



*Welcome all,*

One of the biggest problems we face with ME and fibromyalgia is ignorance. It is perhaps understandable with such complicated and little understood illnesses. A lot of the problem is that we are just not visible in the way many other conditions are. We either don't go out, or when we are well enough to do so, we look relatively well. Awareness week (11<sup>th</sup> – 17<sup>th</sup> May) and Awareness day itself (on May 12<sup>th</sup>) is our chance to explain our illnesses to the world. You'll have noticed a blue ribbon falling out of your envelope. Please wear it with pride during this week. Please explain to family, friends, neighbours - and anyone else who will listen - about your condition and how it affects you. Post about it on Facebook and Twitter and any other social platforms. Let people know that although we may be invisible a lot of the time, we are many in number and we are more badly affected than most would think. Although the energy of the committee is just as limited as most we have taken up the offer from the large Tesco store in Dumfries to man a stand on Awareness Day, to be used to raise awareness and collect donations towards the running costs of this charity. If you feel you could help during the day, even if it's only for a short time, please contact us.

*Craig Woods*

## Monthly Get-Togethers

**First Thursday of every month 1 – 3pm at Midsteeple, Dumfries**

**March 2<sup>nd</sup>** Our usual get-together, themed on what has been helpful in managing our conditions.

**April 6<sup>th</sup>** Our usual social get-together.

**May 4<sup>th</sup>** Our usual social get-together, and preparation for ME/Fibro Awareness event at Tesco.



As with all the Midsteeple get-togethers refreshments will be available. There's no charge to attend. Feel free to bring along a snack. It is fully accessible with a lift to the first floor meeting room (press and hold the button to call it and then again until the door unlocks on the first floor). Entry is through the blue Box Office door - see our website for a video guide. Stay for as much or as little as you'd like. Use the Facebook page to request or offer transport.

## Pop-Up Meetings

**Look out for other pop-up meetings on our Facebook page or the website**

**April 23<sup>rd</sup> Sunday 1 – 3pm** 'pop-up' social at **Castle Douglas Garden Centre Coffee Shop**. There will be the usual menu of meals and snacks, and specials of the day. The Centre is on the edge of Castle Douglas heading out on the Dalbeattie road.

Contact us:

Phone/WhatsApp - 07437 602610

email - [admin@dgmefm.org.uk](mailto:admin@dgmefm.org.uk)

Registered Charity No. SC030641



## What is Post Exertional Malaise?

*Excerpt from a blog by crazypurplemama in Invest in ME Research, My Life.*



Post exertional malaise is by far not the only symptom us ME sufferers have to tolerate, but I am going to focus on it, as it may help friends and family of sufferers to realise that we don't cancel plans or go home early through not wanting to socialise or do things with you - it's quite simply that our bodies won't let us, that we are beyond exhausted, in pain and can't physically do it.

So, what is Post Exertional Malaise (PEM )?

"The predominant symptom of ME/CFS is usually severe fatigue and malaise following mental or physical activity. The full extent of this exhaustion often becomes apparent only 24 to 48 hours after the activity (assuming, of course, the person was not already in a "recovery period" from a previous activity)." *ME Association*

"The most apparent features are extreme post-exertional muscle fatiguability, which is quite distinct from chronic "fatigue" or tiredness, together with recurrent nausea and profound incapacitating malaise. It is striking how consistent are the symptoms that characterize this condition. The exhaustion experienced by patients is so profound that "fatigue" is probably an insult." *Invest in ME Research*

For me personally I find that emotional or mental stressors have double the impact on me than the physical exertion, which is still severe. The fatigue is like no other I have experienced, it is overwhelming and frightening, and usually with terrible cognitive payback, what we call "brain fog".

I wanted to find out if this terrible sensation of having no strength or resilience in your body was common to other illnesses or just ME. Here are some snippets from this article which came up in my search <http://solvecfs.org/post-exertional-malaise-perception-and-reality/>.

"Fatigue is a significant and disabling symptom in many illnesses, including multiple sclerosis (MS), Lupus and Rheumatoid Arthritis. Fatigue in Lupus has been described as "an extreme fatigue that interferes with many aspects of your daily life." MS fatigue or "lassitude" is severe fatigue that is unrelated to physical activity, occurs on a daily basis, and interferes with functioning. Both of these descriptions are similar to how ME/CFS patients describe their fatigue, but is the effect of exercise on these illnesses that may truly distinguish them."

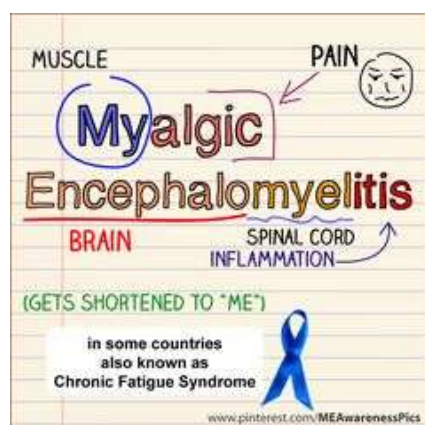
Okay, so far I find that fatigue in ME is similar in many respects to fatigue in MS, Lupus and Rheumatoid Arthritis - so what do they mean by "is the effect of exercise on these illnesses that may truly distinguish them" - so I read on...

"There is a growing body of research that MS patients can tolerate aerobic exercise, and also benefit from it." ... "The Medical Advisory Board to the National Multiple Sclerosis Society recommends regular aerobic exercise geared to the person's ability as one of the clinical

management strategies for MS fatigue, even for the 50- 60 percent of MS patients who say fatigue is one of their most troubling symptoms.”

I find that interesting - so unlike ME, for MS sufferers exercise can help them with their fatigue - I continued reading...

“The same holds true for patients with Lupus and Rheumatoid Arthritis. Aerobic exercise training in Lupus patients has been shown to improve aerobic capacity and exercise tolerance, while also not exacerbating the disease. In Rheumatoid Arthritis, studies show that regular exercise helps reduce joint pain, increase joint mobility and strength and improve mood. While all these illnesses require rest and pacing, exercise does not appear to have the same aggravating effect on symptoms that it does with ME/CFS.”



So basically ME seems to be unique with the symptoms of PEM, therefore gradual exercise therapies (GET), which are thrown at patients not only don't make them any better but instead can in many cases (like ours) make sufferers decidedly worse. For many patients being forced through this therapy means that once it is stopped they may never regain the level of function they had prior to starting GET, but if they do it is a very long and slow process. Simply put, exercise with ME aggravates and exacerbates the illness and does not benefit the sufferer in any way. However, I have to say that within the category of ME diagnosis you will

find sufferers of varying severity and fluctuating symptoms - those mildly affected will be able to tolerate being more physically active than a moderately severe sufferer. A very severe sufferer simply cannot get out of bed, let alone exercise.

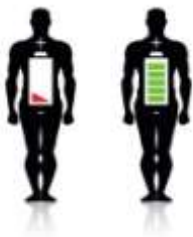
So it would seem post exertion malaise and the exacerbation of symptoms due to exercise is unique to ME. So now you understand how exertion affects a person with ME you are probably wondering how we manage to get anything done at all? Having been down the road of Gradual Exercise Therapy (GET) and Cognitive Behaviour Therapy (CBT), I can tell you that these therapies simply don't work, yet they are still being touted by the media and many health care professionals (within the psychiatric community) that these work and can “cure” two thirds of ME sufferers!

Okay, so if GET and CBT don't work then what can we do - what are our options? Quite simply, not a lot! Over the 6 (almost 7) years we (self and daughters) have dealt with this illness we have really found only one method that works for us and that is what we call “pacing” ~ which is nothing to do with the PACE trial!

For us “pacing” means doing only what we can within our energy limits, to stop before we start to feel any fatigue from any activity, be it physical or mental. To take regular rests and to rest as and when our body dictate. This is to prevent any horrendous “crashes” which leave you bedridden and unable to function. “Pacing” varies for each individual as we all have different limits, different triggers and fluctuations. It means cancelling invitations/plans at the last minute and having to say “no” far more than saying “yes”. It can mean having to forgo a shower in order to have enough energy to prepare a meal. You become adept to using shortcuts to your personal hygiene on days when energy is particularly low - wet wipes instead of a shower, dry shampoo instead of a wet one,

chewable toothbrush to save time over a sink brushing. Wearing head gear if the hair is completely unsolvable with use of dry shampoo. Wearing clothes suitable for wearing and sleeping in (jogging bottoms or leggings, loose tops or jumpers, pull on boots or flip flops). We know if we have a big event coming up to really rest up the preceding days in an effort to try and “store” some energy in reserve for the event, we also need to ensure that we have nothing planned for the next four or five days afterwards so that we can again rest to try and repair the damage caused by depleting the energy levels so severely in order to enjoy the one event we attended. It’s a case of I can do this if I don’t do that - having to cut things out in order to enjoy something else.

This juggling of how you spend your energy was often explained using ‘spoon theory’ where you start the day with a set number of spoons, everything you do from waking takes away spoons and you have to decide how you spend them so you don’t run out. Sometimes you store extra spoons by not using them up on previous days, but it always comes with payback in the form of PEM if you do. Now I find there is a better analogy which explains energy levels and expenditure in the form of a battery and it’s charging ability. In brief this is how it works, a person with ME has a dodgy battery compared to a healthy person.



So when you set it to charge (when we rest and sleep) it never reaches full charge, usually a good rest or sleep will charge it to a maximum of 75%. Throughout the day your battery is drained bit by bit with every small thing you do, remember you start with a battery of 75% charge and “normal” people have 100% battery. During the day a person with ME finds that their battery drains much faster than their well counterpart, the same activity may cause a 10%

battery drain on a ME sufferer but only 1% drain on a well person. This means you have to weigh up your options each and every day and prioritise what you want to do in order to not drain your battery fully before the end of the day. To help with this you can take intermittent rests to try and boost and recharge the battery a little in order to do this, but it means each and every day a ME sufferer has to compromise what they want to do with what they can realistically achieve. Sometimes, it is tempting to add a battery boost pack and do that extra something special that means a lot to you, but sadly this results in serious battery recharging issues, so the next day instead of having a 75% charged battery you find it’s only at 50% - keep pushing it and it will take longer and longer for the battery to charge.



Finally, in my search for information, I also found this...

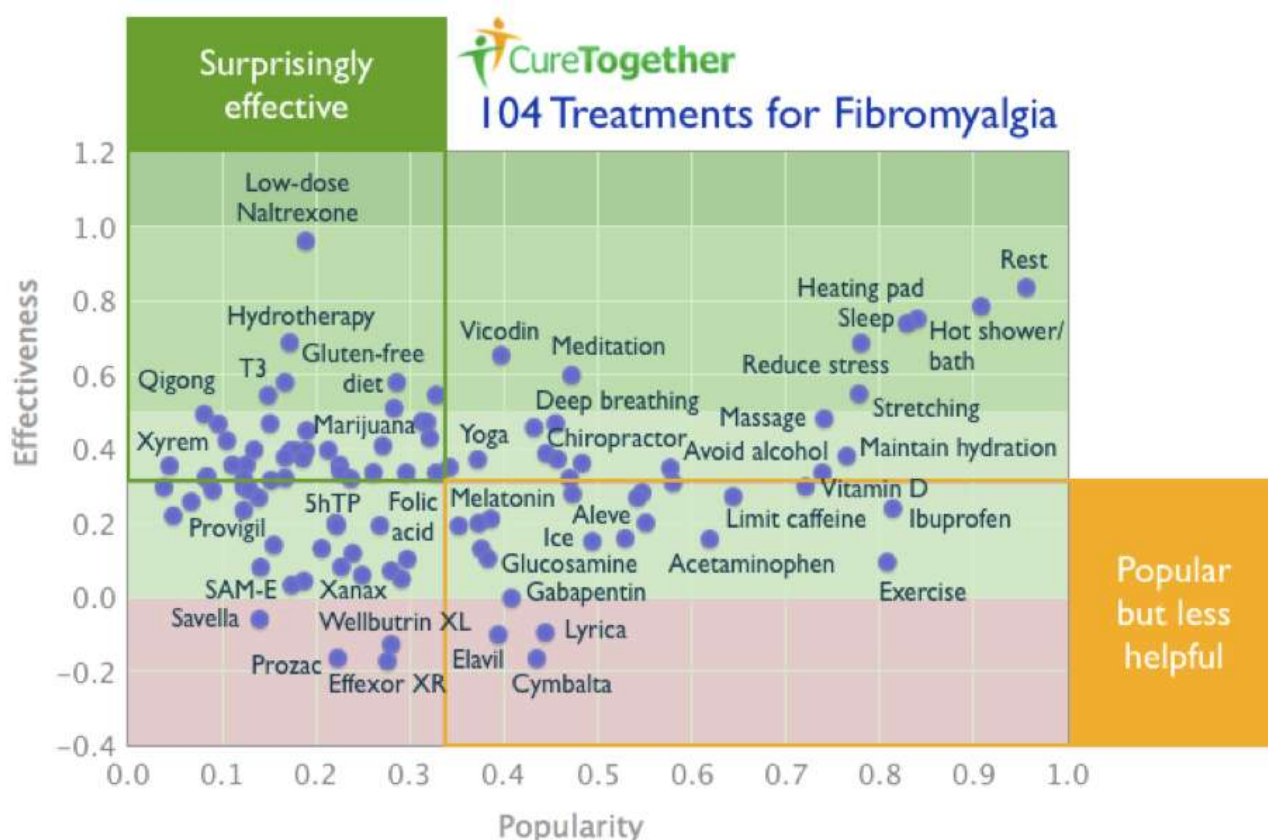


“Post-exertional malaise (PEM), or post-exertional symptom exacerbation, describes a delayed and significant exacerbation of ME/CFS symptoms that always follows physical activity and often follows cognitive activity. PEM is a highly characteristic clinical and diagnostic feature of ME/CFS. In some respects, PEM is an illness within an illness with some studies indicating that the immune system and autonomic nervous system are involved.”



## What Patients Say Works For Fibromyalgia

By Alexandra Carmichael, Co-Founder of CureTogether



In a surprising finding, patients who live with the painful disorder fibromyalgia have reported that commonly prescribed drugs for this condition actually make their symptoms worse. This is according to a new study by CureTogether, a free resource owned by 23andMe that allows people to share information about their health and treatments.

Fibromyalgia affects at least 5 million Americans, according to the Centres for Disease Control. The disorder is characterized by musculoskeletal pain, and other symptoms including fatigue, disrupted sleep, as well as depression. Researchers believe that fibromyalgia amplifies painful sensations by affecting the way a patient's brain processes pain signals. The condition is poorly understood, so finding accurate recommendations on treatments can be challenging. In the CureTogether study, researchers asked 1,401 people suffering from fibromyalgia to rate the effectiveness of 104 different treatments. Participants shared information about their symptoms as well as what treatments worked best for them.

### Most Effective Rated Treatments for People with Fibromyalgia

1. Low-dose Naltrexone (LDN)
2. Rest
3. Hot showers/baths
4. Heating pads
5. Getting enough sleep
6. Hydrotherapy
7. Vicodin
8. Reduce stress
9. Meditation
10. Gluten-free diet

People in the study said they found that lifestyle changes like rest, heat, and various ways of reducing stress offered the most effective relief. In addition, many of those surveyed said that the drug Naltrexone at a low dose worked well. Conversely, well-known fibromyalgia drugs such as Lyrica (known as Pregabalin in the UK), Savella (Milnacipran), Cymbalta (Duloxetine), and Effexor (Venlafaxine), were reported to worsen rather than improve patients' symptoms. Other drugs on the chart also are known by different names in the UK Aleve: Naproxen, Provigil: Modafinil, Xana: Alprazolam, Elavil: Amitriptyline

## How to access LDN

After reading this about LDN, hearing from our Fibromyalgia speaker in December and reading little bits about the benefits of LDN over many years I decided it was time to give it a try. It is available in the UK, but unlikely that your GP will know about it or be willing to prescribe it for you. Mine certainly wouldn't for me. After researching it I discovered it is manufactured in Glasgow by a local pharmacy chain. They will put you in touch with a Glasgow clinic who can give you a telephone consultation by a private doctor. The doctor's consultation cost £35 which includes a 3-month private prescription. Each month's medication costs £20 delivered.

This should not be taken as a recommendation of the drug, the doctor or the suppliers. It is far too early for me to say whether it is working for me personally but I will update you on my experience of it in the next newsletter.

[www.dicksonchemist.co.uk](http://www.dicksonchemist.co.uk) 0141 404 6545

[www.clinic158.com](http://www.clinic158.com) 0141 357 7357

[www.ldnresearchtrust.org](http://www.ldnresearchtrust.org) 01223 926933

*Craig Woods*

## Leaflets and contact cards

Our leaflets, issued with the previous newsletter, have been supplied to libraries and through the Locality offices to health care centres and hospitals across the region. Have you seen them?

We know one was spotted recently in the X-ray Dept at DGRI.

If there are none on display in your health centre, perhaps you could ask about them?

Let us know if you would like more to distribute locally.



We have also produced contact cards and supplied these to pharmacies across the region to display by their counters, and they will be distributed to all GPs, for handing out to sufferers who are not yet aware of us and to those newly diagnosed.

## Gifting

If you would like to help us with our costs, but would prefer to give a small monthly amount rather than donate to our 'Gift Day' in the autumn, then you could set up a standing order to our bank: Bank of Scotland, sort code 80-06-11 account no. 00114884 with your name as the reference detail. Thank you.

### 30 Years

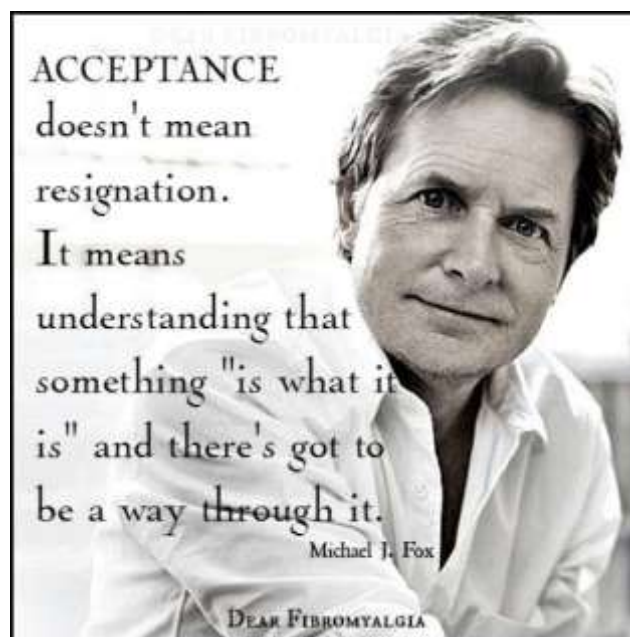
Today, as I write this, I'm acknowledging an anniversary. No, not the 65 years on the throne for our Queen, no, this is not one I am celebrating - certainly not. This year brings a few landmarks for me. I will turn 40 in September, in May I will have lived 20 years in my cottage, but today I have been ill for 30 years.

Unlike for many, I have a definite start date to my ME. It was the first Monday in February when I awoke with the worst headache I'd known. I had to take the day off school, it eased, and I returned on Tuesday, but on Wednesday it was back and as bad, if not worse, than the Monday morning. The other symptoms developed over the coming days and weeks and that was it for me. Tests showed that I had Coxsackie B, a polio virus in my system. It was suspected as being the trigger, and interestingly, post-polio syndrome has the symptoms to ME and was considered as one of the early names. I'd also had bronchitis before, and I hear, anecdotally that it can often precede ME. My symptoms changed somewhat around the 3 year mark, which ties with recent research done in America by Prof Hornig which shows an acute (which you're more likely to recover in) and a chronic phase, but after that the die was cast.

There have been many downs and some ups too. My teenage years and most of my twenties I was in a horrendous amount of pain and very fatigued, to the point of barely being able to leave my bed, at some points, never mind the house. There have been many hard learned lessons over the years in how to manage exertion to reduce pain and increase activity, but in the last 10 years or so, with the help of some medication, but mostly pacing, I am in a better condition and life is much more tolerable and even enjoyable.

Anniversaries like this have a way of making one reflect on the past. It's not something I'm bitter or angry about. I came to an acceptance of the ME roughly 6 years in. At that point I stopped battling it, and stopped allowing myself to be subjected to all the quack cures my parents had read about or were told about. It was a battle which I could never have won, and, instead, I started learning how to outwit it, how to make the energy last longer, while minimising pain. I was so much happier. The depression which had developed was replaced with a determined acceptance. The frustration was still there, and that will never go, but it was greatly diminished once I'd factored in my limits to any calculation about what was possible to achieve.

Please forgive my self-indulgence in writing this. I realise the thought of being ill so long is a terrifying one.



I want you to know that if it is for the long term it doesn't have to be awful. It is something you can learn to adjust to and to cope with – although it takes an almighty amount of patience and the help and support of those around you. I have optimism that, Wesseley school aside, the answer is getting closer. Technology, and quality research, is going to be our saviour - and it's closer now than it has ever been. Be optimistic – realistic, yes, but I think it's safe to have optimism too – and that's not something I'd have ever thought possible to say after all these years.

*Craig Woods*

## **Fibromyalgia Action UK**

The guest speaker at our December get-together was Hazel Borland, administrator with FMA UK. She spoke about her own experiences of living with Fibromyalgia for 23 years, 12 of which she was told it was in her head, she was being neurotic and to get back to work. Hazel explained there are areas where support is good but still a lot of areas where it isn't. Since being medically retired she has been involved with volunteering and setting up local support groups. She described how FMA UK had been established and its aims - to raise awareness about Fibromyalgia, and to give support and information to people with Fibromyalgia; and she spoke about the support they currently provide to over 200 groups and to local help-lines. She went on to answer questions from members which covered topics including research, physiotherapy, advice to health professionals, medication, hereditary pre-disposition, self-management strategies, support to carers, and alternative therapies.

Her concluding important do's and don'ts:

### **What should you do?**

- The most important thing is pacing, get yourself out of pushing yourself too hard.
- Try to do some sort of activity or exercise, which could even be completed in bed.
- Be gentle on yourself, we beat ourselves up because we can't do things. Accept your limitations.

### **What should you not to do?**

- Don't crash and burn.
- Try not to lose hope and go into despair.



For a fuller account of her talk and the discussion see our website homepage or follow the link: <https://tinyurl.com/js2a63j>

## **Host your own meeting**

Please remember this is a Network – if you'd like a meeting locally where committee members are unable to host, could you organise it yourself? We'd be happy to promote it and share it with Network members.

**WhatsApp Messenger** is a free download for mobile phones. WhatsApp uses your phone's Internet connection to let you message and make calls. You can now message or call us on the Network's mobile number for free by using WhatsApp if you are connected to Wi-Fi or are using your included mobile data allowance.



## Metabolic switch may bring on chronic fatigue syndrome

*Chronic fatigue syndrome seems to be caused by changes in the body's metabolism*

*By Andy Coghlan article published in New Scientist magazine, 13<sup>th</sup> February 2017*

It's as if a switch has been flicked. Evidence is mounting that chronic fatigue syndrome (CFS) is caused by the body swapping to less efficient ways of generating energy.

Also known as ME or myalgic encephalomyelitis, CFS affects some 250,000 people in the UK. The main symptom is persistent physical and mental exhaustion that doesn't improve with sleep or rest. It often begins after a mild infection, but its causes are unknown. Some have argued that CFS is a psychological condition, and that it is best treated through strategies like cognitive behavioural therapy.



But several lines of investigation are now suggesting that the profound and painful lack of energy seen in the condition could in many cases be due to people losing their ability to burn carbohydrate sugars in the normal way to generate cellular energy.

Instead, the cells of people with CFS stop making as much energy from sugar as usual, and start relying more on lower-yielding fuels, such as amino acids and fats. This kind of metabolic switch produces lactate, which can cause pain when it accumulates in muscles.

Together, this would explain both the shortness of energy, and why even mild exercise can be exhausting and painful.

**Sex differences** Øystein Fluge of Haukeland University Hospital in Bergen, Norway, and his colleagues studied amino acids in 200 people with CFS, and 102 people without it. The levels of some amino acids in the blood of women with CFS was abnormally low – specifically for the types of amino acid that can be used by the body as an alternative fuel source.

These shortfalls were not seen in men with CFS, but that could be because men tend to extract amino acids for energy from their muscles, instead of their blood. And the team saw higher levels of an amino acid that's a sign of such a process.

"It seems that both male and female CFS patients may have the same obstruction in carbohydrate metabolism to energy, but they may try to compensate differently," says Fluge.

Both sexes had high levels of several enzymes known to suppress pyruvate dehydrogenase (PDH), an enzyme vital for moving carbohydrates and sugars into a cell's mitochondria – a key step for fully exploiting sugar for energy. Fluge thinks PDH is prevented from working in people with CFS, but that it can spontaneously recover.

**Starvation effect** Several studies have now hinted that defects in sugar burning can cause CFS, but there is still uncertainty over how exactly this is disrupted. However, a picture is emerging.

Something makes the body switch from burning sugar to a far less efficient way of making energy.

"We don't think it's just PDH," says Chris Armstrong at the University of Melbourne in Australia, whose research has also uncovered anomalies in amino acid levels in patients. "Broadly, we think it's an issue with sugar metabolism in general."

The result is not unlike starvation, says Armstrong. “When people are facing starvation, the body uses amino acids and fatty acids to fuel energy for most cells in the body, to keep glucose levels vital for the brain and muscles as high as possible.”

“We think that no single enzyme in metabolism will be the answer to CFS, just as no single enzyme is the ‘cause’ of something like hibernation,” says Robert Naviaux of the University of California at San Diego, who has found depletion of fatty acids in patients suggesting they were diverted as fuel.

**Not psychosomatic** So what could flick the switch to a different method of metabolism? Fluge’s team thinks that a person’s own immune system may stop PDH from working, possibly triggered by a mild infection.

His team has previously shown that wiping out a type of white blood cell called B-cells in CFS patients seems to relieve the condition. These white blood cells make antibodies, and Fluge suspects that some antibodies made to combat infections may also recognise something in PDH and disable it.

The team is now conducting a large trial in Norway of the cancer drug rituximab, which destroys the cells that make antibodies, in people with CFS. Results are expected next year.

Together, these metabolic approaches are suggesting that CFS has a chemical cause. “It’s definitely a physiological effect that we’re observing, and not psychosomatic, and I’ll put my head on the block on that,” says Armstrong. However, he adds that psychological and brain chemistry factors might be involved in some cases.

### Donation from Tesco

We were pleased to welcome Anne Croucher, Community Champion with Tesco, to our monthly get-together in February, where she presented us with a £100 donation from Tesco towards our running costs. Anne first came to our meeting last November to find out about our Network, and to see how she could help us as part of her work serving the community. Anne has also booked us in to the Cuckoo Bridge store in Dumfries for an ME/Fibro awareness raising event on May 12<sup>th</sup>.



Phone or WhatsApp: 07437 602610  
Website: [www.dgmefm.org.uk](http://www.dgmefm.org.uk)  
Facebook: [facebook.com/groups/dgmefm](https://facebook.com/groups/dgmefm)  
Email: [craig@dgmefm.org.uk](mailto:craig@dgmefm.org.uk) (Chair)  
[kim@dgmefm.org.uk](mailto:kim@dgmefm.org.uk) (Secretary)  
[paul@dgmefm.org.uk](mailto:paul@dgmefm.org.uk) (Treasurer)