

Pathways

Price £ 3.75 (Free to members)

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

Welcome to Pathways 46 (Christmas 2015 Edition)



The Fountain at Lakeside Doncaster

You Write

Carolyn Writes regarding Vitamin D. I have been taking Fultium-D, 800 IU capsules each day since May this year and the doctor now wants me to have a blood test to see if the levels are back up to normal now. He thinks they should be and that I can then stop taking the tablets. I told a friend who also has M.E. about this and she wrote the following back to me. My question is, is what she has said true and if so, what other supplements should be taken with the Vitamin D to ensure it gets to the bones?

A friend wrote: I think you really should have the Vit D test again. That way you can see if it has benefitted you. I can't remember what you were taking...was it 800i.u? I seem to remember saying that's what the RDA is now for over 70, Even that is woefully low. It's really, really important to take other supplements with the Vit D as well otherwise it only serves to deposit the calcium in your arteries and not in your bones Doctors are dreadful for prescribing things without giving the whole picture...I get so cross when they hand out calcium tablets willy nilly, but don't tell people that you must take the same amount of magnesium in order for the calcium to be absorbed, all these things work synergistically. The trouble is that unless you eat masses of organic seeds and kale you won't actually eat magnesium...because with modern farming methods and farmers fertilizing their fields with high nitrogen fertilizers, the greens may look good but they no longer contain the minerals and vitamins we need. The figure used to be 50% magnesium to calcium, but they now realise that's too low for the reasons I've just mentioned. I can remember seeing patients prescribed calcium and finding lumps of it in their muscles....and spots of it on their faces, and of course doing nothing for their bones!

You can actually take too much Vit D2, but D3 is better and not toxic in large amounts. To reap all the other Vit D benefits you do need huge amounts. Oncologists for instance recommend something like 6,000 - 10,000 iu just as a preventative. To utilize the Vit D you must take magnesium, preferably 400mg and the best is magnesium glycinate, which is the most bioavailable and doesn't upset your tummy, most companies use magnesium oxide which is pretty useless. Magnesium citrate is better but not if you have tummy problems as it can act like lots of Vit c. Plus, and this has been widely studied over the past couple of years, an amino acid now called Vit K is the last piece of the jigsaw, to make your Vit D and calcium go where it's needed. Again there is Vit K and Vit K! The best is made from a product called Natto and is called VitK Mk 7.

By the by... I take Vit D3, 5,000 i.u in a soft gel capsule which contains organic olive oil, because you should always take your Vit D with fat, plus magnesium gluconate 500mg and VitK-MK7 200ug. I cut back on the Vit D in the summer when I am spending lots of time out of doors, but even so, with covering my arms and reactolite lenses I wouldn't think much gets through. Even in a country like India they consider 1,000 iu a day far too low. Did you know that in countries like Australia where everyone smothers themselves in high factor sun creams the rates of osteoporosis (and depression) have become a major, major health problem. Ho hum! Nutrition lecture over!

I've covered this topic of Vitamin D later in this issue in more depth. Vitamin D2 is the inactive form found in many plant sources and needs to be converted to the active form D3 via the action of sunlight & metabolism. Excessive amounts can block the conversion D2 to D3. The Barnsley NHS target level 60-90 nmol/l which I think is the minimum level for ME/CFS. Levels of over 120 nmol/l are considered the upper limit which corresponds around 20,000iu per day. I've heard of doctors declining to test vitamin D levels because of believed cost. I think this is a load of rubbish because the wholesale price of the laboratory test is around £3. There is a relationship between Magnesium and ME/CFS. This is what Dr Myhill wrote

I have struggled for over twenty years to try to make sense of red cell magnesium tests. I actually now believe that a low red cell magnesium is a symptom of mitochondrial failure. It is the job of mitochondria to produce ATP for cell metabolism and about 40% of all mitochondrial output goes into maintaining calcium/magnesium and sodium/potassium ion pumps. I suspect that when mitochondria fail, these pumps malfunction and therefore calcium leaks into cells and magnesium leaks out of cells. This, of course, compounds the underlying mitochondrial failure because calcium is toxic to mitochondria and magnesium necessary for normal mitochondrial function. This is just one of the many vicious cycles we see in patients with fatigue syndromes.

There is more on her website: [http://drmyhill.co.uk/wiki/Magnesium - treating a deficiency](http://drmyhill.co.uk/wiki/Magnesium_-_treating_a_deficiency)

Bill Writes: As I live in a remote part of north Nottinghamshire and can't get to the Redmond Centre, I've found a firm of solicitors who will fill out the PIP form and it only costs £50 which I can afford and they will do it all over the phone. They tell me that the person who I will be dealing with has a law degree. I just thought that it would be of interest to your members,

Hi Bill, something doesn't sound right about this service. Over the years I've done plenty of DWP forms, and can't see how a firm of solicitors can charge that amount of money for a service and give a reliable service. Certainly Solicitors time costs from in the region of £100 per hour. Usually solicitors work with a software package from people like the Law Society, and ask a series of questions which are logged into a computer. A button is pressed and the form is printed out and will most likely be sent for you to sign. There are plenty of organisations who can fill forms out in this way but very few have our experience and insight into ME/CFS like we have. What happens if you get a refusal? Do you have to pay more out for an appeal? Does the firm have any insight into ME/CFS, particularly someone with health qualifications? We would be very interested to hear how you get on and how things work out. For your comparison here is the way we would go about filling in a form. It's a service available to fully paid up Leger ME members. Here is what we do:-

Firstly we carry out a case review. Its aim is to find out more about your health, welfare management, needs of your condition, help identify your current needs and review how they are being managed. It is also to help ensure that you get all the help and support that is available to you and to try and identify any future problems that may arise. The case review is a report that we give to you and can be used in any way you wish.

Once the case review is complete the information gathered is used to help draft the form prior to filling out, explain any issues that many arise from the form fill out service, and to provide additional information that is available to you from other sources. We also try to identify any future problems that may arise. There is no guarantee about the outcome of this service. The DWP check all information you provide and compare it with their own sources of information and advice which is outside our control. Assumptions are often made if the information is insufficient which may be go against your interest.

Over the years, we've also found that the following criteria need to be met. Firstly a record of the last appointment with your G.P. and make sure it is less than 3 months ago. A copy of the Summary Sheet or NHS Patient Summary Record from your G.P. Surgery, list of interventions, medicines (conventional & alternative) you are currently taking irrespective of supplier. A copy of results of any tests e.g. blood or other diagnosis tests at the G.P. surgery or hospital. Overall to do the job to our standard it takes around four hours, very often in several sessions. We also provide the relevant Benefit and Work Guides to cross check the final draft.

Pam Writes I didn't need your help to fill out the form, as I have a friend who is a law student to fill it out for me. The problem is I have been refused, and the overall impression I get is they seem to think I don't look ill. Can you help me with the appeal?

I'm sorry Pam, but the answer is I can't even though you are with Leger ME, but privately, yes at £50 per hour! You need to go back to your friend who is a law student and get him to sort the appeal out since he started it. If you bring all your paperwork to a Leger ME meeting at the Redmond centre we can look through it and usually work out what has gone wrong. This service is free and you don't have to be a member. The only other thing I can do is send you the relevant Benefit and Work Guides as you are a Leger ME member. Once you have a tribunal decision and the case has finished, come back to us and we'll have a look at submitting a new application.

As a rule we will not help people with an appeal when we have not been involved with the initial fill out. It would be totally wrong for us to do that, and that certainly applies to other similar service providers. What we have found over the years is that you could say for example that the moon is made of green cheese on the form, but you have to back it up with evidence if the DWP are going to accept it. For the DWP to believe what you say, everything has to have a track record and be in context. As well you have to go along with the whims and ways and that includes any medical examinations and home visits.

Chair Yoga - Amanda Hoff- Yoga Instructor at the Redmond Centre

Yoga is a practice designed to promote a state of physical and mental wellbeing or good health. Yoga helps to improve and maintain flexibility, particularly in the spine. Yoga tones and rejuvenates the nervous system. The gentle stretching, twisting and bending movements bring flexibility to the joints and muscles as well as massaging the glands and organs. Circulation is improved ensuring a rich supply of oxygen and nutrients to all the cells of the body.

The steady postures or Asana's free the mind from disturbances caused by physical movement promoting steadiness of mind, balancing the emotions and improving your outlook on life. The benefits of yoga are more subtle than many other forms of exercise or therapy, to benefit you must practice yoga regularly over a period of time, but once you feel the benefits they will last much longer! The many different postures purify and strengthen the bodies systems. Alongside Asana, the yoga breathing techniques or 'Pranayama' can improve concentration and clarity of thought, increase your ability to deal with complex situations, reduce stress giving better emotional control and equilibrium as well as improving physical control and coordination.

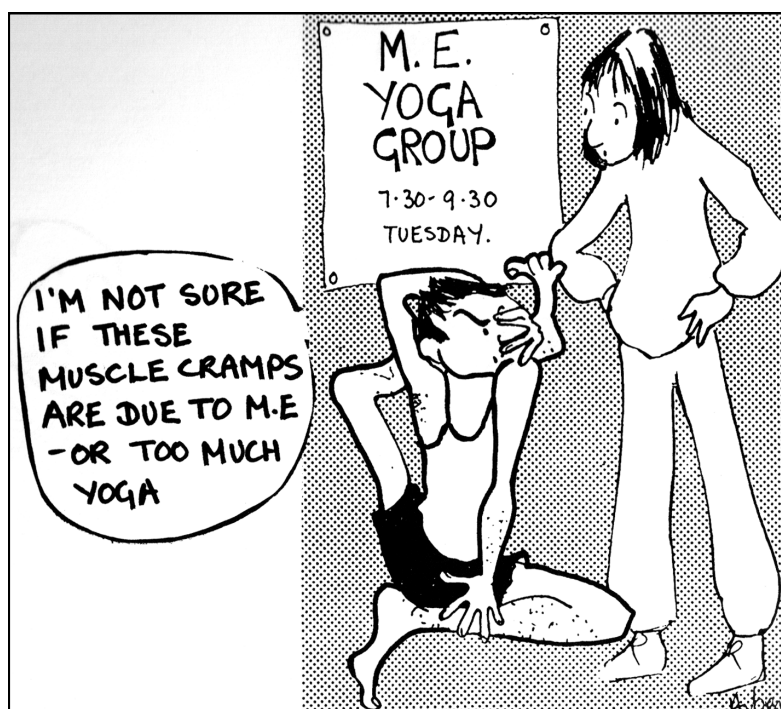
The meditation and relaxation techniques enable the muscles to relax and help to still the mind. Our minds become overloaded and exhausted when constantly bombarded by stimuli. Meditative techniques help to still the mind, reducing mental fatigue which (in some cases and over a prolonged period of time) can manifest as physical problems or illness. It is important to set aside some time each day to allow the mind to unwind and recoup its energies.

The combination of Asana (posture), Pranayama (breathing) and meditative techniques can have a profound effect on the body and mind when practised regularly, improving balance and coordination, helping concentration, building flexibility and improving physical strength as well as reducing stress and promoting peace of mind. Yoga is great for all levels of ability, as unlike many other exercise systems it can be modified and adapted to suit the individual's needs regardless of age, size or physical ability. Chair yoga is good for anyone with balance problems or poor mobility. Each posture can be adapted in a large number of ways to suit the individual and ensure they get the very best out of their practice.

The Redmond Centre Yoga for ME Taster Sessions: Your Feedback

Leger ME funded the instructor's fees, and the Redmond Centre funded the room hire charges. At the Redmond Centre, there is already a pensioner Yoga class. I asked if Amanda the instructor had noticed any difference between the people who attended with ME as opposed to the older end group she deals with at the Redmond Centre. She told me that there is a big difference between the two groups! The pensioners have various problems and there is a wide variety of abilities in the group (there are about 16 of them). Some can do very little and just sit and do the breathing and meditations, others sit in chairs and do what they can and a couple of them are as good as the instructor herself!!

Amanda stated "the ME group all seem to have similar difficulties such as balance and coordination, but I can adapt the poses for this. I also noticed that short sessions of postures work better with relaxation sessions in between, so I am learning a lot! The more I work with the group the more I will be able to adapt to their needs." I understand that Amanda was surprised just how little people could do, and found it necessary to repeat instructions because some people had some difficulty in remembering exactly what she had instructed. That of course is not a surprise for people with ME/CFS. At the time of writing steps are being taken to obtain a grant from DMBC to continue the classes in 2016.



What is important is how other participants found the sessions. Altogether eleven different people attended the sessions/

Here is what Susie W wrote:

"I have been unable to exercise for the past 28 years. Amanda (the yoga instructor) tailored her classes to each individual's capabilities, whilst understanding the importance of not pushing beyond one's limits. Even the most severely affected can benefit from these classes. It was a useful mixture of yoga (I do the floor based activity) meditation and breathing. The three methods provide a good mind/body workout that I can manage and I can take away and do at home. It is a very emotional experience for me, as I feel as though I am doing something positive to help my health."

"I found the yoga class very beneficial, the movements are so flexible can be done standing, sitting or lying down. I thought the meditation and breathing exercises were so relaxing and also very useful for my anxiety. It's only a small group at the moment but very friendly and I'm sure the numbers will rise when the group is more established, to Amanda for having with us, you're a great teacher. "

Here are John's comments:

"I quite enjoyed the sessions and found them useful. Previously I attended free sessions at the Dome; however, I had difficulty with what I could do, and paybacks afterwards. With Amanda's session I was able to take part and fully participate. I'm just disappointed that we didn't get a better attendance and some people who attended on previous sessions did not attend. We all got together and decided we should try and form a specific group to continue and to apply for a grant. We also thought that we should contribute £3 towards each session for future sessions"

Susie S wrote:

"November was the first yoga session I had managed to attend because of having a number of recurrent infections over the past two months. I tried the seated yoga as I have problems with my lumbar and cervical spine as well as CFS, which makes getting down on the floor and back up again extremely difficult. I started out with the resistor bands but soon discovered this was too much for me because of the back problems. Although I found the session incredibly tiring it did feel good to be doing some form of exercise again. I enjoyed the meditation sessions immensely and already practise daily guided meditations as a form of relaxation and to still those ever intrusive thoughts that I find myself bombarded with! Well done Amanda for her speedy adaptation to each of our individual needs"

The Final Word

From 'Living with ME' by Dr Charles Shepherd, Medical Director of the ME Association.

- Some patients also find yoga beneficial, but do take guidance from an experienced teacher, and stick to positions which are not too fatiguing.
- In the end it all comes down to listening to what your body is telling you. If you're going through a good patch don't overdo it, but gradually try to increase your activities on a day-by-day basis.
- Don't push on at a faster pace than you can adequately cope with, or you'll just end up relapsing again.



Recipe Corner by Carolyn**Leftover Turkey Banh Mi**

No apologies for this one which comes from Jamie Oliver as these crispy meat, pâté and pickle filled baguettes are scrumptious.

Serves 4, cooks in 20 minutes, super easy to do.

Per serving: Calories 592, Fat 17g, Saturates 4.8g, Protein 30.6g, Carbs 84g

Ingredients:-

Olive oil
 190g leftover cooked turkey, preferably brown meat
 1 lime
 2 tablespoons sweet chilli sauce
 2 medium baguettes
 1 clove of garlic
 3 cm piece of fresh ginger
 Sea salt
 Extra virgin olive oil
 2 tablespoons Hellmann's mayonnaise
 ½ a small bunch of fresh coriander
 1 carrot
 ¼ of a cucumber
 ¼ of white cabbage
 Sesame oil
 1 teaspoon low-salt soy sauce
 1 tablespoon white wine vinegar
 4 tablespoons leftover chicken liver pate
Optional:- 1 fresh red chilli

Method:-

Preheat the oven to 130C/250F/gas ½

Add a splash of olive oil to a large frying pan over a medium heat. Roughly shred and add the turkey (if you've got the skin, add that too) and cook for 2 to 3 minutes, or until warmed through. Grate in the lime zest and stir in the chilli sauce, then reduce the heat to low and cook for a further 2 to 3 minutes, or until crisp and slightly caramelised.

Meanwhile, place the baguettes in the oven to warm through. Peel and add the garlic and most of the ginger to a pestle and mortar, then bash to a smooth paste with a pinch of salt and 2 to 3 tablespoons of extra olive oil. Muddle in the mayo and the juice from the lime, then add in the coriander leaves and stir to combine. Set aside.

To make the pickle, peel the carrot, then coarsely grate and add to a large bowl along with the cucumber and cabbage. Peel, finely chop and add the remaining ginger, then sprinkle over a pinch of salt and scrunch together with your hands to get rid of any excess liquid. Add 1 teaspoon each of sesame oil, the soy and vinegar and toss well to combine.

Open out the warmed baguettes, spread the chicken liver pâté onto one side of each, then pile over the turkey and pickled veg. Finish with a dollop of lime-spiked mayo, then finely chop and scatter over the chilli (if using) along with the reserved coriander leaves. Press down slightly on the baguettes to close, then cut the banh mi into chunks and tuck in.



Disability Living Allowance (DLA) to Personal Independent Payment (PIP) Change Over. Thanks to Work & Benefits

There are no more new or renewal DLA claims being accepted. PIP has replaced DLA for people who were aged 16 to 64 on 8th April 2013 or reach age 16 after that date. If you are currently in receipt of PIP you do not need to take any further action until your award expires, however if you are in receipt of DLA depending on your circumstances you may have received a letter like the one on the right. It means that the DWP will be terminating your DLA claim at some point in the near future. This may happen because:

- The DWP will have received information there has been a change in circumstances and your award may not be at the right level. This could happen if someone contacts the DWP on your behalf like a doctor or social worker, you have had a DWP medical for another DWP benefit e.g. ESA or you are better or worse. At the time of writing this had happened to one Leger ME member.
- If your DLA award is a fixed term one and it will shortly end. You cannot renew it, you have to claim for PIP instead.
- If you have an indefinite award. We think that there will be a recall five years after the last renewal or when the systemic or random recall occurs. We understand that this started in October in our area — so it will happen to some Leger ME members sooner or later.
- As part of a random routine audit. We think that around one in every 50 cases are audited.

On the right are templates of letters sent to existing Disability Living Allowance (DLA) claimants, inviting them to begin a claim for the new Personal Independence Payment (PIP). If you received one like this, whatever the recall reason is, you need to act ASAP as you have less than a month to reapply, otherwise you could lose money. The first action to take is to contact us or, your welfare rights, if you prefer to use their service. Fully paid up Leger ME Members have access to Benefit & Work Guides and other Leger ME resources. I have dealt with the PIP forms and claims in earlier editions of Pathways. Please refer to these past issues.

- The basic payment rates for DLA and PIP are the same.
- The sort of awards that most Leger ME members have received are similar to what we would have expected from a DWP claim.
- The PIP criteria is different to that of DLA. In general, the ME/CFS has to be a grade 2 (moderate) or grade 3 (severe). If you have mild ME/CFS it is unlikely you would receive anything.
- You need to submit recent medical evidence and expect to be called to a medical examination.
- If you have a mobility contract hire car, there are transitional arrangements if you don't get the enhanced rate of mobility. See our previous advice about mobility cars.

Do not under any circumstances fill out a DWP form without the guidance of a Welfare Rights Advisor

If you contact us, use this reference:
[Ref Number] - PIP. 0201

Department
for Work &
Pensions

[Claimant Title/First Name/Surname]
[Claimant Address Line 1]
[Claimant Address Line 2]
[Claimant Address Line 3]
[Claimant Address Line 4]
[Post Code]

[Department]
[Office Address Line 1]
[Office Address Line 2]
[Office Address Line 3]
[Office Address Line 4]
[Post Code]

www.gov.uk
Telephone: 0845 XXX XXXX
Textphone: 0845 XXX XXX
DD Month YYYY

Personal Independence Payment
Important information for you - action needed

Dear [Claimant Title/First Name/Surname]

We wrote to you recently about how your Disability Living Allowance will be affected by Personal Independence Payment. We're now informing you when and how you can start your claim for Personal Independence Payment.

When do I need to start my claim?

You need to start your claim for Personal Independence Payment within 4 weeks from the date of this letter. If we don't hear from you by DD Month YYYY your Disability Living Allowance payments will be stopped temporarily.

How do I start my claim?

You can start your claim for Personal Independence Payment by phone on 0800 XXX XXXX. A telephone is available for people who do not speak or hear clearly on 0800 XXX XXXX. This will only take a short time. We'll only ask for some basic information including your:

- National Insurance number
- full address including postcode
- date of birth

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[Ref Number] - PIP. 0201

- bank or building society account details
- daytime contact number
- GP or other professional's details

If you think you'll have difficulty starting your claim please phone us as soon as possible on 0800 XXX XXXX. We may be able to give you more time to start your claim.

If you start your claim for Personal Independence Payment by <return date> your Disability Living Allowance will continue until we make a decision on Personal Independence Payment.

Personal Independence Payment may be the same, more or less than your Disability Living Allowance or not awarded at all. This could affect other benefits you may be entitled to.

What happens if I don't start my claim?

If we haven't heard from you by <return date> your Disability Living Allowance payments will be stopped temporarily. If you still don't start your claim for Personal Independence Payment after 4 more weeks your Disability Living Allowance will then be stopped permanently. If you tell us that you don't want to claim Personal Independence Payment your Disability Living Allowance payments will be stopped permanently.

What happens after I start my claim?

We'll send you a form so you can tell us how your condition affects you. If you think you'll need any help to complete the form you should arrange this as soon as possible.

Where can I find out more or get help and advice?

There's more information about Personal Independence Payment on www.gov.uk/PIP

You can also phone us on 0845 XXX XXXX. A telephone is available for people who do not speak or hear clearly on 0845 XXX XXXX.

We're open Monday to Friday 8.00am to 6.00pm.

If you phone us, please have your name, address and National Insurance number to hand.

You could also contact a local support organisation who can provide independent help and support. You can find their details online, your local library or telephone directory.

Yours sincerely

Office Manager.

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IB to ESA work capability assessment linked to almost 600 additional suicides
From Benefits and Work News

The reassessment of incapacity benefit claimants for employment and support allowance using the work

capability assessment is linked to an additional 590 suicides in England, according to new research by academics from Oxford and Liverpool universities. It is also implicated in an additional 279,000 people developing mental health conditions and 725,000 more antidepressant prescriptions being issued. On average there are six suicides for every 10,000 reassessments. The research has just been published in the Journal of Epidemiology and Community Health, a leading medical journal.

The researchers looked at suicide rates, cases of reported mental health problems and prescribing of antidepressants in 149 local authorities in England. They found a direct correlation between the number of IB claimants being reassessed for ESA and the number of suicides and people experiencing mental health issues. For every 10,000 claimants reassessed in each area there were an additional 6 suicides, 2,700 extra cases of reported mental health conditions and 1,020 more

antidepressant prescriptions issued. No other explanation was found. The researchers say they cannot prove a direct causal link, not least because the DWP refuse to publish clear data relating to claimant deaths, but they also say that it is likely that the reassessment process was the cause. They point out that the rises were not linked to the number of claimants in a particular area, to the levels of mental health or to incomes. Instead, the rises were only linked to a rise in reassessments from IB to ESA in any given local authority. In addition, when the researchers looked at groups of people in the same location areas who would not be affected by IB to ESA reassessment, they found that there was no corresponding rise in suicides, mental health problems or antidepressant use. The researchers conclude that:

"The programme of reassessing people on disability benefits using the Work Capability Assessment was independently associated with an increase in suicides, self-reported mental health problems and antidepressant prescribing. This policy may have had serious adverse consequences for mental health in England, which could outweigh any benefits that arise from moving people off disability benefits."

And, they warn that health professionals cannot just ignore the issue. They point out that:

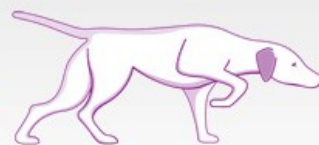
"Given that doctors and other health professionals have a professional and statutory duty to protect and promote the health of patients and the public, our evidence that this process is potentially harming the recipients of these assessments raises major ethical issues for those involved. Regulators and other bodies representing health professionals should advocate for the benefits and harms of alternative disability assessment policies to be established through a well-designed trial."

Legal action. Not surprisingly, the DWP have rejected the report out of hand rather than showing any hint of concern for the people they have a duty to provide support to; but refusing to even consider the possibility that the WCA causes harm, in the face of growing evidence to the contrary, may have consequences. The last few weeks have also seen the revelations that a coroner's prevention of future deaths letter relating to the WCA in 2010 was illegally ignored by the DWP. The department also withheld details of the letter from Professor Harrington, the independent reviewer of the WCA.

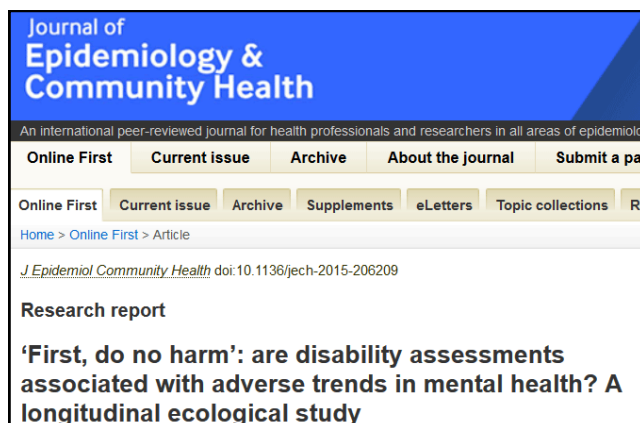
In addition, the DWP appears not to have issued a reminder to health professionals to follow proper procedures relating to potentially suicidal claimants, having said they would do so in response to another prevention of future deaths coroner's letter. We may now be reaching a point where DWP staff, health professionals and government ministers are opening the door to legal action being taken against them for their part in the preventable deaths of many hundreds of sick and disabled claimants.

Do not under any circumstances fill out a DWP form without the guidance of a welfare rights advisor

Benefits and Work Guides you can trust



Benefit and Work guides are available to all Leger ME members. Please email mike@leger.me.uk



Influenza and Flu-like Illness, Flu vaccinations; the General Consensus.

With thanks to Patient UK

Many viruses can cause a flu-like illness. There is usually a seasonal outbreak of flu (influenza) in the UK each winter. Flu-like illnesses typically cause a high temperature (fever), aches and pains in muscles and joints, a cough and various other symptoms. Most people recover fully but complications such as pneumonia can sometimes develop. Complications are sometimes serious. Every year some people die from the complications of flu. If you are at increased risk of developing complications, you should have a flu jab (be immunised against seasonal flu) each autumn.

How do you catch flu?

Flu (influenza) is passed from person to person by droplets created when someone with the infection sneezes or coughs. You can also catch it by touching a surface where the virus has been deposited. Flu can spread quickly in these ways.

What are flu symptoms (or flu-like illness symptoms)?

Common flu (influenza) symptoms in adults and older children include:

- High temperature (fever), Sweats,
- Aches and pains in muscles and joints
- A dry cough,
- Sore throat,
- Sneezing, Headache,
- Feeling sick (nausea)

The illness caused by the influenza virus tends to be worse than illnesses caused by other viruses which cause a flu-like illness. Even if you are young and fit, flu can make you ill enough to need to go to bed. Typically, symptoms are at their worst after 1-2 days. Then they usually gradually ease over several days. An irritating cough may persist for a week or so after other symptoms have gone. Most people recover completely within 2-7 days.

Alarm symptoms

Symptoms to look out for which may mean that you have a different and more severe illness include:

- Rash - in particular if dark red spots develop that do not fade when pressed.
- Stiff neck - particularly if you cannot bend your neck forward.
- A headache that becomes worse and worse.
- Dislike of bright lights - if you need to shut your eyes and turn away from the light.
- Drowsiness and/or confusion.
- Repeatedly being sick (vomiting).
- Chest pains.
- Coughing up blood or blood-stained phlegm (sputum).
- Coughing up green or yellow phlegm

General treatment Measures

Stay at home as much as possible to prevent passing on the infection. Paracetamol and/or Ibuprofen can lower your temperature and also ease aches and pains. Drink plenty of fluids to prevent lack of fluid in the body (dehydration). It is best not to smoke. Decongestant drops, throat lozenges and saline nasal drops may be helpful to ease nose and throat symptoms.

What are flu and flu-like illnesses?

Flu (influenza) is caused by the influenza virus. However, many other viruses can cause an illness similar to flu. It is often difficult to say exactly which virus is causing the illness, so doctors often diagnose a flu-like illness. There are three types of influenza virus - A, B and C. Influenza A and B cause most of the cases of flu. Each winter a different type of influenza virus causes an outbreak of flu which affects many people. This is called seasonal flu. If you get a flu-like illness during an outbreak of seasonal flu, it is likely to be caused by the prevailing influenza virus. Most cases of flu usually occur in a period of six to eight weeks during the winter. Swine flu is caused by a particular strain of influenza A virus which is called H1N1v. It seems to affect children and young adults more commonly than those over the age of 60 years. Most people with this type of flu have a mild flu-like illness.

You are more likely to have sickness and/or diarrhoea with this type of flu.

Who should be immunised against the seasonal flu virus?

Seasonal flu is the strain of influenza virus that arrives in the UK each autumn. The actual strain varies from year to year. A new vaccine (often called the flu jab) is developed each year to protect against the strain that is most common that year. The flu vaccine will protect 7- 8 out of 10 people against infection with flu. It takes up to 14 days for full protection to be reached after having the vaccine. This protection lasts for around one year. The flu vaccine has also been shown to reduce the risk of developing a complication from flu, especially in the elderly. The Department of Health (DH) issues advice on who should be immunised. This is reviewed from time to time. The aim is to protect people who are more likely to develop complications from flu. Current advice is that you should be immunised against the seasonal flu virus each autumn if you:



- Are aged 65 or over.
- Have any ongoing (chronic) lung diseases, e.g. asthma (needing regular treatment)
- Have a chronic heart disease, e.g. angina, heart failure or if you have ever had a heart attack.
- Have a serious kidney disease, chronic kidney disease, a kidney transplant.
- Have a serious liver disease such as cirrhosis.
- Have diabetes.
- Have a poor immune system, e.g. on chemotherapy or steroid treatment
- HIV/AIDS
- Have had your spleen removed.
- Neurological diseases e.g. multiple sclerosis or stroke
- Live in a nursing home or other long-stay residential care accommodation.
- You should be immunised if you are the main carer for an elderly or disabled person.
- Staff who work in care and nursing homes.
- Staff involved in direct patient care.

The role of antimicrobial agents.

Antiviral medicines called oseltamivir (Tamiflu®) and Zanamivir (Relenza®) are sometimes used. They need to be given immediately and can reduce the risk of developing complications and reduce the severity and duration of symptoms by a day or two. Doctors have to justify their use, and usually limit them to people with chronic illness or disease.



Antibiotic medicines. Antibiotics kill germs called bacteria, but not viruses. Therefore, they are not routinely prescribed for viral illnesses such as flu or flu-like illnesses. However, they may be used if a complication develops like a chest infection caused by a germ (bacterium) or pneumonia.

The most common complication is a chest infection caused by a germ (bacterium). This may develop in addition to the viral infection (that is, a secondary infection). This can sometimes become serious and develop into pneumonia. A course of antibiotic medication will often cure this. However, a bacterial infection can sometimes become life-threatening, particularly in those who are frail or elderly.

With flu it is common to have a cough that lingers for 1-2 weeks after other symptoms have gone. Green phlegm (sputum) does not necessarily mean that you have a secondary chest infection. The symptoms to look out for that may indicate a secondary chest infection include: recurrence of a high temperature (fever), worsening of cough, shortness of breath, fast breathing or chest pain. These need the attention of a doctor.

The following feature over the page is a specific feature about flu vaccinations and ME/CFS.

Vaccinations and ME/CFS.

Precis from Action for ME Interaction 57, Autumn 2006

To jab or not to jab?

Given that the immune system has been at the centre of suspicion for what may have 'gone wrong' to make us ill in the first place, whether or not to have vaccinations is a big decision for people with M.E. Our immune system has an inherent capacity to recognise foreign material (such as an infection or a flu jab), produce the appropriate defence molecules or antigens, and subsequently 'remember' this contact for decades. This means that antigens can be mobilised much quicker in the future should a similar agent enter the system again – in other words rendering us immune to the invading bacterium or virus.

Understanding the flu vaccine

However, as the influenza viruses change from year to year, a new flu jab is necessary annually in order for an individual to stay protected. The vaccine is made from two or three different, inactivated forms of the virus in order to protect people against those types of flu most common at the time, as decided by the World Health Organisation (WHO). Because the viruses chosen for the vaccine are inactivated, they cannot cause flu as such, although they may produce flu-like symptoms for up to 48 hours. According to the Scottish Executive Health Department, the influenza vaccine gives 70-80% protection against infection with any virus strains closely matching those in the vaccine. The chosen viruses are grown in poultry eggs and then killed ('inactivated') and purified. Normally some sort of preservative is added. There is also a version of flu vaccine produced by recombinant DLA technology which is egg free which may be helpful to those allergic to eggs..

Feedback on the flu jab: The good :

Of 20 people who wrote earlier this year to tell us about their experience with having the flu jab, 13 had no reaction at all or only minor ones (symptoms lasting less than a week). So nearly two-thirds of this very small group of respondents were reasonably okay having the flu vaccination. The decision about whether or not to be vaccinated is best made in the light of one's overall health and general circumstances. For example, in 2004 Linda had a very bad bout of flu leading to bronchitis, which left her with asthma and reliant on inhalers. She therefore decided to have a flu jab that autumn: "The injection was absolutely fine, as was the following year's; my doctor told me wisely to work out the odds! Asthma can be life threatening, so I had to go for it." Similarly Carolyn, who had also suffered with a nasty flu in previous years, decided to have the vaccination last November and was fine, too. The jab worked and she had a flu-free winter, leaving her resolved to have a flu jab every year from now on. Jane has had several vaccinations over the last eight years since getting M.E. and explains: "I haven't had any bad reactions – just the normally expected things like a sore arm or feeling slightly unwell for a couple of days."



And the not-so-good

Unfortunately, four respondents found that the flu vaccination provoked a marked flare-up in their M.E. symptoms, sometimes lasting months, while two others felt that having a flu jab actually contributed to the onset of their condition. "The vaccination had turned being ill with a 'nameless condition' into actual M.E.," explains one member. "At fourteen I had a flu jab. This precipitated a downward spiral that saw me become very disabled and ultimately receive a diagnosis of M.E." She then risked a second flu jab eight years later, triggering a deterioration which distressingly she hasn't pulled out of. Other readers who had experienced a bad time following a flu jab naturally felt that the months of much worse health outweighed any advantage offered by protection against catching flu.



All the M.E. specialists we spoke to advised against having immunisations while ill with active viral-type symptoms (such as swollen glands or temperature) unless absolutely necessary. Several of you who have written in also say that your consultants have advised not to undertake vaccinations unless a genuine medical need outweighed any possible side effects.

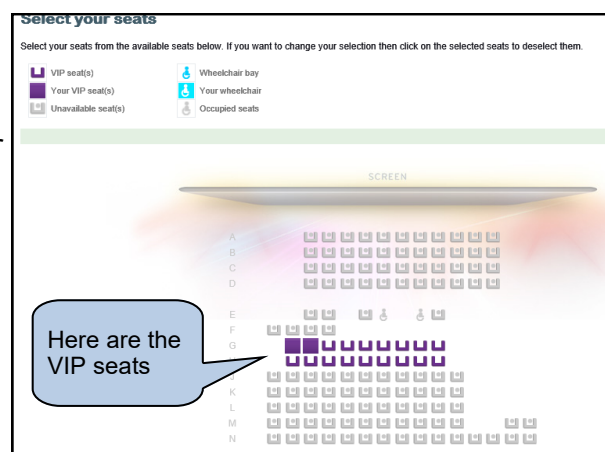
If you have any doubt please discuss with your Doctor

Out and About around Doncaster: Our Visit to the Vue Cinema Doncaster

We recently paid a visit to see the latest James Bond film 'Spectre' at the Vue Cinema in Doncaster. We have been to the Vue on a number of occasions previously.

VIP seats

We prefer to use the VIP seats because of the extra legroom and comfortableness. They charge slightly extra (£1.50 in our case). However the last time we visited all the VIP seats were taken, so we decided to try booking online to choose our seats. You select your seats in the auditorium either by accepting their choice or clicking on vacant seats of your choice. Once you have made your choice payment via card is standard as with any website. If you use this facility we recommend that you print out your booking receipt for reference. We collected our tickets from the concession stand without any problems.



Parking

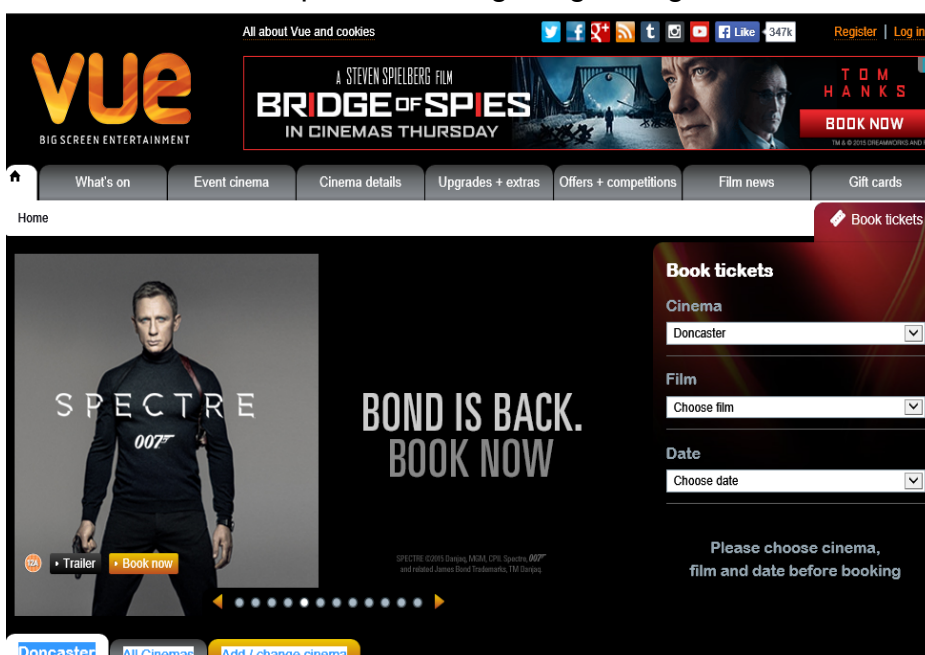
Although the Vue offers free parking with its fair share of disabled bays, it is on a first come first served basis. Also if you do get a space, there is a large area of paving to walk across before you get into the front of the cinema which could cause difficulties for some people with ME/CFS. However, this is outside the control of the Vue management. We also find a problem with getting the right access road to the car park when coming from the Racecourse end.



All the screens are on one level down two corridors. The position of VIP seating and disabled spaces varies with the screen in use, so we recommend that you check carefully beforehand.

The Bond Film

The film itself was slightly different to the usual James Bond with regards to the plot in the sense that in the story was not clear cut as to who the goodies and baddies were until well into the film. There were definite parts of the story line and scenes that are related to earlier Bond films, and the usual generous ration of Bond type chases and action. However there was no breath taking scenes as with its predecessor Skyfall. On the whole it was well worth seeing, and it certainly beats watching it on a TV screen!



Bookings: <http://www.myvue.com> (this is the website we used)

Address: Vue Doncaster, Doncaster Leisure Park, Herten Way, Bawtry Road, Doncaster, DN4 7NW.

October 2015 meeting report: Healthwatch Doncaster

At group meetings we hear a lot of complaints about NHS services – so we invited someone from Healthwatch, Doncaster, (aka NHS complaints department) to speak at the meeting to cover the NHS complaint procedure and explain how Healthwatch can help someone through the NHS bureaucracy. They sent Marion Boyd to speak to us. Marion is an Independent NHS Complaints Advocate, with considerable knowledge and experience around Community Regeneration, Social Inclusion, Empowerment and Health and Wellbeing. She has worked and been based in communities within both Sheffield and Rotherham for more than the past 15 years. Her role is to support and empower individuals in order for them to have their voice heard.

About Healthwatch

Healthwatch was established 1st April 2013. It is an independent organisation that will ensure that everyone in Doncaster has the opportunity to have their voice heard with the objective of making adults and children's health and social care services better in Doncaster. Healthwatch Doncaster will collect people's experiences and stories of health and social care services to help improve them and shape future service provision, signpost/help point you to the service that is right for you and support you in making a complaint about your NHS service experience. To facilitate this they have a Freephone number 0808 801 0391 for people to call if they would like to access any aspect of their service.

Received feedback will be summarised and



The front page of the Doncaster Healthwatch website www.healthwatchdoncaster.org.uk. There are many other useful links to NHS services too numerous to list here. It's well worth visiting.

Do YOU know WHAT we do?

- Collect YOUR experience/stories of health and social care services to help improve them.
- Signpost/help point you to the service that is right for you.
- Contact us on 0808 801 0391 / 01302 378935

Healthwatch Doncaster | 36 Duke Street | Doncaster | DN1 3EA
info@healthwatchdoncaster.org.uk | www.healthwatchdoncaster.org.uk

Facebook: /hwdoncaster | Twitter: @hwdoncaster

Supporting you with your NHS Complaints

provided to the organisations that deliver health and social care services in Doncaster, so they can get an insight of your experiences when using the services they provide. People submitting complaints or compliments (compliments are just as important) will help them encourage and reward good practice, as well as to identify and rectify any problems you may encounter. Healthwatch Doncaster's motto is 'Your Health, Your Care, Your Say' so this is an opportunity for to share your opinions on the health and social care people use.

The local Independent Health Complaints Advocacy Service

This service supports people with NHS complaints. Throughout the complaints process an advocate might do some or all of the following:

- Help you to list all the issues you wish to raise in your complaint
- Help you to write letters to the right people
- Prepare you for a complaint meeting and go to these with you
- Answer questions to help a client make decisions
- Give you the opportunity to speak confidentially to someone who is independent of the NHS
- Where possible, they will meet you face to face to discuss your complaint
- Help you to monitor the progress of your complaint with the organisation responsible

But what if you do not need an Advocate?

Not everyone needs the support of an Advocate to make their complaint. For example, some people just want to know how the complaint system works or know who or where they should direct their letter of complaint to. Everyone who contacts Healthwatch Doncaster Advocacy to request help with an NHS complaint is entitled to receive a free Self Help Information Pack. Alternatively, if you would just like to share your issues or experiences, contact your local Healthwatch.

Face to face meetings

The Healthwatch team are available at locations throughout Doncaster where you can find out more about the Advocacy service. People can visit the Healthwatch Doncaster website to see where you can meet them and enquire about the service. You can find out where your Healthwatch will be through their office at 36, Duke Street; the website or you can phone 0808 801 0391 to get details.

Things to remember

Healthwatch are always out and about in the community, explaining how Healthwatch can help and its services. You can see their website to see their events calendar and meet their friendly Healthwatch Support Team and Volunteers and provide your feedback in person. People can also get in touch via social media through their Twitter and Facebook accounts.

Contact details

Healthwatch Doncaster, 36 Duke Street, Doncaster, DN1 3EA
Office opening hours Monday to Thursday 9:00am to 5:00pm, Friday 9:00am to 4:30pm
Telephone: 0808 8010 391
Email: info@healthwatchdoncaster.org.uk
Twitter: @hwdoncaster
Website: www.healthwatchdoncaster.org.uk

Following the presentation, Marion held an open question and answer session where she dealt with personal specific questions submitted by members. For reasons of confidentiality, we cannot give details. Unsurprisingly, the biggest cause of complaints was matters which related to the NHS waiting list.

Marion can be contacted at the following

*Email: marion.boyd@healthwatchdoncaster.org.uk
Telephone: 378935*

The Myhill Files: Metabolic inflexibility by Dr S Myhill.*Reflections on Mitox Conference: 4 December, 2013*

This conference, held at the John Radcliffe Hospital, Oxford, pertained to mitochondrial function in health and disease. To me the most interesting aspect of the conference was the idea of metabolic inflexibility. Clinically, I believe, this manifests itself where there is an inability to switch from metabolising carbohydrates to metabolising fats. This seems to be a feature of patients with CFS/ME who do not tolerate low carbohydrate diets. Clinically it appears they are unable to mobilise fat as a fuel source to the body. Of course, impaired fuel delivery will result in fatigue.

A paper presented by one of the speakers arose from experience in the Gulf War. Troops in the front line filled their ruck sacks with what they felt would be most important. Individual soldiers threw out their rations for ammunition. This meant many went for some days without food. One of the effects of this was severe mental fatigue and it was notable that most deaths from friendly fire resulted from soldiers in a state of starvation. Therefore, a team of scientists were commissioned by the military to look at foods that could sustain a soldier most efficiently in this situation. The budget for this piece of research was \$10 million!

When fats are metabolised as a fuel they are first converted into ketones. So this team experimented by manufacturing beta hydroxybutyrate – a common ketone. This was then fed to trained athletes at the rate of 1.5 grams of beta hydroxybutyrate per kilogram of body weight per day, spread out in three separate meals. This was supplied in the form of drink which, we were told, tastes pretty disgusting. However, this had some interesting metabolic benefits. On this ketone drink athletes were not hungry, and all lost weight; but despite this, their performance increased by 7%. This, for an elite athlete, is an astonishing improvement and will make the difference between an “also ran” and a “gold medal” performance! However, at a cost of £80 a day only a few could afford it. Blood tests showed that glucose levels came down, as did triglycerides and cholesterol. Fatty liver was improved. Essentially, the metabolic syndrome was reversed.

This study, therefore, shows there are clear benefits to be had when ketones are used as a fuel. The amount of ketones used in this study was a factor of ten; higher than those available in the body when it switches into ketosis. Of course, the success of the Atkins diet can be explained by a switch into ketosis – people do not feel hungry, weight is lost. On the Atkins diet, metabolic syndrome is reversed. What further helps to make this metabolic switch is exercise - I suspect just enough to switch into anaerobic metabolism is sufficient. So whilst this was all very interesting, it still does not tell us how to ensure that CFS sufferers switch from carbohydrate to fat metabolism, especially when they can't exercise. However, what we do know is that practice makes perfect and those individuals who regularly consume a "low carb" diet more easily switch into fat burning than others. I suspect that modern diets, high in sugar and refined carbohydrate, means that people rarely make this metabolic switch and, therefore, it becomes increasingly difficult.

It may be that the 5:2 system of dieting helps us to exercise this metabolic mode. The idea here for the purposes of weight loss is to eat a constant amount of calories each day for 5 - 6 days in a week, for example 2000 calories daily, and then have one or two days of the week on a calorie intake reduced to a quarter of one's usual – in the above example this would be 500 calories. If this is just done for a 24 hour window of time, then one continues to burn calories at the same rate and to achieve this one has to run down glycogen stores in the liver and switch into ketosis. Other conditions which would trigger ketosis include thyrotoxicosis (so it is well worth getting your thyroid function checked on the grounds that hypothyroidism would make it much more difficult to switch into ketosis) and fever (possibly some of the benefits of saunaing could be explained by this mechanism). I wonder if the business of getting hot, i.e. saunaing, facilitates this metabolic switch?

The above ties in with other clinical observations, such as that:

- Diabetes is common in cases of mitochondrial disease;
- Mitochondria function more efficiently when glucose levels are low;
- High levels of glucose increase oxygen consumption but, paradoxically, levels of ATP fall. Incidentally humans generate 87.5 kg of ATP daily! This, of course, is achieved through efficient recycling.

Treatment of metabolic inflexibility (continued)

1. Persist with the diet
2. Avoid snacking - feeling hungry is a powerful stimulus to burn fat
3. Check thyroid function
4. Use Niacinamide slow release 1500mgs daily
5. Take Chromium 2mgs daily for 2 months *
6. Take Berberine 500mgs three times daily - indeed Berberine in these doses is of proven benefit in diabetes. *
7. Brief periods, 1-2 mins, of anaerobic exercise (to produce a lactic acid burn in muscles); repeated several times (interval training) will switch the body into fat burning (this is not for ME sufferers!). Furthermore it stays in a fat burning state for some hours subsequently.

Further details: Sarah Myhill Limited, Upper Weston, Llangunllo, Knighton, Powys, Wales LD7 1SL, UK. Tel 01547 550331 | Fax 01547 550339

Discussion about Dr Myhills feature

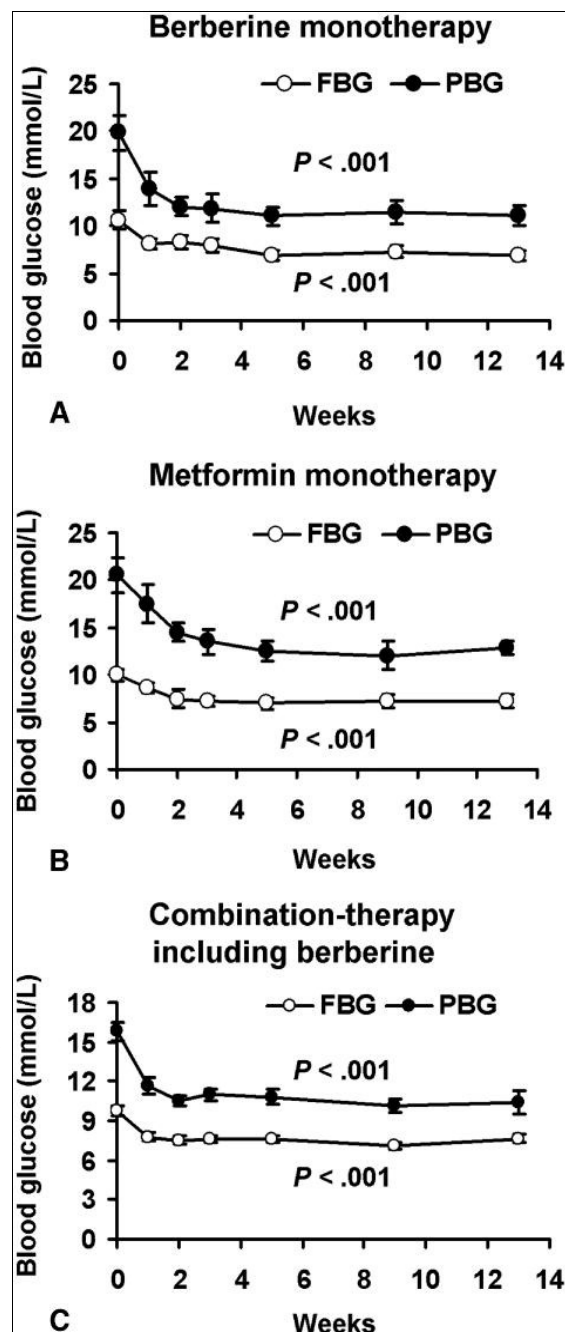
Sarah then quotes a research reference The Efficacy of Berberine in Patients with Type 2 Diabetes by Jun Yin, Huili Xing, and Jianping Yeb.: *Metabolism*. 2008 May; 57(5): 712–717. doi: 10.1016/j.metabol.2008.01.013: You can download the reference from the internet, but here is a brief summary:

Berberine has been shown to regulate glucose and lipid metabolism in vitro and in vivo. This pilot study was to determine the efficacy and safety of Berberine in the treatment of type 2 diabetic patients. In study A, 36 adults with newly diagnosed type 2 diabetes were randomly assigned to treatment with Berberine or Metformin (0.5 g three times daily) in a 3-month trial. They conclude that this pilot study indicates that Berberine is a potent oral hypoglycaemic agent with beneficial effects on lipid metabolism.

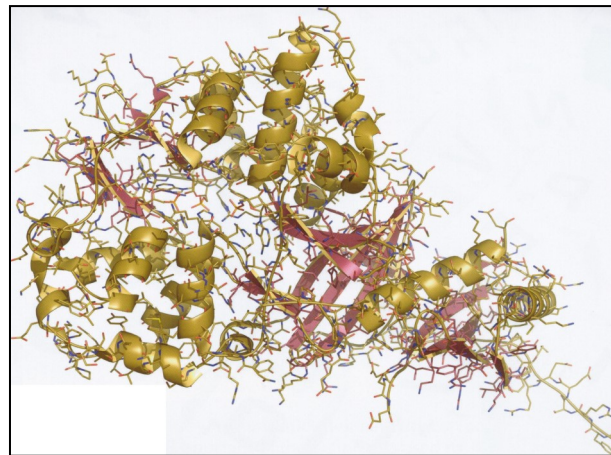
So what is this to do with ME/CFS?

In Pathways 45 we posted a research feature from ME research UK about 'What is AMP- activated protein kinase. Briefly AMPK is activated protein kinase (or AMPK) is an enzyme that has a key role in the regulation of the supply of energy inside cells. It is particularly active in tissues with high energy requirements, such as the liver, brain and skeletal muscle. Sometimes called the cellular fuel gauge, AMPK is activated by a drop in the energy status of the cell, such as when energy is being used up faster than it is being produced. During a bout of exercise, for example, AMPK activity increases as muscle cells experience the stress caused by the increased demands for energy. Such use of AMPK during exercise involves a cascade of processes, including the stimulation of glucose and fatty acid uptake and oxidation. Overall, the effect of AMPK activation is to switch off pathways that use energy and switch on pathways that generate energy helping to restore the energy balance within the cell. Although much remains to be discovered, AMPK is thought to be an important player in conditions such as type 2 diabetes metabolic syndrome and obesity, which are all associated.

If you look it up on Wikipedia you find that 5' AMP-activated protein kinase or AMPK or 5' adenosine monophosphate-activated protein kinase is an enzyme that plays a role in



cellular energy homeostasis. It consists of three proteins (subunits) that together make a functional enzyme. It is found in a number of tissues, including the liver, brain, and skeletal muscle. The net effect of AMPK activation is stimulation of hepatic fatty acid oxidation and ketogenesis, inhibition of cholesterol synthesis, lipogenesis, and triglyceride synthesis, inhibition of adipocyte lipolysis and lipogenesis, stimulation of skeletal muscle fatty acid oxidation and muscle glucose uptake, and modulation of insulin secretion by the pancreas. AMPK acts as a metabolic master switch regulating several intracellular systems including the cellular uptake of glucose, the β -oxidation of fatty acids and the biogenesis of glucose transporter 4 (GLUT4) and mitochondria.

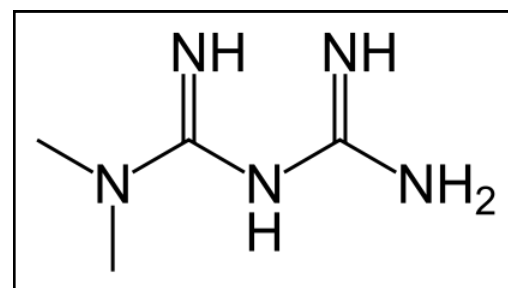


The chemical structure for AMPK

These are all ideal properties of a medicine to be used for diabetic control. There are more details which you can look up yourself. The implication is that Metformin and Berberine are both AMPK activators, and it also implies they may help with fatigue. At present there is no way in ME/CFS that the fatigue can be controlled by any medicines.

Metformin is one of the first choice antidiabetic medicines in the UK for type 2 diabetes. It is a prescription only medicine. The clinical experience of its use for diabetes spans over forty years, to most the adverse effects are well known and documented. The main problem is gastro intestinal tract related to irritable bowel like symptoms. Berberine is a naturally occurring alkaloid which appears in many plant species, and is widely available as a food supplement. It is not classed as medicine, and free from the relevant legal restrictions imposed by UK Law relating to the supply of medicines and yet appears to be as potent as metformin.

The next question is if Berberine is so good at diabetes control why hasn't it been marketed by one of the major drug companies? I think the answer is that Berberine is a naturally occurring product and thus cannot be patented. Metformin is a synthetic chemical compound and could be patented. A patent is a precondition of a drug company to invest in the research needed to bring a product safely to market and retrieve a profit from its development, not possible with natural products.



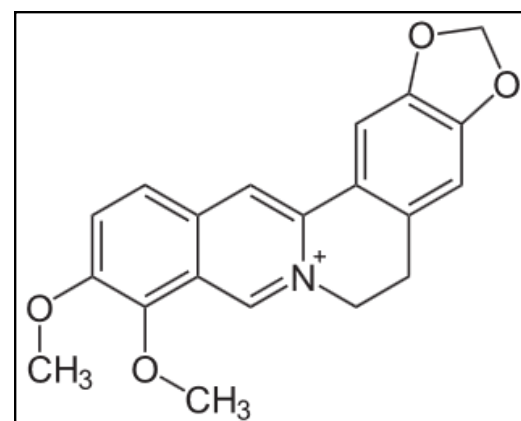
Upper metformin, a guanidine. Chemically it is a complex nitrogenous base related to those found in DNA

So what are the practical implications?

Firstly, if you have ME/CFS and also have type 2 diabetes, and if you are taking Metformin prescribed as part of your treatment – then you may be benefiting from a positive side effect of fatigue reduction. This certainly ties in with what I've noticed with some Leger ME members who are type 2 diabetics who have been prescribed Metformin by their doctors.

Lower Berberine an isoquinoline alkaloid found in many plant species. E.g. (barberry and Chinese goldthread)

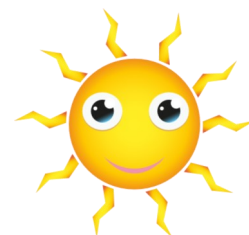
Secondly, if you are taking antidiabetic drugs and taking Berberine or one of the plant products that contain it, it may magnify the antidiabetic effect, and it may cause hypoglycaemia which is a potentially dangerous condition usually caused by overdose of diabetic medications or eating too little food.



Thirdly, both berberine and metformin have the theoretical potential that they could be used to relieve the fatigue in some cases of ME/CFS. Apart from that single research paper, I have not seen any other hard evidence. There would need to be more in depth research and clinical trials to establish safety in use and find the dose and way to use them in ME/CFS. I can't foresee this happening in the future. Sometime in the future just maybe Sometime in the future.

More on Vitamin D and how it could be important for people with ME/CFS

A couple of years ago I was at an LPIG meeting of the Sheffield ME/CFS NHS clinic. Before the main business of the meeting several of the committee members who were ME/CFS patients had a discussion about their own Vitamin D levels. The outcome was that they it been had found by their GP they had low Vitamin D levels. The GP's had prescribed a Vitamin D supplement, and surprisingly they had reported that taking it reduced their pain and fatigue dramatically. I took this up with the head of clinic Ann Nichol in terms of this may be something significant, it should be followed up. The answer that came back was that it was not in NICE guidelines. I felt that the lack of interest was not in the best interests of Leger ME members who use the Sheffield ME/CFS service and from my point of view was a cause of concern for me. Further to this the special Interest attached to the clinic doesn't seem to take interest in anything than other clinic matters, and presumably NICE guidelines.



This was the inspiration for a Vitamin D feature for Pathways which I did several years ago. Ever since then I've made a point of getting members who I have seen for welfare rights and mentoring to ask their GP to check their Vitamin D levels. Without exception in over the dozen or cases which I've followed up members have been found to have Vitamin D deficiency, and their GPs have prescribed supplements on the NHS. The feedback I've received tends to reinforce my initial suspicion that Vitamin D supplementation can reduce ME/CFS aches and pains as well as fatigue. I also had my own GP check my Vitamin D levels which to my surprise were low enough to treat. This as unexpected as I take a multivitamin supplement every day which contains the recommended daily amount and that shouldn't happen. So I decided to ask my GP for a supplement as well.

What was unclear was is why? It was not until I recently attendance a meeting on Vitamin D management given by Dr. Pravin Jha, a consultant geriatrician from Barnsley that the issue was clarified.

If turns out that Vitamin D insufficiency is common in the UK population. Up to 50% of adult population in the UK will be Vitamin D insufficient in winter and spring, with 16% having severe deficiency. There is a significant north-south gradient in the prevalence of Vitamin D insufficiency/ deficiency in summer and autumn, 28% of adult population in Scotland will be Vitamin D insufficient, with 8% having severe deficiency.

The body can obtain Vitamin D in several different forms. Vitamin can be synthesised in the skin; exposure to UVB rays from the sunlight. Also is can be obtained from animal and vegetable sources. Additionally we can ingest dietary sources in the form of cholecalciferol (from predominantly animal sources) and ergocalciferol (vitamin D2, from vegetable sources). It turns out the UK population are prone to deficiency, due to the combination of inadequate levels from the diet and lack of exposure to sunshine.

Sources of Vitamin D

Diet (10-20%)

- Vitamin D3 found in small quantities in a few foods:
 - fatty fish (salmon, herring, mackerel)
 - liver and eggs
 - fortified foods (margarine, some low-fat milks)
- Adequate vitamin D unlikely achieved through diet alone

Skin synthesis 80%

The amount of Vitamin D synthesised in the skin depends on skin exposure to UVB radiation and efficiency of cutaneous synthesis. March to September (9am – 3pm): 70% is delivered during the four hours centred around noon. Serum 25(OH)D concentration decreases from October onwards throughout the winter months.

The main source of Vitamin D is exposure to sunlight

- whole body exposure 10-15 min midday sun in summer equivalent 15 000 IU (375 ug) orally
- exposure of hands, face and arms (which totals around 5% of the bodies surface should produce around 1000 IU
- less vitamin D synthesised in winter, in those with dark skin or older, and those who cover up for cultural reasons or sun protection
- short exposures to UV are more efficient; prolonged exposure to high UV doses may degrade pre-vitamin D and reduces the amount of Vitamin D available

The risk factors for deficiency include:

- Vitamin D production in skin depends on the incidental angle of the sun and thus latitude, season and time of day. Consequently people with dark or covered skin and users of sunscreen synthesise less vitamin D.
- Sun exposure during winter at latitudes above approximately 33 degrees north. Doncaster is at 53 degrees North.
- People taking medications that can significantly deplete vitamin D status e.g. Metformin (often used to treat diabetes), anti-convulsants (sometimes used in ME/CFS for pain control), steroids, and medications that interfere with digestion/absorption such as proton pump inhibitors.
- People who are obese (as vitamin D is deposited in body fat stores, making it less bio-available) and/or have a sedentary lifestyle likely to have reduced sun exposure, like people with ME/CFS.
- People with digestive impairments such as irritable bowel disease, especially those who have had small bowel resections, or fat malabsorption disorders which could include some people with ME/CFS
- Pregnant and breastfeeding women, babies (particularly exclusively breastfed) and young children under the age of five.
- The elderly, due to reduced capacity to synthesise vitamin D in the skin when exposed to UVB radiation.

***What does vitamin D do?***

- Calcium regulation. (Maintenance of plasma calcium levels within a narrow optimum range is vital for normal functioning of the nervous system).
- Bone mineralisation and maintenance.
- Cell differentiation for growth, and may be cancer protective.
- Insulin regulation, reduces risk of diabetes
- Cardiovascular health reduces adverse cardiovascular risk
- Immunity/autoimmunity, vitamin D appears to both enhance innate immunity and inhibit the development of autoimmunity.
- Mood. Vitamin D can also have a positive effect on mood.

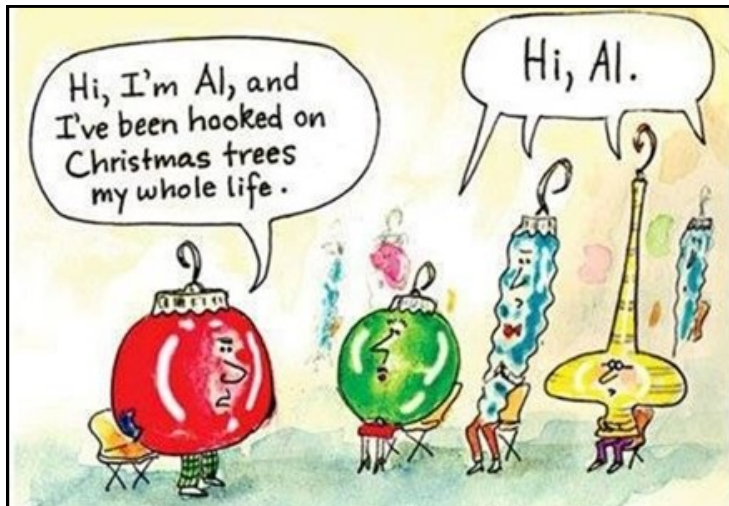
Other research shows that Vitamin D exerts multiple effects on muscle which may be an issue with some people with ME/CFS.

This is what your doctor should consider

Best indicator of total vitamin D exposure is blood plasma level of what is known as 25(OH)D. To check this concentration you need a doctor or practice nurse to take a blood sample and send it off to the local laboratory. The target level is 60-90 nmol/l.

- If the level is less than 25 nmol/L, then the patient is deficient.
- A result of 30–50 nmol/L may be inadequate in some people and is classed as insufficiency.
- A level of above 50 nmol/L is adequately sufficient for almost the whole population. At the same time, serum level of other 'bone health markers' should also be checked such as Calcium, Parathyroid hormone (PTH), Alkaline phosphatase (ALP), Phosphate and eGFR (or Creatinine clearance). A level of above 120 nmol/L is considered abnormal and needs to be investigated further.

You could of course buy your own supplements, but at the time of writing there were several big pharmaceutical companies actively promoting Vitamin D to doctors. The take home message is that there is precious little that helps the pain and fatigue. It would be ironic if something as simple as vitamin D treatment were able to increase the overall quality of life for us is missed. - Mike



Winter Pansies as Tickhill Road Hospital

North of Doncaster Personal comment by Trevor Wainwright.

Is it Christmas or Holiday?

In my last article I was on the road to Lamesa from Austin, actually it's not a bad place so I'm going to stay on it until the next issue. For this issue it is a look at political correctness with a light hearted look at changing the term Christmas for Holiday following posts and discussion on Facebook.



Christmas means different things to different people.

Christmas occurs just after the shortest day of the year. This time of year would be known to many pre-Christian civilisations because the shortening on the days would stop and the days get longer, the winter solstice. The sunset would stop moving south and start moving north. This would indicate the start of the new year. Yuletide ("Yule time") is a religious festival observed by the historical Germanic. Once Christianity came along the season was chosen as the time to celebrate the birth of Jesus, the festival, now known as Christmas. The problem is that many countries are not Christian, or feel that the word Christmas implies a belief in Christianity. Controversies have arisen regarding the celebration or acknowledgment of the Christmas holiday in government, media, advertising, retail, and various secular environments. The controversy also includes objections to policies that prohibit government or schools from forcing unwilling participants to take part in Christmas ceremonies. In the past, Christmas-related controversy was mainly restricted to concerns of a public focus on secular (non-religious) Christmas traditions such as Father Christmas or Santa Claus and gift-giving, rather than the birth of Jesus.

The present controversy occurs mainly in English speaking countries such as the USA but to a lesser extent here. This usually involves governments or corporations avoiding the day's association with Christianity to be multicultural sensitive. In recent years in the United States, public, corporate, and the federal government mention of the term "Christmas" during the Christmas and holiday season has declined and been replaced with a generic term, usually "holiday" or "holidays," to avoid referring to Christmas by name and/or to be inclusive of other end-of-year observances. Some people use terms such as "Happy Holidays" in place of "Merry Christmas", including some atheists (non-believers) and agnostics as well as some adherents of non-Christian religions and Christians who do not observe Christmas as a religious holiday, that may remind others that many of the symbols and traditions that Western societies have come to associate with Christmas, such as carolling, Christmas trees, mistletoe, holly wreaths and yule logs, originally adopted from pre-Christian pagan traditions and festivals that predate Christianity.

So imagination in overdrive as usual, I began to think how would it be if it was so, if Christmas was changed for Holiday. Somehow Greg Lakes I believe in Father Holiday does not have the same ring to it; and what would we make of Boney M singing Mary's boy child Jesus Christ was born on Holiday Day. How would the following sound from I Saw Three Ships—I Saw Three Ships come sailing in on Holiday Day in the Morning ?.. And of course there is the return to school after the holidays essay "How I spent my Christmas Holiday" over the page.

So how would the following Christmas songs

Sound with the word change.
White Holiday – Bing Crosby
Rockin' round the Holiday tree – Brenda Lee
Lonely this Holiday – Mud
Merry Holiday everyone – Slade
Wombling Merry Holiday – The Wombles
Merry Holiday Everyone – Shakin' Stevens
All I want for Holiday is you – Maria Carey
Holiday Time, Mistletoe and Wine – Cliff Richards
Do they know it's Holiday – Band Aid
I wish it could be Holiday Every Day – Wizzard

And so to the following traditional Carols.

A Holiday Lullaby
A Holiday Child
A Holliday Hymn
A Holiday Folk Song
Baby Zulma's Holiday Carol
Holiday Bells
Holiday Day Christ, we have claimed you
Holiday has meaning
Holiday Mummers' Carol

How I spent my Holiday Holidays (A spoof post holidays essay)

I went home from school with the Holiday decorations I had made in art class; mum and dad said they were very good I was pleased, it had been a great afternoon we'd had our annual Holiday party and Holiday carol concert. The following day mum took me Holiday shopping and to see Father Holliday, I was excited at the thought of this, we went for Holiday presents and ingredients for the Holiday Cake which I would help mum make. When we got home we found some more Holiday cards had arrived in the post, we opened them and put them up, mum then decided it was time to put up the Holiday decorations. While we were putting them up we listened to the radio, how nice it was to hear all the old favourite Holiday songs, Dad had been out and came back with the tv Holiday guide so we would not miss our favourite Holiday programmes. I particularly like watching Holiday Carol where Scrooge says "Holiday bah humbug and anyone who goes round wishing Happy Holiday should be boiled in their own pudding".

The following day the weather was bad so mum and I decided to make a start on the Holiday cake. We were mixing the ingredients listening to the radio when the weatherman came on saying we might have snow this Holiday and I started singing "I'm dreaming of a White Holiday". On Holiday Eve mum and dad said it would be okay for me to go out singing Holiday carols with my friends as long as I was back for the Holiday Eve service at church. I think mum was glad to be out as it gave her a chance to get things prepared in advance for Holiday dinner; she always puts a lot of work into it.

We sang two carols at each house before ending with "We wish you a Merry Holiday and a Happy New Year" we came home and went to church where the doorway was lit up with Holliday lights as were many of the houses. We sang carols and my favourite story "The Night before Holiday was read". Back home it was supper and then to bed, mum and dad would do the last minute preparations, so mum wouldn't have too much to do.

We woke on Holiday Day morning; there was a great feeling of expectation as we found our Holiday presents under the Holiday Tree, we were delighted with what we had got. I decided to get out of the way while mum got started on the Holiday dinner; I nipped round to my friends to wish him and his family Happy Holiday, we had a great time in his room as we compared presents.

When I got back home the table was set with Holiday crackers at each place we all sat down to our Holiday dinner, I didn't want to eat too much as there was Holiday pudding with rum sauce to follow. Mum had a rest and we helped Dad wash the dishes and put them away, we then sat and watched the Queens Holiday Speech before enjoying the Holiday programmes.

But all too soon Holiday Day was over and it was to bed, then it was Boxing Day but there was still the rest of the Holiday, Holidays fortnight to look forward to.

Merry Christmas to you all. Have a great Hol***... err...m time –Trev

