for example, 'The office is on fire!' will score no points for speech and deaf claimants who can read the sign will lose all their points for hearing. Meanwhile, for 'health and safety reasons' all points scored for problems with bending and kneeling are to be abolished and claimants who have difficulty walking can be assessed using imaginary wheelchairs. Claimants who have difficulty standing for any length of time will, under the plans, also have to show they have equal difficulty sitting, and vice versa, in order to score any points. And no matter how bad their problems with standing and sitting, they will not score enough points to be awarded ESA. In addition, almost half of the 41 mental health descriptors for which points can be scored are being removed from the new 'simpler' test, greatly reducing the chances of being found incapable of work due to such things as poor memory, confusion, depression and anxiety.

There are some improvements to the test under the plans, including exemptions for people likely to be starting chemotherapy and more mental health grounds for being admitted to the support group. But the changes are overwhelmingly pushing about tens of thousands more people onto JSA. They have not yet been passed into law, but given that the Conservatives seem intent on driving as many people as possible off incapacity related benefits, they are likely to be pursued by the new coalition Government. Many people will find this news deeply upsetting and even frightening and we know that some people will condemn us for publicising the planned changes, but the original changes proposed by the working group were even harsher. It was only after their proposals were looked at by the Chief Medical Adviser at the DWP, following complaints by disability group representatives that some were toned down and additional points attached to some descriptors.

For example, the activity of walking has been replaced by the activity of 'mobilising', with the fifteen points for 'Cannot walk at all' to be removed. Instead of looking at how far you can walk with a walking stick or other aid if such aid is normally used, the test is now 'Mobilising with or without a walking stick, manual wheelchair or other aid if such aid can reasonably be used. In other words, even if you don't use a wheelchair you can be assessed as if you did – an intention which is made clear in the body of the report. To score fifteen points you will need to show that you could neither walk nor wheel a wheelchair 50 metre without stopping in order to avoid significant discomfort or exhaustion. If you cannot do so repeatedly 'within a reasonable timescale' you will also score fifteen points. Nine points are scored for 100 metres and 6 for 200 metres. This means that many people who get the higher rate of the mobility component of DLA may not be awarded ESA at all. Even the fifteen points for being unable to walk up and down two steps is to be cut to nine points. Gone are descriptors for Dealing with other people, Bending or kneeling, (Deleted for 'health and safety reasons'), Memory and concentration, Execution of tasks. How do you deal with it? If you have mild (grade 1) ME/CFS, your are capable of working part time, For moderate and high grades a guidance table is provided overleaf. There is also an ESA 2 draft tool added to the Leger ME website to explain how it works. *If you get an ESA 50 or*

**ESA v2 Draft Tool**

Points: Physical  Points: Mental  Pass(P)

Descriptor	Points
1) Mobilising	Cannot mobilise more than 50 metres on level ground without repeatedly stopping or experiencing severe discomfort
2) Standing and sitting	Cannot mount or descend two steps even with the support of a handrail
3) Reaching	Cannot mobilise more than 100 metres on level ground without stopping or experiencing severe discomfort
4) Picking up	Cannot mobilise more than 200 metres on level ground without stopping or experiencing severe discomfort

*DLA1a from please get the help of a Welfare Rights Advisor. Filling in the form without is the quickest way to get a refusal.*

<u><b>OLD ESA</b></u>	<u><b>ME/CFS issues</b></u>	<u><b>NEW ESA 2</b></u>	<u><b>Grade 2</b></u>	<u><b>Grade 3</b></u>	<u><b>Grade 4</b></u>
<b>1) Walking.</b>	Pain, dizziness tremor, rebound, cognitive, confusion.	<b>Mobilising</b> (stick, manual wheelchair)	<200 metres (6) <100 metres (9)	<50 metres (15)	<50 metres (15) (with no steps)
<b>2) Standing &amp; sitting.</b>	Pain, dizziness stiffness discomfort. muscular weakness	<b>Standing and sitting</b>	Cant remain at workstation >60 minutes (6)	Cant remain at workstation >30 minutes (9)	Can't move between seats (15)
<b>3) Reaching.</b>	Pain, muscle weakness, limited movements, involuntary jerks, POTS	<b>Reaching.</b> Cant raise arm above...		head to put on hat (9) Reach for something (6)	above top pocket (15)
<b>4) Picking up</b>	Clumsiness, manual dexterity, weakness tremor, fasciculation, myoclonus	<b>Picking up</b>	Light bulky object (6)	Litre liquid(9)	Pint liquid (15)
<b>5) Manual dexterity.</b>	Clumsiness, manual dexterity, weakness tremor, fasciculation, myoclonus	<b>Manual dexterity</b>	Pour 1 pint or pickup coin 1 hand (6)	Keyboard. mouse or buttons.(9)	Cannot press button or turn pages of book (15) Cannot Write (15)
<b>6) Speech.</b>	Pausing mid-sentence, forgetting or can't find right word, talk out of context	<b>'Communications out</b> Making self understood through speaking, writing, typing	Simple message: Stranger some difficulty (6)	Simple message: Strangers great difficulty (9)	Can't communicate simple message 150
<b>7) Hearing.</b>	Hyperacusis, competing noise, concentration	<b>Communication In</b> Verbal, lip reading, reading (16 point print)		Some difficulty by a stranger (6)	Great Difficult by a stranger (9) Can't understand fire escape is (15)
<b>8) Vision.</b>	Photophobia, eyes fatigue quickly.	<b>Navigation</b> Sensory impairment	Can't navigate without being accompanied (6)	Cannot cross road safely without supervision (9)	Unable to navigate with help (15)
<b>9) Continence</b>	Leaking, wearing pads IBS	<b>Continence</b> (requires the individual to clean themselves and change clothing)	May get caught short if unable to reach toilet quickly (6)	At least once a month need to change (9)	At least once a week need to change (15)
<b>10) Remaining conscious</b>	Drowsy in a morning. sleep during day. Absences	<b>Consciousness</b>	>1 month disruptive awareness of concentration(6)	>1 weekly disruption awareness of concentration (15)	>1 weekly disruption awareness of concentration (5)
<b>11) Learning</b>	Attention-span limited Confusion, without awareness, aphasia	<b>Learning Tasks</b>		Can't learn to operate washing machine (9)	Cant deal with alarm clock (15)
<b>12) Awareness of hazard.</b>	Concentration-span limited. Inappropriate automaton action Memory	<b>Awareness of hazard.</b> (Reduced awareness)	supervision always needed(6)	Reduced awareness supervision always needed (9)	Not able to do things safely (15)
<b>13) Initiating and sustaining personal action.</b>	Fatigue limits ability to complete tasks. Maybe activity window Fatigue issue. Many avoid activities. EMS	<b>Initiating &amp; sustaining personal action.</b>	Cannot complete 2 sequential actions (6)	Cannot complete 2 sequential actions (15)	Cannot complete 2 sequential actions (15)
<b>14) Coping with routine change.</b>	EMS. Not easy to learn new behaviours, disruptions	<b>Coping with routine change.</b>	Cannot cope with unplanned changes (6)	Cannot cope with minor planned changes (9)	Cannot manage coping with change (15)
<b>15) Getting about.</b>	Anxiety, dizziness, fatigue if driven	<b>Getting about</b>	Frequently supervision required (6)	Supervision mostly (9)	Cannot get to a familiar place (15)
<b>16) Coping with social situations.</b>	Fatigue, pacing strategies don't address, Anxiety, phobia.	<b>Coping with social engagement'</b>		Mostly (9)	Precluded (15)
<b>17) Behaviour with other people.*</b>	Usually depressive, and phobic. Tends to be irritated. Anxiety, poor self-confidence, aphasia, distress	<b>Appropriateness of behaviour with other people</b>		Over-reacts (6)	Over-reacts (15)

## You Write

**Janet Writes:** Just wondered if you could give me any general advice? My husband Nick has had severe M.E. since at least Jan 2006 (was ill before this). For the last 2+ years, he has received DLA, higher rate for mobility, middle rate for personal care. We recently had to reapply for him and I filled out the full form (heeding everyone's warnings), not the shortened version. He has actually got worse since he was originally awarded the benefit, but to my utter amazement and bewilderment they have now refused him the benefit this time. I made it very clear he was worse, new symptoms and health problems have appeared, but they seem to be ignoring this. I can't understand how they could have awarded it before, but now declined despite the fact that he has deteriorated further.

Because I appealed their decision, a couple of weeks ago they sent out a local GP to see my husband to write a report and make his recommendations. He was totally unsympathetic, asked very specific and narrow questions, and didn't allow Nigel to explain symptoms, how they affected him, capabilities. The GP basically told the DWP that there wasn't much wrong with him and that he could do pretty much everything, which is nonsense. On the day of the appointment, my husband felt totally unable to cope mentally (his cognitive problems can be severe) and so I tried to explain various aspects of my husband's disability and condition to the GP but he would not allow me to say anything and kept cutting me off. I was so frustrated I cried when he left.

Since my husband has been retired from work permanently and told that he will never work again because of his disability and condition, we rely heavily on receipt of this benefit. We now have to go through a full appeals process and to a tribunal. The paperwork arrived today. The DWP have sent us a wedge of stuff several inches thick. I feel absolutely overwhelmed by the prospect: I don't know how I should reply, what happens next or how this process works. Do you have any tips? Any guidance or information would be greatly appreciated.

*The first thing to do is review all the papers used in reaching their decision from the DWP, and then hold an inquest with someone independent. I think your first mistake was the form filled out by yourself, and not seeking expert help from a welfare rights service. The next thing was possibly a report from your GP, a DBD370 which does not usually ask the sort of right questions in the first place about ME/CFS. Contributing to this often is that the GP has not been consulted on a frequent basis. The independent GP is known as an EMP. The DLA 140a form the EMP has to fill out does not allow reporting of fatigue-related issues. It sounds like you are in line for a tribunal should you pursue the case further.*

*Firstly, the 'defence' arguments used are generally along the lines that no attempt has been made to fairly assess the fatigue using standard scales or methods of reporting. Secondly, there are legal criteria used to argue ME/CFS which are known as the Case Law Commissioners' Decisions (Jacobs and Higgs), and these are conveniently ignored and usually not brought into consideration until a tribunal is due. It usually takes at least a paralegal or someone who is very good and knows the system inside out to argue this. Usually you need your own private medical reports and this can run into hundreds of pounds. Unless you have access to a solicitor/legal aid or a good welfare rights service or plenty of money, you are really wasting your time. Not attending a tribunal is a waste of time, and all claimants can expect to be questioned Perry Mason style.*

*Before you even submit a DLA form, you have to lay out a foundation, which includes a doctor or consultant or OT being aware of your intentions and understanding all the aspects of the case. You also need a record of treatment e.g. from a NHS ME/CFS clinic or pain control clinic. When I see Leger ME members, part of the workup is establishing a record and backup evidence should the first application fail. This depends on each individual case. There is no guaranteed way to establish success. After 18 years dealing with group members, I find it very difficult to predict the outcome of a DLA application, but when a refusal happens one or more of the above things is present. While I'm happy to exchange hints & tips, I only deal with welfare rights issues for the Leger ME Group members. Even then, LME does not have the resources to pursue cases, and as far as possible these are signposted on to other organisations within our area that get paid to do the job.*

**Janet Writes:** I have recently been turned down when I applied for a blue badge to Doncaster Council. I have been diagnosed with CFS for several years and experience a variety of restrictions on my life, dependent on how I am feeling from day to day.

I have learnt to manage my condition and have been able to continue in full time employment as a nursing lecturer. In fairness this is due in full to the support that I have been given by my employers. I have a parking permit for work, specialist office equipment and a mobility scooter, part funded by the government Access to Work Scheme. I can also be flexible in my work hours and work from home if needed. Whilst this helps when I am on the works site, I also have to visit clients on placement or attend meetings off site. I have found this a real struggle of late and have missed several important appointments as I could not find anywhere to park that was in a distance that I could manage to walk on the day. To some extent this is a problem as my level of ability/disability varies each day.

I am finding this extremely frustrating as I have been informed that if I apply for DLA I may be able to ask for the highest awarded payment and subsequently be given a Blue Badge. I do not want to apply for any benefits as I earn a good wage BUT I do want to be able to continue to work productively, contribute to society and maintain my hard-fought-for independence. I feel that because I continue to fight to overcome this condition (and it would be very easy to give in most days) that I am disadvantaged. I do intend to appeal and have read on some ME web sites that councils often turn down an application from people with ME at first. So my HELP question is - Is this DMBC's usual standpoint and is there anyone specific that I could contact regarding this?

*Like many enquiries I receive, I think that there is more to this than a blue badge issue. Firstly, a blue badge can be awarded by DMBC on a discretionary basis. This is dependent on a favourable report from your GP to DMBC. Is he aware of your situation? Areas vary, e.g. Sheffield requires an OT examination. Secondly if you have high rate mobility DLA, you are legally entitled to a blue badge. DLA is a non contributory benefit and depending on your personal circumstances, you can work and still receive DLA. We have one member in this position. Applications have to be very carefully presented in these circumstances, and you certainly will need the help of a welfare rights expert. DLA is short term only, it is not guaranteed to continue.*

*You sound very positive, but you have to think money. With my experience, I just wonder what the sustainability of work situation is within the long term, and how it will affect your finances. While I see home working as a coping strategy, there may be problems with this in the future. Many firms are looking at reducing their workforce; with your disabilities you could be a candidate for a golden handshake. If you have a final salary pension, reducing the work hours to part time may drastically reduce your pension and in some circumstances early retirement, if possible, would give you a bigger pension payment. One thing I would do in your position is not to tell work any more than you need to, and work to contract, taking on no more than you need to do. You need to be seen to be having some sort of active medical treatment. As you are not getting any younger, it is unlikely that you will work to retirement age with ME, so you need an exit strategy. It goes without saying that you need to consolidate your finances, and not take on any new big financial commitment like mortgages or new cars. Have you discussed this with your Union?*

**Ross Writes** did you know that 'slowly, slowly catchee monkey' comes from the days of British Indian colonialism when many far eastern countries were under British rule. Soldiers posted there used to try to catch monkeys to keep as pets and bring home, but despite all their efforts, they were not very successful. Many natives spoke 'Pidgin English' which was a simplified form of English. They showed the soldiers how to do it by demonstrating a simple but effective method. They would place a basket containing fruit in a clearing in the jungle where the monkeys lived. The basket would have a narrow opening and be tied to the ground. Monkeys would come along and stick their arms inside the basket to get at the fruit. The opening was just wide enough to allow for this but as the fruit was grasped the, fist was too big to get out of the basket. The monkeys were so greedy that even when soldiers approached, they would not release the fruit and thus be easily caught. Naturally this took patience on the part of the captor who would have to wait quietly until the monkey was caught. Thus the slow approach proved to be more effective hence the phrase. This is now used to describe that a slow and patient approach to a problem with careful thought is often better than rushing in.



## **Commonly Asked questions on Information & Communications Technology**

*(From Doncaster CVS Info no 2.)*

### **Why is my computer running slowly?**

If your computer starts running slowly, or takes a long time to start up, it probably needs some attention. You may be able to do quite a lot yourself, or may need to ask for technical help. There are a number of things you could try:

- Reduce the number of applications running in the background.
- Add more RAM (memory). It's cheap to buy and you may be able to install it yourself.
- Run anti-virus software to remove viruses or spyware.
- Run de-fragmenting software to tidy up your files on your hard disk
- Consider replacing the computer.



### **How often should I scan my computer?**

Anti-virus software works by comparing individual files with a list of known viruses. The list is usually updated at least every day by connecting to an online database which monitors the latest threats. You should scan all your files at least weekly as part of your housekeeping routine. Most software checks every file you download from the net before you open it and every email attachment before allowing it into your inbox. It can also run a check on every file you open whenever you open it, to make sure it is using the latest list of known threats. You may also set anti-virus software to check on every file on the computer every time you start up. Although this guarantees safety it is not vital and can slow down your computer.

### **How can I stop viruses attacking my computer?**

It is almost impossible to stop viruses attacking your computer so you must make sure you are able to deal with them. Viruses may be attached to email, downloaded when you're surfing the web or copied from a CD or memory stick. You can't stop them from attacking your computer, but you can stop them from harming it by installing and maintaining anti-virus software and keeping your software up to date. There is a lot of anti-virus software available, some of it free. Look online for recommendations, ask colleagues or refer to a trusted ICT supplier. Once installed on your computer the software links to an online database or known viruses. It scans the files on your computer and deletes any viruses it finds. You can set it to scan every email, or check the whole computer once a day. Your system software, such as Windows XP or Mac OSX must also be kept up-to-date to protect against the latest security threats.

### **Why do IT people tell me to turn off and turn on again?**

It's a well-worn phrase, but does it really work? Before calling for help turn your machine off for 30 seconds and then restart. This may well resolve the issue you were having because closing down your computer shuts all running services and processes, whilst starting up restarts these services and process in the right order. This may help untangle problems in the way the computer is working internally and unblock processes that were causing problems. It isn't guaranteed to work but if you then need to call for technical support you can inform the technician you have rebooted your system. They will then know that they have a 'clean' machine to start the process of diagnosing your problems. You need to shut the computer down completely, rather than just clicking on Restart while the computer is still running. Shutting down takes longer, but is much more effective at clearing temporary problems. Similarly if your Internet connection fails then rebooting the router can often bring things back to life, but remember that it takes several minutes to reset itself so be patient.

## Private Powys GP banned from prescribing drugs by GMC

(From the BBC Wales website)

Dr Myhill, a specialist private practice doctor in Powys has been banned from prescribing drugs and told to take down part of her website after appearing before the General Medical Council. She will have to comply with the order for 18 months after two complaints were made against her. She has a private practice near Knighton, Powys, where she specialises in treating Chronic Fatigue Syndrome. Her supporters were outside the hearing in London and claimed she was the victim of a witch-hunt. There have been complaints against her on seven occasions since 2001, but this the first time Dr Myhill has appeared before a General Medical Council (GMC) panel. Before the hearing, she said that she could not understand why complaints against her were being heard. But the chair of the GMC panel said there were serious concerns about the potential risk to patients and her fitness to practice would continue to be reviewed.



One of the complaints was on the content of Dr Myhill's website, which warned patients against oral contraceptives, the MMR triple vaccine as well as mammogram tests and biopsies for cancer. But Dr Myhill says she tries to find the causes of a disease, rather than treating the symptoms with drugs. Patricia Chell and her husband John say she (Patricia) owes her life to the work of Dr Sarah Myhill. The GMC considered whether there might be "impairment of Dr Myhill's fitness to practise which poses a real risk to members of the public or may adversely affect the public interests or Dr Myhill's own interests". But her supporters say no patient has ever complained about her.

Dr Myhill runs a website which gives information on allergies and hormones, and advocates what she calls a "stone age diet" for people suffering from Myalgic Encephalomyelitis (ME) and other complaints including chemical sensitivity. She treats people from across the UK. However it is the website which has prompted the latest complaints against Dr Myhill. She said in a statement on her website that a group of doctors have complained about her recommending a B12 vitamin injection to a patient. A second complainant said the information on her website was "very worrying" and was concerned "patients are being seriously misled". Supporters of Dr Myhill protested outside the hearing in London. Dr Myhill has already faced six GMC hearings since 2001 following allegations from other doctors. She told BBC Wales: "I think there's a small group of doctors who perceive me as a threat to their professional integrity in some way and it is certainly not my desire to in any way threaten them."

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**Dr Sarah Myhill at Demo**  
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TheOneClickGroup — 29 April 2010 — Dr Sarah Myhill giving her speech at the Demo outside the General Medical Council Offices in London 2,428 views

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Les Miserables - Do You Hear the People Sing? (... 617,239 views dharods 1:49  
Air Travel Can Damage Your Health MASSIVE COVER... 444 views 76CellarDoor 6:02  
Sarah Myhill Interview.mov 168 views doubledmedocs

"My motive is purely to help the patient to get well in as safe a way as is possible." Patricia Chell has been travelling back and forth from Shropshire for three years to receive treatment, and says her health has improved dramatically since being prescribed magnesium by Dr Myhill. "I think it's dreadful, and in fact if she's suspended, my life's at stake - literally. "Without this magnesium, I should eventually get heart failure again."



**Supporting Sarah** (by Elizabeth Mc Donagh, Leger ME).

1.30 p.m. 29<sup>th</sup> April 2010. I am one of over a hundred patients and supporters of Dr Sarah Myhill who is today before the General Medical Council as to her fitness to practise as a Doctor of Medicine. We are assembled, with our placards, outside the London office of the GMC, 350 Euston Road, NW1 3JN.

I am told by a be-suited gentleman that I must move off GMC land i.e. the pavement in front of the GMC office. He, with three officious and uncomfortable-looking colleagues is in charge of GMC security. Three police-people, benign in the face of some clearly sick folks in wheelchairs, stand around in case of conflict.

"They" try to squeeze us into a small enclosure formed of tubular metal barriers – but they haven't counted on so many protestors and it is clearly impossible – indeed perhaps dangerous – to insist that we remain inside the corral. Some of us, including myself, remain outside. We hold up our banners. Mine says simply "Good Doctor Sarah". Others say "I owe my life to Dr Myhill"; "We need Dr Myhill". One shows pictures of three young women who have died because of ME. Folks from Dr Myhill's village unfurl a Welsh flag. A prominent banner is that of the Aerotoxic Association. As the traffic rolls incessantly down Euston Road, there are many curious stares from passer-by. Sarah greets us and introduces us to Ruth, her daughter who has organised the demo.

I have never been a patient of Dr Myhill's but as a recovered former 'person with ME' I've been involved in charities and support groups for ME for almost twenty years and with the NHS ME/CFS clinic in Sheffield since its inception. I have long been aware of Dr Myhill's work, first with farmers suffering from organophosphate poisoning after dipping their sheep and later with ME/CFS patients, Gulf War veterans and other victims of chemical poisoning.

The chasm between Sarah Myhill's understanding of these illnesses and the attitude of the GMC is huge and is a political issue rather than a medical one. Chronic illness through chemical poisoning is scarcely recognised by the Government or the medical establishment. Many, perhaps most, doctors believe that ME/CFS is psychosomatic, the result of a faulty belief system on the part of the patient, and that Cognitive Behavioural Therapy is the only treatment of value. Patients suffer as a result.

The GMC's verdict is expected at 1.15. We wait and wait. Ruth gives a touching little speech about her mother's dedication to nutrition and to her patients. Sarah gives a defiant speech. She says the GMC has no evidence against her. No patient has complained and no patient has been harmed. An anonymous complaint was made to the GMC and we now know who made it because he boasted of same on his own website, calling Sarah an 'Uber-quack'. The complainant writes regularly for *'The Guardian'* – a paper I will never buy again.

Sarah is accompanied by cheers as she claims that "ME patients have been left to rot on the medical vine" She had hoped for a minute's silence to remember our dead but the traffic noise made that impossible. Instead we were led in a rendering of 'Do you hear the people sing?' from *Les Miserables*. We wait and wait and wait. There are rumours that the GMC is waiting for the press to leave. We wait some more.

I talk to a hypothyroid lady who blames bromine for her condition and to the wife of a fireman who has suffered for 30 years from toxic fumes to which he was exposed at work but who has had no compensation and is, as we speak, seeing a psychologist. Another lady tells me that she has worked in aircraft cabins for twenty years and she believes her ME has come about because there are organophosphates in aircraft fuel which contaminate the air within aeroplanes.



At approximately 4 o'clock (we have waited two and a half hours), size 10 Sarah, in a move worthy of a circus performer, balances precariously on a tubular steel barrier to inform us of the verdict. She has not been struck off the Medical Register but severe restrictions have been put on her practice. She will not be allowed to prescribe pharmaceutical drugs and must remove

certain pages from her website as the GMC considers that they could potentially endanger patient safety.

Ruth is near to tears but Sarah is still in fighting spirit. She vows to appeal against what she describes as the 'irrational, illogical and disproportionate' ruling. We hang around discussing the news, comforting Ruth, promising Sarah we will continue to support her. People express their disgust, dissatisfaction and anger towards the GMC whom they perceive to ignore the

views and needs of patients in their determination to discredit a cohort of excellent and caring physicians who use naturopathic detoxification and nutritional treatments to successfully treat patients who have had little or no help from the NHS.

Options are considered. People pledge themselves to join Sarah's 'silent army' (those too ill to come to London who none-the-less support her). They vow to send messages to the GMC, write to the papers, and inform Members of Parliament. The GMC security men look on disconsolately hoping we will soon allow them to go home. And eventually, with trains and coaches to catch, we do. A website has been set up to support Dr Myhill and one can register to receive news bulletins on the issue.

<http://tinyurl.com/2vcvpr8>. Sarah's speech at the demo go to <http://tinyurl.com/2ukygdgm>





## Pathways Comment

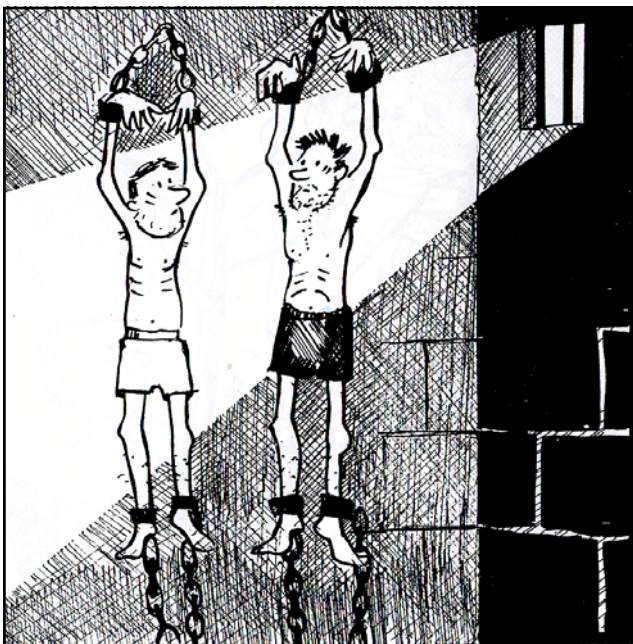
There seems to be some difficulty for the normal 'man in the street' in understanding the reasons behind the GMC's action. As far as I can see, the argument is based on a potentially perceived threat seen by the doctor 'policing' side of the General Medical Council. There is a type of thinking here from the GMC is difficult for anyone not familiar with professional world to understand. In order to illustrate the way things could happen, let's take a fictional example.

Suppose there was a village called Belton, with two doctors' practices, Dr. Smith and Dr. Jones. Belton is built on the side of a hill, and halfway up the hill there is a railway line which splits the village in two, with the high street connecting the two parts going under a railway bridge. Locals call the two parts 'top end' and 'bottom end'. Dr. Smith's surgery is in the top end and Dr. Jones in the bottom end. A local organisation decides to hold a baby show, and advertise the judge to be 'Dr. Smith, The Top End Doctor' in a poster. Someone brings the poster in to Dr. Jones surgery, and Dr. Jones complains that the poster implies that Dr. Smith is better than himself at the bottom end. That's when the arguments start.



There are specific rules about how doctors behave and practice to avoid upstaging, as all doctors are supposed to be equal. If for example Dr. Smith had called his practice by the name of Upper Belton Medical practice a similar sort of argument would start. The same applies to solicitors, dentists, vets, banks. etc. Each professional has its own rules and code of ethics. Breaking these is regarded as a serious professional offence, and will often result in the professional body taking action because *"There is a potential risk to public safety"* because professionals are not supposed to argue or imply one is better than the other, bringing the profession into disrepute. Similar action can happen for example if a doctor is found guilty of a minor criminal offence, for example a speeding ticket, or travelling on a train without buying a ticket.

With the B12 issue, I just wonder if the GMC is fully aware that it is used in the same context by many other doctors. Regarding immunisation or vaccination; many cases of ME have been caused by vaccination. Along with vascular disease and statins they do cause more than their fair share of problems with ME /CFS patients. If Sarah is guilty of anything it is being open and honest, and



THE WOMAN ON THE ASSERTION COURSE SAID IT WOULDN'T DO ANY HARM TO ASK FOR A SECOND OPINION.

publically airing her views and allowing herself to be criticised. The GMC have so far steered clear of ME/CFS issues, and are really having a go at side issues. Sarah has placed herself in a vulnerable position in the way she practices, being a private GP, and is her own boss with no moderation.

If she worked in a normal practice with other doctors, there would be some degree of check and balance. The next layer up would be the NHS or employers, and again there would be a further degree of check and balances, and finally the GMC. As she stands, the GMC is the 'supervisor' and provider of professional guidance and supervision to Sarah. Looking at her previous run-ins with the GMC, I don't think that this will be the last. What does concern me, it that this *'is the thin end of the wedge'*, and what about the thirty or so other doctors that practice in a similar way?

I do wonder as well, about the GMC's fitness to regulate. They didn't detect Harold Shipman. They allow foreign locum doctors to practise who are not conversant with the U.K.'s language or system. Who regulates the GMC?



**Good Medical Practice and the duties of a doctor.** (From the GMC website).

To practise as a doctor in the UK, a person must, by law, be registered with the General Medical Council. The GMC is a licensing organisation, a bit like the DVLC for drivers. Patients must be able to trust doctors with their lives and health. A doctor is personally accountable for their professional practice and must always be prepared to justify their decisions and actions. To justify that trust a doctor must show respect for human life and a doctor must:

- Make the care of his patient his first concern.
  - Protect and promote the health of patients and the public.
  - Provide a good standard of practice and care.
  - Keep his professional knowledge and skills up to date.
  - Recognise and work within the limits of his competence.
  - Work with colleagues in ways that best serve patients' interests.
- 
- Treat patients as individuals and respect their dignity.
  - Treat patients politely and considerately.
  - Respect patients' right to confidentiality.
- 
- Work in partnership with patients.
  - Listen to patients and respond to their concerns and preferences.
  - Give patients the information they want or need in a way they can understand.
  - Respect a patients' right to reach decisions with him about their treatment and care.
  - Support patients in caring for themselves to improve and maintain their health.
- 
- Be honest and open and act with integrity.
  - Act without delay, if he has good reason to believe that he or a colleague may be putting patients at risk.
  - Never discriminate unfairly against patients or colleagues.
  - Never abuse his patients' trust in him or the public's trust in the profession.

**Handling Complaints & Fitness to Practise.**

The Fitness to Practise Panel hearing is the final stage of the complaint procedure when a complaint is substantiated against a doctor. The Fitness to Practise Panel hears evidence and decides whether a doctor's fitness to practise is impaired in other words *are they fit to be a doctor?* The Fitness to Practise Panel meets in public, except when considering evidence relating to a doctor's health. It is a sort of trial, and the setting is similar to that of a court of law. There is legal representation for the defence and prosecution. If a panel concludes that the doctor's fitness to practise is not impaired, it may decide to issue a warning to the doctor. However, if the Panel concludes that a doctor's fitness to practise is impaired it may:

- take no action
- accept undertakings offered by the doctor provided the panel is satisfied that such undertakings protect patients and the wider public interest
- place conditions on the doctor's registration - so that they are only allowed to do medical work under supervision, or so that they are restricted to certain areas of practice
- suspend the doctor's registration - so that they cannot practise during the suspension period
- Erase the doctor's name from the Medical Register, so that they can no longer practise or work at all as a doctor.

*This is on top of any action that may be taken against the doctor by a private individual, the NHS, the courts or an employer. Each professional body has an equivalent General Council. There is a similar organisation for professional footballers and even magicians in The Magic Circle.*

## ***The Verdict in Dr Myhill's Case***

The Panel has determined that in accordance with Section 41A of the Medical Act 1983, as amended, it is necessary for the protection of members of the public and in the public interest to make an order imposing the following interim conditions on your registration for a period of 18 months, with effect from today.

1) You must not prescribe any prescription-only medication, as detailed in the British National Formulary;

2) Within 14 days of today's hearing you must ensure that in relation to your website, or any website relating to your medical practice or business, all pages, downloadable content, including documents, forum or discussion board content, or other references or online media relating to the following subjects must be removed:

- a) The medical management of cases relating to cardiology, or cardiovascular disease including; chest pain due to ischemic heart disease; acute coronary syndrome; heart failure; or pulmonary embolus;
- b) The treatment of asthma;
- c) The treatment, testing, identification, diagnosis or management of breast cancer;
- d) The use of hormonal contraceptive medication;
- e) The pharmacological management of primary or secondary prevention of vascular disease;
- f) Any immunisation or vaccination;

3) You must obtain the approval of the GMC before accepting any post for which registration with the GMC is required;

4) You must inform the GMC if you apply for medical employment outside the UK;

5) You must inform the following parties that your registration is subject to the conditions, listed at 1 to 4 above—Any organisation or person employing or contracting with you to undertake medical work; and any prospective employer or contracting body (at the time of application).



In reaching its decision the Panel first considered whether it was necessary for the protection of members of the public, in the public interest, or in your own interests to impose any interim order. It is not the Panel's purpose to test the veracity of any information put before it. It has reminded itself of the test it must apply and of its nature, function and powers, as well as its duty to consider each case on its individual merits. The Panel's function is not one of fact-finding and the Panel must impose the order it determines necessary, notwithstanding any potential for loss or hardship.

In considering the protection of members of the public and the public interest, the Panel is concerned by the allegations made and is satisfied that, if substantiated, your actions could indicate a potentially serious limitation on your insight into your fitness to practise and the consequences of your actions, particularly for vulnerable people who may be accessing your website. As a consequence, if the allegations are proven your behaviour could have an adverse effect on the confidence and trust that the members of the public are entitled to place in the profession and its practitioners.

The Panel was concerned that some of the information contained within your website may indicate that you are practising outside your area of expertise and therefore are potentially putting patients at risk by providing misleading or inaccurate information. The Panel was also troubled that on the basis of your statement and evidence today, you may lack insight into the issues raised by the GMC. In considering the GMC's document Good Medical Practice the Panel has borne in mind that it is a fundamental duty of a doctor to recognise and work within the limits of your competence. Furthermore, the Panel notes that, as a doctor, if you publish information about your medical services you must make sure the information is factual and verifiable.

Accordingly, the Panel is satisfied that there is sufficient information before it to indicate that there may be impairment of your fitness to practise and that such impairment may pose a real risk to members of the public, and may adversely affect the public interest. You are a registered medical practitioner and are expected to behave in a manner that justifies the public trust in the profession and its practitioners at all times. Having determined that an interim order is necessary, the Panel then went on to consider if an interim order for conditions would be workable, practicable, sufficient and appropriate. In all the circumstances, the Panel is satisfied that a restriction, by way of interim conditions, is appropriate and sufficient to guard against the risk that your actions potentially have for patients, the public, and the public interest. The public interest includes not only upholding and declaring the appropriate standards of professional behaviour, but also maintaining trust in the profession. Trust is crucial to the doctor/patient relationship.

The Panel is required to consider for what duration an interim order is necessary. The Panel notes that there are a number of issues to investigate and that the GMC's final consideration of your case may take some time. Therefore, it is necessary to impose the above conditions on your registration for a period of 18 months. In doing so the Panel notes that the order will be reviewed within six months, or earlier should circumstances surrounding your case change. The Panel has taken account of the issue of proportionality in that it must act in a way which is fair and reasonable. Whilst it notes that its order restricts your ability to practise medicine, the Panel has determined that, given the nature of this case, imposing conditions on your registration, at this time, is a necessary and proportionate response to the risks posed by you practising medicine unrestricted.

## **Sarah told 'Pathways'.**

*The GMC behaved as badly yesterday as they have been for the past 9 years but no-one would quite believe me! Their actions were disproportionate and inconsistent. For example Dr Jane Barton, who murdered 12 patients (and probably many more), faced a GMC hearing on January 29th 2010. She retained her full rights as a doctor except she was not allowed to prescribe morphine. I have lost my rights to prescribe any prescription medication listed in British National Formulary. My view is that we must not lose sight of the big issue which is that the GMC have been taking patients' private and confidential medical notes illegally. I have this fully documented. Furthermore the Charities Commission (25th July 2009), the Solicitors' Regulation Authority (Feb 7th 2010 and March 13th 2010), the Independent Complaints Reviewer (22nd September 2008) and of course the GMC (Meeting with Jackie Smith 12.8.09) were all informed but took no action, so they too are complicit. It was a great day with, I believe, about 130 at the Demo. Pat has a list of all those attending which I will put on the website – it was wonderful for people to see how difficult that GMC are – we were not allowed to demonstrate immediately outside "on their land" so we were crushed in between barriers. An official complaint has gone in to the GMC about their uncaring attitude.....*



*I shall be in London on Tues with a top solicitor to discuss strategy and will keep you all in the loop – I have some great ideas to kick the hornet's nest again.....The day was won by all who attended the Hearing and Demo. The GMC were seriously rattled by that. They did their best to freeze you out but well done for sticking to guns and giving the Press some great moments – as one said - there is a documentary to come out of this! I have been contacted to day by Independent on Sunday and the One Show - I think something may come out of both! We can defeat the GMC with a combination of dignity, fact and biting humour!*

### **Implications for Leger ME members who are Sarah's patients.**

- 1) It does not appear to directly restrict her right to examine, diagnose, and perform tests, issue medical reports and support letters.
- 2) The restriction only appears to stop her supplying prescription only medicines (POM). It does not stop her supplying over the counter medicines available without a prescription, general sales list medicines, and herbal medicines & foods supplements. For example all 'Biocare' products are unaffected. I'm not clear about AAA or MMM.
- 3) Some of the website content is contentious, and the areas that the GMC see that she has no expertise in are to be removed within 14 days. They seem to have steered clear of ME/CFS content, possibly intimidated by the mass protest of Myhill's supporters.
- 4) Her right to work as a doctor is restricted and will be scrutinised and closely supervised. She is not barred as yet. If she complies with the GMC order then she can possibly continue to practise with restrictions. If she does not, there is a high risk she will be struck off the Medical Register. I suspect that there will be further scrutiny of her methods in the future. I don't think that the GMC is really in a position to criticise her ME/CFS work similar methods are also practised by about 30 other doctors, and this would prove a minefield as they all would have to go on 'trial'.

If you have been prescribed any injectables (e.g. B12, magnesium, lidocaine) these are POM's and there may be a workaround as some other doctors may prescribe these items less contentiously.

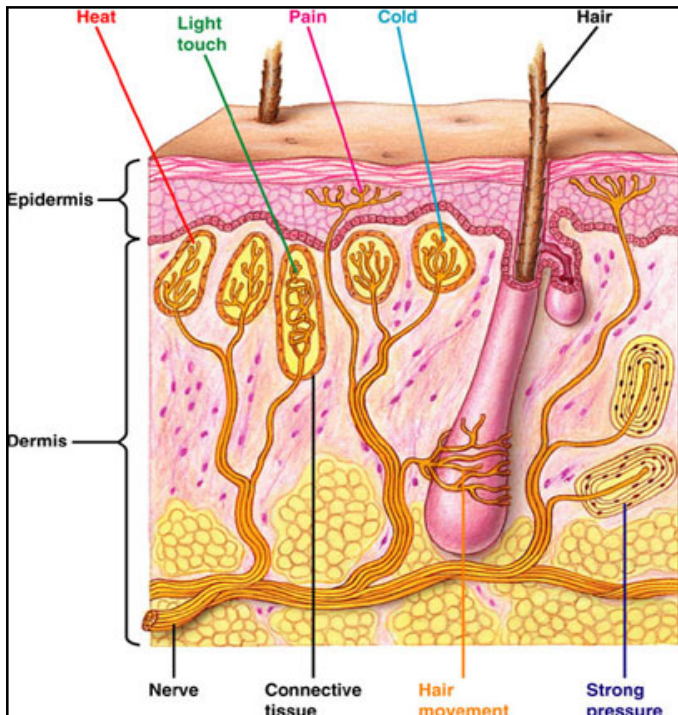
If you have been prescribed thyroid type drugs (thyroxin, liothyronine or armour thyroid) you must keep taking these, as sudden withdrawal could be dangerous because of thyroid suppression issues. You will certainly need to contact another doctor ASAP to get a continuing supply or for reassessment.



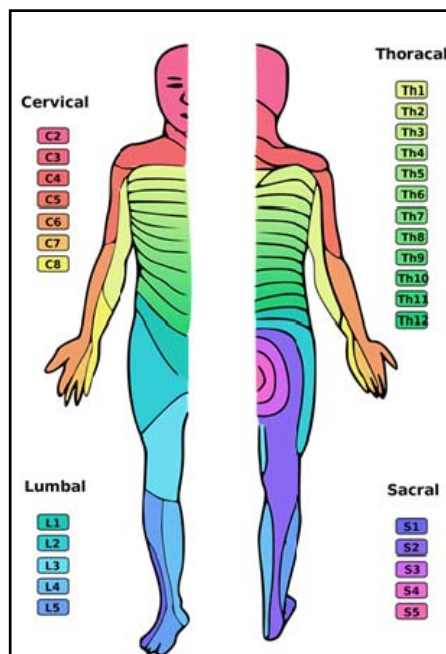
## Neuropathic Pain from the Skin in ME/CFS

I very often hear descriptions like 'I'm burning'—but there is no heat, and 'I'm cold' but their temperature is normal or 'I'm itching', but there is no rash or anything, just unmarked skin. Also people with ME/CFS find pressure from tight clothing uncomfortable, and thus wear loose fitting clothes as a coping strategy. It is not unusual for the sensation to travel around the skin area, and people to feel hot and cold at the same time. Amputees get something similar, e.g. soldiers who have lost a leg. They feel pain and other sensations in their missing leg. It is known as 'phantom limb syndrome'. The pain is just as real as if there was an intact limb there. So what's behind it all? It is neuropathic pain, arising from abnormalities in the central or peripheral nervous system, and

is associated with dysfunction of the nervous system, rather than a direct physical injury. There are different receptors in your skin for heat, light touch, pain, cold, movement and strong pressure.



If a particular receptor is stimulated, an impulse goes along the nerve pathway via the spinal chord to the brain where it is perceived and registered. If the nerve itself is stimulated e.g. by injury for example a slipped disc or sciatica, then pain is felt in the area the nerve covers, rather than at the point of injury. With ME/CFS, for reasons not fully understood, individual nerves groups of nerves produce false signals perceived as pain or odd sensations. So hot and cold may be felt together. The medicinal management is anything from paracetamol to morphine working up the WHO pain control



ladder. Pain control clinics use various things like amitriptyline, acupuncture, TENS machines etc. Many people find the intensity of pain is related to the level of ME/CFS, and find if they can get the pacing right, ME symptoms will reduce with minimal medication.

**Examples of Dermatomes.** The left shows the area served by spinal various nerves and the right the branches of the nerve. Very often areas affected can be traced directly to the spinal root or area that the nerve serves. For example C6 covers the thumb and first finger. The pain or odd sensation is limited to that area, and not felt in the ring or little finger. Right shows more detail. Very often in ME the pain is felt in both sides equally. If it is felt in only one side, that needs further investigation.

## Jargon Buster

**Allodynia:** Pain produced by a stimulus that does not normally provoke pain. The person's pain threshold is lowered. A change in temperature, windy weather conditions, bed sheets or clothing rubbing against a patient can precipitate pain

**Hyperalgesia:** An increased response (intensity and duration) to a stimulus that is not normally painful.

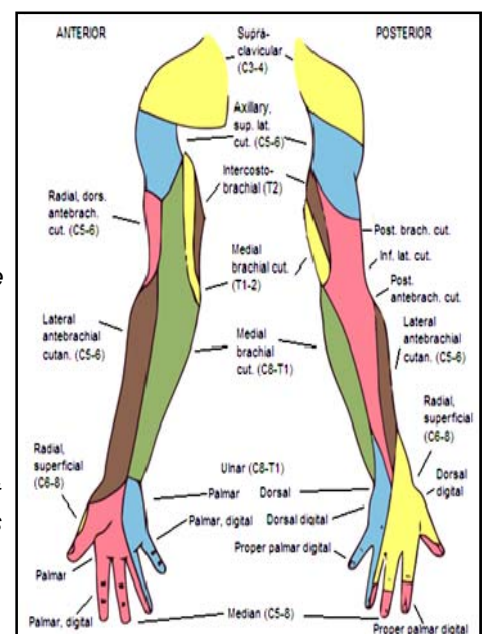
**Innocuous stimuli:** Pain from something not normally painful, e.g., windy weather conditions.

**Dysphoria** Abnormal depression and negative mood due to pain.

**Nociceptors:** Nerves, widely distributed throughout the body, which detect a potentially harmful stimulus, such as injury, chemicals or heat.

**Paraesthesia** Sensation of tingling, prickling or numbness of the skin; commonly referred to as pins and needles.

**Pain threshold** The level at which a stimulus is perceived to be painful.



## **Exercise, Immunology and Pain** (From Spring 2010 Breakthrough ([www.meresearch.org.uk](http://www.meresearch.org.uk)))

Traditionally the cardinal symptom of ME was profound, post-exertional loss of muscle power (fatigability) associated - with muscle pain, tenderness and swelling. And still today, "post-exertional" symptoms are key; the NICE Clinical Guideline of 2007 informs GPs that, for a diagnosis of ME/CFS to be made, fatigue characterised by post- exertional malaise "typically delayed, for example by at least 24 hours, with slow recovery over several days" has to be present. It is worth emphasising that post-exercise symptoms are not present in other fatigue-related disorders, and that their very presence greatly helps to distinguish ME/CFS from, say, any major depressive disorder.

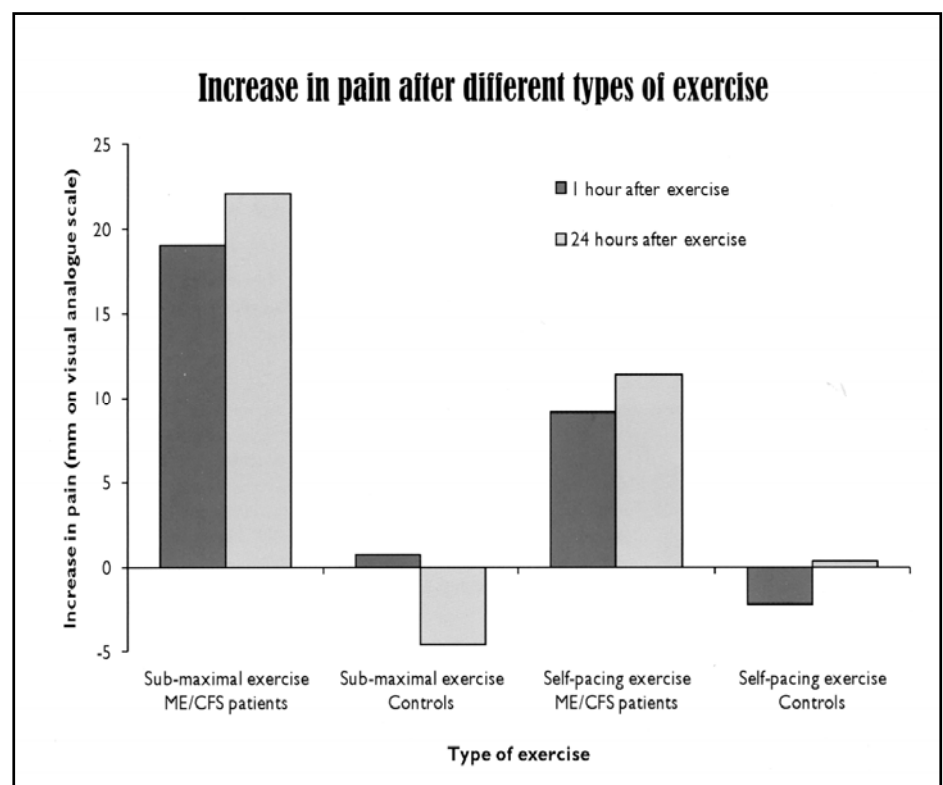
Given this, it is surprising that so little is known about muscle physiology, the role of exercise, or indeed about patients' responses to exercise in a laboratory setting. One research group, however, has a long-standing interest in this aspect: Prof. Jo Nijs and his colleagues at Vrije Universiteit Brussels and University College Antwerp in Belgium. With funding from ME Research UK, these researchers have been investigating immunological responses to exercise, and the effect of different kinds of exercise on these responses, and their latest scientific report has just been published in the Journal of Internal Medicine (April 2010).

Prof. Nijs and his team were looking at whether different exercise regimes trigger increases in elastase activity, IL-1 and complement C4a levels, and whether changes in these parameters might be associated with exacerbations of symptoms following exercise in people with ME/CFS. The experimental group consisted of women with ME/CFS plus ACR-defined chronic widespread pain (a group the researchers believed would more closely represent ME/CFS patients in the community in whom pain is a major symptom), and 22 non-athletic female controls.

Participants completed two exercise tests one week apart. At each visit they were required to fill out a range of outcome measure questionnaires, and had blood samples taken for determination of immune variables such as elastase activity and G-actin cleavage. One hour after exercise testing, patients again provided samples and outcome information, and 24 hours later again reported their symptoms. The first exercise test involved a well-studied "sub maximal exercise protocol" using a bicycle. The second exercise was a "self-paced and physiologically limited bicycle exercise" with three "safety breaks"; the exercise duration was determined using the principles of pacing self-management as commonly used in people with ME/CFS, and the activity duration estimated by the participants was then further reduced to account for typical overestimations.

The results (graph opposite) were interesting on a number of levels. As regards post-exercise symptoms, the sub maximal exercise and the self-paced, physiologically limited exercise both triggered symptoms, such as pain, after one and 24 hours - as the graph clearly shows - highlighting that exercise needs to be employed with caution in ME/CFS patients.

Looking at the immunology, however, neither type of exercise altered circulating levels of IL-1 b, complement C4a split product or elastase activity—a most unexpected result. Most fascinatingly, the complement C4a level, measured after exercise, was identified as a possible biomarker for the development of post- exertional symptoms in people with ME/CFS.



### What did the results show?

- Exercise, even when self-limited, triggered post-exertional symptoms.
- Baseline elastase activity was significantly higher in patients than in controls ( $p=0.03$ ).
- Exercise did not alter elastase activity, IL-1 $\beta$  or complement C4a split product levels ( $p>0.05$ ).
- The change in complement C4a was strongly related to the increase in pain and fatigue 24 hours after self-limited exercise.
- Post-exercise elastase activity, and change in elastase activity, was inversely related to the increase in fatigue one hour after the self-limited exercise.
- There were a number of correlations between post-exercise quality of life subscale scores (e.g., physical activity/function and concentration) and both elastase activity and C4a levels, supporting the clinical importance of both immune markers for these patients.
- The level of complement C4a following sub maximal exercise was identified as a clinically important biomarker of post-exercise malaise in people with ME/CFS.

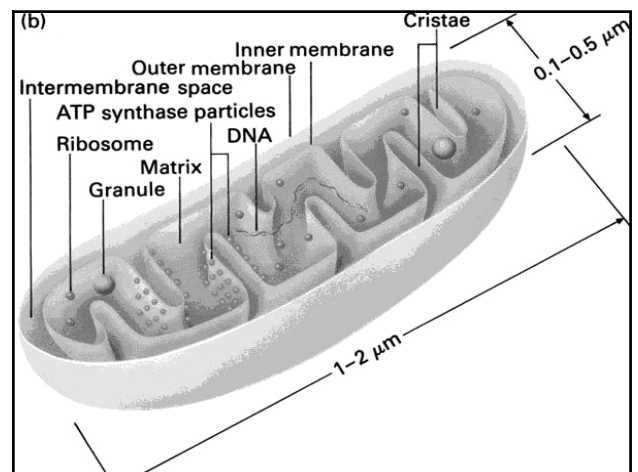
### Exercise and ME/CFS

Much of the current thinking about the role of exercise in CFS and ME is driven by models of "deconditioning", and the notion that regular exercise will be beneficial. And overall that is true; regular exercise is good for us all up to a point.

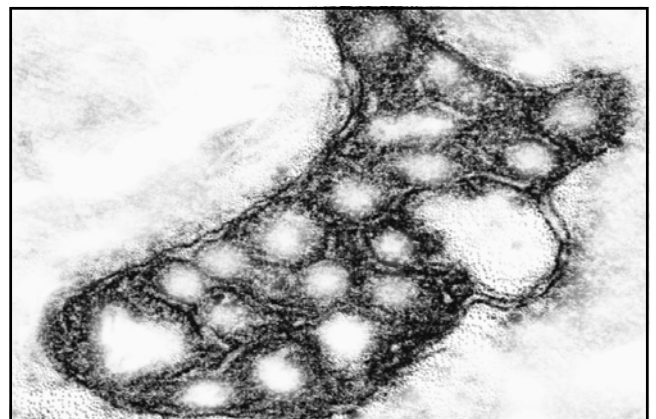
However, we already know that too vigorous exercise or activity can trigger post-exertional symptoms in most people with ME/CFS. And we know from research that these patients respond to an exercise challenge with enhanced complement activation, increased oxidative stress, and an exaggeration of resting differences in the gene expression profile in peripheral blood mononuclear cells. So, it is entirely possible, perhaps even likely that over exercising causes harm, simply because something is organically wrong with muscle metabolism. What value do exercise programmes have in these circumstances?

In fact, the characteristic delay in muscle recovery after exercise in ME/CFS (with pain and fatigue occurring for days afterwards) is a phenomenon which few have studied, and which the deconditioning hypothesis does not address. Many questions remain. For instance, studies show that 20 to 30% of ME/CFS patients have abnormal mitochondrial structure and enzyme function and/or evidence of viral activity in skeletal muscle tissue; are viral particles interfering with the muscles' ability to carry out specialised functions! Again, post-exercise muscle pain is a widespread symptom - but why there is muscle pain, and could a state of energy depletion during exercise and the development of noxious free radicals be responsible?

Furthermore, and most pertinently, how many ME/CFS patients have ever had a comprehensive clinical examination by a GP or consultant, never mind formal muscle testing by a clinical scientist?



Normal Mitochondrion, theoretical diagram (top), and a normal; electron micrograph image below.



Bottom right (Behan). This is an abnormal mitochondrion from a ME/CFS patient. While some ME/CFS patients may have these abnormalities, they are not limited to ME/CFS. Other mitochondrial myopathies result in similar issues. One well known local diabetic consultant has been involved in research with mitochondrial abnormalities is diabetics.



## Recipe Corner

### Asparagus and Pea Risotto

Early summer is the best time of year to enjoy UK grown asparagus and this quick and creamy risotto makes a wonderful light lunch or supper.

Serves 4. Ready in 45 minutes.

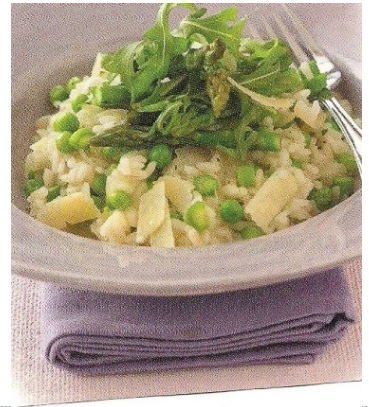
Heat the oil and butter in a large deep frying pan and fry the onion for 5 minutes. Add the rice and cook for 1 min, then stir in the wine and boil rapidly until the wine has evaporated.

Gradually add the hot stock, one ladleful at a time, stirring all the time and allowing the liquid to evaporate before adding more. Continue adding the stock in this way for 20-25mins until the rice is just tender.

Meanwhile, steam the asparagus and peas in a steamer or metal colander set over a pan of simmering water for 2-3mins.

Stir the asparagus stalks and peas into the risotto with the grated Parmesan cheese.

Season to taste with salt and freshly ground black pepper and serve topped with the asparagus spears, rocket and Parmesan cheese shavings.



#### Ingredients:-

15ml (1tbsp) olive oil  
25g (1oz) butter  
1 small onion, peeled and finely chopped  
250g (9oz) risotto rice  
150ml (1/4pt) dry white wine  
900ml (1½pt) hot vegetable stock  
225g (8oz) thin asparagus spears, trimmed and stalks chopped  
175g (6oz) frozen peas  
25g (1oz) finely grated Parmesan cheese  
Rocket leaves and Parmesan cheese shavings, to serve

### Chicken and Rice Hotpot

This is a recipe taken from the Bolton NHS Easy Recipes booklet and has the following nutritional comment:

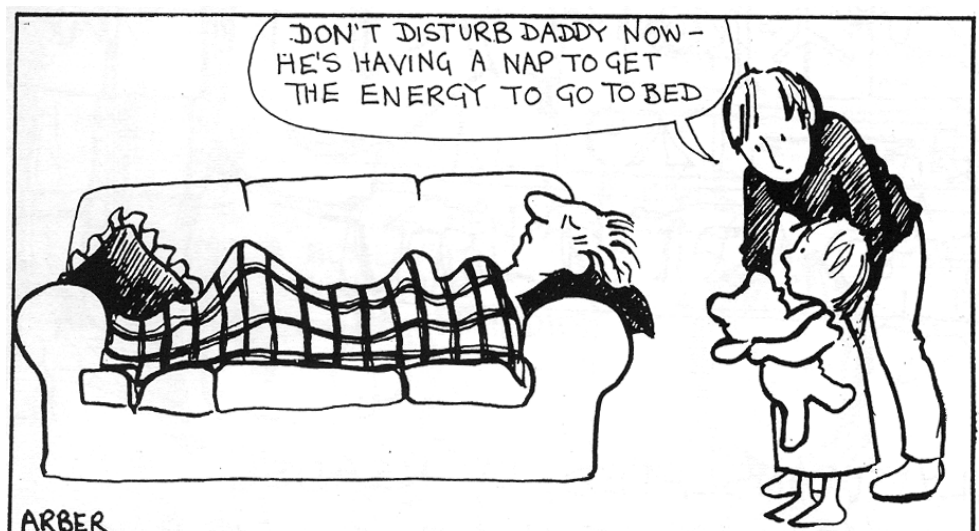
Chicken is a great source of protein but make sure you remove the skin because it is very high in saturated fat. Why not try using wholegrain rice? It's got a great nutty taste, is better for your heart and will keep you feeling full for longer.

Serves 2  
Calories per portion 686

Fry the onions in the oil for about 3 minutes. Add the chicken drumsticks and fry until lightly browned. Add the rice and cook for 1 minute. Stir in the chicken stock, carrots, bay leaves, salt and pepper. Cover and simmer gently for 35-40 minutes. Serve with vegetables of your choice.

#### Ingredients:-

2 medium onions, chopped  
1 tablespoon of olive or sunflower oil  
(vegetable oil also works but is not a healthy option)  
4 chicken drumsticks  
175g long grain rice  
1 pint of vegetable stock  
2 carrots, chopped  
2 bay leaves  
Salt and pepper



## ***From Spring 2010 Breakthrough*** ([www.meresearch.org.uk](http://www.meresearch.org.uk))

### ***Immune links between ME/CFS and Cancer***

Cancer fatigue is a well-recognised, often intense symptom experienced both during and after treatment. Since cancer and ME/CFS share both fatigue and severe disability, researchers in Antwerp speculated that there could be other links between the two pathologies, particularly as regards immune abnormalities. The key findings of their in-depth review, published in *Anticancer Research* in 2009, were that both conditions share abnormalities in the RNase L antiviral pathway and in the major intracellular mechanism NF-KB which regulates inflammatory and oxidative stress (see the table to the right). In addition, natural killer cell malfunction has long been recognised as an important factor in the development and reoccurrence of cancer, and this has also been documented repeatedly in people with ME/CFS. The researchers point out that these immunological problems are clearly apparent and quite similar in both diseases. While there are clear differences between cancer and ME/CFS—most prominently in cause, illness progression and mortality—the researchers are nevertheless intrigued by the shared immune abnormalities. It may be that these overlapping immune dysfunctions are involved in shaping some of the symptoms shared by both illnesses.

Factor	ME/CFS	Cancer
Ribonuclease L (RNase L)	Increased activity leading to increased apoptosis	Decreased activity leading to decreased apoptosis
Nuclear factor kappa beta (NF-κB)	Increased activation	Increased activation
Natural killer cells	Decreased activity	Decreased activity

### ***Signs & symptoms in the Eyes***

In the early 1990s, two reports appeared in the scientific literature reporting ocular (eye) symptoms in ME/CFS. In the first (published in *Optometry and Vision Science* 1992), a research group in Boston, Massachusetts surveyed 190 patients and 198 healthy controls by written questionnaire, and found a range of symptoms to do with dysfunction of the eyes, including sensitivity to light (photophobia) and problems with accommodation probably associated with the ocular muscles. In the study, 24.7% of patients had reduced or stopped driving because of eye problems, compared with only 3% of controls.

In the second study (published in the journal of the American Optometry Association 1994), all of the 25 consecutive CFS patients reported eye symptoms; the most common clinical findings were abnormalities of the pre-ocular tear film and ocular surface (in 19 patients), reduced accommodation for age (18 patients) and dry eyes (9 patients). Then, in the decade 2000 to 2010, two further reports appeared. The first was a case-control study (in the *Annals of Ophthalmology* 2000) in which the 37 ME/CFS patients had significant eye impairments compared with controls; the impairments included foggy/shadowed vision and sensitivity to light, and there were associated problems of eyeball movement (oculomotor impairments) or tear deficiency. The second, from Russia (*Vestnik Oftal'mologii* 2003), reported "vascular pathology" of the eye in 70.2% of the 218 ME/CFS patients and "dystrophic pathology" in 52.8%.

The astounding thing is that these four smallish studies represent (almost) the sum total of research into eye problems in ME/CFS in the past 30 years, even though such symptoms concern many patients today. Indeed, around 75% of the 2,073 consecutive patients described in the Canadian review of 2003 specifically reported sensitivity to light and dullness of vision to be significant problems. Astonishing, isn't it? But, as we've said before, time marches on but sometimes it can seem to stand very still indeed where research into ME/CFS is concerned!

## **Local History: The Thellusson Will and what went wrong**

*I quite often get asked where the name on my street came from. The Thellussons were the local landowners of Brodsworth Hall, which is now conserved by English Heritage. Like Cusworth Hall, it fell into decline. Helen Hood (Minster Legal Services) continues the story:*

It all started back in the 1700s with our gentleman called Peter Thellusson. He came from the Continent and settled in England, gradually acquiring land including the Brodsworth estate. He was a very wealthy man, he was in fact a banker, and he wrote what has since become a very famous will. In his will he put the bulk of his fortune into a trust fund. This was around £700,000 – in today's money this is worth around £54 million, so you can appreciate how wealthy he was. The money was to stay in the trust fund for three generations accumulating interest all the time. When the third generation had passed on, the fourth, then unborn, generation, could eventually inherit.

He left to his family living at the time, about £100,000 to share between them. His will was read in 1797 – and initially his family were delighted - £100,000 to share was an awful lot of money (about 7½ million in today's money.) Of course they soon realised that there was another £700,000, locked away in a trust fund that they couldn't get their hands on at all. Well—the family weren't going to stand for this, so they took the will straight to court. The courts of the time had never seen anything like it—such a huge amount of money put by for such a length of time, and to be quite honest they didn't know what to do about it at all. Charles Dickens' particular novel *Bleak House* has a legal case in it, of *Jarndyce versus Jarndyce*. Charles Dickens actually based his story on, among others, the real-life case of the Thellusson family versus Peter Thellusson's will – so you can appreciate how important it was in its day.

The courts did allow the will to stand, but it took over half a century for them to reach this decision. Many lawyers were disappointed when the Thellusson case eventually came to a close as they had been earning hefty fees from it for so long! The money that Peter Thellusson had left in his will was supposed to have accumulated interest over the years, and accrue into an unimaginable sum—in fact Peter had stated that if there wasn't a fourth generation to inherit, then the money should be used to help pay off the National Debt! However, all the interest that should have accrued was spent on lawyers and legal fees. SO—the amount that was inherited was about the same that was put into trust—about £700,000.

To prevent such a disposition of property in the future, the Accumulations Act 1800 (known also as the "Thellusson Act") was passed, by which it was enacted that no property should be accumulated for any longer term than either:

the life of the grantor; or  
the term of twenty-one years from his death; or  
during the minority of any person living or '*en ventre sa mere*' at the time of the death of the grantor; or  
during the minority of any person who, if of full age, would be entitled to the income directed to be accumulated.

The act, however, did not extend to any provision for payment of the debts of the grantor or of any other person, nor to any provision for raising portions for the children of the settler, or any person interested under the settlement, nor to any direction touching the produce of timber or wood upon any lands or tenements. The Act was extended to heritable property in Scotland by the Entail Amendment Act 1848, but does not apply to property in Ireland. The act was further amended by the Accumulations Act 1892, which forbids accumulations for the purpose of the purchase of land for any longer period than during the minority of any person or persons who, if of full age, would be entitled to receive the income.



*Brodsworth Hall*



## ***Making a Will and Power of Attorney***

A good example of why we need to make a will is that of our local man, Peter Thellusson, who's wishes were not met due to family intervention. In the modern world there are really two situations necessitating a Will, firstly when you die and secondly, if you become unable to look after your own affairs. Making your will is probably the most thoughtful thing you could ever do. With a Will 'you decide who receives your home, savings, investments, insurance policies, possessions and sentimental items. It stops relatives have complications with Probate issues. Many people make the mistake of a 'do it yourself' will which is bought from stationers and via the internet. Solicitors tell us that this type of Will can easily be disputed and challenged by family and beneficiaries. A qualified solicitor would ensure all the legal safeguards, procedures and requirements are followed. You appoint executor(s) to handle your estate, and very often this includes a solicitor or other financial institution. Even then a Will can be legally challenged. One well known case is veteran entertainer George Formby. When his Will was disputed, the outcome was that everything was auctioned off, and in his case, even his underwear went under the auctioneers hammer. In a recent case there was a legal challenge by a daughter when a father left all his estate to the RSPCA, ignoring the family. Wills have to be updated. A marriage invalidates a previously-made Will. For unmarried cohabiting couples (common law partnerships), there is a belief that should one partner die, the other would inherit the estate automatically. In law this has no standing, and the widowed partner could easily be evicted by family. Wills are legal documents, and anyone can have access to them. Perhaps the most well known example is that of Diana, Princess of Wales. After her death Somerset House was swamped by requests for copies of her Will, and parts of it were published in newspapers.

The second scenario, if you become unable to look after your own affairs is becoming more frequent and is particularly an issue if someone is taken into nursing care unable to administer their own affairs. Many people choose to make a 'living Will' type document, which is known as 'Lasting Power of Attorney'. This is a similar document to a Will, and a qualified solicitor would ensure that your wishes, all the legal safeguards, procedures and requirements are followed. There are many issues. In a nursing home, you are responsible for the fees, which are between £500-600 a week. If you own property like a house, you could be legally made to sell it to cover care fees. This sometimes happens with social services. Many solicitors offer these services in addition to specialised will-writing, and legal services also offer products that will protect your home against the ravages of the 'Community Care Act' and possible future care-costs. In many cases, particularly to avoid death duties, and ceasing of property arrangements need to be over seven years old to be secure. There are legal limits as to how much you can give away and it can be taxed. There are many solicitors practices around. Some practices actually do home visits.



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Home Library Service**

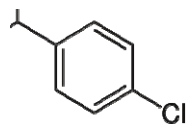
Doncaster Council's Home Library Service brings the library direct to you if you are unable to visit your local branch

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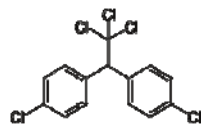
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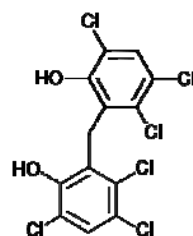
## DNA Adducts: A Chemical Detective Story



The villain of this story to watch for is the chlorine atom attached to the aromatic ring nucleus as illustrated on the left. The Cl (chlorine) magnifies the activity of whatever it does compared to its absence. Other similar infamous villains are:

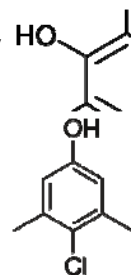


**DDT** (dicophane) as an insecticide was prominent from the 1940's. For a while it proved effective, and was heavily used in agriculture and to control malaria-carrying mosquitoes, but organisms rapidly developed a tolerance for it. It is now widely banned because of the toxicity due to its environmental persistence. DDT residues are appearing in the food chain, and in the blubber of some whales. For wildlife the most well documented problems is thinning of birds' eggshells. In the UK, its use has been banned from the early 70's.

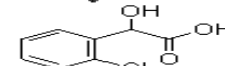
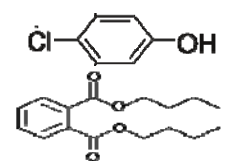


**Hexachlorophene** a topical anti-infective, anti-bacterial agent, often used in soaps and toothpaste. It is also used in agriculture as a soil fungicide, plant bactericide, and for parasitic worms. It can be lethal from absorption through the skin, especially in children. I can remember, in the early 70's, the withdrawal of many baby products containing it.

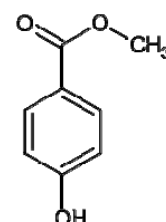
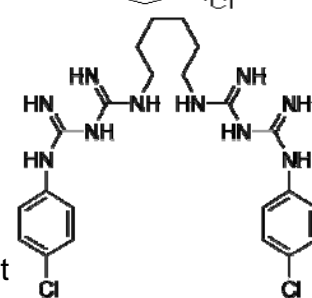
Prior to getting a diagnosis of ME, I became sensitive to a number of chemicals I had previously dealt with for many years without issue. Many were coal tar-derived phenolics, particularly the chlorinated type where the OH group is attached to the aromatic ring. One particular one was chlorxylenol (contained in dettol); there are no prizes for coming to the conclusion that it has both hallmarks of trouble, the OH phenolic group and the Cl. Obviously, the thing to do was avoid them, which to some extent has worked. While the multiple chemical sensitivity is controlled well by EPD, only in the past few years has it come to my attention that some of my health problems could still be related to this group of organo-chloro compounds. Of particular concern to me are DNA adducts, which are capable of causing many health problems later in life. Dr. Sarah suggested that I have the test done just as a precaution. Blood samples were taken, and to my dismay the results came back with three abnormalities which were as follows.



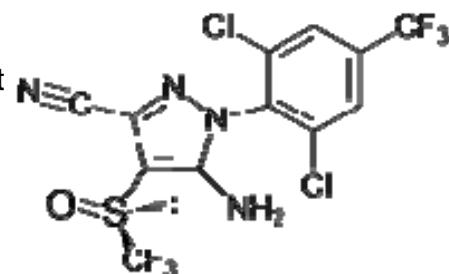
Adduct	Chromosome/Gene	Possible sources
Chlorinated phenol	GSH-PX, chromosome 8	Bactericidal-type chlorinated phenol
Dibutyl phthalate	Spread	Common plasticiser
Chloromandelic acid derivative	SOD1 gene, chromosome 21	Chloromandelic acid derivatives are usually metabolites of organophosphates.



The GSH-PX gene codes for glutathione peroxidase, and the SOD1 gene codes for superoxide dismutase, both of which deal with oxidative stress, a process implicated in the biochemistry ME/CFS. Although I know that it is possible to treat oxidative stress with antioxidants, e.g. B12, ascorbic acid, why should I do that, when I could be producing faulty enzymes though DNA adducts? A bit of head scratching and detective work came up with a partial answer. I was a regular user of Savlon cream, which I thought was safe as it didn't produce a obvious reaction. It contains chlorhexidine, a possibly a source of the chlorinated phenol. The propylhydroxybenzoate may be responsible for the dibutyl phthalate. So I stopped the use of Savlon and I began to feel much better. The chloromandelic acid derivatives (usually metabolites of organophosphates) were a puzzle. I don't use organophosphorus compounds because I know they are liable to cause ME/CFS. I assumed that I may have picked it up from the environment. I was retested 15 months later, good news this time from Acumen. The test is clear.



A couple of months later I was clearing out a drawer, and found a packet of 'Frontline'. This stuff contains fipronil, an insecticide intended to kill cat flea—a spot on the back of the neck job. Cats are notorious for emitting dander (dried skin) and dried saliva from their fur into the air which is a major cause of allergies and asthma. I had recently lost marmalade my 18 year old cat and obviously stopped using Frontline. I reckon that it was the source of the chloromandelic acid derivative. I certainly will not be using anything like it in future, Would you?



## ***The Role of Medicines & Food Supplements in CFS/ME Management.***

You should be able to get medicines for pain control, allergies, sleep issues, depression & anxiety and other ME/CFS symptoms from your NHS doctor. Treatment for common associated conditions like hypothyroid, diabetes and asthma is well supported via the NHS and well documented. There are no medicines specifically for ME/CFS within the NHS British National Formulary.

One of the biggest mistakes that the NICE Guidelines for ME/CFS did was not include many of the products available from Pharmacies. Many are conventional drugs used to treat other conditions, but there are no specific guidelines within the NHS. There is plenty of research evidence for essential fatty acids like VegEPA and Carnitine, which were very strong contenders for inclusion in to the NICE guidelines, but lack of credible clinical trials and experience caused rejection.

There is a big temptation to go and see the private doctors. The catch is the bill would possibly be in the region of £400+ with tests and treatment. I reckon that £100 would trial most medicines/food supplements. The most relevant information about what is being used can be found from private doctors' price lists and treatment notes. Please note that while some are on general sale, some are restricted to via your doctor. The basic rule is try it, if it works fine, but if not forget it. Here is what I come across most frequently:

**Ribose** is maize derived sugar sold as a sports nutritional supplement for cyclists. It shortens fatigue 'red card time' from 3 days to about 4 hours if it works. It is not suitable for diabetics as it shares the glucose metabolic pathways.

**Fish Oils** (sometimes given on a prescription as MaxEPA or EPA oil) where works clears brain fog and joint pains. It is made from cod liver oil, a bit like taking school CLO capsules.

**Evening Primrose Oil** (Efamol, GLA oil) seems to work for some people, but is expensive. Flax seed oil and borage oil are cheaper alternatives.

**Combined Oils (essential fatty acids. EPA & GLA)** are branded versions of the above. Lamberts and Biocare have their own versions, but the most well known one is VegEPA. There has been convincing research trials at Hammersmith Hospital, that have shown beyond a doubt this product works for some. The manufacturers chose not to apply for a medicines product licence for the NHS, and choose instead to promote it as a food supplement.

**Vitamin B12** by weekly injection via a doctor. Where it works, it works well. Oral B12 tablets do not work that well, but an alternative sublingual spray is available which some say helps just as much as injections. B12 injections are Prescription Only Medicines. NHS GPs have insurance/guidelines which cause problems supplying; where it is privately supplied there is not usually an issue. Some hospital consultants use it, but not locally.

**Magnesium** on a daily basis by mouth seems to be as effective as injected magnesium. Injected magnesium has the same supply problems as injected B12, and can be very painful.

**Coenzyme Q10** works for a few individuals. A common complaint is an increase in IBS-type symptoms. A precursor of Q10 is vitamin B3, which is freely available as nicotinamide in health shops, and is cheap. An expensive form Enada is promoted, but I am not convinced it is any better than B3.

**General A-Z Multivitamin/Minerals** cover works for most to some extent. Doctors will not usually prescribe these on the NHS. The A-Z types contain recommended daily amounts of everything, and cost about the same as individual multivitamins. Most of the brands of A-Z products contain the same ingredients, with some minor variations. Private Doctors tend to major on these. Some people go for specific B vitamins or Vitamin C in high doses.

**Carnitine** is reported to work, no first hand experience. It is an amino acid, and very expensive.



**North of Doncaster** *Personal comment by Trevor Wainwright*

This issue an article about my voluntary work with the British Red Cross and how the organisation may be able to help you should the need arise. Every year, hundreds of families and individuals suffer damage to their home following a fire, flood or similar incident. Imagine if this was you, how would you cope? Who would you turn to?

There is a free service from the British Red Cross staffed by trained volunteers working in co-operation with local fire services across the UK and they are ready to respond, particularly outside normal office hours. They will arrive at the scene of the incident within 90 minutes of call-out. The fire and emergency support service, using a specially adapted vehicle, provides practical help and emotional support to vulnerable people affected by a domestic fire, floods, evacuations or any other incident to which the Fire Service has been called.

Known as the Fire Emergency Support Service (FESS) the aim is to provide ongoing support for people in the first 24 to 48 hours following an incident. The service does not aim to duplicate the work of the statutory bodies such as social services, but rather assists people in planning their recovery and helps them access help that is available from such agencies.

***This support includes:***

- **Immediate temporary shelter in the FESS vehicle**
- **First aid and emotional support.**
- **Use of shower and toilet facilities**
- **Clothing, toiletries and refreshments**
- **Support with the care of children and pets**
- **Sign-posting to other organisations: e.g. social services, housing.**
- **Assistance in seeking temporary accommodation.**

South Yorkshire has two FESS vehicles one based at Adwick Fire Station Doncaster and Tankersley Fire Station near Sheffield. These vehicles carry all equipment needed for the purpose, and although working as an emergency vehicle do not



have the rights to legally exceed the speed limit. I have to date attended seven incidents which have ranged from providing refreshments to arranging re-housing and taking the people to alternative accommodation. No two jobs have been the same. I'm usually on call three nights a week. When I get a call and am leaving the house there is a feeling of anticipation that I am going to help someone, this increases as I head South down the motorway, but even better is the feeling of satisfaction I get heading North, job done, even more so when the service user has said before we have come away, "thanks guys....." How do you get this service?

Well, hopefully you won't need it, but if you do and the fire brigade are in attendance just ask.