Price £ 5.00 (Free to members)

Pathways

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

Welcome to Pathways No 78.

Winter Edition 2023

With thanks to the Winter Light Show at the Yorkshire Wildlife Park, Doncaster

You Write In: A selection of questions from the Leger ME Inbox.

Peter Writes: Thank you for your help with dealing with my PIP problems. I am pleased to tell you that I have just received a letter from the DWP saying I have been awarded PIP at the Standard Care rate for mobility and the Standard Mobility rate for until April 2026 three years. I have sent you copies of the DWP decision letter. I notice they say they will contact me ago in April 2025 to see it things are still the same. Is this routine?

Previously I was awarded Enhanced Mobility, and this appears to be a reduction in the money I receive, although I am worse off than before. Is it worth appealing or would I be better if I just accepted what I've got? The problem I have got is that I cannot be dealing with the stress of it. It makes me more ill. Is it worth the hassle?

For the benefit of Pathways readers, we help Leger ME members with welfare rights matters including PIP forms. We can usually help people get something, but not always what they had before or what they expect. Nothing is guaranteed.

Based on what other people are currently receiving the double Standard rates was the most likely outcome I would expect from Peter's application. To upgrade to a higher award would need more input from a specialist care team. Also, the problem is currently there is a waiting period between 12 and 18 months to get a tribunal hearing and then any award would be dated back to the original date of the form. I also advised Peter that from my experience it is better to accept the award it as is, and then sometime in the New Year look at it again for additional evidence from the Care team. Upgrades can happen very quickly if the evidence is there and are not usually challenged.

- *A tribunal can reduce an award or cancel it altogether. It is the last resort; it is only worth pursuing if there is no award at all.*

- *If anyone has a DWP form to fill out, always ask for help. Over the years, the biggest cause of benefit refusals is self-filled out forms without help from a Welfare Rights Advisor.*

- *Currently, the DWP are reviewing PIP awards after 18 months, even though they initially may have been awarded from longer. Any review or renewal form must be treated like an original PIP form and the appropriate supporting evidence sent in at the same time.*

Gillian Writes: Having has ME/CFS a couple of years I am finding that my options are limited. The NHS clinic is not really helping and further. I am not sure where to look next form help. I have thought about joining the National Association or looking for a private doctor. Do you have any suggestions?

You've come to the point where most people ask the question where do I go next. It usually occurs at the 18 month to two years after diagnosis. Regarding the two national associations:

The ME Association: *Dr Charles Shepheard is the medical director and author of one of the best text books on MECFS 'Living with ME'. Much of the magazine 'ME Essential' reflects current conservative medical opinion.*

Action for ME: *This organisation is more open about the reality of ME/CFS and more people based. Much of its magazine 'Interaction' is based on a more open approach and practicalities of living with ME.*

Both organisation have strengths and weaknesses. I would advise you to check out both the organisations website before making any decisions, and join both if you could afford it.

Regarding Doctors — I suggest you check out Sarah Myhill's website and her book 'Diagnosis and Management of Chronic fatigue syndrome.' Bear in mind that personal consultations and private tests are expensive. Over the years her patients have achieved more than those treated with the Standard NHS Clinics.

Welfare Rights NEWS

With thanks to Benefit and Work.

DWP Considers Powers of Arrest and Monitoring Claimant Spending

The DWP have published the results of a survey on the public's attitudes to a worrying list of new powers it is considering acquiring.

The powers include:

- Trained DWP investigators having arrest powers
- Trained DWP investigators having search and seizure powers
- Collecting information about where claimants are spending money

The DWP research claims to show that a majority of the public were in favour of every one of these measures being introduced. Given the levels of incompetence, data loss and unaccountability at the DWP, the possibility that staff could arrest claimants and seize their possessions is likely to alarm many readers. Equally, the idea that the DWP could begin looking at how claimants spend their money is a cause for real concern. The recent King's Speech promised proposals to *"reform welfare and support more people into work",* without giving any more details. We hope very much that this set of draconian powers is not one of the "reforms".

A Quarter of a Million PIP Claimants May Still Be Owed Thousands.

The DWP is moving inexcusably slowly in considering the cases of PIP claimants who may be owed thousands of pounds back payments, its latest progress report reveals.

The review of claims relates to PIP activity 9. *Engaging with other people face to face.*

In a case known as MM, the Supreme Court decided that where prompting needs to be given by someone 'trained or experienced in assisting people to engage in social situations', then it may count as social support and score 4 points. In the same case, the Supreme Court held that social support does not have to take place during or immediately before a social engagement, it could take place weeks before or even after the event. This means that many people who got zero points or two points for this activity may have been to four points and possibly to an award, or higher award, of PIP.

In two years, the DWP have dealt with just 79,000 cases with almost a quarter of a million left to examine. And there may also be thousands of other cases that the DWP have simply failed to identify. More than one in five claimants who have been reviewed has received a back payment. So far, around 14,000 payments have been made, totalling £74 million. Overall, the average payment is around £5,285 per claimant. There's more information, and a range of resources for members who think they may be affected, on the Benefits and Work website.

New Pre-WCA Employment Interviews Rolled Out To 12 New Areas.

The DWP have rolled out a new, pre-WCA interview to 12 new areas in an effort to get more sick and disabled claimants moving towards work. The interviews take place before any decision has been made about whether they have Limited Capability for Work-Related Activity (LCWRA). The DWP claim that an "Employment and Health Discussion" (EHD) trial that took place in Leeds "helped hundreds of people move

Leger.ME has an organisational subscription to B&W. Members have access to B&W Guides as part of the membership deal. These detail how of apply for Personal Independence payment (PIP), Attendance Allowance (AA), Employment and Support Allowance (ESA) and Universal Credit (UC) and related benefits. Please contact the office for a copy of the latest guide if you require one. Please remember over the years, we have found that the biggest cause of benefit refusal is self-filled out forms without the guidance of a welfare rights advisor.

towards work". A 'work ability plan' is created in the course of a one-hour conversation between a health practitioner and the claimant. The plan identifies barriers to work and actions that can be taken to overcome them. The plan is then shared with the claimant's work coach. The DWP says that this means that "health claimants can highlight and begin to overcome any work barriers prior to undergoing a Work Capability Assessment, potentially realising a job outcome sooner."

Benefits and Work would advise claimants to consider very carefully whether they wish to take part in an EHD, as long as they remain entirely voluntary.

PIP Appeal Outline Creator.

If you are having difficulty knowing how to start providing evidence for a PIP appeal for yourself or your client, then begin with our very simple PIP Appeal Outline creator. This allows you to rapidly create a document which shows what the DWP scored you for each activity and what you scored yourself. highlights which activities you agree with the DWP about and which you don't. If you submit this as evidence, it helps the appeal tribunal panel to quickly focus on the activities you think you should score more highly for, rather than wasting time trying to decide which activities they should be looking at. It also allows you to know where to focus your own energy when writing an appeal submission or simply preparing to give oral evidence. If you include your email address when you complete the PIP Appeal Outline form, we will instantly send you a .pdf copy of the results as an attachment. The accompanying email will also give you more information about how to use your PIP Appeal Outline in order to create detailed evidence.

Please note: If you need to appeal a PIP application outcome you are best talking things over with a welfare rights adviser first. We advise members use our who Welfare rights service need to contact the office first for assistance and advice on what to do next.

DWP Sanctions.

The government is planning tougher sanctions for some universal credit (UC) claimants, which will see them stripped of their cash and their free prescriptions. Sanctions are already approaching their previous record levels, with over half a million UC claimants sanctioned in the last year. Statistics also show that one in seven claimants migrated to UC don't manage to complete the journey. In spite of the DWP's claim that they had paid 99% of the £300 Cost of Living payment by 7 November, we are still hearing from people who haven't received it.

Back Payments.

We have heard that for engaging with people face-to-face, we've heard from several readers who have received £11,000 in PIP back payments.

Almost 9 Million Claimant Bank Accounts To Be Put Under Continuous Surveillance.

The DWP is to begin continuous surveillance of the bank accounts of all pension credit, universal credit and employment and support allowance claimants using powers under a bill currently going through Parliament. Initially, the DWP say that they will use their powers to oblige the UK's top 15 banks to monitor the accounts of all means-tested benefits claimants. The banks will be required to report every time an account goes over the limit or is used abroad for more than four weeks. Almost 9 million claimants will be caught in the surveillance net, including:

- 5.8 million universal credit claimants
- 1.6 million employment and support allowance claimants
- 1.4 million pension credit claimants

Any bank failing to collect and pass on data to the DWP will be subject to heavy fines. The new system will start in 2025, though all banks may not be fully involved before 2030. But this won't be the end of it. DWP is being granted the power to force any third party to pass on any data the DWP considers it needs to reduce fraud and error. The department says in its impact assessment that it

intends to use these new powers more widely in the future. Anyone who imagines that the DWP will use such sweeping powers reasonably and proportionately probably hasn't ever claimed benefits.

Has The DWP Already Stopped Reassessing Support Group And LCWRA Claimants?

Benefits Uprating

The DWP have published the updated benefits rates for 2024/25

Benefit		Component	Old rate	New rate
ESA components		Work-related activity	£33.70	£35 95
		Support	£44.70	£47.70
Personal Independence Payment	Daily living component	Standard	£68.10	£72.65
		Enhanced	£101.75	£108.55
	Mobility component	Standard	£26.90	£28.70
		Enhanced	£71.00	£71.75

The government's response to the WCA consultation gives contradictory messages about whether reassessments for claimants in the support group/limited capability for work-related activity (LCWRA) group have already ended or whether they will not end until 2025. The government's proposals introduce something called the Chance to Work Guarantee.
The Chance to Work Guarantee "is for existing claimants on UC and ESA with LCWRA. This change will be effective from 2025, at the same time as WCA changes are introduced. This change will in effect abolish the WCA for the vast majority of this group, bringing forward a key element of our White Paper proposals and giving people the confidence to try work." The meaning of this paragraph seems clear: the abolition of the WCA for existing LCWRA claimants will take place in 2025.
However, in the next paragraph the government states:

"These changes will mean that almost all people who are currently assessed as having LCWRA will never face a WCA reassessment again."

Work Capability Assessment (WCA) Changes Explained

Late last month, the government published its response to the WCA consultation. It's clear that the 1,348 responses to the consultation from individuals and organisations were almost unanimously against any of the proposed changes., the government has decided to go ahead with some of them. In brief, the proposed changes from 2025 will be:

- Mobilising: points will be unchanged, but the highest scoring descriptor will no longer give claimants LCWRA.
- Getting about: highest scoring descriptor will still give limited capability for work (LCW), but the scores for the other descriptors will be reduced, though we don't yet know what to.
- Substantial risk for LCWRA: will be unchanged for physical health. For mental health the criteria will be made much stricter. We don't have details yet, but it may only apply to people with specified mental health conditions who are experiencing an acute episode for which there is medical evidence.
- Chance to Work Guarantee: existing claimants with LCWRA will never be reassessed again, even if they try work and it is not successful.
- Name change: LCW will become "Work Preparation" and LCWRA will become "Health Group".
- Claimant numbers: As a result of these changes, the Office for Budget Responsibility (OBR) estimates that by 2028/29 there will be 371,000 fewer people with LCWRA than would be the case if no changes had been made.

Please do remember, whether any of this happens or not will be decided by a new government following an election in 2024.

Recipe Corner –Recopies from People with ME/CFS.

With thanks to 'Perspectives', Sue Luscombe and her team

Sue and her team have produced a cookbook specifically for people with ME/CFS.

Festive Food Cranberry Balsamic Chicken

Preparation time: 15 Minutes. Cooking time: 30 Minutes.
Serves: 2

If there are only a small number for your festive lunch, then why go to the trouble of cooking a huge roast? Cranberries and balsamic vinegar create a deliciously festive flavour and this dish is super- special. In fact, you may never cook a turkey ever again!

Ingredients:

1 tablespoon olive oil
2 boneless chicken breasts
2 tablespoon butter
110g fresh cranberries
75ml balsamic vinegar
2 cloves garlic, minced
6 sprigs rosemary
1 tablespoon brown sugar
Zest of 1 orange

Cooking Method

1) In a large ovenproof pan, heat the oil.
2) Add the chicken, skin-side down, and cook on a medium heat for about five minutes until the skin is golden and crispy.
3) Move the chicken to a plate, skin-side up.
   Melt the butter in the same pan and add the cranberries, vinegar, garlic, brown sugar and orange zest.
4) Return the chicken to the pan and scatter the herbs all around. Simmer for 5-10 minutes until the liquid begins to thicken and the cranberries start to soften.
5) Transfer the pan to the oven and cook for 20-25 minutes, at 180C/Gas 4, until the chicken thighs are cooked through.
   Serve with your favourite veg.

Caramel, Banana and *Pannetone Bread and Butter Pudding

Preparation time: 15 Minutes. Cooking time: 30 Minutes.
Serves: 6
****Panettone** is an Italian type of sweet bread, and fruitcake, originally from Milan, usually prepared and enjoyed for Christmas and New Year*

Ingredients:

1 medium-sized panettone
2 bananas, sliced
Butter
I tub of good quality vanilla custard
A good handful of walnut halves
1 jar salted caramel sauce
Vanilla ice cream to serve

Cooking Method

1) Grease an oven-proof dish with plenty of butter.
2) Slice the panettone and put a layer of it over the bottom of the dish. Add some custard and spread it over the top.
3) Repeat until the dish is almost full. Put the dish in the oven for 15 minutes at 180C/ Gas 4.
4) Spread the walnut halves and banana pieces over the top and drizzle over some warmed salted caramel sauce.
5) Put it back in the oven for 10-15 minutes.
6) Serve with extra warmed salted caramel sauce and vanilla ice cream.

If you enjoyed these recipes, Sue's book is available from the ME Association or through Amazon.
http://meassociation.org.uk/product/four-seasons-cooking-for-me-book-2/

Update from Decode ME: Early Analysis.

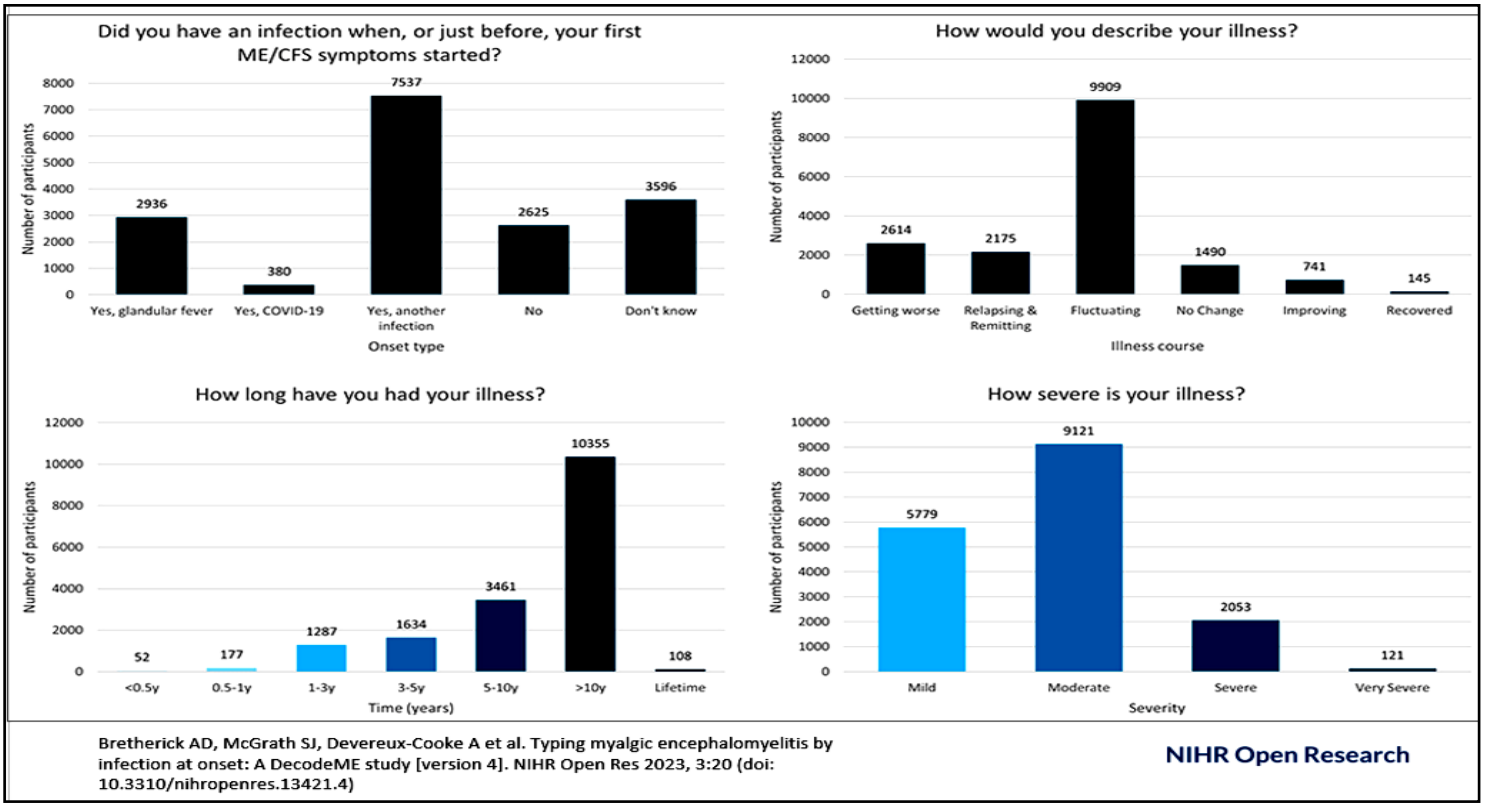
As the largest ever ME/CFS study, DecodeME is aiming to work out whether the disease is partly genetic and, if so, help pinpoint what causes it. The study should help us understand the disease and ultimately find treatments. DecodeME is looking for DNA differences between thousands of people with ME/CFS and people without any health problems. People with ME/CFS who took part in DecodeME firstly completed a questionnaire that assessed their symptoms and many were then invited to provide a spit sample, which will form the DNA analysis. While the DNA results will come later, the team has analysed the questionnaire answers from the first 17,000 DecodeME participants and the results have been published by NIHR Open Research - read the paper here:

tinyurl.com/NIHRMEstudy1

This initial analysis supports the assumption that ME/CFS is significantly more common in females. Furthermore, data suggests that females are more likely to experience severe symptoms. This likelihood further increases with age and if they have had the condition for more than 10 years. Additionally, a higher percentage of female participants reported other co-occurring health conditions. The most common active co-occurring condition was irritable bowel syndrome (41.3 per cent), with clinical depression (32.4 per cent), fibromyalgia (29.5 per cent), anaemia (14.1 per cent) and hypothyroidism (12.8 per cent) also featuring prominently.

Experts say that gaining a better understanding of how ME/CFS affects people is the first step to developing effective treatment options. These findings may also indicate that by studying people with different ME/CFS onset-type separately - rather than analysing people with ME/CFS together – may make it easier to understand what is going wrong. A webinar, held on 12 October, provided more information about the initial questionnaire analysis, plans for the DNA analysis and upcoming deadlines. You can watch listen or read the transcript on the DecodeME webpage:

tinyurl.com/DecodeMEWebinar



Above is just one example of the results so far: There is much more on:

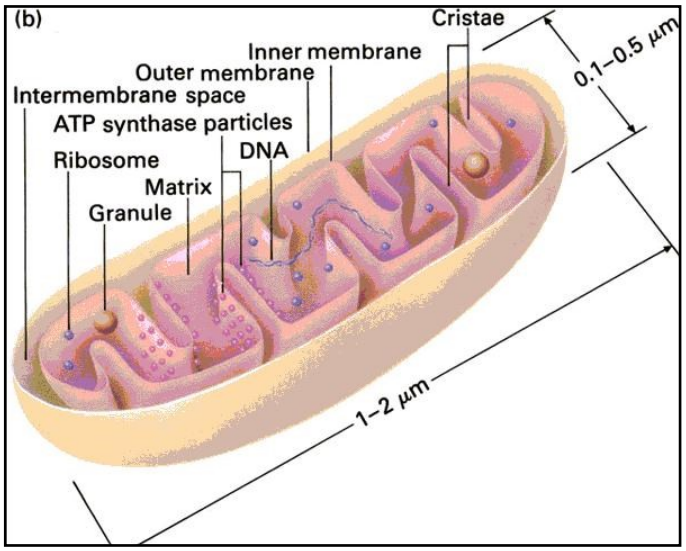
https://openresearch.nihr.ac.uk/articles/3-20/v4

Essential Fatty Acids and ME/CFS
With thanks to Sarah Myhill.

During the 1980s Professor Behan from Glasgow demonstrated that essential fatty acids could be very helpful in treating fatigue syndromes and indeed he conducted a placebo controlled double blind trial using 'Efamol Marine' – a mixture of evening primrose oil and fish oil, with beneficial results. Professor Puri, who is a Professor at the MRI Unit, Hammersmith Hospital and also Head of the Lipid Neuroscience Group at Imperial College, London, has picked up on some of this work and had similarly good clinical results. He wrote a book called "Chronic Fatigue Syndrome, a Natural Way to Treat ME" published in 2005.

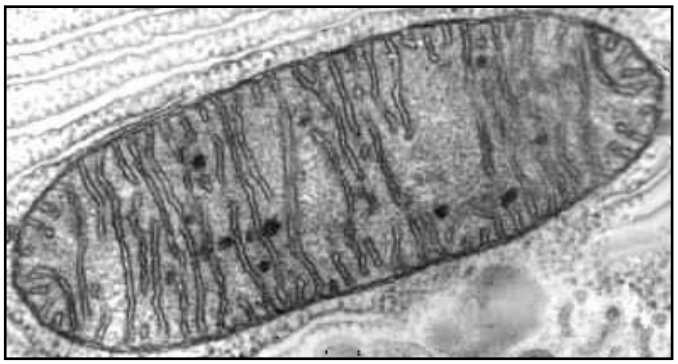
Professor Puri's main work is to do with neuro-development in children and he demonstrated that getting the right balance of essential fatty acids was essential for normal brain development, behaviour and intelligence. Correct balance of essential fatty acids in the body is essential for many normal processes.

They are vital to maintain the correct structure of cell membranes. Without EFAs the cell membrane becomes more rigid and this reduced flexibility may result in abnormal functioning of receptors and enzymes that lie in or are held on membranes. One of the things that I often find in the people on whom I do mitochondrial function tests are problems with oxidative phosphorylation. The bundles of enzymes which are responsible for oxidative phosphorylation lie on mitochondrial membranes and are called cristae. If these enzymes are not held in their correct configuration, then they cannot work properly and so this could be a reason why oxidative phosphorylation goes slow in some patients.



Normal Mitochondrion diagrammatic

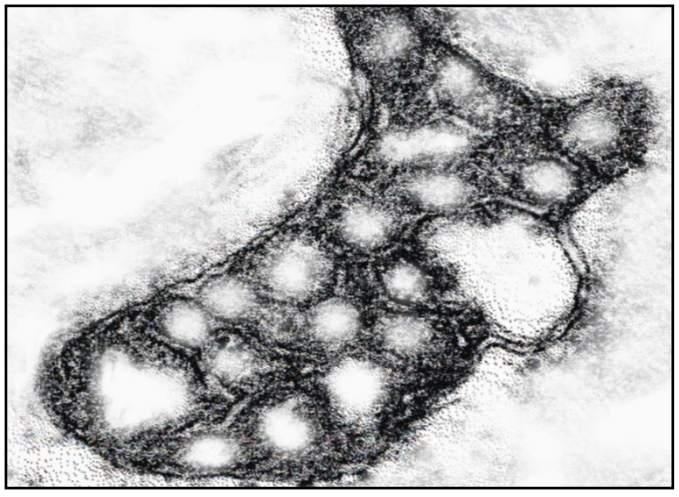
There is a particular phospholipid peculiar to mitochondrial membranes, called cardiolipin, and by doing cardiolipin studies, this gives us some insights into what is going wrong with mitochondrial membranes.



Normal Mitochondrion Electron Micrograph

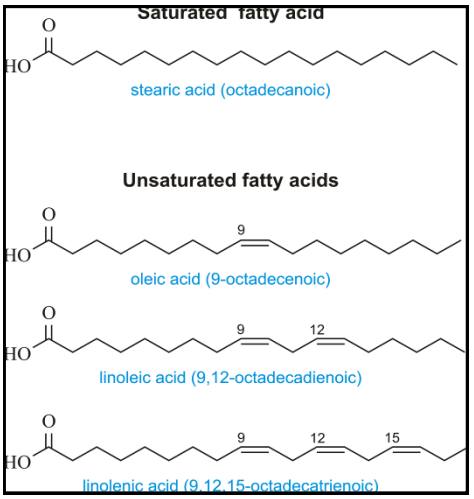
- Essential fatty acids are necessary to make the eicosanoids, which are essential for normal inflammatory responses.
- Essential fatty acids are necessary to make natural sleep mediators.
- Essential fatty acids, particularly EPA, are directly and indirectly virucidal – that is to say they kill viruses.

EFAs protect us from viral infection. Chronic fatigue syndrome is often triggered by viral infection. Normally we can get all the essential fatty acids we need from natural oils in the diet such as sunflower oil, safflower oil (Omega 6) and linseed oil (Omega 3). However, the first step for these fats to be converted into essential fatty acids requires an enzyme delta 6 desaturase. This enzyme is inhibited by viruses. So, the viruses have worked out a very clever way of ensuring their survival in the body. If they inhibit delta-6-desaturase, then the body cannot make the essential fatty acids it needs in order to kill the virus.

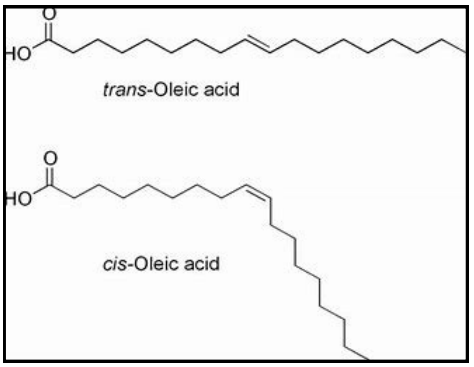


Mitochondrion from an ME patient

Professor Puri and Professor Behan therefore worked out that we can get around this problem by supplying essential fatty acids, which are already converted, namely evening primrose oil and fish oil. The actual preparation of oil and the dose seems to be quite critical. That is why Professor Puri specifically recommends a product called VegEPA, which contains the right balance of evening primrose and fish oil, which is in the correct form to get the result. He recommends high doses, i.e., eight capsules a day for three months and then reducing to a maintenance dose of four capsules daily. For children under the age of 14 the adult dose should be halved.



Above and below—term use to describe fatty acids.



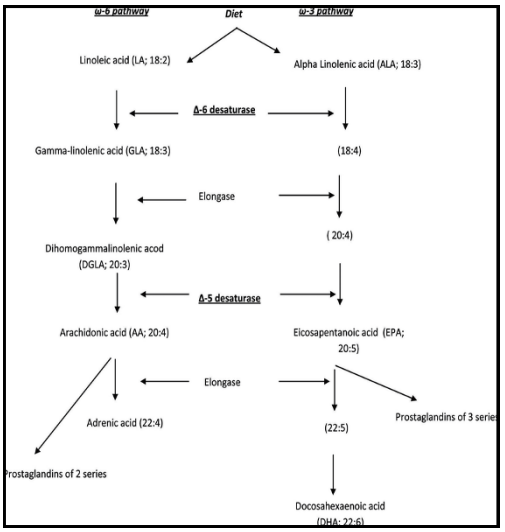
Good fats and bad fats

Treating chronic fatigue syndrome is all about balance and in addition to getting the right balance of essential fatty acids in the supplements, it is also important to avoid the bad fats in the diet. The main oils used for cooking should be olive oil, animal fats (such as lard or mutton fat) and butter (so long as one is not allergic to dairy products). The bad fats which should be used with caution are the trans fatty acids, hydrogenated fats and margarines. Because of where the block is in the system, one should use sunflower oil and safflower oil in moderation.

Essential fatty acids cannot be made in the body – they have to be consumed in food.

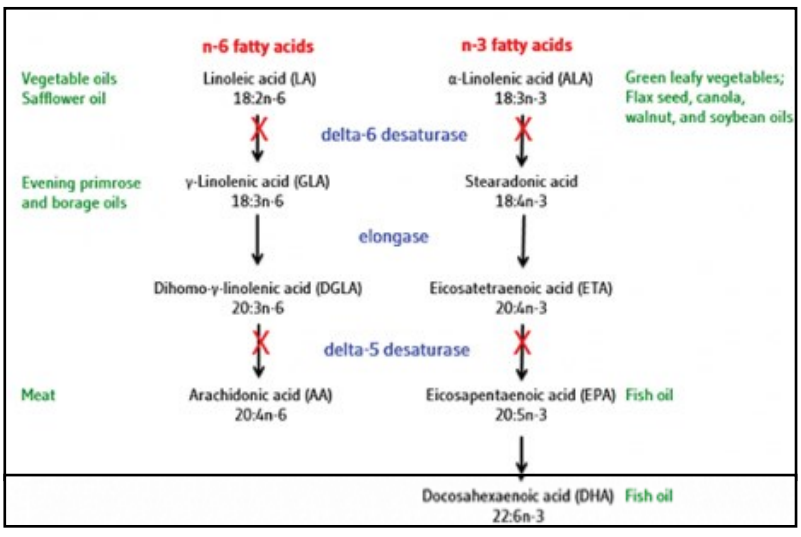
OMEGA-6 FATTY ACIDS - linoleic acid, i.e., sunflower, safflower

OMEGA-3 FATTY ACIDS - alpha-linolenic acid, i.e., linseed oil (otherwise known as flaxseed oil)
Delta-6-desaturase is the enzyme which converts the above oils into the oils below - see the first step in the diagram below. This enzyme can be blocked by viruses. Further conversion of these oils occurs in a 'metabolic line' - again please see the diagram below.



--Gamma linolenic acid (GLA) i.e., Evening Primrose Oil, borage seed oil
--Dihomo-gamma-linolenic acid (DGLA)
--Arachidonic acid (AA)
--Eicosapentanoic acid (EPA) i.e., fish oil
--Docosahexanoic acid (DHA)

Essential Fatty Acids Metabolic Line



AA is essential for killing viruses and making sleep hormones. AA and DHA are essential for membrane fluidity and may have profound effects on communication between cells, including nerve cells – clinically deficiency may cause poor short-term memory and inability to think clearly. The diagram helps explain one of the reasons why vegetarianism is a risk factor for CFS – if vegetarians don't eat fish, then they may get very little DHA through their diet and if they also have a blockage of delta-6 -desaturase then they cannot make DHA in the body. That is the advantage of VegEPA – it bypasses this block by directly providing EPA which helps to metabolise DHA.

Clinical Improvements in CFS/ME: The Role of Fatty Acids

by Professor Basant K Puri

Chronic Fatigue Syndrome (CFS) or Myalgic Encephalomyelitis (ME) is a disorder affecting multiple body systems. When defined rigorously for research purposes, according to the revised criteria of the Centres for Disease Control and Prevention in Atlanta, it has been estimated to affect around three per cent of the general population. These revised diagnostic criteria are as follows:

1. Exclude any other cause for chronic fatigue;
2. Self-reported persistent or relapsing fatigue for six or more consecutive months;
3. Four or more of the following symptoms are concurrently present for over six months:

i. Impaired memory or concentration;
ii. Sore throat;
iii. Tender cervical (neck) or axillary (armpit) lymph nodes;
iv. Muscle pain;
v. Multi-joint pain;
vi. New headaches;
vii. Unrefreshing sleep;
viii. Post-exertion malaise.

As most practitioners of Complementary and Alternative Medicine will be aware, symptoms such as long-term fatigue and unrefreshing sleep are very common. Fortunately, the purely natural treatment with fatty acids (pure EPA and virgin Evening Primrose Oil) advocated in this article also gives excellent results in cases of chronic fatigue or unrefreshing sleep that do not meet rigorous research diagnostic criteria.

In the first section of this article, I shall explain why I believe that CFS has an infectious cause. This is important because it means that it is a physical illness rather than being, as some of my colleagues in the medical profession still advocate, a 'psychosomatic disorder'. The next section then details certain important aspects relating to long-chain polyunsaturated fatty acids of the Omega-3 and Omega-6 groups, and, in particular, why they can be used to treat CFS. Finally, specific details about prescribing fatty acids are given for Complementary and Alternative Medicine practitioners.

The Cause of CFS

Five converging strands of evidence now point to the main cause of CFS as being infectious in nature. I believe that the infectious agent is probably viral.

The first strand of evidence is derived from a consideration of some of the major outbreaks of this illness (albeit under different names in the past). A detailed examination of the illnesses suffered by those who were afflicted by the Los Angeles County Hospital epidemic of 1934 and the Royal Free Hospital epidemic of 1955 strongly points to an infectious agent. There appeared to be person-to-person contact between those affected, who all tended to be medical and paramedical staff. (To this day, I am told by one of my patients that there is a victim of the Royal Free outbreak who is still suffering from CFS; she was working as a radiographer at the Royal Free Hospital in 1955.) In my clinical practice, it is also the case that there tends to be a common occurrence of a history of a viral-like illness just before the onset of CFS. Sometimes this is put down to having suffered from an episode of influenza. Some of the features of CFS, such as the chronic fatiguing illness itself and the muscle weakness, are known consequences of viral infections.

The second line of evidence is from studies of the immune system. Changes in particular types of white blood cell have been noted in well-conducted studies of CFS. In summary, these are:

Reduced NK cell (killer cell) activity;
Reduced Th1 cell (helper cell type 1) activity;
Increased Th2 cell (helper cell type 2) activity;
Increased Tc cell (cytotoxic cell) activity.

If you are not familiar with killer, helper and cytotoxic cells, there is no need to worry. The important thing is that the changes described above are consistent with the immune system reacting to a pre-existing long-term viral infection.

The third strand of evidence comes from direct studies of blood levels of fatty acids in CFS patients. Professors Peter Behan, Wilhelmina Behan and David Horrobin published a key paper in 1990 showing that there were reduced levels of some long-chain fatty acids in the CFS patients they studied.[3] (In those days, the condition was also known as post viral fatigue syndrome.) A more recent study by Professor Malcolm Peet's group in Sheffield, published in 1999, found that CFS patients had a reduced level of the long-chain polyunsaturated Omega-3 fatty acid eicosapentaenoic acid, or EPA for short.[4] EPA is an extremely important fatty acid, and I shall have more to say about it later in this article. Meanwhile, suffice it to say that viral infections are one of the factors that can prevent the body from synthesizing its own long-chain polyunsaturated fatty acids from dietary short-chain precursors. So, the blood results from these two studies are consistent with a viral infection in CFS.

The fourth line of evidence was first discovered at Hammersmith Hospital in London by my group.[5] By carrying out a specialized brain examination known as proton neurospectroscopy, using a magnetic resonance imaging scanner, we were able directly to examine the chemistry of the living brain in patients with CFS. We found strong evidence of a chemical signature in the patients which was consistent with an inability of the body to create the all-important phospholipid molecules (see the next section) in cell membranes in the brain. This could easily result from a lack of long-chain polyunsaturated fatty acids in the brain. In turn, this could be caused by a viral infection stopping the body from being able to manufacture these fatty acids. Our Hammersmith Hospital results were replicated by another group, working in Glasgow, under Professor (then Dr) Abhijit Chaudhuri, who also found evidence of the same chemical signature.[6]

Finally, just this year Dr Jonathan Kerr's group at Imperial College London reported the results of their work on gene expression in white blood cells (mononuclear cells) taken from patients with CFS Using a special microarray technique, which is rather like examining genes on a chip, Jonathan Kerr's group looked to see which, if any, of almost ten thousand human genes were expressed differently in 25 CFS patients compared with 25 age-, sex- and geographical location-matched normal controls. They found upregulation of the EIF4G1 gene in CFS. This is a fascinating finding which is consistent with the occurrence of a persistent viral infection in this disorder.

Fatty Acids

All human living cells have a boundary double-layered membrane. These membranes also surround certain organelles inside cells, such as the nucleus. The basic unit that makes up each layer is the phospholipid molecule. This consists of two water-hating fatty acids and a water-loving 'head' group. These are attached to a three-carbon glycerol backbone. Floating, as it were, within the double-layered membrane are membrane receptors. In order for these receptors to function properly, the phospholipid molecules must be properly constituted. In turn, this means that the right fatty acids should be present.
Cell Membrane Structure

Omega 3 and 6 Fatty Acids

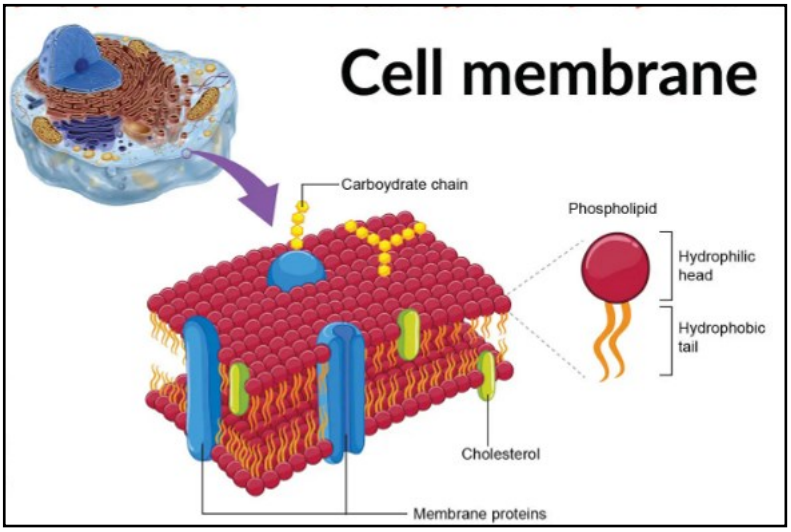
The Omega-3 and Omega-6 fatty acids have very important roles in maintaining the correct structure of cell membranes. In particular, for a membrane to function properly, it needs to have sufficient levels of the Omega-6 long-chain polyunsaturated fatty acid arachidonic acid (AA), and the Omega-3 long-chain polyunsaturated fatty acid docosahexaenoic acid (DHA). Without these fatty acids, cell membranes become more rigid, and this reduced flexibility is reflected in poorer or abnormal functioning of receptors that lie in the membranes. In turn, this leads to impaired communication between cells, including brain cells.

An even more important role is that of the synthesis of eicosanoids in the body. These functions fall to two of the Omega-6 long-chain polyunsaturated fatty acids, dihomo-gamma-linolenic acid (DGLA) and arachidonic acid (AA), and one of the Omega-3 long-chain polyunsaturated fatty acids, namely eicosapentaenoic acid (EPA). Starting from dihomo-gamma-linolenic acid, arachidonic acid and EPA,

the body can make all the families of prostaglandins, thromboxanes and leukotrienes (which collectively are eicosanoids). They are intimately involved in processes that are of the utmost importance in maintaining the health and wellbeing of the body and in fighting disease. These processes include:

Blood clotting;
Regulating the blood pressure;
Reproduction;
The response to disease or trauma (including inflammation responses, pain and fever);
The secretion of acid by the stomach.

If the body has sufficient EPA, some of this can be converted into natural sleep mediators. This is one of the reasons why our patients (whether or not they had CFS to begin with) enjoy such wonderful, deep, refreshing sleep if they follow the advice to take a formulation each day that contains ultra-pure EPA (that is, EPA without any DHA) as mentioned in the last section below.



EPA is also important in helping the body to combat viral infections. It turns out that EPA can actually kill viruses in the body, without harming us in the process. It does this in at least two ways. First, EPA is itself directly viricidal. That is, if you add small amounts of EPA solution to harmful viruses (such as the Epstein Barr Virus that causes glandular fever), then the EPA actually kills the virus. Second, EPA is also indirectly viricidal. After being acted on by two sets of enzymes, EPA is converted into families of interferons, which, in turn, are powerfully antiviral.

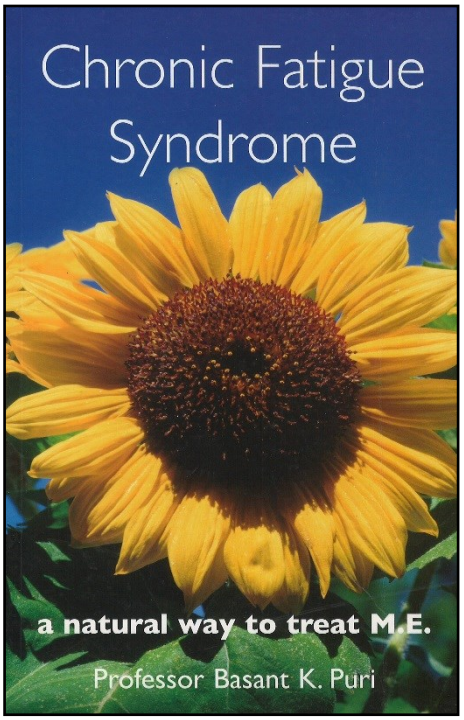
Many viral species block the delta-6-desaturase enzyme. As you can see from Figure 2, this means that the body is no longer able to produce the long-chain Omega-3 and Omega-6 fatty acids. In the case of CFS, if I am right and there is a persistent (albeit perhaps low-grade) viral infection present, as suggested by the five strands of evidence detailed above, then there will be a long-term functional deficiency in these long-chain fatty acids. One result will be that there is insufficient EPA produced by the body to fight the viruses. There are other results too, as stated in my book1 on CFS:

Unable to make sufficient quantities of EPA, the human body is no longer able to manufacture sufficient quantities of the EPA-based natural sleep mediators. As a result, the body does not get enough deep refreshing sleep and ends up tired and even less able to resist the viruses. The lack of DGLA, arachidonic acid and EPA also means that the body cannot produce enough eicosanoids, and so the general health and wellbeing of the body suffers. The body cannot mount proper immune response measures against the invader, and has to endure long bouts of painful sore throats, and enlarged and tender neck (cervical) and armpit (axillary) lymph glands. EPA and certain eicosanoids normally help to keep our joints working properly and 'well-oiled'; their disappearance means that the body has to endure pains (arthralgia) in many different joints.

If these consequences were not bad enough, there is even worse to come. Blocking that first enzyme (delta-6-desaturase) also means that cell membranes cannot get enough arachidonic acid and docosahexaenoic acid so that they become more rigid and lose their normal flexibility. The effects on the protein receptor molecules that lie in the cell membranes are profound; the size and shape of these receptors change so that they no longer accept and pass on signals in the right way. Communication between cells is impaired. It would be like an enemy hitting our satellite and radar communications during a war. The results of this in the human brain are cognitive defects, such as problems with short-term memory and with concentration.

These results will sound familiar to any reader who is suffering from CFS. They constitute key symptoms and signs of this disease.

How to use Fatty Acids in Treatment



If you want to read more about Prof Puris work, his book on the topic is in the Leger.ME library

From what I have said so far, you might think that an effective way to treat CFS would be to by-pass the block at delta-6-desaturase by giving patients the long-chain Omega-3 and Omega-6 fatty acids directly. That is precisely what I do. There is evidence from two sets of studies that this approach works well [3] [,][8] although one study was essentially negative.[4] Not only do the symptoms improve, but by giving EPA there is actually an improvement in the amount of brain tissue and its functioning.[9], [10]

In terms of the fatty acids actually used by me, with good effect, I favour a combination of virgin evening primrose oil with ultra-pure EPA (that is, a DHA-free preparation).

The Evening Primrose Oil is a good source of GLA. From this fatty acid, the body's cells can easily biosynthesize dihomo-gamma-linolenic acid and arachidonic acid. By choosing the virgin (that is, cold-pressed, non-raffinated) form rather than ordinary (refined) Evening Primrose Oil, patients gain the added benefits of natural triterpenes which act as free radical scavengers.[11]

On the EPA front, I definitely do not favour the use of ordinary fish oils at all for any of my patients. There are several reasons for this. I detailed these in my CFS book [1]:

Ordinary fish oil suffers from the same problems as the ones we have just mentioned: the risk from pollutants such as lead, mercury, cadmium, dioxins and PCBs. In fact, there are at least four reasons why the situation is even worse in respect of fish oil compared with just ordinary fish in the diet.

First, many of the harmful pollutants that are concentrated in the bodies of fish, such as dioxins and PCBs, are highly fat-soluble. This means that they are even more concentrated in fish oils (which, by definition, are oils and therefore fatty).

Second, we need to consider how fish oils tend to be extracted in industrial quantities from the bodies of fish. One method often used in industry is simply to squeeze the livers of the fish, and use (and sell) the liver oil thereby produced. A common example is cod liver oil, which has a good deal of EPA in it, and is extracted from the liver of cod. A major problem with this process is that in vertebrates such as fish (and, indeed, us), the liver is the main organ used for the detoxification of the blood. So, the liver oils can offer an even more concentrated concoction of dangerous pollutants. Another commonly used method is not to squeeze just the liver of the fish, but instead to squeeze the whole body of the fish, and collect the oil that comes out of the back passage. Needless to say, the alimentary tract is a very good source of the poisons of which the vertebrate body may wish to rid itself.

The third reason is that fish oil is rich in vitamin A. If taken in excess, vitamin A is toxic, and can even be fatal. Unfortunately, in order to obtain the levels of EPA needed to treat CFS the amount of fish oil that has to be consumed could be dangerous.

The fourth reason is that, in addition to containing EPA, fish oil also contains DHA.

DHA in supplement form is highly susceptible to lipid peroxidation. The renal products of this reaction are highly reactive free radicals that can damage DNA molecules.

In my view the best preparation to use in CFS patients and in any patients who suffer from sleep problems, tiredness or fatigue is VegEPA; each capsule contains 280 mg ultra-pure EPA, 100 mg virgin Evening Primrose Oil, and zero DHA. For adult patients, I prescribe eight capsules daily (unless the patient happens to be on blood thinning anticoagulant medication such as warfarin or heparin). As an added bonus, in the long-term, taking VegEPA regularly reduces the chances of your patient suffering from a heart attack, thrombotic stroke or deep-vein thrombosis. It is also very good for arthritis.

It is also important to encourage your patients to eat a varied and healthy diet that contains sufficient levels of certain vitamin and mineral cofactors that help with fatty acid metabolism. (These are also all contained within the vitamin and mineral supplement VegeCO, obtainable from the same sources as VegEPA; the adult dose is one VegeCO tablet daily, until the diet is adequate.)

One of the most delightful aspects of my job is seeing patients who have improved markedly on the above regime. Also, after just six to eight weeks of taking the fatty acid supplementation, do not be surprised if your patients find that their hair and nails are in better condition, and their skin looks and feels younger.

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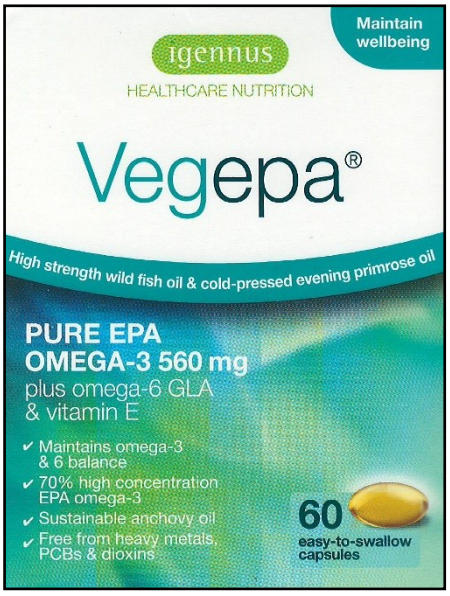
Editor's Note

A number of your ago a South African consultant working at DRI prescribed VegEPA though the NHS hospital service. However, when patients tried to access VegEPA through the Community services, its supply was blocked by the local NHS because there was ***no evidence it is effective and not value for money.***



With the research from Dr Puri's and others work, they formulated Veg EPA. They had a dilemma. If it was marketed as a medicine it would have to go through clinical trials costing millions of pounds. As with many clinical trials for medicines with ME/CFS the result would have been inconclusive because ME/CFS is a heterogeneous condition with more than one causal mechanism. There was no guarantee of the outcome, and potentially millions of pounds could have been lost.

So, instead they decided to market Veg EPA as a food supplement where the regulations are more relaxed. That strategy worked. If you read the classified advertisements on the national ME organisations magazine, you will see it heavily advertised.

This begs the question does it work. Most people who I have spoken who to try it say it helps particularly with brain fog and joint pain. Due to the EPA content, it also reduces bad (LDL) cholesterol, so reducing the risk of a heart attack and stroke. A prescription product Icosopentyl Ethyl is marketed for cholesterol control. EPA has a side effect in that it increases blood clotting time - so if you were on anticoagulant treatment or having an operation the EPA would have to be taken into account. Cost per month is around £15—but discounts are available from many suppliers. There are similar products available from other manufacturers.

BDA Food Facts: Omega 3 Fact Sheet

This feature has been produced by the BDA in partnership with Dietitian Julie Lanigan.

You may have heard that eating foods rich in omega-3 fats could help to keep you healthy. This Food Fact Sheet looks at which foods contain omega-3 fats, how much we need and the benefits for our health.

What are omega-3 fats?
Omega-3s are a family of fats and oils that are important for your health.

- Alpha-linolenic acid (ALA) is an essential dietary fat. You need ALA to make other omega-3 fats called long-chain (LCN-3).
- Eicosapentaenoic acid (EPA) and Docosahexaenoic acid (DHA) are LCN-3 fats. ALA makes these in your body. This happens slowly and only small amounts are formed.
- EPA and DHA are important for your heart, blood vessels, lungs and the immune and hormone systems.
- DHA is also important for the development of the retina (eyes) and brain in infants.
- Where do omega-3 fats come from?
- Nuts and seeds, and their oils, contain ALA - walnuts, flaxseeds and rapeseed oil are particularly good sources. Fish and especially oily fish are good sources of EPA and DHA.

White fish (cod, haddock, plaice, pollack, coley, dover sole, dab, flounder, red mullet and gurnard) and shellfish contain some LCN-3, but at much lower levels than oily fish. You should try and include both types of fish in your usual diet. Some foods have DHA added (fortified). Human milk contains DHA and infant formulas must have this fat added. The best way of ensuring we are getting enough omega-3 is to eat foods rich in these fats.

Which fish/seafood are good sources of omega-3?

The following are examples of good fish/seafood sources of omega-3:

Mackerel, kippers, Pilchards, Trout, Sprats. Salmon, Herring, Sardines, crab (fresh), Whitebait, Swordfish

Benefits of eating oily fish
People from countries such as Japan and Greenland who eat a diet rich in omega-3s, have been shown to have a lower risk of heart disease than other countries including the UK Because of this and other health benefits, the NHS recommends you eat more foods containing omega-3.

As well as omega-3, fish are good sources of other nutrients and:

- Provide vitamins A and D, protein, and minerals such as iodine, calcium, and selenium
- May protect the heart and blood vessels from disease
- Support the healthy development of your baby during pregnancy and breastfeeding
- May help to maintain good memory and the prevention and treatment of depression

Sustainability.

The richest dietary sources of long-chain omega-3 fats are marine fish oils. The omega-3 in fish comes from micro-algae, small plants found in water. Stocks of some fish species like wild salmon and trout are declining. So, to ensure the sustainability of our fish stocks, you can try to choose fish from sustainable sources. Look for products certified by the Marine Stewardship Council. The Good Fish Guide from the Marine Conservation Society provides details of sustainable fish sources.

Top tips Increase intake of omega-3 fats

- Eat more fish and from sustainable sources
- Limit oily fish (two portions per week) if you are pregnant or planning a baby
- Avoid shark, swordfish and marlin if pregnant, planning a baby or under 16
- Cook with an omega-3 rich oil
- Include plant-based omega-3
- Include canned fish and other fish products
- Check labels for omega-3 content
- Include fortified foods if you don't eat fish

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How much should we eat?
You should try to eat two portions of fish per week, one of which should be oily, to get the most benefit.

Portion size guide for adults and children	
Age	**One portion size**
18 months to three years	¼ - ¾ small fillet or one to three tablespoons
four to six years	½ – one small fillet or two to four tablespoons
seven to eleven years	one – 1 ½ small fillets or four to six tablespoons
12 years to adult	140g (5 oz) fresh fish or one small can oily fish

Is eating fish safe?
Some types of fish (shark, swordfish and marlin) may be high in mercury. This chemical may be harmful to the developing nervous system in babies. Avoid these fish if you are pregnant, planning to become pregnant or under 16 years old. All other adults, including those who are breastfeeding, should eat no more than one portion of these fish per week. If you are past childbearing age or not intending to have children, you can eat up to four portions of all other fish per week. You can safely have up to two portions of oily fish per week if you are pregnant, breastfeeding, planning a pregnancy or may become pregnant in future.

What if I don't like or eat fish?
If you do not eat fish or you eat a vegan, vegetarian or plant-based diet, you can get omega-3 from:

nuts and seeds (e.g. walnuts, pumpkin and chia seeds), vegetable oils (e.g. rapeseed and linseed), soya and soya products (e.g. beans, milk and tofu), Omega-3 enriched foods
If your diet is plant-based or you are vegetarian, foods that are acceptable to you and have had omega -3 added can also be useful sources. These include certain brands of eggs, milk, yoghurt, bread, and spreads. Check the labels to make sure.

Supplements (*Please note that this applies to the general public and Not people with ME/CFS ed.)*

Omega-3 supplements are not recommended in the UK general population. This is because evidence of benefits is inconclusive. If you are considering a supplement, you should:

- Choose omega-3 rather than fish liver oil
- Check the vitamin A content - you should not have more than a total of 1.5mg vitamin A (1500ug) a day from food and supplements combined
- Do not take supplements containing vitamin A if you are pregnant or planning to become pregnant
- Check labels for DHA and EPA content
- Choose a supplement that provides you with the same daily amount provided by eating one to two portions of fish per week (about 450mg EPA and DHA per daily adult dose)
- Choose an age-appropriate supplement – children will need less than adults
- Seek advice from a dietitian if in doubt
- Some supplements contain only algae so are suitable for vegetarians and vegans.

Sources of Omega 3 fats and oils.

Memebers Crafters Corner

Very often people with a long term Chronic condition find that they have previously hidden talents that come to the fore, and they find that they and can do thing they never ever did before. In this edition of Pathways, we feature the recent work of three our members.

Here are some examples of Ann`s pottery crafting which she has just finished. The Hedgehogs and chickens are now in her garden. The landscape is now hung on the wall.

Here to the right we have two examples of two examples of Claire's work. The gingerbread men are clay and are intended as tree decorations. The gongs are something different.

On the row below is a selection of Kerry`s various sets of drinks mats and decorated tumblers.

If you are interested in buying any of these item the contributors are all on the Leger ME Facebook group.

Brain Fog in ME/CFS and Long Covid

Frontiers of Neuroscience recently published a paper about possible causes of brain fog in ME/CFS and Long COVID. This study included a large group of ME/CFS patients, Long COVID patients, and matched healthy controls, hypothesizing that cognitive impairment characterized by slower reaction time was caused by blood pressure and heart rate disturbances of orthostatic intolerance. The take home message is that being sick with Long COVID together with orthostatic intolerance is driving brain fog. Cognitive impairment in ME/CFS patients sick for more than four years was partially associated with the likely adaptive response of elevated heart rate. It appears that the longer the duration of illness with ME/CFS, the more likely cognition is impaired in response to physiological stressors.

How to get Support with your energy bills this winter

If you're struggling with your energy bills this winter, help may be available, especially for those of retirement age or with chronic sickness. The National Energy Action (NEA) has some essential tips to make sure you're getting the support you're entitled to. Although energy bills may not be as high as they were six months ago, the average household still pays approximately £1,923 a year that's almost £650 more than in October 2021. Sadly, NEA estimates there are currently 6.3 million UK households in fuel poverty, but some help is on hand if you need it.

Contact your energy supplier : If you're having problems paying your energy bills, your first port of call should always be your energy supplier. If they know there's a problem, they're required by the energy regulator, Ofgem, to work with you to find a solution. You can also contact your energy supplier to see if you qualify for the Energy Company Obligation, a scheme that obligates the largest energy suppliers to support households with energy-efficiency improvements.

Check if you're eligible for benefits: Make sure you're claiming the correct benefits – this could increase your income as well as make you eligible for other types of assistance. Take advice from your local Citizens Advice or go to gov.uk/browse/benefits

Warm Home Discount: The Warm Home Discount is a payment of £150 off your electricity bill paid automatically to eligible customers in two core groups:

Core group one: individuals of pensionable age and in receipt of Pension Credit.

Core group two: individuals dependent on means-tested benefits and with high energy costs (there is a separate process in Scotland for core group two, with households selected through eligibility criteria that change from supplier to supplier). Go to gov.uk/the-warm-home-discount-scheme

Winter Fuel Payment : The Winter Fuel Payment is for people born before a specific date (this date changes annually and at the date of publication is listed as 25th September 1957. You can find the current date on gov.uk). With this payment, you could claim between £100 and £300 to help you pay your heating bills. It's paid automatically between November and December if you have claimed before or are in receipt of some other benefits. Others will need to apply for it.
Go to gov.uk/winter-fuel-payment for more information.

Cold Weather Payment: Some households may be eligible for the Cold Weather Payment of £25 per qualifying week. This is paid automatically to those on certain benefits when the average temperature in their area \ is recorded as, or forecast to be, 0°C or below for seven '-consecutive days. Find out more at **gov.uk/cold-weather-payment**

Additional cost-of-living payments: There are additional cost-of-living payments available to some households. You may be entitled to these if you get any of the following benefits or tax credits on certain dates:

- Income-based Jobseeker's Allowance (JSA)
- Income-related Employment and Support Allowance (ESA)
- Income Support
- Pension Credit
- Universal Credit
- Child Tax Credit
- Working Tax Credit

Are You Getting All The Tax-Free Income That You're Entitled To?

Being aware of your tax position and the allowances that are available to you means you can save money on the tax you pay. If you need assistance with your tax and are on a lower income, this information may be able to help you:

Tax Help for Older People

If you're over 60, contact Tax Help for Older People by calling the helpline on 01308 488066.The helpline is open 9am to 5pm Monday to Friday, excluding bank holidays. You can also email via taxvol@taxvol.org.uk

TaxAid

If you're under 60, contact TaxAid on the helpline number 0345 120 3779. The helpline is open 9am to 5pm Monday to Friday, excluding bank holidays. You can also email via help@taxaid.org.uk

Personal Allowance

This allowance applies to most people and is generally used for income from work or pensions (including the State Pension). It is automatically allocated via the tax code system which determines PAYE tax deductions.

Your Personal Allowance means the first £12,570 you receive of taxable income won't be taxed. If you earn over £100,000 then your Personal Allowance is reduced, and if your income exceeds £125,140 then your Personal Allowance is reduced to £0.

Married Couple's Allowance (MCA)

MCA applies to marriages and civil partnerships where at least one person in the relationship was born before 6 April 1935. You generally need to be living together, but if separated through circumstance rather than choice it could still be claimed for the 2023-24 tax year, it could cut your tax bill by between £401 and £1,037.50 a year.

Marriage Allowance (MA)

If you're too young for MCA then you may qualify for MA, but you can't claim both MA allows the transfer of 10% of the Personal Allowance from one spouse or civil partner (who is unable to use it) to the other This usually means that one of the individuals in the marriage or civil partnership will have an income below the Personal Allowance and the other will be a basic-rate taxpayer (higher-rate taxpayers can't have it) The transferable amount of £1,260 can save up to £252 in tax It was introduced six years ago but still goes unclaimed by some who would qualify New claims can be backdated for up to four years, if appropriate.

Allowances for savings interest

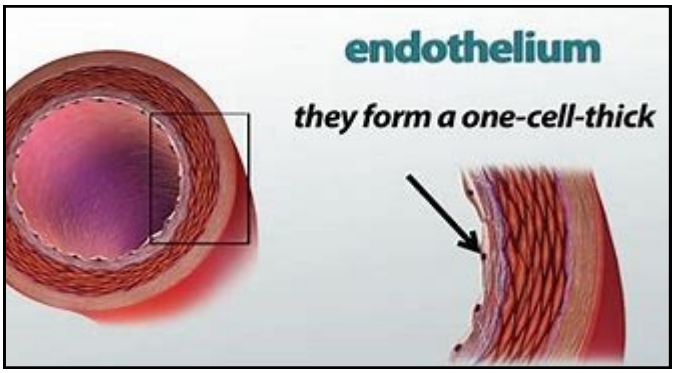
There are also allowances for savings interest, for example, the Personal Savings Allowance (PSA) permits £1,000 of taxable savings interest to be received tax free by anyone who pays no more than basic rate tax. The PSA for higher-rate taxpayers is £500.

Other allowances

There are other allowances available, depending on your circumstances, such as the Dividend Allowance, Property Allowance or Trading Allowance. Further details are available online.

Impaired Endothelial function in ME/CFS and Long COVID

With thanks to ME Research UK



The endothelium – a thin layer of cells lining every blood vessel – plays a pivotal role in regulating the dilation and constriction of blood vessels, blood clotting, and inflammatory responses.

Emerging theories that post-viral conditions, including ME/CFS and long COVID, involve damage to the endothelium. The resulting endothelial dysfunction may lead to the formation of clots blocking capillaries, reducing tissue blood flow and oxygenation, and potentially driving symptoms such as fatigue, cognitive impairment and pain.
Endothelial dysfunction is also characterised by reduced nitric oxide production. In a healthy endothelium, increased blood flow triggers nitric oxide release which aids blood vessel dilation, allowing more blood to flow through. This physiological response is referred to as-mediated dilation, and can be assessed in order to gauge whether or not the endothelium is functioning properly. Through assessing flow-mediated dilation, Marie Mclaughlin and colleagues that individuals with ME/CFS and those with long COVID displayed notable and similarly impaired endothelial function. This highlights potential vascular (blood vessel-related) involvement in the pathogenesis of these conditions.

What did the study do? The study aimed to compare flow-mediated dilation between individuals with ME/CFS, those with long COVID, and healthy controls. The rationale behind selecting these patient groups was that, while vascular function impairments have been reported in people with ME/CFS and those with long COVID, they have never been compared directly in the same study, despite considerable overlap between the conditions. Recruited via social media, the study included 51 participants in total – 17 with ME/CFS, 17 with long COVID, and 17 healthy controls. The paper does not mention whether ME/CFS diagnoses were confirmed, if so, which diagnostic/research criteria were used. Whilst the healthy controls were matched with the disease cohorts in terms of age, there were some substantial differences in body mass index (BMI), blood pressure, and heart rate between the groups. The authors mention that to “reduce participant burden, participants were not advised to fast before the test”. Yet, they acknowledge that dietary intake immediately prior to flow-mediated dilation assessment can have a potentially confounding effect on the results. Assessment of flow-mediated dilation, the four main steps:

- Ultrasound scans of the brachial artery (a major blood vessel in the arm) were taken to obtain baseline measurements of blood vessel diameter and blood flow.
- A pressure cuff around the upper forearm was inflated, temporarily blocking blood flow to the lower arm. (This is a variation of the common technique to measure blood pressure.)
- After five minutes, the cuff was deflated, allowing a rush of blood to flow through the brachial artery. Once again ultrasound scans were used to monitor blood vessel diameter and blood flow.
- Any increase in blood vessel diameter following cuff release indicates dilation. The extent of flow-mediated dilation for each participant was taken as the highest percentage increase in vessel diameter compared to baseline.

What did they find? The study demonstrated significantly impaired endothelial function in both ME/CFS and long COVID groups in comparison to healthy controls as assessed by flow-mediated dilation. However, the effect size of these differences was relatively small. The smaller the size, the less the practical significance of results (their real-world impact), and versa.

As mentioned in the paper, it might be hypothesised that individuals with ME/CFS would have poorer vascular function than people with long COVID, due to a longer duration of post-viral illness and ‘multi-system’ (which is known to reduce flow-mediated dilation). Yet, interestingly, there was no difference in flow-mediated dilation between participants with ME/CFS and those with long COVID. The authors state this could suggest that endothelial damage is experienced in the early post-viral phase, without a further reduction in flow-mediated dilation after this initial reduction, and that impairment in flow-mediated dilation is unlikely to be due to deconditioning.

It is also worth noting that there was a large spread of the data, meaning that some individuals with ME/CFS or long COVID had “very severely impaired endothelial function, whereas others had comparable flow-mediated dilation to that of the controls”. According to the authors, this suggests “endothelial dysfunction may not be ubiquitous in post-viral conditions” with potentially different disease trajectories and symptomology on an individual level.

Discussion In summary, the study found that participants with either ME/CFS or long COVID had significantly impaired endothelial function in comparison to controls as assessed by flow-mediated dilation. Also, there were no significant differences in endothelial function between the ME/CFS and long COVID groups, further highlighting the overlap between the two conditions. However, there may be questions about the practical significance of the results given the often-small effect sizes, in addition to a large spread of data making it challenging to generalise findings. Furthermore, the study had major limitations which go beyond the common issue of having a small sample size.

Not providing details of criteria used or whether participants had a confirmed diagnosis of ME/CFS or long COVID limits our ability to draw conclusions and compare findings with other research. As post-exertional malaise (PEM) is a cardinal feature of ME/CFS, it would have at least been useful to mention if any of the participants experienced this symptom. Additionally, the participants were not matched for BMI or blood pressure despite knowledge that both variables can affect flow-mediated dilation.

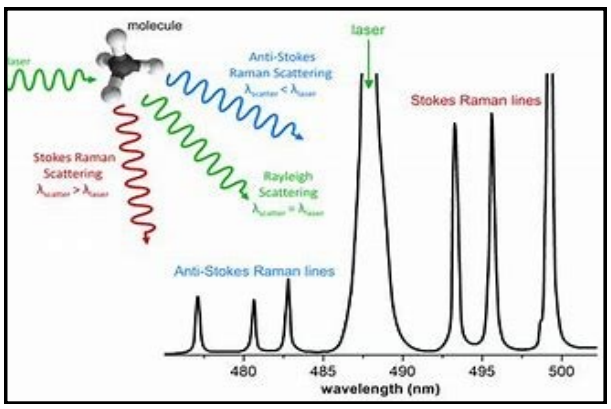
While the researchers mention that consensus guidelines flow-mediated dilation assessment were followed where possible, they did not adhere to recommendations for fasting. Foods, such as those rich in nitric oxide precursors, can affect blood vessel diameter. Therefore, the lack of fasting prior to the study may have had a confounding effect on the results. Although this study provides interesting insights into endothelial function in ME/CFS and long COVID, further research with improved methodology is necessary to understand the implications for cardiovascular health in these conditions and to explore potential intervention.

Developing a Blood Cell-Based Diagnostic Test for ME/CFS Using Peripheral Blood Mononuclear Cells (PBMC)

With Thanks to the Ramsey research Fund

With PBMC being an easily accessible target, we believe that Raman spectroscopy combined with advanced artificial intelligence could offer an affordable and non-invasive screening tool for ME/CFS when the condition is first identified."

Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) is characterized by debilitating fatigue that profoundly impacts patients' lives. Diagnosis of ME/CFS remains challenging, with most patients relying on self-report, questionnaires, and subjective measures to receive a diagnosis, and many never receiving a clear diagnosis at all. In this study, a single-cell Raman platform and artificial intelligence are utilized to analyse blood cells from 98 human subjects, including 61 ME/CFS patients of varying disease severity and 37 healthy subjects and disease controls. These results demonstrate that Raman profiles of blood cells can distinguish between healthy individuals, disease controls, and ME/CFS patients with high accuracy (91%), and can further differentiate between mild, moderate, and severe ME/CFS patients (84%). Additionally, specific Raman peaks that correlate with ME/CFS phenotypes and have the potential to provide insights into biological changes and support the development of new therapeutics are identified. This study presents a promising approach for aiding in the diagnosis and management of ME/CFS and can be extended to other unexplained chronic diseases such as long COVID and post-treatment Lyme disease syndrome, which share many of the same symptoms as ME/CFS.



We are all aware of a rainbow which is caused by sunlight shining through rain. The white light is split into the familiar rainbow colours. A Raman spectrometer is a scientific instrument which shines laser light though a sample. The colour (wavelength) of the light is changed by the sample and it is displayed as a graph.

Nutritional Deficiencies Linked to Medicines

The number of medicines prescribed in the UK has increased significantly in the last decade. Nearly 70% of the UK population receives one or more prescriptions, and an increasing number have prescriptions for more than five different medications. Over the last five years, there have been over one billion prescriptions dispensed in England. If you think about your local pharmacies, on average each one is prescribing 6,600 items per month. The most popular drugs prescribed are for cardiovascular systems. Then the nervous system, hormone system, gastro-intestinal system and respiratory system are the next four areas that require the most prescriptions. There are many proven links between prescription drugs and nutrient deficiencies. Some are very significant for people with ME/CFS.

The Statin Family of Medicies
There are at least half a dozen statins prescribed to insure against or reduce the risk of heart attacks and strokes in those with high cholesterol. Statins as a group to deplete Coenzyme Q10 (CoQ10) level. CoQ10 is an essential component of our mitochondrial electron transport chain and an antioxidant in our plasma membranes and lipoprotein.

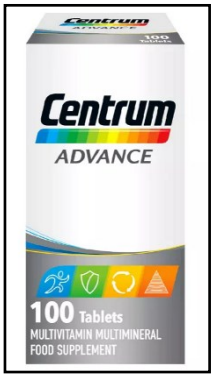
Most people with ME/CFS are deficient on Q10. Some supplement suppliers try to capitalise on this by promoting Q10 supplements. This is not in anyone's interest prescribed a statin because it just reduces the statins effectiveness. Statins and ME/CFS don't mix. They are best avoided and only should be prescribed if really necessary e.g. after a heart attack. At that point the two least detrimental statins for ME/CFS are Pravastatin and Rosuvastantin. Both are water soluble. Fat soluble statins like Atrovastin should be avoided. The local NHS consensus is that Simvastatin, the first statin available should be avoided because of its 'dirty' side effect profile. Statins also deplete Copper, Selenium and Zinc.

The Proton Pump Inhibitor (PPI) family of medicines
Omeprazole and Lansoprazole are common examples of PPI 's. These medications are and have been shown to reduce the acidity of stomach contents, thus impacting on our ability to absorb Iron and B12. In addition, they may also promote hypomagnesemia (low Magnesium levels) and impact on. This may be detrimental for people with ME/CFS.

Paracetamol Containing Medicines
A commonly used medicine that can help treat pain and reduce a high temperature (fever). Paracetamol my appear in many medicines unnamed for example co-codamol and night nurse. Always read the label and check for the wording 'Controls Paracetamol'. Paracetamol intake influences our Glutathione status and Cysteine levels which are in short supply in ME/CFS.

The Beta Blocker Family
Beta blockers are a family of medicies frequently prescribed for people with ME/CFS who have a fast heartbeat. There are many members of this family, some sedating like propranolol. Others like Atenolol area frequently prescribed for high blood pressure and heart problems. Some are claimed to be cardio specific. Sleep disturbances are a common side effect of their use. They have also been shown to reduce the production of Melatonin levels. There is also research indicating that Zinc levels may be compromised in hypertensive patients.

Metformin
The main first-line medication for the treatment of type 2 diabetes and polycystic ovaries. Anyone taking Metformin, we need to consider our levels of two essential B-vitamins. Specifically, Vitamin B12 and Folate. This could be detrimental for anyone with ME/CFS. Your GP can check your B12 levels.

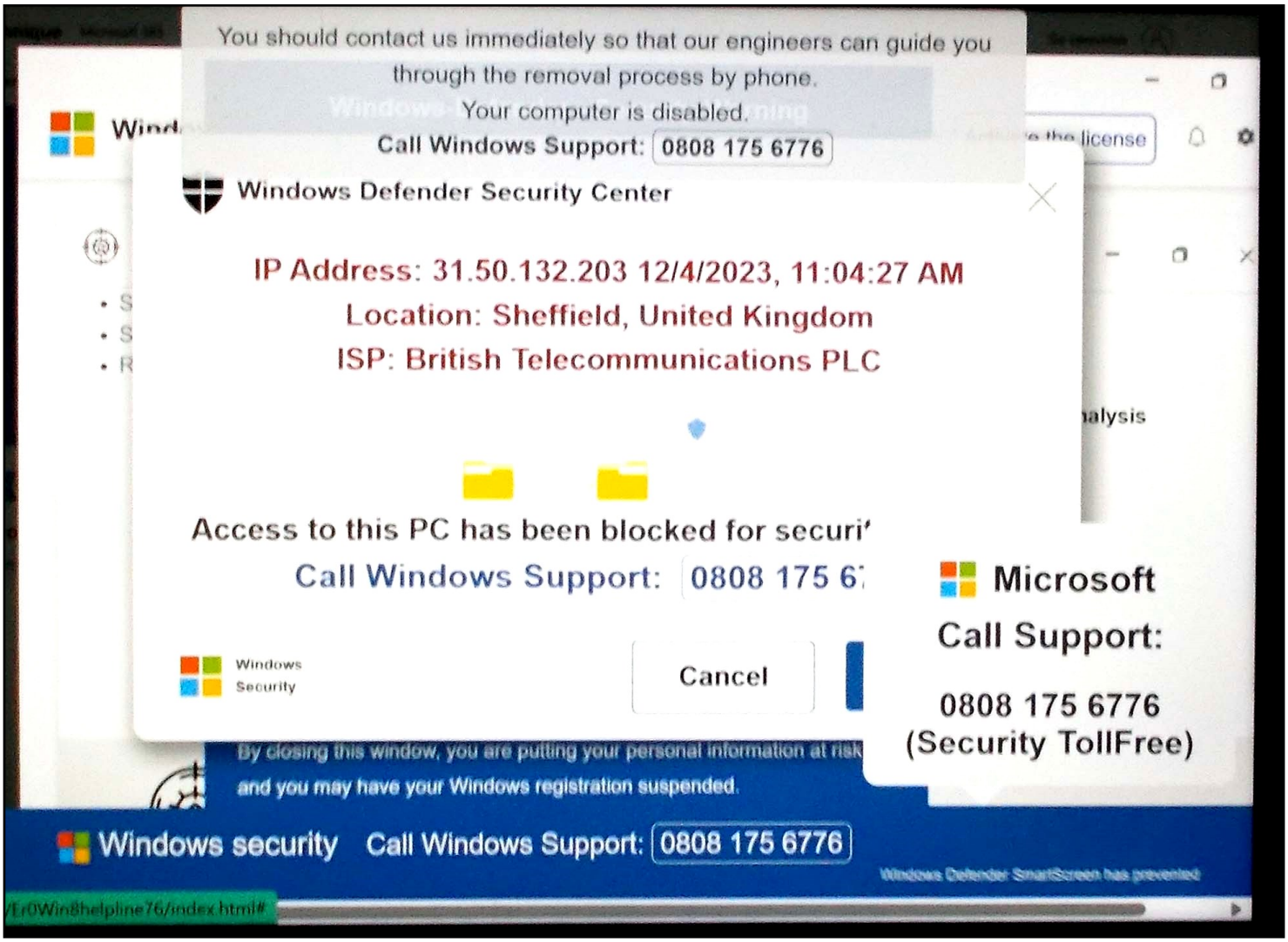


There are really two options to guard against nutritional deficiencies. Firstly, take a A-Z multivitamin supplement like the Biocare or Centrium range or get your doctor to check levels and treat appropriately. Not all multivitamins are appropriate ME/CFS patients.

I will check for these sort of issues when a do a 1 to1 session - *Mike*

An Example of an Internet Scam and How it was Fixed.

This scam is a quite a nasty one. It was picked up by browsing the Leger ME Facebook Pages and following the links. What happens is the computer freezes and a raucous voice speaks the “Do not switch off or reset your computer. Do not…. Do not ...Call.”



We were fortunate to be able to photograph the screen as displayed above. The scam works by getting you to call the number displayed which claims to be a Microsoft number, but is really a scammers number. Then they will try to get you to give your bank details which of course opens the flood gates for the scammer to empty your bank account. This particular computer had Norton Antivirus installed which didn’t detect it. The scammer uses a sound file and picture for this attack, which cannot be checked.

With this and similar scams the fix is simple. Turn off your computer or hit the reset button if you have one on your device. However, this could corrupt files and cause data loss. A safer fix is to press the control, alt and delete keys together. This brings up the Task Master menu. Select Task Master. Allow it to modify your computer. Left click on the browser entry you were using and select ‘End task’. You might have to repeat the last stage several times and there may be multiple sessions of the browser active. That should get you back to the startup screen. At that point restart your computer in the usual way. Be aware that the scammers have a way of leaving a link scam link in your web browser history — so select the option to delete all browning history. Since using this procedure, we have had no trouble with the affected computer.

North of Doncaster

Personal thoughts of Trevor Wainwright.

Christmas Poetry

For this issue Mike asked if I could do something seasonal so I thought maybe some Christmas poetry and the story behind the poems. First a check on what I have already published. That done here are some being publicised in Pathways for the first time.

My first poem began as to how I felt when I saw my first daughter Lisa just after she was born, I got to "hand in mine" and was stuck, then one Sunday lunch in November. The inspiration came at it became a poem dedicated to God's first born, which Lisa would read out in church that Christmas.

The First Christmas Morning

Into the manger I looked down at a baby all head and gown
I gently took his hand in mine; a star above had been the sign
The baby's coming had been foretold by the prophets in days of old
It seemed the prophecy had come true; Slowly behind me there formed a queue
The shepherds who had been fast asleep; Came in from the fields leaving their sheep
Soon others would come from afar, led here by that very same star
Into the manger again I looked down at the baby all head and gown
Suddenly I glowed with pleasure; this to me was a moment to treasure
Then away from the stable I came I thought of the baby, Jesus his name
Walking away as day was dawning on that very First Christmas Morning

It came to the attention of one of Lisa's teachers who put a tune to it (a gentle lilt) and it became part of their Christmas carol repertoire, ending with the line "I knew that I'd seen the Saviour". I always thought it was a shame it couldn't have been recorded and given the title "The Castleford Carol".

The second poem came about as a result of a modern-day Mystery Play, I was commissioned to write by what was then Yorkshire Arts Circus, an organisation bringing the arts to local communities and the people given chance to be part. If you remember Pathways 62 and A Yorkshire Nativity, that was an updated version of the original which was set in a renewal area and called The Builders Play using the structure of the Second Shepherds Play form The Wakefield Mystery Plays cycle.

The Smawthorne Child

We'll have a census the Government said, a count of the population head
So, they'd to go to where he'd been born,
The part of Castleford called Smawthorne
A pit joiner in the mining town,
He'd moved south when the mine shut down
Setting up on his own a successful business in an enterprise zone
The start of a brand-new life, a local girl for his wife
It was for them a time for glee as soon a baby would make three
Now they were going to where he'd been born
The part of Castleford called Smawthorne
But it was late and getting dark when outside the pub they did park
But no rooms to be had there not in Castleford or elsewhere
But there was no need for gloom a bed was but up in a back storeroom
An electric heater they could borrow
And sort out something better tomorrow
And they thought it was really grand when t'local folk lent a hand
Then after all the chaos and mirth in the storeroom his wife gave birth
And people came from far and wide to stand at the baby's side
To see the child that had been born
In the part of Castleford, they call Smawthorne

The third poem came about when I decided to make a trilogy covering Advent Christmas and Epiphany

The New Star (A poem for Epiphany)

We looked up from our evening feast at a new star risen in the East
The night sky a jet-black wall, this star the brightest of them all
Slowly brighter it grew signifying something new
We remembered prophets past and what they had forecast
"One night a star will shine bright you will move from dark to light
the news to you the star will bring the birth of a saviour and King"
Again, we looked up from our feast the new star no longer in the east
Drifting westward brightest of all "Follow me" it seemed to call
We'd follow it each night till dawn to where the baby King was born
Travelling by night and resting by day letting the star lead the way
When we reached Bethlehem town the star stopped and shone down
Gently down it had led us to an old cattle shed
At last, the end of our ride, joyfully we went inside
Words couldn't describe the joy we felt as before the Christ Child we knelt
Our gifts we did bring, Gold to crown him a King
Frankincense to heaven raising to worship him all people praising
Lastly Myrrh a bitter perfume preparation for his tomb
Then time for us to leave, in the prophecy we did believe
Or why had we come so far following the New Star?

My final poem is from the comments of a young child who when told his uncle who had been ill for a while had died just before Christmas said "good", at first his parents were shocked until he said "He'll be in heaven in time for Jesus' birthday"

Jesus' Birthday

Remembering those who will not be with us this Christmas
Hopefully at a special party singing:
Happy Birthday to you, Happy Birthday to you,
Happy Birthday Dear Jesus, Happy Birthday to you,

I Hope you enjoy the poems and wish you all Merry Christmas and Happy New Year

Trev.

The Trouble With Pets At Christmas