



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 No. 51 (Spring 2017)



You Write In.

Sandra writes: I've been following the progress of President Trump with interest. The problem is that he seems to be in his own world with his own agenda. Furthermore, I get worried because he is supporting the US miners at the expense of other people's health like happened in the coal industry here. I notice also that he seems to be have problems implementing his election promises, e.g. his Muslim travel barring and Mexican border wall policy. Also, I notice that he is not getting his way dismantling Obamacare.

I studied history of the second world war at school, and I see shades of fanatical nationalism. I get worried about when news is not convenient to his wishes and labelled as "Fake" and how he derides the BBC.

Even more worrying, if the dreaded ever happened and he had to press the button to release and atomic bomb, could he make a rational sound decision?

Well Sandra, I certainly think that you summarise in a nutshell what a lot of people are thinking. There was flurry of correspondence following a feature in a US newspaper in February 'Mental Health Professionals Warn About Trump'. He has a strong sense of self-confidence. He tends to disregard opinions and the wishes of others, however well founded. I am also seeing an inability to tolerate criticism, and a tendency to belittle others to validate this own view (e.g. the BBC and 'fake news').

I think we are seeing shades of a Narcissistic personality. On top of this you should understand that he is self-made millionaire who claims he has given up all his business interests to put "America First". Not being a career politician, he is not predictable, thinks out of the box, and he makes it clear via social media what he is thinking. Is this a good thing or bad? Look at it this way, would you believe everything the Russian President says?

Unlike us in the UK, America has a written constitution. I think President Trump is finding out the constitution is more powerful than himself, and he is unsure how to deal with that concept. Just remember that as well the USA has two houses of government, the Congress and the Senate. Like him they are both Republican (the equivariant of our conservatives), and they can override his rulings – so he can't always get his own way. What will he do next? I think that there a little more to come about his own personal health, personal income tax affairs and Russian connections. Place your bets...



Front Page Picture. A sign of spring. Wild primroses emerging through the bracken litter on the forest floor. The picture is taken Primroses in the wooded area, just off Garden Lane Cadby, Doncaster. Primroses like many plants emerge and flower early in the season to grow before the light is blocked by then other ground vegetation and the tree canopy.



Leger ME has acquired a new printer, a Canon MF8550Cdn.

The advantage of this printer is that it will print double sided –so all we need to do is press a button on the computer and Pathways comes out ready to staple and put in an envelope. This will make Pathways easier to produce.

Georgina writes: There was a recent feature in a well-known daily newspaper about a lady who became ill from eating something grown in pigeon droppings as the journalist claims is the case. But that is NOTHING compared to the damage that has been done to the health and lives of countless residents over many years - including fatalities - because of exposure to cocktails of poisonous pesticides used in conventional farming and sprayed where we rural residents live and breathe! The fact that successive Governments' have allowed this chemical warfare in the countryside is without a doubt one of the biggest public health scandals of our time.

There have always been fundamental failings in the way pesticides have been approved. As to date, the official method produced by regulators for assessing the risks to people from crop spraying - and under which many thousands of products have been approved - has been based on the model of a short term 'bystander', occasionally exposed, for just a few minutes, and to just one pesticide at any time. Yet this model clearly does not address the real-life exposure of people who live in pesticide sprayed areas, as exposure for rural residents is both repeated acute, and chronic over the long-term, it is cumulative, and is to innumerable mixtures/cocktails of pesticides used on crops, throughout every year.

The fact that there has never been an actual risk assessment for the real-life exposure of rural residents means that no pesticide should ever have been approved for use in the first place for spraying in the locality of resident's homes, schools, children's playgrounds, nurseries, amongst other areas.

Whilst operators will be in filtered cabs and/or have personal protective equipment when using pesticides, rural residents and communities have no protection at all. Instead residents have been put in a massive guinea pig-style experiment and for which many of us have had to suffer the horrific and truly devastating consequences. It is now beyond dispute that pesticides can cause a wide range of both acute, and chronic - including irreversible and permanent - adverse effects on human health.

The manufacturers own product data sheets themselves can carry various warnings such as "Very toxic by inhalation," "Do not breathe spray; fumes; vapour," "Risk of serious damage to eyes," "Harmful, possible risk of irreversible effects through inhalation," "May cause cancer by inhalation," and even "May be fatal if inhaled." The economic costs of just some of the health conditions that pesticides are known to cause are massive. Obviously, it goes without saying that the personal and human costs to all those suffering health damage cannot be calculated in financial terms.

Rural residents are currently calling in their thousands on the Prime Minister to immediately secure our protection by banning all crop spraying and use of any pesticides near residents' homes, schools and playgrounds.

Anyone who wants to sign this petition see

<https://www.change.org/p/the-prime-minister-rt-hon-theresa-may-mp-ban-all-crop-spraying-of-poisonous-pesticides-near-our-homes-schools-and-playgrounds>

Totally agree. This contains many echo's and is the sort of thing that Sarah Myhill has interests in. Perhaps the most notorious are the organo-phosphate sheep dips causing ME/CFS. Locally here in South Yorkshire, our area is rural and most of the agriculture is arable, so yes locally there could be a problem. In our area, there is an even bigger legacy problem—and this is because of coal mining. We are all aware of lung problems caused by coal, but I worry about the land of former coal industry sites being used for housing estates. Here there are areas where soil is contaminated with nasties like arsenic and cadmium because of previous land use. And there again look at smoking, and the recent fashion for e cigarettes. Some of the liquids are not proven safe and yet many people believe they are. Just on a personal note, I had a test for DNA adducts a few years ago, which found mandelic acid residues. It turned out to be from a flea control product called 'Frontline' that I used on my cat. And again, look at the cases for DDT (now banned) which has entered the food chain, and been concentrated on marine mammals like whales of all things. This could be this mechanism of the pigeon droppings.

But there is a real world out there and there is a cost benefit trade off.

Changes in PIP Mobility component by Steve Donnison Benefits and Work

Changes to the PIP mobility component are due to come into force on 16 March, despite widespread opposition. The DWP have said that people who may be affected by this change in the law are those with conditions including:

Learning disabilities, Autism, Schizophrenia, Anxiety disorders, Cognitive disorder due to a stroke, Dementia, Depressive disorders, Post-traumatic stress disorder Phobias, Obsessive compulsive disorder.

In our latest update on the changes, we have news of a 38 Degrees petition against the new regulations, an Early Day Motion seeking to overturn them and the response of the Social Security Advisory Committee (SSAC). SSAC make it clear that they do not accept the argument that no existing claimants will be affected by the changes. They point out that some claimants may have been awarded the mobility component based on Upper Tribunal decisions that found in favour of taking psychological distress into account for descriptors where it was not specifically included. This would be descriptor c, d and f of the 'Planning and following journeys' activity. Thus, these claimants may lose out in the future when their award is reviewed. Though, as SSAC also point out, where people have lots of difficulties with following a journey, trying to disentangle psychological distress from other factors is likely to be very difficult and lead to inconsistent decision making. So, it's far too early to be sure which current claimants might lose out and we're likely to have many more years of court battles.

The best thing you can do if you think you might be affected is to make sure you keep yourself updated about any changes in the law and, if you do lose out, consider an appeal. However, given that the new regulations are due to come into force on 16th March and will affect new claims made from that date onwards, as well as review decisions made from that date onwards, we have now published an updated guide to PIP claims and reviews. The updated guide takes full account to the changes that affect the 'Going out' and the 'Managing treatments' sections of the PIP 2 'How your disability affects you' claim form.

Leger ME members can obtain the updated guide to PIP claims and reviews from the office.

PIP AND ESA HOME ASSESSMENTS – YOUR MP WON'T LIKE THIS

We've now published the results of our survey into PIP and ESA home assessments. Many thanks to the almost 1,900 people who took part. Your MP probably won't like what we discovered, though. Amongst our findings:

83% of the people who completed the PIP survey had been allowed a home assessment, whilst the figure for ESA was only 41%.

3% of PIP claimants had a decision on the paper evidence alone, without needing a face-to-face assessment, but this leapt to 28% for ESA.

38% of PIP claimants who had a home assessment hadn't even asked for one, whilst for ESA it was just 7%.

51% of ESA home assessments were carried out by doctors, for PIP the figure was just 4%.

And, as in assessment centre medicals, many home assessments still involve a health professional staring at a computer screen and reading off questions, with no hint of empathy for the person sitting opposite them.

Or, in one bizarre case, for the person sitting in the next room: "The assessor sat in a different room to me as he needed a table for his laptop. He complained about the software for home visits throughout and never broke from typing to even look up when I spoke."

But what your MP really won't like is the fact that, repeatedly, people told us that when they were unreasonably refused a home assessment, contacting their MP about it had a dramatic effect. We didn't hear from a single person who had been refused a home assessment once their MP was involved.



Problems with DPA to PIP Changeover

Most of the group members DLA to PIP changeover so far have been successful from the point of view of receiving something, but there are some issues which are predominating which are totally outrageous. Here are a few.

Mobility.

The awards are mainly standard rate mobility. No account seems to be taken of fatigue or related issues. If a mobility award is given it is usually given for other reasons e.g. arthritis rather than ME/CFS.

Mental Health Issues

Two recent cases have caused me concern because when members have been called to a medical examination they have been seen and assessed by a physiotherapist for depression. It looks like the decision-makers are not doing their job and just rubber stamping the physiotherapist recommendation. I know the identity of the physiotherapist concerned. If you have a medical at Doncaster, please contact me first.

Initial interview.

The DWP state that all DLA claimants will be reassessed for PIP by October 2017. What seems to be happening is that a telephone interview is taking place and then a PIP2 form is sent. What is being missed are the PIP1 forms. There are two pages which are critical. They are not giving people the opportunity request these use of their DLA evidence. I've reproduced that PIP1 form pages for information which seems to get conveniently missed. I've reproduced the two critical pages opposite.

Medical examination venues.

Unusually there have been a couple of cases where members have been requested to attend at Scunthorpe and Hull. One was at 9.00 am. They are not considering information given on the PIP form.

I recommend attending a medical examination for you to request a copy of the medical report which is known as RV4 form. Certainly, if there are any disputes that is one of the first things that I will ask to see.

Please note the walking distance between the nearest road and Doncaster examination centre is about 50 meters. So, if you walk into the centre you can guarantee that you will just blow and hope of Enhanced Rate Mobility.

This area for automatic personalisation for customer's name and post code.

The next stage of claiming

If you have not claimed under the special rules for terminally ill people

The next stage of claiming Personal Independence Payment will start when we send you another form through the post so you can tell us how your condition affects you. You need to fill in the form and send it back to us.

If you think you'll need any help or support to fill in the form, contact a local support organisation as soon as possible to arrange help.

If you are signing the form for someone else go to page 18.

If you are signing the form for yourself, read the information and complete the questions below.

We understand that some people find it difficult to return forms because of a mental health or behavioural condition, learning difficulty, developmental disorder or memory problems. This could mean any kind of learning difficulty or dementia. It could mean anxiety or depression, obsessive-compulsive disorder, psychosis, schizophrenia or personality disorder, attention deficit hyperactivity disorder (ADHD), autistic spectrum disorder, or developmental delay.

By mental-health conditions we mean, for example

- depression, anxiety, post-traumatic stress disorder (PTSD), obsessive-compulsive disorder (OCD), psychosis, schizophrenia, personality disorder.

By behavioural conditions we mean, for example

- attention deficit hyperactivity disorder (ADHD), conduct disorder.

By learning difficulty we mean, for example

- Down's syndrome, fragile X syndrome.

By developmental disorder we mean, for example

- autistic spectrum disorder, developmental delay, speech or language disorder.

By memory problems we mean, for example

- any form of dementia – for example Alzheimer's, dementia with Lewy bodies, vascular dementia, dementia associated with other conditions. Memory problems as a result of brain injury after an accident.

Do you have a condition like this? Yes ☐
No ☐
Don't know ☐

Do you see a psychiatrist or community psychiatric nurse (CPN), psychologist or counsellor about your condition? Yes ☐
No ☐
Don't know ☐

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This area for automatic personalisation for customer's name and post code.

About Disability Living Allowance (DLA)

a Are you getting DLA, or have you ever been awarded DLA?

Yes ☐ Go to question b.

No ☐ Go to page 19.

b Is there any medical evidence from your DLA claim that you think might help us understand how your disability affects you?

This evidence could be a report from: a GP, hospital, school or other health or social care professional. If you've had a medical examination for DLA we could use the report from the examining medical practitioner (EMP). If an Employment and Support Allowance report was used to support your DLA claim we could use this report.

No ☐ Go to page 19. We will not use any medical evidence from your DLA claim.

Yes ☐ Please use the following medical evidence (tick all that apply):

- ☐ GP report
- ☐ Hospital report
- ☐ School report
- ☐ Employment and Support Allowance (ESA) report
- ☐ Examining medical practitioner (EMP) report
- ☐ Consultant report or supporting letter
- ☐ Health and social care professional report
- ☐ Other medical evidence.
Please tell us what other medical evidence

☐ I want you to use all the medical evidence from my DLA claim.

☐ I want to see all the medical evidence from my DLA claim before I decide.

If requested, we can get your DLA file and make sure this medical evidence is used. Because of the laws about Data Protection and how long we're allowed to keep documents, old evidence may not be available. If evidence is still on your DLA file, we'll make sure that it is used.

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The Krupp The Fatigue Severity Scale

Fatigue is our major business, but one of the biggest problems I come across with ME/CFS is how do you measure it ?

There is a blood test the Acumen Mitochondrial Function test. The results can be correlated with observed fatigue levels and the ME/CFS Ability/disability scales used by Sarah Myhill and other private practitioners, but not accepted by NHS clinics. It is not easy to access and costs in excess of £400. There are other different are ways to do this, and it is not unusual for many ME/CFS patients when first attending a clinic to be handed a pile of questionnaires. While researching the ME/CFS literature from the ME Association I came the Krupp Fatigue Severity Scale. Although this is was originally intended for MS and Lupus patients, it appears to be suitable for ME/CFS. The scale can be used to monitor change in fatigue over time or in response to therapeutic interventions.

Patients are given a questionnaire and then are asked to respond to each statement on a questionnaire a scale of 1 to 7 as follows:-

- 1) Strongly Disagree
- 2) Moderately Disagree
- 3) Weakly Disagree
- 4) No Opinion
- 5) Weakly Agree
- 6) Moderately Agree
- 7) Strongly Agree

The questions are:-

- 1) My motivation is lower when I am fatigued?
- 2) Exercise brings on my fatigue?
- 3) I am easily fatigued?
- 4) Fatigue interferes with my physical functioning?
- 5) Fatigue causes frequent problems for me?
- 6) My fatigue prevents sustained physical functioning?
- 7) Fatigue interferes with carrying out certain duties and responsibilities?
- 8) Fatigue is among my three most disabling symptoms?
- 9) Fatigue interferes with my work, family or social life?

[Print Form](#)

The Krupp The Fatigue Severity Scale

The Fatigue Severity Scale can be used to monitor change in fatigue over time or in response to therapeutic interventions.

Patients are asked to respond to each statement on a scale of 1 to 7, with 1 indicating "Strongly Disagree" and 7 indicating "Strongly Agree."

Name, Date & Reference	A ME patient for example
1) My motivation is lower when I am fatigued.	1) Strongly Disagree
2) Exercise brings on my fatigue.	2) Moderately Disagree
3) I am easily fatigued.	3) Weakly Disagree
4) Fatigue interferes with my physical functioning.	4) No Opinion
5) Fatigue causes frequent problems for me.	5) Weakly Agree
6) My fatigue prevents sustained physical functioning.	6) Moderately Agree
7) Fatigue interferes with carrying out certain duties and responsibilities.	7) Strongly Agree
8) Fatigue is among my three most disabling symptoms.	7) Strongly Agree
9) Fatigue interferes with my work, family or social life	7) Strongly Agree
Total Score	4.6666666667 Weakly fatigued

Score = Sum of responses divided by 9. Higher score indicates higher fatigue levels.

Reference:
Krupp LB et al. The Fatigue Severity Scale: Application to patents with multiple sclerosis and systemic Lupus erythematosus. Arch Neurol. 1989; 46:1121-3.

This is The Leger ME version of the Krupp fatigue questionnaire which ion the Leger ME Website in the members resource area.

The higher the score, the worse the fatigue.

Recipe Corner by Carolyn**Fast rhubarb tart with mascarpone cream**Preparation time **less than 30 minutes**Cooking takes **30 minutes to 1 hour**. Serves **3**

For the roasted rhubarb, preheat the oven to 200C/400F/Gas6. Cut the rhubarb into 15cm/6in or so lengths (about the length of a wooden spoon handle) and place in a roasting tin with half a teacup of water and the light brown sugar. Roast until just soft enough to take the point of a knife, about 10-15 minutes. Allow to cool, then drain, reserving the cooking juices.

For the tart, preheat the oven to 220C/425F/Gas7. Unroll the puff pastry, and using a rolling pin, roll it again to make pastry slightly thinner. Cut the pastry into three even-sized rectangles. Using a sharp knife, score a 1.5cm/½in border around each rectangle, being careful not to cut through the pastry. Place the pastry rectangles on a lightly greased baking sheet.

Arrange 3-4 lengths of drained rhubarb, depending on the thickness of them, into the middle of the pastry rectangles and brush some of the reserved juice from the roasted rhubarb around the edges to give the pastry a shine. Bake for 20 minutes, until golden and risen.

Meanwhile, beat the egg yolks and sugar in a bowl for a few seconds, until thoroughly mixed. Beat in the mascarpone until you have a custard coloured cream. Stir in a little vanilla extract; a couple of drops should be enough. With a clean whisk, beat the egg white in a bowl until it stands in stiff peaks, then fold into the creamed mascarpone mixture.

Tip: The rhubarb tart on its own is quite sharp, so the sweetened mascarpone cream helps to balance the dessert. This cream works wonders with any soft fruit.

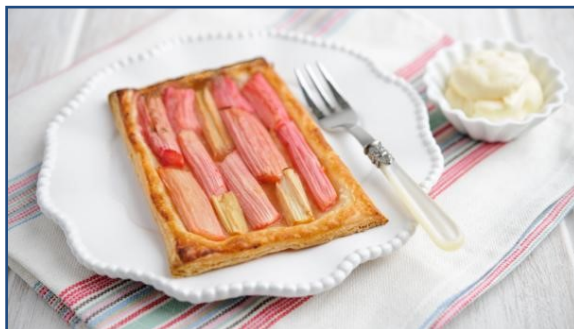
ingredients:

For the roasted rhubarb

5-6 stalks rhubarb
Good shake of light brown sugar

For the tart

Frozen ready-rolled all-butter puff pastry, defrosted
1 tsp butter for greasing
Flour, for dusting
2 large eggs, separated
2 tbsp unrefined caster sugar
250g/9oz tub mascarpone
2-3 drops vanilla extract.

**Winter vegetable Soup (with thanks to Winter Warmth)**

Peel the potato and chop into small chunks. Wash the leeks, carrots and then slice thinly. Peel the onion and finely chop. Place all the above vegetables in a pan add 750mls of water and crumble in the vegetable stock cube.

Gently heat the stock and vegetables until they start to boil. Turn the heat down, put a lid on the pan and simmer for 20 minutes or until the vegetables are tender. If the water starts to simmer dry add a little more.

When the vegetables are tender remove from the heat.

Take out about ⅓ of the vegetables add half of the tinned tomatoes and blend (puree) them to a smooth paste. You can use a blender or push the vegetables through a sieve with a spoon to do this. Put the puree back in the pan with the rest of the stock and vegetables. Add the frozen peas, tin of mixed beans and the rest of the tinned tomatoes. Put the pan back on the heat and cook until boiling hot.

Season with a little pepper.

ingredients:

2 medium sized potatoes
2 leeks
2 carrots
1 onion
50g frozen peas
1 x 454g (1lb) tin chopped tomatoes
1 x 454g (1lb) tin mixed beans (drained) V
vegetable stock cube
Pepper
750 ml(1 pints) water



Garden Watch through Winter to end of February by Carolyn

This has seemed to be a very long, grey winter, with many days of low levels of light which I know is not my imagination as everyone has noticeably been driving around much of the time with dipped headlights on during the day, including me! So, I cannot tell you what a lovely cheery surprise it was just before to Christmas to see the Mahonia in flower for the first time since we placed it in the back garden up on the orchard patch, where it not only looks good but smells lovely when in flower too. It has grown quite a bit and considering we thought at first it wasn't going to flourish, we are really pleased with the progress.

In the house a pretty orchid bought as a Christmas present has also been a delight in full flower along with 'old faithful' the white Christmas Cactus that was full of blooms this time.



Last year I planted clumps of snowdrops 'in the green' after flowering time, and it has been fun to see them already appearing in and amongst the tete-a-tete daffodils this time. I also planted bluebells in the same

areas but cannot see much sign of their green leaves appearing so far and am just hoping the field mice haven't made a meal of the bulbs!



In the front garden the Winter Aconites that I planted in Autumn around the edges of the pots containing the two maples beside the front doorway are just peeping through with their bright yellow flowers and deep green foliage.



The bird feeders are busy with hungry blackbirds, robin, blue tits, great tits, long tailed tits, pretty goldfinches, collared doves, the odd magpie AND, Squirrel who insists on burying peanuts in my plant pot! No sign of the hedgehogs yet.

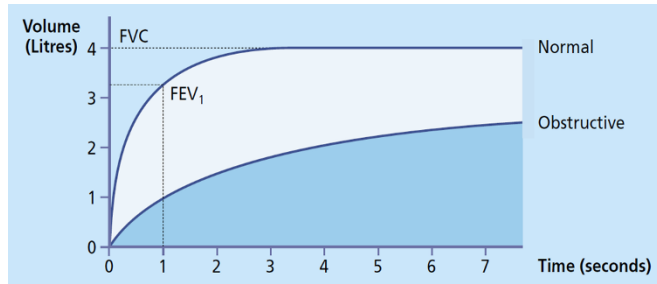


As I write this it is still very cold outside and there was ice on the Wildlife Pond this morning which tells us Spring is not quite here yet even though the bulbs appearing in many pots and containers around the garden let us know it is somewhere just around the corner.

Lastly, I have a request. Does anyone know the name of the houseplant pictured in the bowl? I brought it back from a holiday cottage last year as a very small cutting and it is growing nicely with the only trouble being – I haven't a clue what it is, can any of you help?

Home Medical Instruments –The Peak Flow Meter. (PFM)

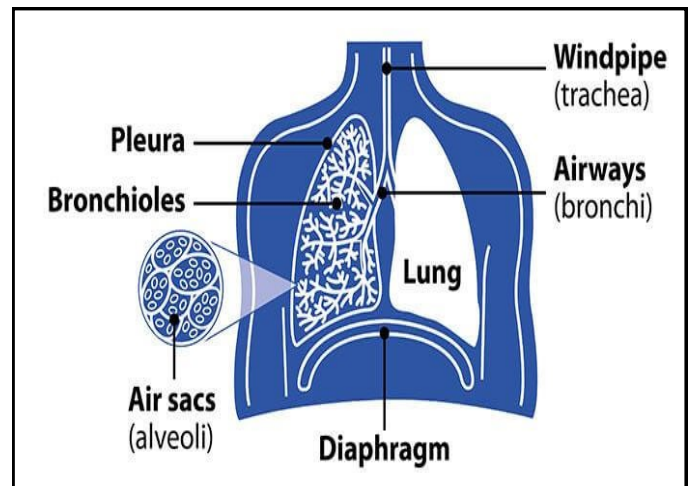
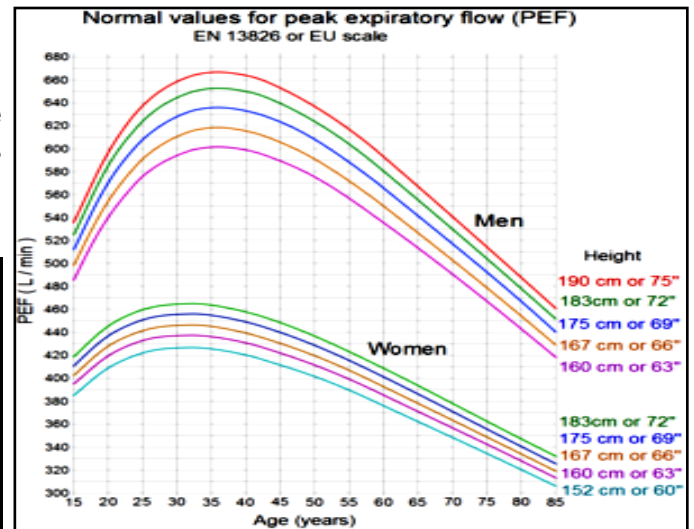
The use of medical devices to monitor chronic conditions is becoming more common. They are a good way to help patients take control of their problem and increase overall concordance. The first one is the Peak Flow Meter. This is used to measure something called FEV₁.



This is the **F**orced **E**xpiratory **V**olume of air you can expel in **1** second after taking a deep breath. If you are short of breath for your weight or height according to a standard chart then something is wrong.

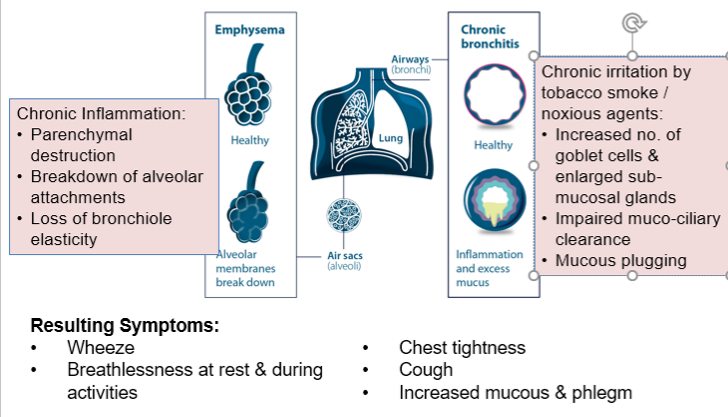
The two most common conditions that PFM's are used to monitor are Asthma and COPD (Chronic Obstructive Pulmonary disease). Both can be managed by various inhalers for other medicines. There is difference between the two conditions:

<u>Feature</u>	<u>COPD</u>	<u>Asthma</u>
Symptoms under age 35	Rare	Often
Chronic productive cough	Common	Uncommon
Breathlessness	Persistent & progressive	Variable
Night time waking with breathlessness and/or wheeze	Uncommon	Common
Significant diurnal or day-to-day variability of symptoms	Uncommon	Common
Family history	Uncommon?	Common
History of eczema or allergic rhinitis	Uncommon	Common

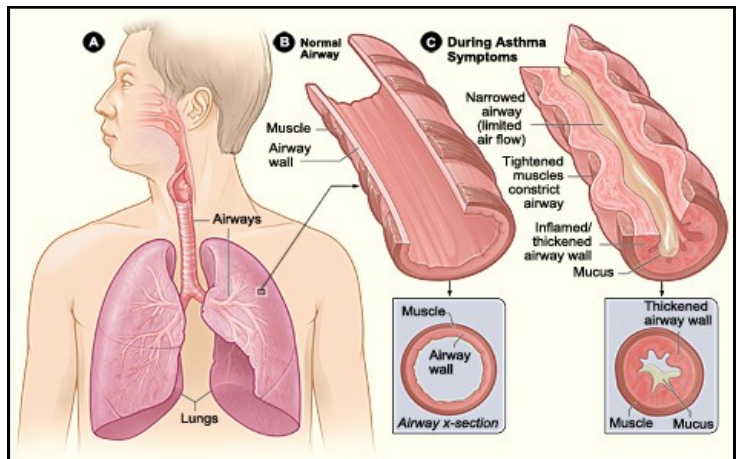


COPD

What is COPD?



Asthma

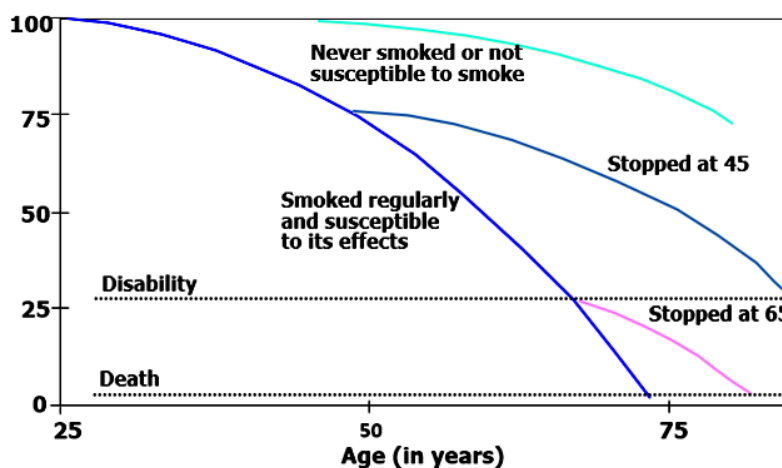


About 30% of Leger ME members smoke and will have some degree of COPD. The FEV1 readings of asthma are reversible whereas the COPD reading are not. Some people have a combination of the two. Specialist practice nurses quite often manage these two conditions. It is important that FEV1 readings are carried out under the supervision of a doctor or trained nurse. The nurse will generally use a spirometer, a sort of a PFM more sophisticated version to keep an additional check. While medicines are helpful in controlling the condition, they don't cure or compensate for the chronic deterioration of lung function. If causal stopping smoking is the only method to stop deterioration.

About 40% of Leger ME members are asthmatic, mainly the seasonal allergic type, and it tends to run in families. I very often come across members who quite unwisely use relatives of inhalers to treat asthma without their doctors' knowledge to avoid the prescriptions charge and the stress of attending a chest clinic. Unlike COPD, in asthma if properly managed most of the lung function can be restored in a matter of hours. Usually a drop in FEV1 indicates an onset of an attack, and a 'rescue' inhaler used on the SABA type (Short Acting Beta Agonist). FEV1 is an important tool because its changes and SABA give an asthma nurse a good indication of how well the treatments are working and if any changes are needed to the LABA (Long Acting Beta Agonist) or ICS (Inhaled corticosteroids) doses.

COPD & smoking

FEV1 (% of value at age 25)



How is your COPD? Take the COPD Assessment Test™ (CAT)

This questionnaire will help you and your healthcare professional measure the impact COPD (Chronic Obstructive Pulmonary Disease) is having on your wellbeing and daily life. Your answers, and test score, can be used by you and your healthcare professional to help improve the management of your COPD and get the greatest benefit from treatment.

For each item below, place a mark (X) in the box that best describes you currently. Be sure to only select one response for each question.

Example: I am very happy 0 1 2 3 4 5 I am very sad

I never cough 0 1 2 3 4 5 I cough all the time

I have no phlegm (mucus) in my chest at all 0 1 2 3 4 5 My chest is completely full of phlegm (mucus)

My chest does not feel tight at all 0 1 2 3 4 5 My chest feels very tight

When I walk up a hill or one flight of stairs I am not breathless 0 1 2 3 4 5 When I walk up a hill or one flight of stairs I am very breathless

I am not limited doing any activities at home 0 1 2 3 4 5 I am very limited doing activities at home

I am confident leaving my home despite my lung condition 0 1 2 3 4 5 I am not at all confident leaving my home because of my lung condition

I sleep soundly 0 1 2 3 4 5 I don't sleep soundly because of my lung condition

I have lots of energy 0 1 2 3 4 5 I have no energy at all

TOTAL SCORE

COPD Assessment Test (CAT)

(<http://catestonline.org>).

- 8 Questions (max score 40)
- Score ≤5: normal healthy non-smokers
- <10: low impact of COPD on health status
- 10-20: medium impact
- >20: high impact
- >30: very high impact
- A change of 2 is clinically meaningful.

Severity	Symptom frequency	Night time symptoms	%FEV ₁ of predicted	FEV ₁ Variability	SABA use
Intermittent	≤2/week	≤2/month	≥80%	<20%	≤2 days/week
Mild persistent	>2/week	3–4/month	≥80%	20–30%	>2 days/week
Moderate persistent	Daily	>1/week	60–80%	>30%	daily
Severe persistent	Continuously	Frequent (7×/week)	<60%	>30%	≥twice/day

Very often asthma attacks in a given area may all occur at the same time. There is a well-documented Spanish case where asthmatic hospital admissions reached crisis levels. This was eventually tracked down to when soya beans were unloaded from ship as a at the local docks. Another example is when the heather is burned on the North Yorkshire Moors, the local hospitals always expect a massive influx of urgent asthma cases.

Overall the PFM is a cheap (costing about £10) useful instrument to help patients manage their own chest problems. Obviously if you suspect you have a breathing problem your first port of call should be your practice nurse or doctor.

Smoking Cession Service available at the Redmond Centre

You quit, your way

We know that different things work for different people, so our free and confidential NHS stop smoking specialists can help find what's right for you. You can use any combination of our support, whatever suits you best.

Stopping smoking can be a challenge but we are here to support you. In fact, with NHS support you're up to four times more likely to quit successfully! We've already helped thousands of people in Yorkshire quit, so let us help you. You quit, your way. We know that different things work for different people, so our free and confidential NHS stop smoking specialists can help find what's right for you. You can use any combination of our support, whatever suits you best.

Come and see us We'd love to see you! We run a variety of groups and clinics so there are plenty of opportunities for you to come and see us, whether you want to come somewhere close to where you live or where you work. You can find all our locations on our website or just give us a call. If you'd like to meet with us in person then just give them a call on 0800 612 0011 (free from landlines) or 0330 660 1166.

It's amazing what can happen in a day!

The amazing thing about the human body is that it takes just 20 minutes for health benefits to start. Look what happens after you smoke your last cigarette:



20 minutes – Blood pressure and pulse return to normal



1 hour – Your circulation improves; your hands and feet feel warmer



8 hours – Nicotine levels fall, circulation improves



24 hours – Lungs begin to work better, carbon monoxide leaves the body

Foot Clinics at the Redmond Centre

Foot Clinics are held at The Redmond Centre, Carcroft on Tuesdays. For further information and/or appointments please contact: Redmond Centre – 01302 724501 or email: RedmondCentre@doncaster.gov.uk

Treatments are £15 for 45 minutes. Services are provided by a Foot Health Practitioner:

Michelle Prendergast
MCFHP MAFHP



NHS funding Cuts: Proposed Medicines Restrictions.

With Thanks to the NHS Clinical Commissioners

NHS England announced a review after local health bosses identified £400m of spending they believe has little or no clinical value. It also includes some types of pain relief and travel vaccines. The proposals could see an outright ban or tighter restrictions on some products being prescribed by GPs.

An initial list of 10 products has been drawn up by NHS Clinical Commissioners. A few of them are available over-the-counter at a lower price than the cost to the NHS of prescribing them. The bad news is that for people with ME/CFS, the list of products include omega 3 and fish oils, travel vaccines and gluten-free foods as well as a range of pain relief drugs for which there is said to be limited evidence. 'Low value' medicines on the list and their annual cost to the NHS:

- £30.93m on Liothyronine (T3) to treat underactive thyroid. *Many ME's buy Armour thyroid privately already.*
- £21.88m on gluten-free foods. *Already banned in some parts of the country. There are expensive, and there are massive selections of gluten free food on supermarket shelves. This may cause problems with some people who are both coeliac and have ME/CFS.*
- £17.58m on Lidocaine plasters for treating nerve-related pain. *These have always been seen to be of little value.*
- £10.51m on Tadalafil, an alternative to Viagra. *These are for diabetic or people which neurological conditions like MS.*
- £10.13m on Fentanyl, a drug to treat pain in terminally ill patients for pain control.
- £8.32m on the painkiller Co-proxamol—*this seems strange because this was withdrawn from general distributions years ago.*
- £9.47m on travel vaccines. *These are holiday add ins—for which there is no need in the UK*
- £7.12m on Doxazosin, a drug for high blood pressure. *Even the manufacturers stopped recommending this one because it didn't reduce the number of deaths due to heart disease.*
- £6.43m on rubs and ointments—*difficult to say which but NSAID voltarol and movelat are in the firing line.*
- £5.65m on omega 3 and fish oils. *In Doncaster Veg EPA is backlisted already, but a similar product Omcor is available. It is not promoted for ME/CFS on the NHS and therefore should not be proscribed for such according to the NHS.*

NHS Clinical Commissioners - which represents local health managers who oversee spending - has also highlighted other products which it also wants reviewed.

This includes sun cream, cough and cold remedies and indigestion and heartburn medicines, which could bring the saving to £400m a year.

NHS Clinical Commissioners chief executive Julie Wood said, "difficult choices" had to be made given the unprecedented financial and deming challenges facing the NHS.

Comment: Has anyone told them about CBT and GET for ME/CFS???



ME/CFS According to patient.info/

With thanks to Dr. Tim Kenny, Dr. Colin Tidy and Dr. Adrian Bonsall and patient.info/pdf/4859.pdf

Chronic fatigue syndrome (ME/CFS) is a condition where you have long-term disabling tiredness (fatigue). Most people with also have one or more other symptoms such as muscular pains, joint pains, disturbed sleep patterns, poor concentration or headaches. The cause is not known. Treatments that may help in some cases (but not all) include a programme of graded exercise therapy (GET) and cognitive behavioural therapy (CBT).

What is myalgic encephalomyelitis/chronic fatigue syndrome?

ME/CFS, also referred to as chronic fatigue syndrome (CFS), is a condition that causes marked long-term tiredness (fatigue) and other symptoms which are not caused by any other known medical condition.

ME stands for **myalgic encephalomyelitis**. Myalgic means muscle aches or pains.
(Encephalomyelitis means inflammation of the brain and spinal cord.)

CFS stands for **chronic fatigue syndrome**. Chronic means persistent or long-term.

However, there is controversy about the nature of this condition. There is no test to diagnose the condition. The diagnosis is made in people who have a certain set of symptoms (which can vary in their type and severity). There is even controversy about what to call this condition. Many people, including some doctors, now think that ME represents several different conditions rather than just one condition. This would explain the considerable variety of different symptoms and the severity of symptoms.

The rest of this feature just uses the term ME/CFS.

What causes ME/CFS?

The cause of ME is not known. There are various theories but none has been proved. A popular theory is that a viral infection may trigger the condition. It is well known that tiredness (fatigue) is a symptom that can persist for a short time after having certain viral infections. For example, infection with the glandular fever virus or the influenza virus can cause fatigue for several weeks after other symptoms have gone. However, most people recover within a few weeks from the tiredness that follows known viral infections. Even if a viral infection is a trigger of ME, it is not clear why symptoms persist when there is no evidence of persisting infection. Also, the symptoms of many people with ME do not start with a viral infection. Factors that are thought to contribute to some people developing ME include:

- Inherited genetic susceptibility (it is more common in some families).
- Viral infections such as glandular fever.
- Exhaustion and mental stress.
- Depression.
- A traumatic event such as bereavement, divorce or redundancy.

The following factors are thought to make ME worse:

- Recurring infections with viral or bacterial germs.
- Not being active enough, or even being too active.
- Stress.
- Poor diet.
- Being socially isolated and/or feeling frustrated and depressed.
- Environmental pollution.

It is hoped that research will clarify the cause of ME in the future.

Causes of ME/CFS.

- Recent research shows at least seven types of gene expression in ME/CFS patients.
- Some doctors believe that in some patients auto immune disease is the main mechanism..
- There is research evidence that mitochondrial function is compromised in some cases.

Who develops ME/CFS?

ME can affect anyone. It is estimated that ME affects about 1 in 300 people in the UK, possibly more. It is about three times as common in women as in men. The most common age for it to develop is in the early twenties to mid-forties. In children, the most common age for it to develop is 13-15 years but it can develop at an earlier age.

How is ME/CFS diagnosed?

There is no test that proves that you have ME. A doctor will usually diagnose ME based on your symptoms. Some tests are usually done to rule out other causes of your tiredness (fatigue) or other symptoms. For example, blood tests may be done to rule out anaemia, an underactive thyroid gland, liver problems and kidney problems. All these tests are normal in people with ME.

The medical definition of ME used in the UK states that symptoms should have lasted for at least four **months in adults and three months in children and young adults.**

What are the symptoms of ME/CFS?

The onset of ME symptoms can be sudden (over a few days or so), or more gradual.

“Tiredness” (Fatigue).

The most common main symptom is persistent tiredness. The tiredness is of new onset. That is, it has not been lifelong but started at a point in time and causes you to limit your activities compared with what you were used to. It is often felt to be both physical and mental tiredness and is said to be overwhelming, or to be like no other type of tiredness. For example:

*Tiredness is natural,
Fatigue is sinister.*

- It is very different to everyday tiredness (such as after a day's work).
- It is not eased much by rest.
- It is not due to, or like, tiredness following over-exertion.
- It is not due to muscle weakness.
- It is not loss of motivation or pleasure which occurs in people who are depressed.

The tiredness is often made worse by activity. This is called post-exertional malaise. However, the post-exertional malaise usually does not develop until the day following the activity. It then takes several days to improve.

Other symptoms

In addition to tiredness, one or more of the following symptoms are common (but most people do not have them all). In some people, one of the following symptoms is more dominant than the tiredness and is the main symptom:

- Mental (cognitive) difficulties such as poor concentration, poor short-term memory, reduced attention span, poor memory for recent events, difficulty with planning or organising your thoughts, difficulty finding the right words to say, sometimes feeling disorientated.
- Sleeping difficulties. For example, early waking, being unable to sleep, too much sleep, disrupted sleep/wake patterns.
- Pains - most commonly, muscular pains (myalgia), joint pains and headaches.
- Recurring sore throat, often with tenderness of the nearby lymph glands.

A range of other symptoms has been reported in some cases. For example, dizziness, a feeling of sickness (nausea) and a 'thumping heart' (palpitations). Physical or mental exertion will often make your symptoms worse.

Severity of symptoms

The severity of ME can roughly be divided into three levels:

Mild cases - you can care for yourself and can do light domestic tasks, but with difficulty. You are still

likely to be able to do a job but may often take days off work. To remain in work, you are likely to have stopped most leisure and social activities. Weekends or other days off from work are used to rest to cope.

Moderate cases - you have reduced mobility and are restricted in most activities of daily living. The level of ability and severity of symptoms often varies from time to time (peaks and troughs). You are likely to have stopped work and require rest periods. Sleep at night tends to be poor and disturbed.

Severe cases - you can carry out only minimal daily tasks such as face washing and cleaning teeth. You are likely to have severe difficulties with some mental processes such as concentrating. You may be wheelchair dependent for mobility and may be unable to leave your home except on rare occasions. You usually have severe prolonged after effects from effort. You may spend most of your time in bed. You are often unable to tolerate any noise and are generally very sensitive to bright light.

What is the treatment for ME/CFS?

There is no known cure for ME, although treatment may help to ease symptoms. You are likely to be referred to a specialist who will be able to offer you support and treatment. Treatments that may be considered include the following.

Management of your symptoms

- Painkillers may help if muscle or joint pains are troublesome symptoms. Eating little and often may help any feeling of sickness (nausea). Specific diets have not been shown to be beneficial.
- Depression can occur in people with ME - as it can in many other persistent (chronic) diseases. Depression can make many symptoms worse. Antidepressants may be prescribed if depression develops.
- Management of your quality of life and function
- Managing your sleep
- It is likely you will be given advice about your sleep. Any changes to your sleep pattern (for example, having too little, or even too much, sleep) may make your tiredness (fatigue) worse. This includes sleeping in the daytime, which should ideally be avoided. Any changes to your sleep pattern should be done gradually.
- Managing rest
- Rest (rather than actual sleep) is very beneficial. You should introduce rest periods into your daily routine. These should ideally be limited to 30 minutes at a time and be a period of relaxation.
- Relaxation
- Relaxation can help to improve pain, sleep problems and any stress or anxiety you may have. There are various relaxation techniques (such as guided visualization or breathing techniques) which you may find useful when they are built into your rest periods.

Diet

It is very important that you have a well-balanced diet. You should try to avoid any foods and drinks to which you are sensitive. Eating small, regular meals which contain some starchy foods is often beneficial.

Specific treatments for ME/CFS

Cognitive behavioural therapy (CBT) and/or graded exercise therapy (GET) are often used to treat people with ME. Several large studies have shown these treatments to be beneficial for many people with ME. However, some people with ME have not found benefit with these treatments. Some people have also felt that these treatments have made them feel worse. It is therefore essential for you to find what seems best for you as an individual.

Graded exercise therapy (GET)

GET is a gradual, progressive increase in exercise or physical activity, such as walking or swimming. The level of exercise recommended will depend upon your symptoms and current level of activity.

Graded exercise is a structured treatment during which you are closely monitored. It is **not** the same as going to the gym or doing more exercise by yourself. It should be tailored to suit each individual case. Ideally, it should be supervised by a physiotherapist or occupational therapist who is used to treating people with ME. GET can improve symptoms for some people. However, some people report that they do not find it beneficial.

Cognitive behavioural therapy (CBT)

Cognitive therapy is based on the idea that certain ways of thinking can fuel certain health problems. Behavioural therapy aims to change any behaviours that are harmful or not helpful. CBT is a combination of cognitive and behavioural therapy. The use of CBT does not imply that the cause of an illness is psychological. CBT is one of the most effective treatments for ME.

- *Our local ME/CFS clinic in Sheffield prefer to use Adaptive Pacing with includes elements of GET and CBT.*
- *The ME Association have reservations about GET and CBT*

Although CBT does not aim to cure the condition, it helps to improve symptoms, coping strategies and day-to-day functioning. For people with ME the core components of CBT would normally include:

- Energy/activity management.
- Establishment of a sleep routine.
- Goal setting.
- Psychological support.

General support

Depending on the severity of illness, other support may be needed - for example, Carers, nursing support, equipment and adaptations to the home to help overcome disability.

If you are employed, your doctor will be able to advise you about whether you should take time off work. And, if you take time off work, when you may be ready to go back to work. It may be that you need to work doing slightly different hours or even with different duties. If you have an occupational health department at work, they are likely to be involved with you also regarding work and going back to work if you take time off.

- *Our experience is that almost members with ME/CFS are Vitamin D depleted, and if corrected reduces fatigue. We recommend that all our members ask their GP to Check*

Complementary treatments

As there is only limited success with conventional treatments, it is understandable that people turn to complementary practitioners. Many people with ME/CFS find various therapies helpful. However, there is not enough research evidence to support the use of complementary therapies for the treatment of ME.

There is also insufficient evidence to recommend the use of supplements (for example, vitamins).

Managing setbacks (relapses)

It can be common to have setbacks when symptoms become worse for a while. These can have various triggers - for example, poor sleep, infection or stress. Your doctor may discuss with your strategies which may help during a setback. These may include relaxation techniques, talking with your family, and maintaining your activity and exercise levels, if possible. However, it may be necessary for you to reduce or even stop some of your activities and increase the amount of rest you have during a setback. Following a setback, you should usually be able gradually to return to your previous activity level.

What is the outlook (prognosis)?

In most cases, the condition has a fluctuating course. There may be times when symptoms are not too bad and times when symptoms flare up and become worse (a setback). The long-term outlook is variable:

- Most people with myalgic encephalomyelitis/chronic fatigue syndrome (ME) will show some improvement

- *We find that many people with ME/CFS are prone to type 2 diabetes, asthma and other atopic diseases..*
- *We recommended that at least yearly and when new symptoms occur members are reviewed and checked for the above by their GP*

over time, especially with treatment. Some people recover in less than two years, while others remain ill for many years. However, health and functioning rarely return completely to previous levels.

- Some people will continue to have symptoms or have relapses of their symptoms.
- In some cases, the condition is severe and/or goes on (persists) for many years. Those who have been affected for several years seem less likely to recover. The outlook in children and young people is usually better.

Further help & information

Action for M.E.

42 Temple Street, Keynsham, BS31 1EH

Tel: (Information and Support) 0117 927 9551, (Welfare Advice) 0800 138 6544

Web: www.actionforme.org.uk

AYME - Association of Young People with ME

Tickford House, Silver Street, Tongwell, Newport Pagnell, MK16 0EX

Tel: (Helpline) 0330 2211223, (Office) 01908 379737 Web: www.ayme.org.uk

M.E. Support

Web: www.mesupport.co.uk/

ME Association

7 Apollo Office Court, Radclive Road, Gawcott, Bucks, MK18 4DF

Tel: (Helpline) 0844 576 3626, (Admin) 01280 818968

Web: www.meassociation.org.uk

The 25% ME Group

21 Church Street, Troon, Ayrshire, KA10 6HT

Tel: 01292 318611

Web: www.25megroup.org

Tymes Trust -The Young ME Sufferers Trust

PO Box 4347, Stock, Ingatestone, CM4 9TE

Tel: 0845 003 9002

Web: www.tymestrust.org

WAMES - Welsh Association of ME and CF Support

Tel: Helpline: 029 2051 5061 Web: wames.org.uk/

Further reading & references

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Newly diagnosed with M.E./CFS - information and advice for you and your GP; Action for ME

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Patient.info/health/myalgic-encephalomyelitischronic-fatigue-syndrome-mecfs-leaflet

Editor's Note: It is Leger ME policy that all members must have a diagnosis of ME/CFS by a registered doctor.

Recent News from ME Research UK

Is mitochondrial function abnormal? Mitochondria are often referred to as the power plants of the body because they are responsible for generating nearly all the energy needed to support life. These kidney sausage shaped structures are found in most cells and are made up of different compartments, each with a specific role related to the metabolism of the cell they inhabit.

One of these roles is the generation of adenosine triphosphate (ATP), a molecule that is used to transport energy within a cell and thereby enable it to function properly (for example, allowing a muscle fibre to contract). It is not surprising, therefore, that scientists have considered whether abnormalities in the mitochondria might be involved in ME/CFS, an illness characterised by a loss of muscle power following exertion, which may be due to insufficient energy within the muscle cells. We have reported on several such studies over the last few years (from the Netherlands, Spain and the UK), but the overall picture is still not clear. Some studies have shown reduced concentrations of ATP in ME/CFS patients, while others have not.

Adding to this story (but not yet making it much clearer) is new research published in the Journal of Nature and Science. US researchers at Stanford and Columbia took blood samples from 42 ME/CFS patients and 42 healthy people in five different clinics, including the Levine Clinic and Sierra Internal Medicine. Their main aim was to look for defects in the structure or function of the mitochondria that might explain some of the symptoms of ME/CFS. Overall, the researchers found no difference in the density, size or shape of mitochondria in patients, nor in several other aspects of their structure and function, although the cristae (protrusions of the membranes inside the mitochondria) were more condensed than usual. They did find that ATP levels were higher than normal in the blood samples from ME/CFS patients. Further testing showed that the mitochondrial production of ATP was relatively normal, suggesting that the extra ATP was being generated elsewhere.

The main conclusion of the study, however, was that there were no major abnormalities in the mitochondria of ME/CFS patients: the important parts of this structure were all intact and functioning, and ATP production was normal. It is important to note that these measurements were made in mitochondria from blood cells, and it is possible that the situation in muscle cells is quite different. But at least one study that did look at muscle mitochondria has also reported normal ATP production. If the muscle fatigue in ME/CFS is not a result of a lack of mitochondrial ATP, then what is the cause? We still don't know, but the intriguing hypothesis suggested by these researchers is that there is some pathological process occurring by which extra ATP is being produced somewhere else. And the scientists' next step is to identify where and why this is happening.

Shifting focus. Problems with vision are relatively common among people with ME/CFS, most of whom report symptoms such as hypersensitivity to light, difficulties focusing, and dry eyes. But despite their significant impact on quality of life, there is still a lack of scientific research into these symptoms, and they are not included in any clinical and diagnostic guidelines for ME/CFS. Fortunately, scientists such as Dr. Claire Hutchinson of the University of Leicester have recognised that this is an area worthy of study. Supported in part by grants from ME Research UK, Dr. Hutchinson and her group have looked at several vision-related problems in ME/CFS. Applying sophisticated eye-tracking techniques, they showed that patients have difficulties focusing on an object while ignoring irrelevant information, are slower than normal in shifting attention between objects, are slower and less accurate in their eye movements, and are vulnerable to pattern-related visual stress.

Furthermore, the group found that around 90% of ME/CFS patients reported a degree of eye pain and sensitivity to bright lights at least some of the time. Also, helping to fill this gap in our knowledge is a group from Antwerp in Belgium, which has recently published an interesting study on binocular vision in the American Orthoptic Journal. The investigators carried out full Orthoptic examinations on 41 patients fulfilling the CDC criteria for CFS and 41 healthy individuals matched for age and gender. A series of tests looked at how the eye adjusts to keep focus on an object as it moves closer or further away, an adjustment that requires both vergence and accommodation. Vergence is the simultaneous movement of the pupils of both eyes, either inwards (convergence) or outwards (divergence), while accommodation is the ability of the eye to change its focal length to maintain a clear image.

How your tax contributed to public spending in 2015-2016

With Thanks to HM Treasury

Here is some information derived from income tax documentation. It's presented as a table and as a pie chart.

The information in this table and chart shows you how your Income Tax and National Insurance contributions were spent in 2015-16. This does not include indirect taxes such as VAT and other duties.

For more information about your tax and public spending, go to www.gov.uk/annual-tax-summary.

All figures are rounded to the nearest pound.

These figures are intended as a guide to how taxes are spent and not as a direct link between your Income Tax, National Insurance contributions and any specific expenditure. For further information see:

www.gov.uk/annual-tax-summary

Health (mainly National Health Service) is the biggest spend followed by Welfare (includes DWP statements that most Leger ME Members rely on).

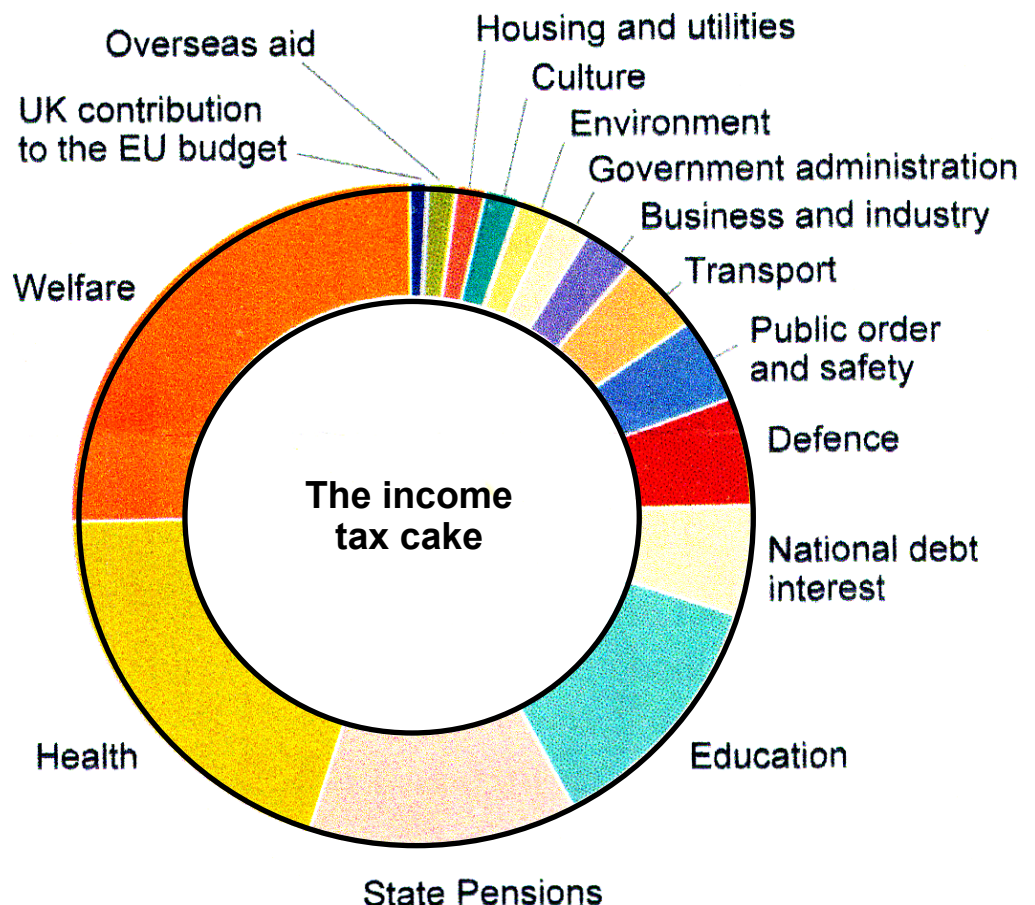
Looking at the table it is obvious why the NHS is tightening up of spending. National debt interest is very often difficult for people to understand. At first it seems a strange way to raise money. The government has no money of its own, and so must borrow from other people.

This usually takes the form of government bonds which are loans from the public or other institutions. The national debt is the total interest paid to lenders.

This must be paid, in is usually take from income tax. It's best thought of as interest on a massive loan (like from a credit card for example).

Small amounts of interest are manageable, but large amounts of borrowing just massively reduce the money available for other functions. There is a fine balance must be achieved and that is the purpose of the budget.

Spending	£
Welfare	250.55
Health	299.27
State Pensions	128.21
Education	120.15
National debt interest	52.75
Defence	52.01
Public order and safety	43.22
Transport	40.29
Business and industry	24.18
Government administration	19.78
Environment	16.85
Culture e.g. sports, libraries, museums	16.12
Housing and utilities e.g. street lights	13.92
Overseas aid	11.72
UK contribution to the EU budget	10.99
Total	£ 1000



Nutritional Management of Chronic Fatigue Syndrome

Nutrition management of ME/CFS is a way of managing ME/CFS through food supplements. Nutritional management is well within the private sector and is discouraged by the NHS. However for some this strategy works well, for others it doesn't help. This information is based on Biocare practitioners information.

Chronic Fatigue Syndrome (CFS) involves persistent fatigue, which is not relieved by rest and is often triggered by viral infection. ME/CFS is known to significantly impact upon the quality of life of sufferers, ranging from mild symptoms, to more severe symptoms where individuals are unable to carry out any daily tasks. Around 250,000 people in the UK suffer from ME/CFS. It is more common in women than men and usually develops between the early 20s and mid-40s.

Symptoms

Fatigue which is not due to exhaustion and is not relieved by sleep.

- Muscular pain, joint pain and severe headaches.
- Poor stamina.
- Sleeping problems, such as insomnia and feeling that sleep is not refreshing.
- Sensitivity or intolerance to light, loud noise, alcohol and certain foods.
- Impaired cognitive and mental function

Medical Management *(this is the what the NHS does.)*

- Cognitive behavioural therapy (CBT) aims to change the way individuals think, feel and behave, helping to address 'internally created stress'.
- Graded exercise therapy (GET) is a structured exercise programme that aims to gradually increase how long individuals can carry out a physical activity.
- Anti-depressants such as amitriptyline are used for people with CFS who are in pain or having trouble sleeping.

Clinical Considerations *(these are mainly with the private practitioners.)*

Patients with ME/CFS experience a wide, varied range of symptoms with high variability between individuals, and the pathophysiology is unknown.

- Possible underlying factors may include nutritional deficiencies, acquired toxicities, sensitivities and allergies, hormonal imbalances, viral, parasitic, yeast or bacterial infections, impaired digestion, emotional distress and blood glucose imbalances.
- Clinical considerations for treatment should be individual but always consider adrenal fatigue, digestive health, nutritional deficiencies, liver function and blood glucose control.
- More recent research suggests that mitochondrial dysfunction may play a significant role in the aetiology (*origin*) ME/CFS¹. Body energy demands exceed the supply of ATP produced by mitochondria, due perhaps to lack of essential substrates and partial blocking of the translocator protein sites in mitochondria. Poor stamina is a key differentiator and suggestive of mitochondrial involvement. These dysfunctions can be identified using ATP profiling², and providing synergistic co-factor support for mitochondrial function may achieve favorable results³

Nutritional Management

Designing a staged protocol is very important. Severe CFS patients may require very low dose, easily tolerated supplements at first, with the doses gradually increased.

Mitochondrial Support Strategy

- **Vitamins B2 and B3** are needed for synthesis of NADH and FADH₂⁴. Supplemented NADH has been shown to improve symptoms of ME/CFS⁵.
- **Magnesium** is commonly insufficient in CFS sufferers^{6,7} and magnesium malate may help to reduce fibromyalgia and muscle weakness^{8,9}.
- **CoQ 10** supports energy release and forms part of complex III in the electron transport chain¹⁰. CoQ 10 also acts as a potent antioxidant and immunomodulator in the mitochondrial¹¹.

- **Carnitine** deficiency is common in CFS¹². Carnitine transports fats across the mitochondrial membrane¹³ and contributes to increased capacity for physical and cognitive activity¹⁴. Carnitine also protects mitochondria by transporting xenobiotics out¹⁵.
- **N-acetyl cysteine** supports mitochondrial protection and function¹⁶, possibly by increasing intra-cellular glutathione^{17 18}.
- **D-ribose** can directly synthesize ATP and reduces symptoms of CFS¹⁹, improves energy restoration in muscles²⁰-and speeds up regeneration of ATP in muscle cells²¹. Furthermore, it may increase ventilatory efficiency, improve peak exercise performance²² and modulate glucose levels²³.
- **Citrulline** improves nitric oxide deficiency related manifestations of mitochondrial diseases²⁴.

HPA Axis Support

- **Panax ginseng** is an adaptogen and has antioxidant properties that can improve energy metabolism, glycaemic control and adrenal hormone balance^{25 26 27}

Additional Support

Vitamin D levels may be decreased in CFS sufferers²⁸ This applies to most *members* in Leger ME.

Adjuncts

- Diet to balance blood sugar and thus optimise energy production and circadian rhythm.
- Stress reduction and relaxation techniques are an important component of any ME/CFS treatment.
- Food sensitivity testing with avoidance or rotation of problem foods.

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Windowsill Ginger by Sandy Nye

With thanks to our American Group Member, Sandy, who cleverly spotted this article and though you might like to know about it too!

Anyone who has space for a pot can grow this delicious crop inside on a windowsill. Growing edibles isn't just for the outdoors, just think about being able to walk across a room to pick a leaf or lift a rhizome to flavour dinner – especially in mid-winter. Growing tropical spices is as easy as planting gingerroot you buy at the local supermarket or rhizomes ordered on your laptop.

The procedure starts:

- Ginger grows in tropical shade, but with good drainage and consistent moisture, store-bought rhizomes can yield an indoor crop.
- *When planting, avoid peeled ginger which is available in this county*
- Choose plump rhizomes from the supermarket and leave them in a dry place until pale nodes, or "eyes", appear (each node produces a stem – see picture).
- Cut the rhizomes into pieces, each with one or two nodes. Fill a 10-inch pot with quality potting compost; cover the rhizomes one inch below the surface. Water well.
- Place on a windowsill or in a bright room, avoiding direct sunlight.



Care and feeding:

Once shoots emerge (in about three weeks' time), water deeply, then after that water only when the soil surface dries out.

- A spray bottle filled with water is useful to mimic tropic humidity.
- After a year:
- Once your Ginger is established it needs room so move it to the largest pot possible.

If anyone decides to give this a go or maybe chooses another tropical plant to grow as an edible houseplant such as Curry Leaf or Thai Lime or Allspice, we would love to know how you get on.



North of Doncaster Personal Comment by Trevor Wainwright**A travel diary to the Holy Land Part 2: The Jezreel Valley, Cana and Nazareth.**

I left my room and went for a brief walk on the small beach by the hotel, I had stated in my closing poem of last night that I would be doing it, and did. It would make a good subject for my first poem of the day albeit a short one, I thought listening to the water lap gently on the beach, and again looking at the mist covered hills to the East, more would hopefully be written later. Then it was back into the hotel for breakfast and it was a breakfast indeed quite a choice every possible taste considered a case of lead me not into gastronomic temptation, it would have so easy.

We began our pilgrimage with a ride to Mount Tabor, associated with the Transfiguration, to celebrate Mass but not before having a short service on the bus. Our first stop was the terminal where we would transfer to taxis to take us to the summit, the reason would become obvious. We looked in the souvenir shop whilst waiting; I bought some bracelets for my wife and daughters, small but significant in that two had a small hand which I interpreted as Jesus putting his hand out to the leper in St Matthew, and to others, the third a small fish representing fishers of men. The taxis arrived we boarded and set off. Along the narrow road with its hairpin bends, the busses would have never made it. We were rewarded with fantastic views of the Jezreel Valley also known as the plains of Armageddon. We arrived at the church for Mass, where are two side chapels either side of the main body. One for Moses and one for Elijah with images of them on the domed roof above the altars in their respective chapels. We held out mass in the Moses Chapel, after which we took in the beauty of the main church as the images told the story of Jesus' infancy, suffering, death and resurrection. Pride of place going to the Transfiguration scene above the main altar. Outside on the terrace once again we were rewarded with magnificent views over the valley in addition to looking down onto some ruins of an earlier church, possibly crusader. Then it was time to make our way back to the bus.



Our next stop was Cana and the site of his first miracle. Turning the water into wine. Walking to the site which is now The Franciscan Wedding Church; we passed a variety of shops on the way. Selling various items from fruit to souvenirs, it would have been much like that in Jesus' day, pilgrims in need of refreshment after many days journey, wanting refreshment, maybe replace some worn out sandals, commercial enterprise reliant on tourism still prevalent today, only much of it cheap tat to say you'd been there. To our right, we passed the Chapel of St Nathaniel one of the Apostles also known as Bartholomew, then we were at the gates, through the courtyard and we were there. Our first call was the excavations where the changing of the water to wine took place; pride of place was a large stone water jar, stone used as unlike clay it did not absorb the water.

The excavations were behind Perspex sheets. What I first thought was litter was in fact prayers and messages left by previous pilgrims, one even in a brown envelope perhaps asking for help in paying his tax bill. This would be prevalent at many of the excavations we visited. As we stood by the water jar there was an offer of marriage vows renewal. Some of the couples took up the offer while the rest of us watched in respectful silence, noting the emotion on the faces of the couples. After this we moved up into the main body of the church the entire altar area dedicated to the first miracle. Already my mind was working overtime, how would I rhyme all with this. We moved out into the courtyard passed the Chapel of Simon the Canaanite, orange and grapefruit trees grew there, easy to pick, we resisted the temptation and made our way back to the bus, past the small tourist shops where two of us bought fresh pressed pomegranate juice the way pilgrims would have done in the old days.

A short bus ride took us to Nazareth passing what seems to be obligatory McDonald's. We drove into Nazareth walked through what looked like a market arcade to a shopping mall, again a variety of goods on sale. Then we were in front of a large imposing stone building 'The Holy Land Restaurant'. We went in and sat down. To our right was an arched alcove, its wall decorated with carpentry tools as would have been used by Joseph.

Whilst waiting for our meal another group came in found their tables, and once their wine was poured began singing as if it was a meal ritual. A few of them raised their glasses to us, and we raised ours in acknowledgment both groups smiling. Then it was lunch, and a look forward to following further in the steps of Jesus. Leaving the restaurant, we made our way to the Basilica of the Annunciation, on the site where Gabriel told Mary she would bear Jesus. Like many others, it had been built on the site of a previous church, the remains at times often visible. In the lower parts of the church was the cave of Mary where the angel is said to have appeared to her. It was then to the upper level which is the local Catholic Church for Nazareth before making our way to the old town for a look at the excavations and the old street layout.



Nazareth - Part of the wall that commemorates 15 May 1948, note 2 languages

Onwards then via another souk (market) selling Christmas tat, but more traditional goods further on, to the Synagogue where Jesus was disbelieved, giving rise to his saying "a prophet is never accepted in his own land". Another mass was held there, yes, we really were following in his footsteps, and I was scribbling away every chance I got. It was a short walk to Mary's Well which is said by the Greek Orthodox Church also to be where the annunciation took place. On the way, we passed a reminder of the Holy Lands troubled history in the form of a protest wall depicting May 15, 1948, the day of the Palestine Nakaba on which more than 780,000 Palestinians were forced from their homes and lands, with more than 500 villages destroyed by Zionist forces, with 50 civilian massacres resulting in 15,000 martyrs. It was written in English and Arabic.



Nazareth - Inside, pick a Saint to pray to

We reached the church and went in. Again, there were prayer requests for a donation, many churches relied on this type of income, as they did in the days of Jesus relying on pilgrims and their needs, as a result small businesses set up and communities formed around the church. Inside the church was an array of images of the saints, so pilgrims could choose whichever one they wanted to pray to for which ever reason. We moved deeper into the church to where the annunciation is said to have taken place, on this excavation too, money and prayer requests had been thrown in. Above the excavation was a picture of the annunciation. Our guide Joseph had proved very knowledgeable. His Christian faith was apparent in the way he explained things, images were being conjured in my mind and I was feeling the inspiration flowing, I was going to be busy that night.

Then back to the hotel, with dinner on a grand scale, plenty of choice, best to have a bit of everything, then go back, rather than pile it on and feel uncomfortable. Then it was time to relax, enjoy the evening, have a drink at the bar or outside overlooking the Sea of Galilee. Every room had a sea view, even the side rooms. I went back to my room to reflect on the day, and after making myself a coffee to sit on the balcony look out over the sea and write. By the end of the day I had brought my total to 13 poems, 2 had been written on the run up about why I wanted to visit the Holy Land, 5 had been written on the journey out and 6 more by the end of the first day.

Closing the book, I looked forward to tomorrow, and seeing more of where Jesus' ministry took place, including the Sermon on the Mount and those wonderful messages of hope to the down trodden, The Beatitudes.

To be continued



Nazareth - Mary's Well, the Greek Orthodox Church site of the Annunciation