

# Pathways

Price £ 5.00 (Free to members)

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 79. Spring Edition 2024



**Evelyn writes:** Spring is in the air. I had just set up my gear to photograph a robin in the garden when another one appeared.

I could not resist taking this shot.

Robins are fiercely territorial at most times of the year. We only see close contact between two robins in the breeding season. There must be a nest nearby.

**You write in.**

**Tom Writes:** I am suffering from Chronic Pain and Fatigue Syndrome following a Covid vaccination two years ago. The problem is that I have put on two stone since my problem started. I am being treated by the local pain control clinic with high dose Gabapentin, but they want me to move onto a medicine called Duloxetine. I have Oromorph for breakthrough pain. I am still able to carry out my job as a factory mechanic but increasingly I am finding it harder to work, and I am having increasingly less time for my social life. Also, I am finding that my driving is becoming increasingly more difficult with a manual car. Could you help me get a Blue badge?

*Firstly, you should check that a yellow adverse reaction card has been sent in reporting vaccine damage. Your doctor should have done this. Of major importance is the vaccine batch number and manufacturer. It is possible that there may be a class legal action for vaccine damage at a future date.*

*Gabapentin and related medicines like Pregabalin which are very good at pain control. However it is the experience of many Leger ME members that their weight increases massively, and it is almost impossible to lose. It is quite clear that your pain control clinic is aware of this, and is Duloxetine safer in the long term because it is an SSRI based medicine. Oromorph is OK, but is related to heroin and other opiates, and has the problem of addiction, dependence and constipation, so it is not in your interest to use it in the long term.*

*You may come across unusual medicines to treat chronic pain. We find that most people with chronic pain are depleted in Vitamin D3. We advise people if depleted and corrected through D3 treatment or dietary supplementation that this reduces chronic pain and fatigue. Another unusual treatment is magnesium salts like magnesium malonate which sometimes helps. Then there is EPA derived from fish oil. We know that it helps with brain fog, fatigue and joint pain. It also helps to reduce the LDL cholesterol and so has a protective effect against heart attacks and strokes. D3, magnesium and EPA are all sold as food supplements and can be purchased over the counter.*

*Regarding driving an automatic car would reduce the pain and fatigue of driving especially on your left-hand side. One of our members who couldn't afford a new car found that relearning driving through the Institute of Advanced Motorists reduced her need to use the clutch and gear lever beneficial. Also, it saved her money by improving fuel consumption.*

*As your job goes, you need to be registered as being disabled, which gives you more job protection and a protected environment. Regarding a blue badge and Personal Independence Payment (PIP), we, Leger ME can help you claim these benefits*

*Your problems are likely to be chronic and unremitting. While the NHS pain control clinic can help, you can achieve a lot by keeping as healthy as possible maintaining your ideal weight, and modified diet along with good sleep hygiene. This will help avoid age related heart disease and cholesterol problems in the long term.*

**Gwen Writes:** I have had ME/CFS for about 20 years. I have just been given a diagnosis for Glucose Intolerance, but my GP has not given me any medicines or advised on any treatment. Is this right and what problems could I get in the long term. Is there anything I can do now?

*Glucose intolerance is regarded as pre-diabetes state rather than being fully blown diabetes. It is usually diagnosed when someone has a Glycolated Haemoglobin (Hb1ac) blood test above 42mm/l. A value of 42-47 mm/l, sometimes expressed as 6— 6.5% suggests pre diabetes. A value of Hb1AC above 48 mm/l or 6.5% is full blown diabetes. For clinical economic reasons Glucose Intolerance is generally not treated with medicines, but lifestyle changes and diet. It is possible to get a remission from Glucose Intolerance or early Type 2 diabetes by losing weight for up to five years. However, as type 2 diabetes is a progressive disease, it only gets worse with age. While type 1 diabetes is due to the total failure of the pancreas to produce insulin due to auto immune damage, Type 2 diabetes is considered to be due to partial failure of the pancreas and insulin resistance caused by many multiple factors. In fact, some people with Type 2 diabetes have high levels of circulating insulin that does not seem to control the blood sugar successfully. Eventually given time over many years most type 2 diabetes cases will result in pancreatic failure, and will need to be considered as type 1 needing insulin.*

While type 2 diabetes used to be considered 'mild diabetes', it is far from reality. High insulin levels, and other factors cause high blood pressure, high cholesterol levels and raised Hb1ac levels causing red blood cell damage. These can lead to an increased risk of cardiovascular disease which includes strokes and heart attacks. Medical treatment of type 2 diabetes focuses on keeping blood sugar levels (Hb1Ac) as near normal as possible, as well as tight control of cholesterol and blood pressure. The actual numbers have got tighter over the years. It is well known that the tighter the control in early diabetes, the better the outcome in the long term. I completely disagree with the NHS way of not treating glucose intolerance with medicines. My view is that some sort of antidiabetic treatment should be implemented as soon as possible. For people with ME/CFS the first medicine to try is Metformin as this can be beneficial. A second choice would be a SGLT1 inhibitor. This class of medicines has a similar effect to the PK Diet, and is also cardiovascular protective. A last choice would be insulin. Guidelines change every few years, so anyone with Type2 diabetes needs to be regularly checked several times a year by the local diabetic clinic and to keep up with the latest treatment guidelines.

People with ME/CFS are susceptible to hypoglycaemic episodes because of impaired activation of the HPA (Hypothalamic–Pituitary-Adrenal ) axis. Some diabetic medicines particularly insulins and sulphonylureas (e.g. gliclazide) can cause hypoglycaemic episodes in people with ME/CFS when the blood sugars levels are in the normal low range, and this can be very dangerous.

Even with almost perfect diabetic control there are often long-term complications. The major long-term problems relate to damage to blood vessels. Diabetes doubles the risk of disease, and about 75% of deaths in people with diabetes are due to artery disease. Other macrovascular morbidities include stroke and artery disease. Microvascular disease affects the retina, known as retinopathy, is the most common cause of blindness in people of working age and needs to be checked for annually. The eyes can also be affected in other ways, including development of cataracts. It is recommended that people with diabetes living locally have their eyes checked at the local hospital with the eye camera.

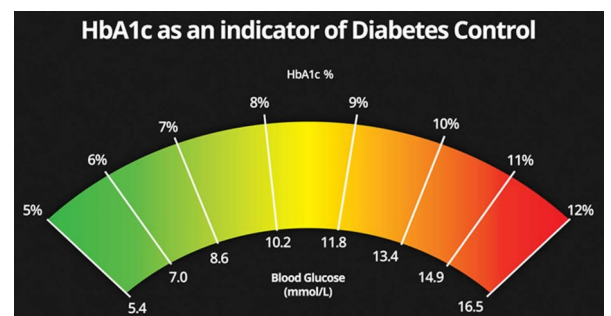
Diabetic nephropathy, a major cause of chronic kidney disease, accounting for over 50% of patients on dialysis. Diabetic neuropathy, damage to nerves, which manifests in various ways, including sensory loss, pain, and dysfunction (such as hypotension, and erectile dysfunction). Loss of pain sensation predisposes diabetics to trauma that can lead to the foot problems (such as ulcers), the most common cause of non-traumatic lower-limb.

Based on extensive data and numerous cases of gallstone disease, it appears that a causal link might exist between type 2 diabetes and gallstones. People with diabetes are at a higher risk of developing gallstones compared to those without diabetes.

There is a link between neurological deficit and diabetes; studies have shown that diabetic individuals are at a greater risk of cognitive decline, and have a greater rate of decline compared to those without the disease. The condition also predisposes the elderly to falls in , especially those treated with insulin or sulphonyureas.

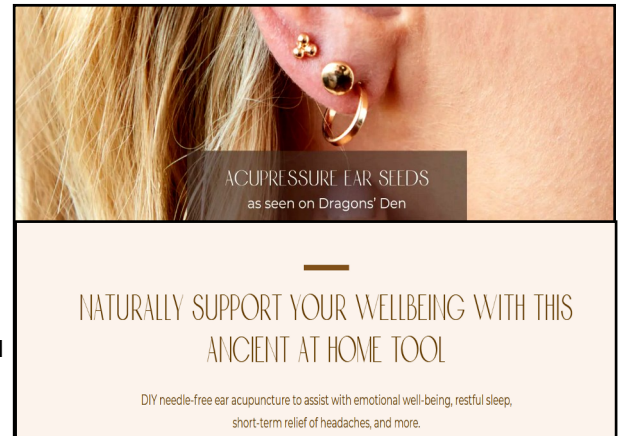
Depending on the local area, people with early diabetes are sent to "Diabetes School" where the dietary and lifestyle interventions are taught. If this is not available, see your local diabetic practice's Diabetic nurse for further guidance. The routine checks should be carried out at least twice a year.

HbA <sub>1c</sub> test score	MEAN BLOOD GLUCOSE mg/dL	mmol/L
14.0	380	21.1
13.0	350	19.3
12.0	315	17.4
11.0	280	15.6
10.0	250	13.7
9.0	215	11.9
8.0	180	10.0
7.0	150	8.2
6.0	115	6.3
5.0	80	4.7
4.0	50	2.6



Treating type 2 diabetes is a matter of keeping the numbers within the right range. The are different ways the number can be expressed. The above images give an indication to the way the various numbers can be expressed.

**Julie Writes:** I was watching an edition of the BBC Dragons Den, a programme where budding entrepreneurs bid for development finance for some product or service. I saw a presentation by businesswoman Giselle Boxer for a ME/CFS treatment product that received six offers and an investment from entrepreneur and podcaster Steven Bartlett. In the presentation episode, Ms. Boxer said she had used “diet, acupuncture, Chinese herbs and ear seeds” to aid her recovery from ME/CFS. Being an entrepreneur, she had spotted a business opportunity to sell the brand Acu Seeds. However, shortly after, an open letter, organised by Action for ME, to the chairs of two House of Commons select committees, expressed concern over the pitch’s suggestion the product was “responsible for her recovery and should therefore be considered an effective treatment”.



*This advertisement appeared on Amazon shortly after the BBC programme with a Heath Disclaimer. However it was quickly removed.*

Are these worth trying ?

*I saw the programme too, and I thought 'not again'. It appears that the ear seeds are a type of stick-on jewellery for the ear, and nothing more.*

*Over the years I have seen a number of so called ME/CFS treatments. I certainly believe that ear seeds fall into this category. Most of these products are promoted by word of mouth and reputation. It is most likely that the placebo effect and psychology plays a large part in the reputation and promotion of these products. So far, there is no credible high quality hard scientific evidence that ear seeds are effective for ME/CFS. Certainly, over the years I have not met anyone who has benefited from these type of products. Also, the ME Associations Medical director and others prompted the British Acupuncture Council for a statement on ear seeds for ME/CFS. Their statement includes*

*Unfortunately, due to the lack of high-quality clinical trials it is currently not possible to draw firm conclusions about the benefits of acupuncture for chronic fatigue syndrome. However, the evidence that does exist indicates that acupuncture and moxibustion may have positive benefits.*

*The BBC has been forced to edit an episode of Dragon’s Den following concerns over “unfounded claims” regarding a product that historically received offers from all six Dragons. Days after it was revealed the corporation had the recent episode from streaming platform BBC iPlayer, the instalment, which aired on 18th January, has been reinstated, but with a health disclaimer.*

*My experience is that most people recover from ME/CFS over time to a lower level of ability. However all too frequently even after an apparent remission for many years people some can get an ME/CFS relapse.*

**Barry Writes:** Just to let you know that the IAS rang me at my appointment time on Tuesday and for the second time cancelled the meeting. I have looked online and it appears that this is something they are doing often to a lot of people, leaving them upset and distressed. They have deferred it again until the 17th of this month. Is this a common problem?

*(For the benefit of Pathways readers, IAS is an independent contractor for the DWP to carry out medical reviews for benefits like PIP, DLA and ESA.)*

*This is something which all too frequently happens, but for you to continue to receive your benefits is essential you attend that medical and go along with the system.*

*I suspect what is happening is that there is a large problem of people not attending their appointment so they are deliberately overbooking to ensure that all their appointment slots are filled. Some of the budget airlines quite deliberately overbook in the same way to ensure the aircraft is full and avoid empty seats. It is not until someone turns up at the check in desk that they find out that their flight is cancelled.*

*Contact me again if the 17th is cancelled, and I’ll put in a harassment complaint from the group.*

## **Welfare Rights Matters**

*with thanks to Benefits and Work*

### **The DWP and The Post Office Horizon Scandal: Did the DWP see through the Horizon scheme?**



The Horizon software at the centre of the current Post Office scandal was originally designed to save money and reduce fraud in connection with benefits and pension payments. Even though the Benefits Agency dropped the software, there are disturbing parallels between the way sub-postmasters were, and claimants still are, treated. Horizon was a joint venture between the Post Office, the Benefits Agency (as the DWP was then called) and ICL, a subsidiary of Fujitsu. The intention was to create a swipe card system for benefits and pensions to be paid out at Post Offices, replacing paper payment books.

The project began in 1996, but by 1999 the Benefits agency had lost all faith in the system and pulled out, leaving the taxpayer with a massive £700 million bill. In desperation, the project was repurposed to allow electronic bookkeeping to replace paper accounts in post offices. The result of that is now playing out in the media, the courts and a public inquiry. That the Benefits Agency pulled out of the Horizon system is to its credit. But there are many alarming parallels the current DWP and the Post Office. Both have the power to conduct their own criminal investigations and both routinely misuse these powers.

The Post Office threatened sub-postmasters with prosecution for theft unless they admitted wrongdoing and agreed to pay back all the money they allegedly owed. In reality, the Post office had no evidence whatsoever of theft having taken place in most cases. Similarly, claimants interviewed under caution by the DWP are often told that if they end their claim, and agree terms to pay back any alleged overpayment, they will escape prosecution for theft. However, if such cases go to a tribunal, rather than a criminal court, they are very often thrown out because of a lack of evidence. It is telling that both sub-postmasters and claimants are routinely interviewed under caution without any legal representation being offered or provided. Both the DWP and the Post Office are obsessively secretive. The Post Office's attempts to hide information from the courts and the current public inquiry are a scandal in themselves.

There are also many examples of the DWP keeping evidence from inquiries, government committees and even coroners' courts. In addition, Post Office investigators, were on a bonus system for any cash they recovered by threatening and misleading sub-postmasters into repaying money they never owed. We don't know if DWP investigators are also on a bonus system for recovering money from claimants. But we do know that in the past the DWP has paid bonuses to teams for pushing claimants off benefits, including by way of sanctions. So, there is every possibility that fraud teams are incentivised in this way. Yet, in spite of all this, the DWP is now being given powers to carry out mass surveillance of claimants' bank accounts. It wants to go much further. The department is hoping to get the power to arrest claimants, search their homes and seize evidence. Imagine how much evidence supporting a claimant's innocence might go missing after such a search and seizure operation.

In the wake of the Post Office scandal, there is a very strong argument that the DWP should be stripped of its current power to prosecute claimants. There is an absolutely overwhelming argument against it gaining any additional powers. But, as the tide of anti-claimant rhetoric rises again, is there anyone who will effectively make that argument?

### **Number of pip reviews increases by 68%**

The latest quarterly statistics published by the DWP show that the number of claimants having their PIP award reviewed has leapt by 68% compared to the same period a year ago.

*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.*

Whilst many claimants dread an award review, and 30% will be worse off as a result, the failure to carry out reviews on time also causes a great deal of distress. For example, many claimants have difficulties with Blue Badge applications and mobility vehicle agreements as a result of reviews being postponed. In August of 2023, Citizens Advice estimated that of 430,000 people awaiting a PIP review, 100,000 were entitled to higher payments because their needs have increased.

### **Scottish ADP success rates continue to fall**

The difference in success rates between personal independence payment (PIP) and its Scottish equivalent Adult Disability Payment (ADP) are becoming smaller as time passes. According to the latest official figures, the success rate for ADP has fallen from 69% when it was first introduced in September 2022 to 53% in October 2023. For comparison, the success rate for PIP in October 2023 was 50%.

Whilst this was the highest recent percentage for PIP, success rates have remained at 48% or above for the past six months. Social Security Scotland have offered no explanation for the continuing fall in award rates.

### **Forcible Entry For Pre-Payment Meters Returns**

Ofgem has given three energy suppliers permission to restart forcible entry to people's homes to install prepayment meters after the practice was banned last February. The fact that forcible entry has been restarted at the coldest time of year says a great deal about the degree to which Ofgem is prepared to protect customers. However, high risk customers must not have a prepayment meter forced on them. These include:

- Households which require a continuous supply for health reasons, including dependence on powered medical equipment
- Households with residents with severe health issues including terminal illnesses or those with a medical dependency on a warm home (for example due to illness such as emphysema, chronic bronchitis, sickle cell disease)
- Where there is no one within the household that has the ability to top up the meter due to physical or mental incapacity.

### **Government Dismisses Bank Surveillance Petition And Ignores DWP Blueprint For Fraudsters**

The government has issued a dismissive response to a petition on the Parliament website in relation to surveillance of claimants' bank accounts, claiming that concerns are based on misconceptions. In its response, the government argues that:

*“There are a number of misconceptions about this measure, namely, it does not grant DWP access to any bank accounts and it does not allow DWP to see how claimants are spending their money.”*

Benefits and Work has always been clear that the current plan is restricted to checking whether accounts have gone over the capital limit and whether claimants have been using their account abroad for an extended period. However, many people would consider the requirement for banks to share any data on claimants of means-tested benefits to be over-intrusive and discriminatory in itself, regardless of the nature of the data. The blanket nature of the legislation allows the DWP to require any organisation to hand over any data the DWP requests or face a large fine.

So, the department may be starting small with its data collection, but there are literally no limits to how far it could extend its reach. The response makes no mention of the fact that, in its published impact statement, the DWP provides a list of all 15 banks that they plan to monitor, leaving fraudsters free to simply to bank elsewhere. Additionally, the DWP also admit that they will only be monitoring the account that the claimant has their benefit paid into. The impact statement explains, this means that fraudsters:

*“ . . . may split capital across multiple bank accounts to ensure that there is not £16,000 or above with one provider. This would allow claimants to go undetected by this measure and reduce its effectiveness.”*

As an anti-fraud measure, banking surveillance of this sort seems designed solely to catch those who innocently or mistakenly break the rules, not those who do so in a deliberate and organised fashion.

### **400,000 Claimants To Be Migrated To Universal Credit In 2024-25**

The DWP estimate that around 440,000 legacy benefit claimants will be forced to migrate to universal credit in 2024-2025. This number includes:

- Income-based ESA with child tax credits
- Income support
- Claimants who receive IB-ESA with child tax credits will receive mandatory migration notices to move to universal credit between July and September 2024.

Anyone receiving IB-ESA only or IB-ESA with housing benefit, you can expect to be asked to migrate to UC in 2028 or 2029. If anyone receives-based ESA without any legacy benefits, you will not be affected by managed migration.

### **Only One In A Hundred Pip Appeals Won On New Claimant Evidence.**

Figures produced by the DWP show that just one in a hundred successful PIP tribunals is won because the claimant produced new written evidence. In other words, in over half of all successful tribunals, the panel reaches a different decision simply by looking at the PIP 'How your disability affects you', the assessor's report and any other evidence submitted by the claimant. In just over a third of cases, the tribunal is persuaded by what the claimant tells them at the hearing. These figures should encourage claimants who are anxious about appealing a PIP decision. Because you don't need expensive medical evidence to win your appeal. You just need to show up and answer the questions as accurately as you can.

### **Shambolic Severe Disability Group Assessment System Revealed**

The DWP has revealed more details of what now seems to be a shambolic system for assessing claimants for the Severe Disability Group. Depending on the claimant's diagnosis, entry may be based on:

- medically precise definitions that have no connection with the benefits system at all; or
- on information that only the claimant or carer will know, but a specialist will still have to provide; or
- the availability of specialist services where the claimant lives; or
- even on no clear criteria at all.

There is also a lack of clarity on the overlap between the Severe Disability Group and the light-touch review system for PIP. Some claimants are voicing the suspicion that the creation of a separate group of severely disabled claimants could be aimed at reducing future payments for those allegedly less severely disabled.

Benefits and Work have details of the qualifying criteria for a range of conditions, including:

Arthritis, Autism, Bipolar disorder, Depression, COPD, Epilepsy, OCD, ME/CFS Parkinson's disease

### **Claimant Bank Accounts Surveillance Warning**

A total of 42 organisations including Disability Rights UK, Big Brother Watch, Child Poverty Action Group, Mind and Age UK have written to Mel Stride, the work and pensions secretary.

In the letter they stress the dangers involved in the DWP bank surveillance plan, arguing that

*"There are approximately 22.6 million individuals in the welfare system, including those who are disabled, sick, caregivers, job seekers, and pensioners. They should not be treated like criminals by default ... The Horizon scandal saw hundreds of people wrongfully prosecuted using data from faulty software. The government must learn from this mistake – not replicate it en masse."*

Meanwhile, there is a disturbing example on the Disability News Service (DNS) website of how wrong the DWP can get bank surveillance.

The DWP threatened to suspend the benefits of a disabled woman because of bank accounts they wrongly believed belonged to her husband. They claimed that they had information that showed an undeclared ISA savings account and a current account in his name, with his national insurance number, address and date of birth. The claimant was given just two weeks to prove that the accounts were not her husband's or have her benefits suspended.

Not surprisingly, the bank refused to supply any details to the husband about any accounts other than his own, because that would have breached data protection laws. The claimant was thus left in the impossible position of being required by the DWP to provide evidence it was illegal for them to be given. If the DWP can already get things this wrong, imagine the level of error when an understaffed and badly trained department is dealing with many thousands of items of data constantly being forwarded to them by all the UK's major banks.

The Department for Work and Pensions (DWP) has confirmed it will be checking for two main things when inspecting bank accounts in 2024. This is part of a new rule to crack down on fraudulent benefit claims, according to Birmingham Live. The DWP's priority is to check bank balances that exceed the capital limits. Officials have confirmed that people won't be able to claim Universal Credit if they have over £16,000 in money, savings and investments. The DWP will also monitor if claimants are staying overseas for longer than current rules allow. This comes ahead of new rules and restrictions being launched.

Banks including Bank of Scotland, Barclays Bank, Monzo Bank Limited, Metro Bank, Lloyds Bank, HSBC, Halifax, National Westminster Bank (NATWEST), Nationwide Building Society and Santander will be checked.

Starling Bank, Co-Operative Bank, The Royal Bank of Scotland (RBS), Yorkshire Bank and TSB Bank will also be checked. Currently, the DWP can investigate any bank account where fraud is suspected, and HMRC shares banking data with the DWP each year.

The new rules will require banks and building societies to monitor everyone who claims benefits. Officials at the Department for Work and Pensions assured: "DWP staff will follow the usual business processes when looking into any cases, taking account of circumstances and wider vulnerabilities before deciding on a course of action."

However, civil liberties group Big Brother Watch warned against this invasion of privacy. They declared: *"The government should not intrude on the privacy of anyone's bank account in this country without very good reason, whether a person is receiving benefits or not. People who are disabled, sick, carers, looking for work, or indeed linked to any of those people should not be treated like criminals by default."*

They also defended the principle of presumed innocence, stating: "Such proposals do away with the long-standing democratic principle in Britain that state surveillance should follow suspicion rather than vice versa." And they added: "It would be dangerous for everyone if the government reverses this presumption of innocence. This level of financial intrusion and monitoring affecting millions of people is highly likely to result in serious mistakes and sets an incredibly dangerous precedent."



## From Across the Pond

Sandy Nye has sent us a section of Topics from the latest American Myalgic Encephalomyelitis and Chronic Fatigue Syndrome Society Newsletter for Pathways readers.

See [American ME and CFS Society \(ammes.org\)](http://ammes.org)

## 'Solve' Responds to Findings From the NIH Intramural ME/CFS Clinical Study Published in Nature

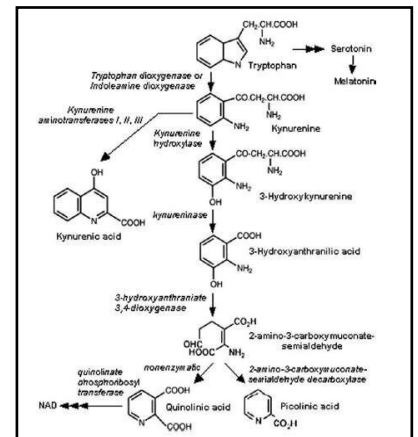
On a positive note, the study underscores the commitment of the NIH to understanding ME/CFS, highlighting that patients are often neglected or ignored. Researchers discovered other biological differences between ME/CFS patients and healthy controls, including elevated heart rates and blood pressure normalization after exertion. The researchers also discovered that several patients were living with other undiagnosed health issues, making clear we need to see improvements in how patients get diagnosed, nationwide.

### A blood test will diagnose fibromyalgia more reliably?

A research team from the Universitat Rovira i Virgili, University of Ohio and the University of Texas has developed an innovative method that allows fibromyalgia to be reliably diagnosed from a blood sample. Identifying this disease nowadays is highly complex, especially because the symptoms are similar to those of other rheumatic pathologies and persistent Covid.

### Urine Metabolite Analysis to Identify Patho-mechanisms of Long COVID: A Pilot Study

Conclusively, our results suggest that amino acid metabolism and neurotransmitter synthesis is disturbed in patients with LC and ME/CFS. The identified metabolites and their associated dysregulations could serve as potential biomarkers for elucidating underlying Patho mechanisms thus enabling personalized treatment strategies for these patient populations.



A Metabolic Pathway map

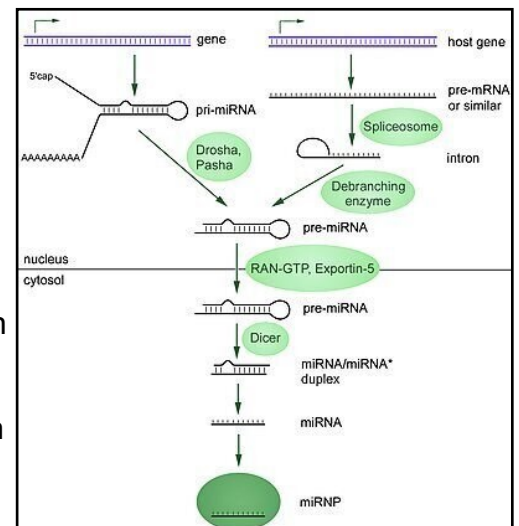
## Why the Psychosomatic View on Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Is Inconsistent with Current Evidence and Harmful to Patients

Although numerous studies over time have uncovered organic abnormalities in patients with ME/CFS, and the majority of researchers to date classify the disease as organic, many physicians still believe that ME/CFS is a psychosomatic illness. In this article, we show how detrimental this belief is to the care and well-being of affected patients and, as a consequence, how important the education of physicians and the public is to stop misdiagnosis, mistreatment, and stigmatization on the grounds of incorrect psychosomatic attributions about the origin and clinical course of ME/CFS.

## Heterogenous circulating miRNA changes in ME/CFS converge on a unified cluster of target genes: A computational analysis

As the results show significant similarity to previous research on latent herpesvirus involvement in ME/CFS, the possibility of a herpesvirus origin of these miRNA changes is also explored through further computational analysis and literature review, showing that 8 out of the 10 most central miRNAs analysed are known to be upregulated by various herpesviruses. In total, the results establish an appreciable and possibly central role for circulating microRNAs in ME/CFS origin that merits further experimental research.

Therapist, Amy Mooney, MS, OTR/L, and physical therapist, Clayton Powers, DPT address the importance of screening for PEM and redefine "exercise" in patients with PEM/PESE.



## Medicine Matters: Omega-3 Fatty Acids (EPA and DHA) and Atrial Fibrillation (AF)

In 2019, the global market for omega-3 fatty acids reached \$4.1 billion, and it is expected to double by 2025. These impressive expenditures reflect the worldwide popularity of these products and the belief by many that omega-3 fatty acids are beneficial to their health. Although the health benefits of these products remain questionable, it is important for people who take them to understand their potential risks. Eicosapentaenoic acid (EPA) and docosahexaenoic acid (DHA), both omega-3 fatty acids, have been the subject of much debate regarding their impact on cardiovascular (CV) risk reduction. Both EPA and DHA appear to have favourable effects on:

- Lipid metabolism: They can positively influence cholesterol levels.
- Blood pressure regulation: They may help maintain healthy blood pressure.
- Cardiac function: They might support heart health.
- Inflammation: They could reduce inflammation in the body.

These properties suggest that EPA and DHA supplementation may contribute to CV risk reduction. However, recent clinical trials have yielded mixed results: Some studies show a reduction in CV risk using EPA alone in specific populations. Others demonstrate no benefit and even potential side effects, such as new-onset atrial fibrillation. The benefit of EPA seems to be dose-dependent, but higher doses may come with more side effects. While the American Heart Association encourages fish consumption for overall heart health, studies indicate that EPA in fish oil supplements can help lower several important CV risk factors, including arterial calcification, high blood pressure, and elevated triglycerides. From reading the literature 1000mg of EPA daily seems to be at the threshold before AF occurs.

- **VegEPA** is a popular food supplement which helps many people with ME/CFS. The is approximately equivariant to two Veg EPA capsules daily. The manufactures recommend a much higher starting dose than this. See the feature on VegEPA in Pathways 78
- **Icosopentyl Ethyl (Vazkepa)** is a prescription medicine used to lower blood triglycerides as protection against strokes and heart attacks. Each capsule contains 998 mg of EPA.

There are many other fatty acid food supplement supplements available containing EPA and DHA

### What is Atrial fibrillation ?

Atrial fibrillation is a heart condition that causes an irregular and often abnormally fast heart rate. A heart rate should be regular and between 60 and 100 beats minute when you're resting. You can measure your heart rate by checking your pulse in your wrist or neck.

**Symptoms of atrial fibrillation:** In atrial fibrillation, the heart rate is irregular and can sometimes be very fast. In cases, it can be considerably higher than 100 beats a minute. This can cause problems including, shortness of breath tiredness. People may be aware of the heart, where you feel like it's pounding, fluttering or beating irregularly, often for a few seconds or, in some cases, a few minutes. Sometimes atrial fibrillation does not cause any symptoms and a person who has it is unaware that their heart rate is irregular. Many medical devices that can check your heart rate this include pulse oximeters, home blood pressure machine and with some mobile phone apps with an accessory.

The danger of atrial fibrillation is that it can cause damage to the heart muscle in the long term and lead to an increased stroke risk. Like many other medical condition if caught early enough the damage may be avoided. Management through medicines usually involve taking something to slow the heart rate down, controlling cholesterol levels and anticoagulants of control the stroke risk. However, some people may need a pacemaker type device.

People with ME/CFS have a faster heart rhythm than healthy people, and also are prone to abnormal heart rhythms due to ME/CFS affecting the nerves that control the heart. The most common cause is anxiety. Any persistent heart rate abnormalities need to be investigated by your doctor. Any sudden unexplained chest pain should be treated as a medical emergency via the 999 system.

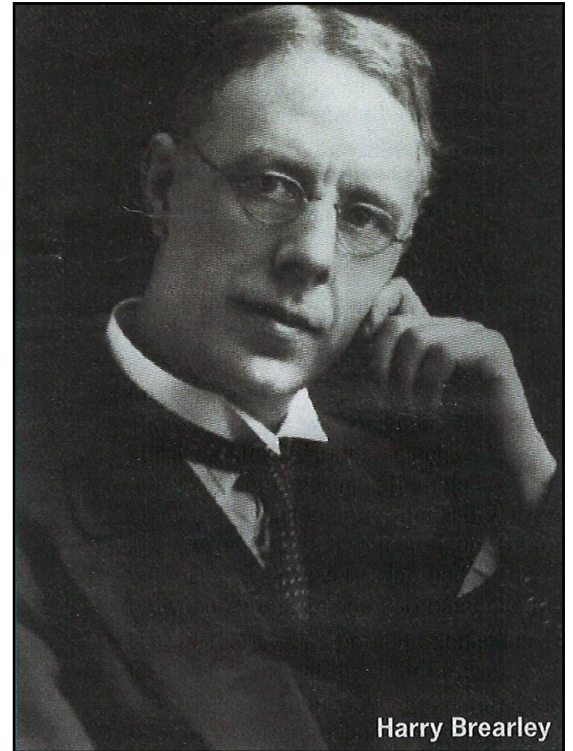
## **Local Historical Interest: How Sheffield Gave the world Stainless Steel**

*With thanks to Jon Howe and Tito*

Stainless Steel is everywhere in modern life, and it is hard to imagine a time when it didn't exist, except that we only have to look back 111 years. Iron has been in existence for thousands of years, but stainless steel is a relatively recent discovery that has subsequently revolutionised modern life. There is plenty of conjecture over who discovered stainless steel. Various scientists around Europe and the USA were making attempts to create a type of steel that didn't deteriorate and was more durable. They experimented with iron and chromium alloys, but the key discovery was finding the right balance between chromium and carbon content.

Harry Brearley was born in Sheffield in 1871 and was lead researcher at the Firth Brown Laboratories deep in the city's famous industrial sector. He was tasked by a small arms manufacturer with finding a solution to the problem of gun barrels eroding. Harry tried several variations of chromium content, ranging from 6 to 15%, but one day discovered that a low carbon content was the critical factor, albeit he was actually attempting to find a steel that didn't erode, rather than one that didn't corrode.

Nevertheless, on August 13th 1913, Brearley's latest attempt used a 12.8% chromium and 0.24% carbon alloy, and this produced a metal he found was resistant to both corrosion and rust. It resisted chemical attack Harry Brearley was being used to store nitric acid, produce surgical implants and even to brew beer. Stainless steel very quickly started to outperform copper and aluminium. There are now over 100 grades of stainless steel commercially available, and it is used for a wide variety of applications in building, healthcare, catering and the automotive industry. Harry Brearley wanted to call his from nitric acid, and also from vinegar and lemon juice. However, Brearley struggled to obtain any support from his employer and went to rival cutlers to develop the idea.



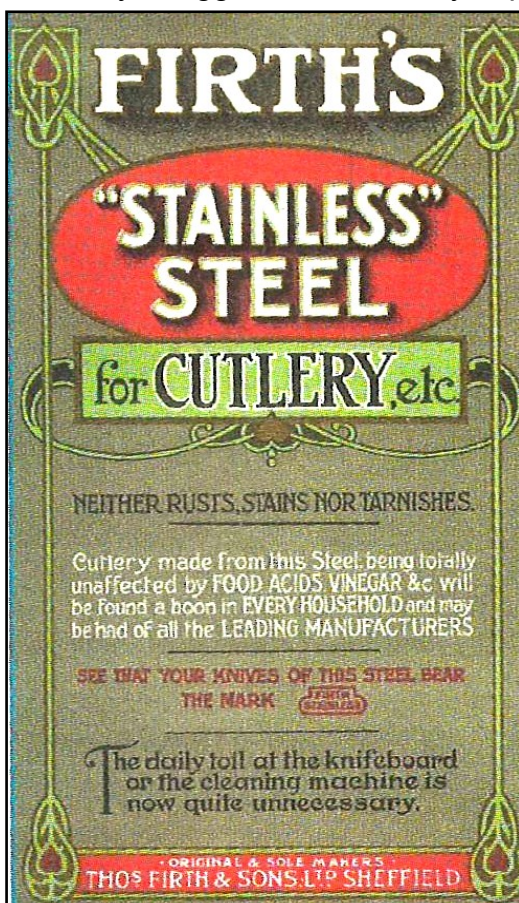
Harry Brearley

The discovery spread rapidly and other variations were quickly developed to create stainless steels with differing qualities. Stainless steel was patented in 1919, and by 1925 Sheffield manufacturers were producing surgical tools and cutlery, and within five years stainless steel was being used to store nitric acid, produce surgical implants and even brew beer.

Harry Brearley wanted to call his discovery 'rustless steel', but it was his old school friend Ernest Stuart, who worked at Mosley's Portland Works in Sheffield, who came up with the name 'stainless steel' after he left Brearley's material soaked in vinegar overnight and no stain was produced. So, while many people may argue about who actually developed the stainless steel we use today, there can be no doubt that Harry Brearley developed the material that was first called stainless steel.

Stainless steel very quickly started to outperform copper and aluminium. There are now over 100 grades of stainless steel commercially available, and it is used for a variety of applications in building, healthcare, catering and the automotive industry.

*Might have been a different story had they used salt and water as salt corrodes some grades of stainless steel.*



## The Blue Badge Scheme

Nearly every Leger ME member is entitled to a Blue Badge which helps you to park closer to your destination and get other benefits like free parking in certain places. The badge costs £10 for people in England and £20 in Scotland. It is free in Wales, and whichever country you apply from the badges usually last three years. There are two pathways to get a Blue Badge:

A Blue badge of right is available on application if you meeting one of the following criteria

- you receive the higher rate of the mobility component of the Disability Living Allowance (DLA)
- you receive a Personal Independence Payment (PIP) because you can't walk more than 50 meters (a score of 8 points or more under the 'moving around' activity of the mobility component)
- you are registered blind (severely sight impaired)
- you receive a War Pensioners' Mobility Supplement
- you have received a lump sum benefit within tariff levels 1 to 8 of the Armed Forces and Reserve Forces (Compensation) Scheme and have been certified as having a permanent and substantial disability that causes inability to walk or very considerable difficulty in walking
- you receive the mobility component of PIP and have obtained 10 points specifically for descriptor E under the 'planning and following journeys' activity, on the grounds that you are unable to undertake any journey because it would cause you overwhelming psychological distress
- People may also be eligible for a badge if one or more of the following applies:

If you don't qualify for a Blue Badge of right, you may qualify for a Discretionary blue badge if the following applies.

- you cannot walk at all
- you cannot walk without help from someone else or using mobility aids
- you find walking very difficult due to pain, breathlessness or the time it takes
- walking is dangerous to your health and safety
- you have a life limiting illness, which means you cannot walk or find walking very difficult and have a SR1 form
- you have a severe disability in both arms and drive regularly, but cannot operate pay-and-display parking machines
- you have a child under the age of 3 with a medical condition that means the child always needs to be accompanied by bulky medical equipment
- you have a child under the age of 3 with a medical condition that means the child must always be kept near a vehicle in case they need emergency medical treatment
- you are constantly a significant risk to yourself or others near vehicles, in traffic or car parks
- you struggle severely to plan or follow a journey
- you find it difficult or impossible to control your actions and lack awareness of the impact you could have on others
- you regularly have intense and overwhelming responses to situations causing temporary loss of behavioural control
- you frequently become extremely anxious or fearful of public/open spaces



Your local council decides whether or not you are entitled to a Blue Badge, and you can apply through your local council. Arrangements vary area to area, but in Doncaster applications are mainly online. You are able to apply for a badge yourself or can make an application on behalf of someone else or an organisation.

The discretionary Blue Badge for our members is usually for people of pension age who receive Attendance Allowance. Normally if you have had a recent case review done through Leger ME; we will prepare a support letter which can be used as supporting evidence for your application. On rare occasions people are asked to attend a medical examination. For further information please contact the Leger ME office.

## ***Medicine Matters: The effect of sea kelp on thyroid function in hypothyroidism***

Hypothyroidism is a common condition caused by an underactive thyroid, resulting in deficiency of the thyroid hormones thyroxine (T4) and tri-iodothyronine (T3). This results in reduced metabolism rate, affecting multiple functions in the body. Symptoms of hypothyroidism usually develop gradually over time and can seem very general. They include:

Fatigue; Constipation; Weight gain; Depression and reduced libido; Numbness and tingling sensation in hands; Inability to tolerate cold temperatures; Dry skin and hair. *(Many of these symptoms overlap with those of ME/CFS)*



Hypothyroidism is a result of thyroid hormone deficiency. Unless there is a secondary cause (e.g. tumour) that needs surgical intervention, this hormone deficiency is usually treated with a medication. In the UK, levothyroxine is the most commonly used medication to correct this deficiency. Treatment is usually lifelong to allow the body to normalise the amount of thyroid hormone continuously. The dose can vary over time and is usually monitored and adjusted according to the thyroid function tests.

Furthermore, iodine-containing herbal supplements available over the counter in herbal shops will impact thyroid function. Examples of these nutraceuticals include sea kelp, carnitine, inositol, melatonin and resveratrol. Patients with thyroid dysfunction, whether hyperthyroidism or hypothyroidism, need to be made aware of the significant impact iodine-containing products can have on their thyroid profile.

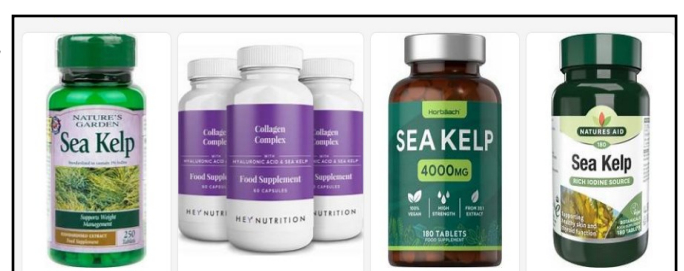
### **Supplementation with Sea Kelp**

Sea kelp is the name given to the collection of brown seaweed species Laminariales. Owing to their iodine content, kelp formulations are promoted as a way to manage thyroid deficiency and promote weight loss. Herbal supplements are often considered safe by the public as they are thought to be 'natural', but they can interact with other medicines.

According to the British Dietetic Association and the European Food Safety Authority (EFSA), the recommended daily intake of iodine is 150 micrograms in adults (increasing to 200 micrograms in pregnant or breastfeeding adults). Iodine is present in a range of foods and is particularly rich in dairy products, milk and fish. The concentration of iodine can vary within different seaweed products and can occasionally lead to excessive iodine intake. The average Laminaria-based supplement contains up to 1,000 micrograms of iodine. Ingestion of iodine at daily levels exceeding 150 micrograms has the potential to cause thyroid disorders.

**An example case.** A lady aged 50 years presents for a structured medication review (SMR) with the clinical pharmacist. She is taking a total of 19 medicines for multiple comorbidities: hypothyroidism, fibromyalgia, post-traumatic stress disorder (PTSD) and urinary incontinence. She has no significant medical family history but reports the loss of her sister and nephew in the Grenfell Tower fire in 2017, which has significantly affected her mental health. On further questioning, the patient complains of a general history of fatigue, weight gain, constipation, dry skin, muscle aches and low mood. The patient has been making a concerted effort to lose weight but is, in fact, gaining weight.

Three months before the review, the patient visited Egypt and sought medical guidance for management of weight gain and low mood. She was advised by a medical practitioner in Egypt to start on sea kelp supplements. At this point, she started on sea kelp tablets and has been taking three tablets daily for the past three months. She has remained compliant with the levothyroxine dose previously prescribed for her hypothyroidism. Each sea kelp tablet contains 150



*Sea Kelp food supplement's are available from many health food suppliers.*

micrograms of iodine; therefore, 450 micrograms of iodine are being ingested daily by the patient.

The ladies symptoms are consistent with hypothyroidism but also overlap with her history of PTSD and fibromyalgia. She was diagnosed with uncontrolled hypothyroidism aggravated by ingestion of sea kelp, a herbal supplement high in iodine content. It was clear that the daily iodine intake of the case study patient exceeded the daily recommended intake and has adversely affected her thyroid function. The lady discontinued sea kelp supplement. As the same time she was advised that weight loss would be a struggle with uncontrolled hypothyroidism. She continued with the same dosage of levothyroxine.

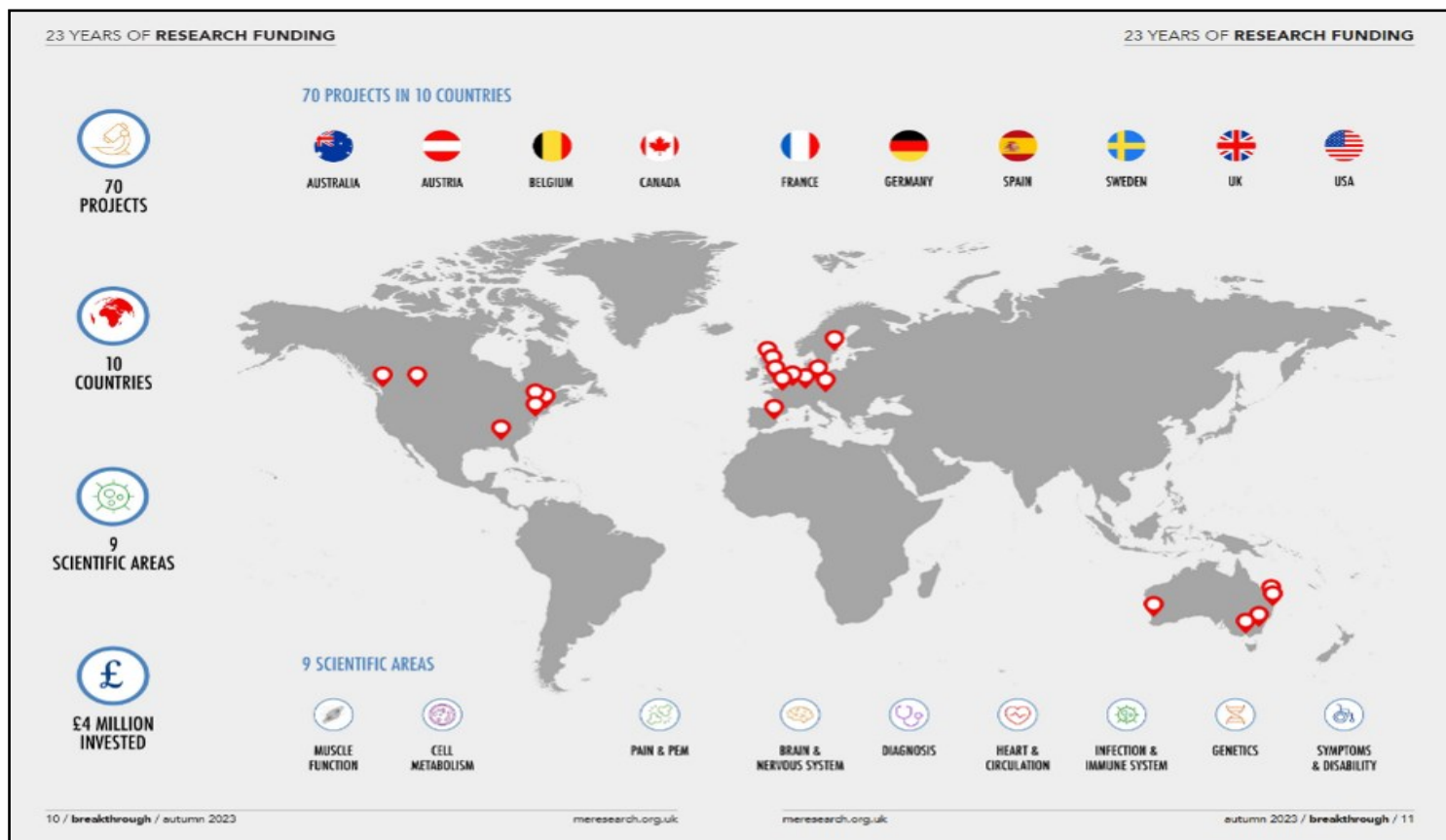
At 16 weeks, the her blood test results reflected the significant impact sea kelp discontinuation had on her TSH. Her TSH was almost reversed eight-fold and approaching normal levels. The patient reported that her dry skin had improved vastly, along with her ability to exercise as she was feeling less fatigued. She had lost some weight but was not happy with her progress. Unfortunately, her history of PTSD and fibromyalgia along with her commitments as a full-time carer to her autistic son hindered her ability to include more exercise in her lifestyle.

Although sea kelp supplements are widely available, the adverse effects on thyroid function are not clearly publicised on the packaging. It is a common patient misconception that herbal products are safe because they are 'natural' and lack any side effects; therefore, it is vital to ask patients about their consumption of prescribed medications, over-the-counter products and herbal remedies.

In this case, the consumption of sea kelp and consequent excessive daily intake of iodine proved to negatively impact the patient's thyroid function, resulting in overt hypothyroidism.

### Take home messages

- If you have ME/CFS avoid Sea Kelp and any other Iodine rich food supplement/
- Be aware that doctors abroad very often do not have the expertise that the UK Health Service has
- Always tell you doctor if you are taking any food supplements as they can interfere with conventional medicines.
- So called nutraceuticals (naturally occurring medicines) are not always safe.



**Don't Confuse ME/CFS and Cancer.**

*With thanks of Cancer Research UK*

Fatigue is a common symptom of Cancer. We know that the fatigue of ME/CFS is indistinguishable from that of some Cancers. It is important that any new symptoms are reported to your doctor and checked out. Cancer is much more common in people over 50, but it can affect anyone of any age. If something looks or feels unusual, remember – you're in charge. In most cases it won't be cancer, but if it is, finding it at an early stage can make a real difference.

Take charge. You might be reading this feature because you'd like to know about spotting the symptoms of cancer. Perhaps someone you know has had it, or maybe you're just curious. Whatever your situation, you'll find information about when to talk to your doctor, tips for getting the most out of your appointment, and some key facts about screening.

**None specific Cancer Symptoms**  
(but are not always cancer)

- Unexplained bleeding (rectal, vaginal, bruising);
- An unusual lump or swelling anywhere on the body;
- A sore that does not heal — skin or surface symptoms;
- Unexplained weight loss;
- Very heavy night sweats;
- An unexplained pain or ache;
  - Appetite loss;
  - New Fatigue;
  - Pruritis (Itching).

## Listen to your body

You know your body best, so take action if something doesn't look or feel quite right or won't go away. And don't assume unusual changes are down to 'just getting older', or part of another health condition.

Long-lasting heartburn or indigestion

Unusual breast changes such as any change in the size, shape or feel of a breast, including any nipple or skin changes

A change in bowel habit, such as constipation, looser poo or pooing more often

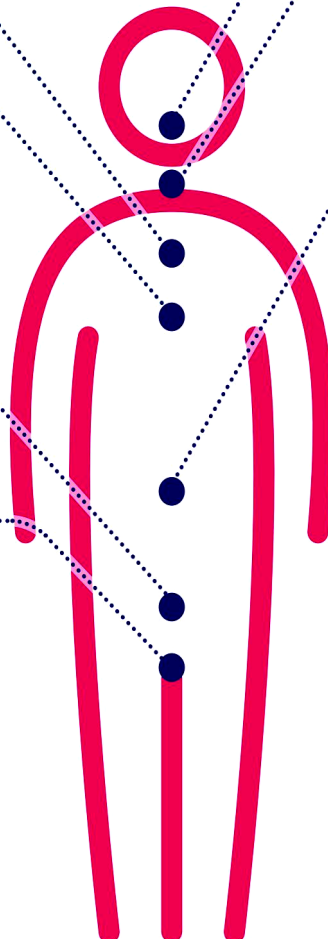
Persistent bloating

Unexplained vaginal bleeding, including after sex, between periods or after the menopause

Blood in your poo (stools)

Blood in your pee (urine)

Problems peeing



Croaky voice or hoarseness that won't go away  
Mouth or tongue ulcer that lasts longer than three weeks  
Coughing up blood  
Persistent cough

Breathlessness  
Difficulty swallowing

Very heavy night sweats  
A sore that won't heal  
Appetite loss  
Unexplained weight loss  
A new mole or changes to a mole  
An unexplained pain or ache  
An unusual lump or swelling anywhere on your body  
Fatigue (feeling more tired than usual)

**If you do notice any of these symptoms, or something else unusual, it's good to talk about it, so make an appointment to chat to your doctor.**

## Talk to your doctor

When you're worried that there's something wrong, telling a doctor can seem difficult.

Here are some ideas for how to get the most out of your appointment, whether it's via phone, video or a face to face conversation.



**Be honest.** Tell the doctor about anything unusual, even if it doesn't seem that important or you think it might be a bit embarrassing.



**Be thorough.** Mention all your symptoms and don't put it down to 'just getting older', or another health condition. If it's something that's bothering you, then your doctor will want to hear about it.



**Stick with it.** Don't worry you might be wasting your doctor's time. Even if you've spoken to them already, they want to know if your symptoms haven't gone away, or if something still doesn't feel quite right.



**Be prepared.** Think about how to describe any changes and how long you've had them for. Writing down what you want to say can help. It can also be useful to have a list of any medications that you take, including over-the-counter or herbal remedies.

**Experienced any of the listed symptoms? You could highlight or circle them on the previous page and show it to your doctor.**

## Look out for your screening invitation

Screening is for people who don't have any symptoms. There are three national cancer screening programmes in the UK: breast, bowel and cervical.

To be invited for screening, you need to be registered with a GP. When you receive your screening invitation, you'll also be sent information about the screening test. It's important you read this, so you can decide if you'd like to take part.

People become eligible for the different screening tests at different ages. Visit [cruk.org/screening](https://cruk.org/screening) for more information.

Even if you've been screened, and no matter what age you are, it's important to tell your doctor if you notice anything that's not normal for you.

## Early diagnosis saves lives

What if it is cancer? When cancer's spotted at an early stage, treatment is more likely to be successful. Thanks to research, treatments are now kinder and more effective than ever. And survival is on the up.

## How to find out more

### We're online...



Find out more about spotting cancer early, including information about cancer screening across the UK, at [cruk.org/spotcancerearly](https://cruk.org/spotcancerearly)

### ...and on the phone



Our Nurse Helpline is there if you're looking for information or support. Just call **0808 800 4040**.

If you'd like to provide any feedback on this leaflet or would like to know more about the information sources used in creating it, please email [publications@cancer.org.uk](mailto:publications@cancer.org.uk)

And if you have any questions about Cancer Research UK or would like to support what we're doing, you can call **0300 123 1022**.



**CANCER  
RESEARCH  
UK**

Together we will beat cancer



## Recipe Corner

### Cauliflower Stir Fry

This tasty dish is ready in only 30 minutes and makes the perfect midweek meal option for one. When prepared as written this recipe is low fat, low sugar, vegetarian and vegan. The quantities are suitable for one person. The preparation time is 15 minutes, and the cooking time is 15 minutes

#### Cooking Method

- 1) Heat a small frying pan and dry-fry the sesame seeds for 1–2 mins until lightly browned and fragrant. Set aside.
- 2) Add the oil, onion and leek to the pan, cover and cook over a very low heat for 5 mins, stirring frequently until softened. Add the garlic and ginger. Cook for a further 1 min.
- 3) Give the cauliflower a good spray with 1cal oil, at least 5-6 pumps, and to the onion pan with 3tsp water. Cook over a medium heat for 5-6 mins, stirring occasionally, until the florets start to brown.
- 4) Add the Tabasco or Sriracha, stir in and cook for a further 1 minute. Spoon into a bowl, scatter with spring onion, coriander and sesame seeds, and serve.
- 5) Enjoy !

### Green Thai Fish Curry

This flavourful dish makes a great healthy dinner option. When prepared as written this recipe is dairy free, low in fat and low in sugar. The preparation time is 10-15 minutes, and the cooking time is 15 minutes. The quantities are suitable for one person.

#### Cooking Method

- 1) Reserve a few leaves of coriander for garnish and then place the remainder, including stalks, into a food processor. Add the green chillies, spring onion, root ginger, lemongrass, garlic, ground cumin and coriander. Blend to a coarse paste.
- 2) Heat the oil in a wok or large saucepan, add the green beans and stir fry for 2–3 minutes. Add the curry paste, coconut milk, soya milk and salmon. Bring to the boil, cover and simmer for 5 minutes.
- 3) Scatter over the prawns, baby spinach and lime zest. Serve with extra lime wedges to squeeze over.
- 4) Enjoy !



#### Ingredients

1½ tsp sesame seeds  
 1 small onion, thinly sliced (approx. 60g unpeeled)  
 1tsp rapeseed oil  
 60g leek, thinly sliced  
 1 clove garlic, crushed  
 1tsp freshly grated ginger  
 250g cauliflower florets  
 5-6 sprays 1cal oil  
 1tsp Tabasco or other hot sauce  
 1tbsp spring onion, finely chopped  
 1tbsp coriander, torn



#### Ingredients

30g pack fresh coriander  
 3 green chillies, trimmed  
 6 spring onions, trimmed  
 2inch piece fresh root ginger, peeled and chopped  
 2 lemongrass stalks, trimmed and chopped  
 3 garlic cloves  
 1tsp each ground cumin and ground coriander  
 2 limes, finely grated zest and juice  
 1tsp olive oil  
 200g fine green beans, trimmed  
 2 skinless salmon fillets, about 260g, cut into chunks (or firm white fish)  
 200ml light coconut milk  
 250ml unsweetened soya milk  
 200g cooked jumbo prawns  
 75g baby spinach leaves

## **CFS Treatment Checklist by (Dr) Sarah Myhill**

*(Dr) Sarah Myhill is a former GP who has for many years supported people with ME/CFS. While conventional medicine does have very much to offer is the line of treatment Sarah offers a Naturopathic approach which seems to help. This feature is abridged from her Website [www.drmyhill.co.uk](http://www.drmyhill.co.uk).*

Chronic fatigue syndrome is not a diagnosis - merely a group of symptoms which may have many causes. By the time someone has been ill for several years there are often several causes. The best results are obtained by identifying as many different causes as possible and tackling them all at once. Known disease processes must first be considered. By the time people come to see me they have already had a series of blood tests. If you have not had tests done recently, then I recommend doing the disease screening group of tests.

I used to do things one at a time in order to see what does and does not work. I now do things the other way round - treat everything I think to be important, get the patient better, then relax the regime to end up with a balance between the patient's wellness and the toughness of the regime. Indeed, there is now good evidence that mitochondrial failure is not just a part of chronic fatigue syndrome – it is also part of the normal ageing process. What this means in practice is that as we get older, we can stay just as fit and just as well but we have to work harder at it and become more disciplined with respect to diet, sleep, micronutrient supplements, the right balance between work and rest, detox regimes and so on. The following is the program of treatment I go through with every patient. If I try to cut corners, I often end up missing important problems. The patient who thinks about their illness and works out things for themselves has the best chance of getting better. I can point you in the right direction, but you have to do the donkey work! I suggest you print this checklist out and use it to find your way round the website! It lists the things I need to think of in the management of CFS.

Don't go on to the next stage until the earlier ones have been fully explored.

*Note: Before considering this list, please ensure that if you have another known chronic condition e.g. asthma, diabetes etc. is fully treated and controlled ed.*

### **Stage 1: Make Sure It's CFS**

#### *Primary or secondary fatigue?*

Is the diagnosis right - has known pathology been excluded? e.g. cancer, MS, autoimmune disorders.

The two symptoms which are common to every case of chronic fatigue syndrome/ME are poor stamina and delayed fatigue. These are explained by mitochondrial failure. CFS - The Central Cause: Mitochondrial Failure. Indeed, it is the delayed fatigue which should determine how much or little you can do in a day. If you get fatigue the next day then you have overdone things and must pace more carefully. Actually, this is true for everybody – athletes who do not observe this rule develop overtraining syndrome and worsen their performance.

Have a careful think about what caused your CFS as this will give a guide to treatment. Think about the time building up to the start of the illness, what the trigger was, which illnesses run in the family?

CFS is a diagnosis of exclusion. Tests to exclude serious disease may be helpful, but even if they are all normal, you could still have other serious disease. The opinion of a good physician should always be taken to make the diagnosis. Recent onset of symptoms which may be worsening would suggest serious underlying disease.

## Stage 2 - Observe six fundamental rules

- 1) Pacing: adopt the 80% rule (which means: know what you are capable of in a day and do just 80% of that. 20% is "getting better" energy), get enough mental and physical rest. Get organised. Accept help. Arrange for deliveries to house. Delegate work. Prioritise: list the 10 most important things in your life, then ignore the last five. You can't do everything. Getting enough rest is an essential part of managing CFS.
- 2) Sleep: quality sleep is essential to life. Don't be afraid to use tablets to restore the normal day/night diurnal rhythm. Sleep disorders. Avoid caffeine after 4pm as it will interfere with sleep. Sleep is vital for good health - especially in CFS.
- 3) Supplements: It takes at least 6 months for body stores to replete. Supplements are for life. Everybody, regardless of whether they have chronic fatigue syndrome or not, should take a basic package of nutritional supplements. This is because Western agriculture has resulted in food which is deficient in essential micronutrients. We then have what I call the "bolt-on extras" for specific problems. For people with fatigue syndromes there is a package of supplements to support mitochondria which one can either take empirically or, ideally, do the mitochondrial function test first to define this further. The Central Cause: Mitochondrial Failure.
- 4) Diet: the two dietary problems most often linked to fatigue are a tendency to hypoglycaemia and allergy. The starting point is always the Ketogenic diet.
- 5) Avoid infections whenever possible. At the first sign of a cough, cold or sore throat use vitamin A (not if pregnant), vitamin C, zinc, selenium and propolis. If you don't believe you could have any deficiencies, then do the disease prevention screening tests. Also see Infections: how to prevent and cure – first improve the defences.
- 6) Do a chemical clean up: throw out all the smellies in your house, keep the house well ventilated, avoid sprays, polishes, aerosols, new paints, new carpets, gas cookers and heaters etc.

Many of the above issues are covered in her book *The general approach to maintaining and restoring good health*. For most people this is the most difficult part of treatment and for many people all they have to do to recover! It is tempting to miss out the bits that entail major lifestyle changes and cherry pick the easier changes, but you will just cheat yourself in the long term!

## Stage 3: fighting and nurturing

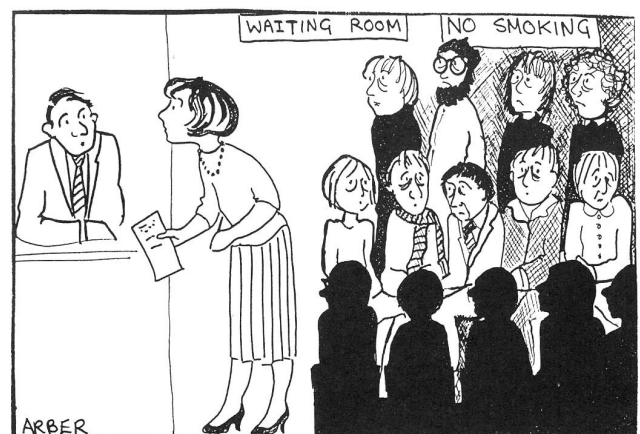
The interventions below need to be done over and above all the interventions listed in Stage 2 above.

At this stage you should consider the nutritional regime specifically designed to support your mitochondria.

Some interventions work for a high proportion of sufferers (B12 injections, magnesium injections, D-ribose, Coenzyme Q 10 etc.). Do as many of these things at the same time as you can. By the time you have been ill for several years, more than one thing will be wrong - you need to tackle them all at the same time to see improvement. The priority is to get well. Once you are better, these things can be knocked off one at a time to find out which is important.

The maneuvers to try, in order of importance, are:

- Feed your mitochondria - The Central Cause: Mitochondrial Failure
- Get magnesium levels checked. See Magnesium - treating a deficiency and Magnesium test - whole blood.
- Pain: This too is just a symptom - try to work out the cause.
- B12 injections: should be tried at some stage. Don't waste money measuring B12 levels, they are irrelevant. It is the response to injections which is important. See B12 - rationale for using vitamin B12 in CFS. Make sure you are on a multivitamin containing folic acid when you have injections.
- Correct hormonal disturbances: adrenal gland dysfunction, hypothyroidism. See Common Hormonal Problems in CFS - Adrenal and Thyroid - the correct prescribing of thyroid hormones. See also Adrenal stress profile - salivary and Thyroid profile: free T3, free T4 and TSH
- Gut symptoms: getting gut symptoms right is central to getting the CFS right. Consider Fermentation in the gut and CFS and Comprehensive Digestive Stool Analysis with parasitology.
- Care with female sex hormones. The Pill and HRT worsen CFS in the long term and certainly predispose you to getting CFS because they suppress the immune system and induce nutritional deficiencies.
- Low dose antidepressants: many CFSs do well on tiny doses of tricyclic antidepressants such as amitriptyline 10mgs, dothiepin 10mgs, trimipramine 10mgs at night. In these doses I would not expect much effect on depression.
- Chronic low grade undiagnosed infection. See CFS - can be caused by chronic infection, Chronic viral presence in CFS/ME, Valacyclovir in the treatment of post viral fatigue syndrome, and Lyme Disease and other Co-infections. Also see Chronic infection – Life is an arms race – how to tackle with natural remedies and My book The Infection Game - life is an arms race
- Hyperventilation can cause fatigue. Often driven by food intolerance and low magnesium levels. Helped by relaxation techniques. See Hyperventilation - makes you feel as if you can't get your breath.
- Chemical poisoning: exposure at work to organophosphates (farmers), dog and cat flea treatments, human head lice treatments, Vapona fly blocks/sprays, woodworm treatments. Contaminated water. Any silicone implants - Siliconosis? Gulf War Syndrome? Chemical poisoning often leads on to MCS.  
(Several of our members have got ME/CFS from leaking implants)
- MCS (Multiple chemical sensitivity) Suspect if symptoms are better out of doors, better in the summer, better away on holiday. Do chemical clean up. Eat organic where possible. See Multiple Chemical Sensitivity (MCS) - a common problem and often triggered by exposure to chemicals and Multiple Chemical Sensitivity (MCS).
- Consider Mercury - Toxicity of Dental Amalgam - Why you should have your dental amalgams removed.  
(Most NHS dentists do not agree with this.)



THERE'S A RUMOUR GOING ROUND THAT YOU WERE KIND TO SOMEONE WITH M.E .

## Stage 4: Allergy

If you are still struggling despite having tried all the above. Have you? Have you really honestly done it properly?!), then it is likely your problems are caused by multiple allergies to foods, to chemicals or to moulds.

Get mould allergy tested: either by skin tests or by going abroad to a warm dry climate, ideally for one month, but two weeks may give you an idea. Make sure that the holiday house is chemically clean. I know it is not easy, but it is important.

Consider Desensitisation such as Neutralization or my preferred technique Enzyme Potentiated Desensitisation (EPD) for foods and possibly chemicals. EPD does not work so well for mould allergy.

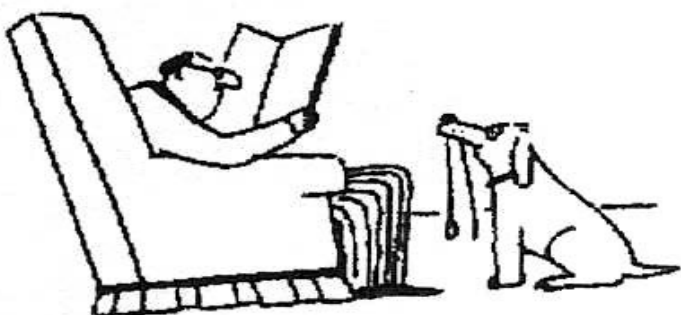
Consider Reprogramming the Immune System – where conventional and complementary medicine can come together.

Consider Mast Cell Activation Syndrome (MCAS)

## Stage 5: New ideas (The Exotic, Weird, Speculative and Spiritual)

*One of the problems with CFS is that it is a quack's charter! It is important to look at new ideas and treatments, but not before all the known, and tried and tested, treatments have not succeeded. Especially the psychological treatments should not be considered until the physical issues have been sorted.*

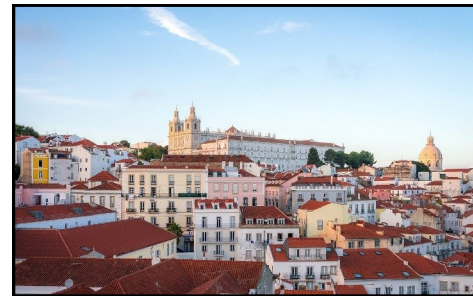
- Consider Reprogramming the brain in CFS/ME
- Consider Reprogram the immune system with micro-immunotherapy
- Consider Retroviruses in CFS/ME and more - think retrovirus when you get stuck.
- Having said that, there are some people who have benefited from the following:
- Healing:
- Geopathic stress:
- Immunovir - again some patients have reported improvement but it is too early to say if this is going to be useful.
- Gammaglobulin injections - I am uncertain about these - they do help some patients but they are derived from blood products and could theoretically transmit viruses and prions (BSE).
- Consider Hyperbaric oxygen therapy (HBOT).



## **Conference News Feature** *with Thanks to ME Research UK*

### **Brief Overview of 1st International Conference on Clinical and Scientific Advances in ME/CFS and Long COVID – Lisbon, April 2024**

Last week, ME Research UK attended, virtually, the “1st International Conference on Clinical and Scientific Advances in ME/CFS and Long COVID” held in Portugal. The conference spanned two days and featured talks by established ME/CFS researchers (several of whom have previously received funding from ME Research UK), as well as discussions with early career researchers. The presentations and discussions were informative and covered a wide range of topics, providing valuable insights into ME/CFS and long COVID in terms of history, epidemiology, biological findings, potential underlying mechanisms, diagnosis and management, and lived experiences.



Key themes and topics discussed included –

#### **History of ME/CFS**

The conference delved into the extensive history of ME/CFS resulting from infectious outbreaks and pandemics, such as the Akureyri outbreak in Iceland, the Royal Free Hospital outbreak in the UK, the Lake Tahoe outbreak in the US, up to the recent 2019 Coronavirus pandemic. Whilst each infectious outbreak/pandemic has unique symptom features, the similarities in resulting symptoms are even greater.

#### **Challenges in determining prevalence**

As a result of the COVID-19 pandemic, there is thought to be a considerable rise in ME/CFS cases, with many individuals with long COVID fulfilling ME/CFS criteria. However, longstanding difficulties in accurately determining the prevalence of ME/CFS were acknowledged, citing factors such as the mislabelling of ME/CFS as psychogenic, and underreporting in underserved communities, and amongst certain ethnic groups.

#### **Biological abnormalities**

A wide range of biological abnormalities were discussed, often overlapping in ME/CFS and long COVID research. These included cardiovascular abnormalities, neuropathy, disturbed metabolism, immune abnormalities, and potential mitochondrial dysfunction. Additionally, complications specific to COVID-19, such as myocarditis and pleural effusions, were addressed.

#### **Disease heterogeneity**

The conference highlighted the heterogeneity of both ME/CFS and long COVID, emphasising a need for subtyping to increase the reproducibility of research. Factors such as core symptoms, disease triggers, and disease stage were suggested for consideration in subtyping.

#### **Need for comprehensive clinical assessment**

The importance of comprehensive clinical assessment of individuals with ME/CFS was highlighted, emphasising the need for clinicians to manage major symptomatic aspects and to identify and treat all identifiable medical conditions (co-morbid and otherwise). Interventions for orthostatic intolerance and mast cell activation syndrome (MCAS) were described.

**1ST INTERNATIONAL CONFERENCE  
ON CLINICAL AND SCIENTIFIC  
ADVANCES IN ME/CFS  
AND LONG COVID**

**KEY DISCUSSIONS:**

**HISTORY OF ME/CFS**  
History of ME/CFS following infectious outbreaks, such as the Royal Free Hospital outbreak, up to the recent COVID-19 pandemic

**CHALLENGES IN DETERMINING PREVALENCE**  
Factors affecting prevalence estimates including the mislabelling of ME/CFS, and underreporting in underserved communities

**DISEASE HETEROGENEITY**  
The need for subtyping to increase the reproducibility of research

**BIOLOGICAL ABNORMALITIES**  
ME/CFS and long COVID research findings - cardiovascular abnormalities, neuropathy, disturbed metabolism, immune abnormalities, and potential mitochondrial dysfunction

**NEED FOR COMPREHENSIVE CLINICAL ASSESSMENT**  
The need to manage major symptomatic aspects and identify/treat all identifiable medical conditions

  
SC036942

## ***Long COVID information for patients from Tickhill Road Hospital Doncaster.***

With thanks <https://www.rdash.nhs.uk/documents/long-covid-information-for-patients/>

### **What is long COVID and how can it affect me**

Long COVID is being recognised widely as a long-term condition. It is diagnosed when symptoms which have developed during or after infection with COVID 19, continue for more than 12 weeks. There are many different symptoms of long COVID. Research is continuing to enhance our understanding of this condition. We know that symptoms can cluster and change over time. You are not in this alone. Long COVID is affecting large numbers of patients across the world. Although at this stage we don't have all the answers, we are seeing people make slow and steady recovery over time. We are here to support you through this journey.

### **What causes long COVID?**

The mechanisms which lead to long COVID are not yet fully understood. We know that the condition can sometimes lead to many of the body's systems being affected. The condition most commonly affects women, adults aged 35 to 69 years old and people with pre-existing health conditions.

### **Common symptoms of long COVID**

If the respiratory system is affected, you may be experiencing breathing difficulties at rest or when active. You may have noticed that you have developed a dry and persistent cough or a cough which produces secretions

- When the cardiovascular system is affected, you may notice a faster heartbeat and or palpitations. Usually, palpitations are not a cause for concern, but it is sensible to seek medical advice if you are concerned. Call 999 if the palpitations or a faster than normal heart rate are accompanied by chest pain, dizziness, or fainting.
- The neurological system can be affected, and you may experience brain fog, impaired concentration, short term memory problems, word finding difficulties and sleep disorders. Other common neurological symptoms include pain, headaches, visual disturbances and altered sensations such as numbness or pins and needles.
- Where the musculoskeletal system is affected, you may find that you have new joint and or muscle pain since having COVID or pre-existing pain such as arthritis could have been exacerbated by COVID.
- The digestive system can also be affected resulting in a loss of appetite, weight loss, nausea, acid reflux, abdominal pain, or diarrhoea.
- Psychological problems are common and may include anxiety, depression, or post-traumatic stress disorder (PTSD).
- Ear, nose and throat problems may include tinnitus, dizziness, ear pain, a sore throat, voice changes, loss of taste or smell.
- Dermatological problems can include skin rashes, itchy skin, and hair loss.

### **What kind of recovery can I expect?**

Most of the people we see make a good or full recovery from their symptoms. We find that treating and improving one or two of the key symptoms can often improve a number of other symptoms. Recovery isn't always linear. Symptoms can remit and relapse making recovery inconsistent at times. Symptoms can come and go and new symptoms can sometimes develop. What we know is that returning to work or physical activity too early in your recovery can sometimes result in a more prolonged recovery period. It is vital that we stress the importance of pacing yourself to prevent post exertional symptom exacerbation (PESE). Good breathing habits, pacing yourself, relaxation and maintaining a positive attitude are key factors which can help with your ongoing recovery.

## Fatigue

Fatigue can be a normal part of the body's response to fighting a viral infection. It is not uncommon for the fatigue to linger after the initial infectious period has ended. Primary fatigue is related to the pathology of the condition (virus), secondary fatigue is related to other factors/ triggers such as overdoing it. Post viral fatigue is different to everyday 'tiredness' and has been described as feeling as though 'someone has pulled the plug out on my energy'. Fatigue does not affect everybody in the same way and everyone's personal experience will differ. It is known to have an impact on day-to-day life including work and personal life, it can be unpredictable and is known to have periods of 'relapse and remit' in symptoms. Fatigue can impact us physically, mentally, and emotionally, affecting how we think, what we do and how we feel.

Fatigue is caused by an interruption to our nervous system. This is made up of two parts:

- central nervous system, which consists of the brain, spinal cord and nerves, this controls conscious actions i.e. reaching out to pick up a fork to eat your dinner
- the autonomic nervous system, controls 'automatic' processes in the body that we are not aware of, for example, blood pressure regulation, temperature regulation, breathing rate (among others)

Post viral fatigue is known to affect the autonomic nervous system which has two parts.

- Controls the fight or flight response, which causes issues with dysautonomia response (sympathetic nervous system).
- Controls the rest and digest response (parasympathetic nervous system).

These parts are usually fairly well balanced.

## What is dysautonomia?

Is felt to be responsible for triggering many of the symptoms of long COVID. The body remains in 'fight or flight' mode after the initial infection has gone. The body is almost on alert looking for any other 'dangers or threats' that may be coming and almost loses its ability to switch off and relax. This can throw many of the body's systems out of sync, for example, increased need to urinate, difficulty regulating body temperature, breathing pattern, heart rate etc.

## Post exertional malaise (PEM)

Is a marked rapid physical or cognitive fatigue in response to exertion and increased activity. Often a delayed onset can occur 24 to 72 hours after the activity and exertion, hence the importance of monitoring activity and fatigue levels. It can result in both physical and mental symptoms such as poor concentration, difficulty in thinking, flu like symptoms (muscle aches, pains, headaches, and sore throat). It can cause increased difficulty in sleeping and also orthostatic intolerances (issue balancing blood pressure and heart rate when standing upright).

## How to recognise fatigue onset

Good management of fatigue requires a variety of strategies in order to recognise any contributing factors and triggers. Common things that our service users report are:

- feelings of extreme tiredness or complete lack of energy
- inability to complete activities
- muscle aches and joint pains
- reduction in appetite
- mental fatigue, such as issues with concentration and memory (brain fog)
- difficulty communicating or word finding
- mood changes such as increase in anxiety levels or irritability



## Maintaining activity

All activities that we do are composed of many skills: physical, cognitive, psychological, and interpersonal. In everyday life, we often complete activities without having to really think about what we are doing. For us to complete what might seem like a ‘simple activity’, such as making a cup of tea, lots of different skills are required, all of which use up our energy to different levels.

## Use the 3Ps

Planning: how can you spread your activities out over the day and week?

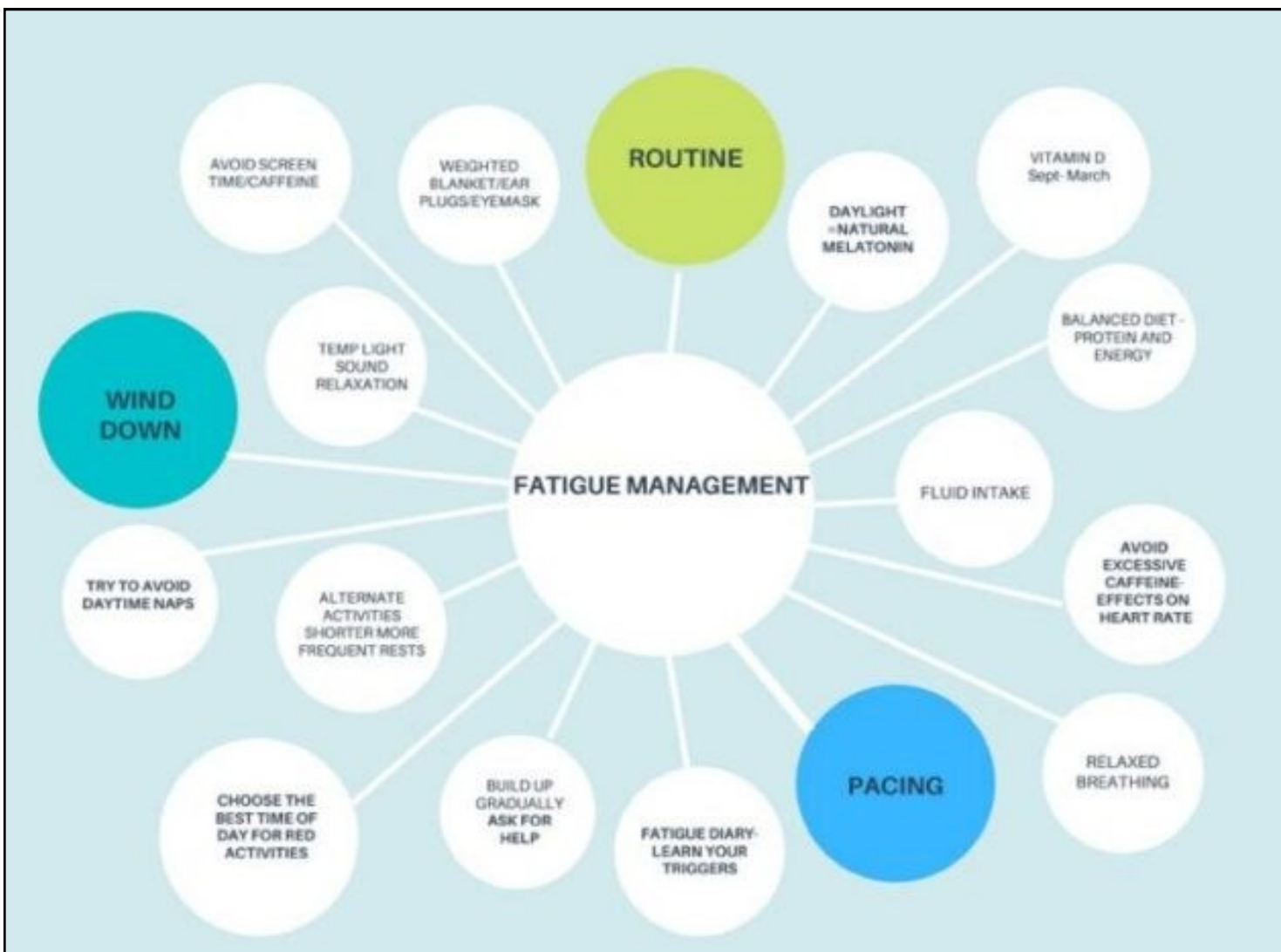
Can higher energy tasks be carried out at a different time? Thinking through activities before you do them, could they be done differently to make them easier and therefore less strenuous?

## Pacing

Looking at your diary and identifying how activities can be broken up rather than being done all in one go. Finding your baseline level (a level which you are comfortable at and can complete without fatigue) and ensuring that you have a middle ground of not doing too much or too little. Ensure that you incorporate rest periods in between activities to help ‘recharge’.

## Prioritising

- What is necessary and what could wait?
- What do I want to do today and what do I need to do today?
- Could the task be carried out by someone else could they help me?



**What you can do to help**

- Complete diaphragmatic breathing exercises.
- Mindfulness and meditation.
- Guided relaxation.
- Gentle exercise such as yoga and Tai Chi which is very useful for managing breathing.
- Other activities that you find relaxing, for example, listening to calming music.

**Fatigue patterns**

Fatigue is a common symptom following infection with COVID 19.

Fatigue can also be more significant if your body has become deconditioned due to being less active than normal. Inactivity can commonly cause stiff and painful joints and muscle weakness. If you are experiencing breathlessness or feelings of stress and anxiety, these factors can also increase your fatigue.

Fatigue can affect us in different ways, it can cause us to feel discomfort or pain, general weakness, anxiety, difficulty with memory and concentration, tearfulness and frustration. There are many things that you can do to help with your fatigue levels, but first it is helpful to know which activities may be triggering your fatigue in order to identify patterns. Some activities will require more exertion than others and it may be that these activities need to be spread out over your week to help you to pace yourself.

To give you an idea, some examples are below.

Red activities	Amber activities	Green activities
Taking a shower	Walking up and downstairs	Making breakfast
Vacuuming the house	Loading the dishwasher	Having a telephone conversation
Gardening	Driving	Cooking a meal
Jogging	Walking the dog	Attending an appointment

These are just examples, when you start to fill in your own diary and scores, you will build up a picture of the activities which have the most impact on your energy levels and which may be triggering your fatigue (these are your red activities). Once you can see this pattern and the triggers, try to space these red activities out over the week so that you reduce the amount of red activities you do in the same day or consecutive days. You may need to do the same with the amber activities, depending on your levels of fatigue.

*There is much more to download, about 30 pages in all. These can be downloaded from the TRH website.*

**So what's new?**

*Some veteran Pathways readers will notice that a lot of the strategies are borrowed from some of the NHS ME/CFS clinics. This is no coincidence. In fact quite a lot of long covid knowledge has been borrowed or hijacked from the ME/CFS world. I don't see any difference between Long Covid and ME/CFS. In fact I believe that they are variants of the same disorder.*

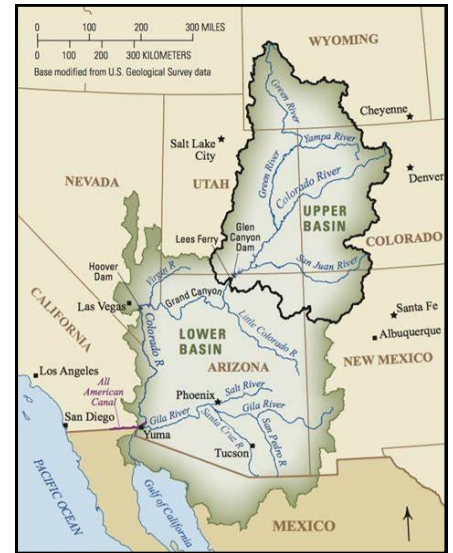
## North of Doncaster – Goes West -

*From the Travel Diary of Trevor Wainwright*

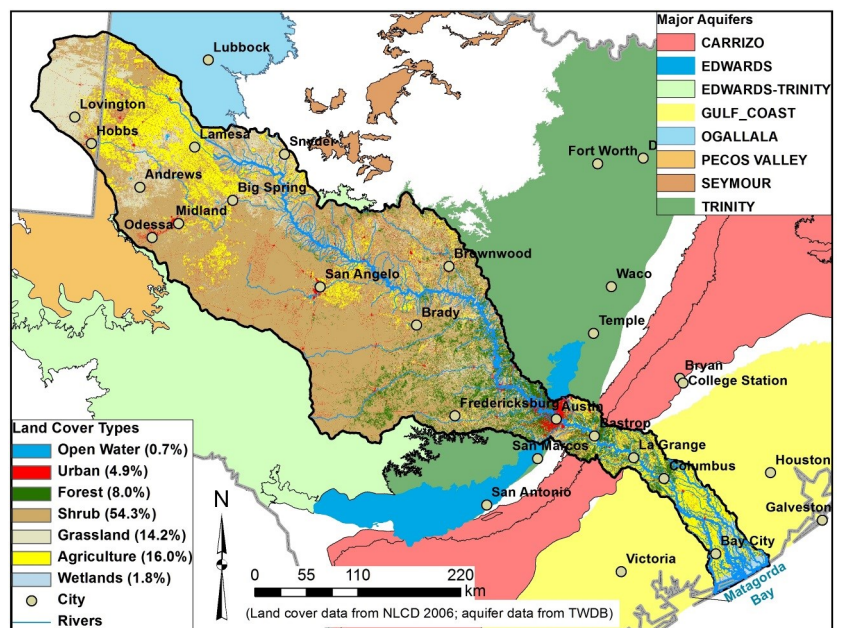
### The Colorado River in Texas

There are actually two Colorado Rivers in America hence the title. The first Colorado River is one of the principal rivers in the Southwestern United States and in northern Mexico.

The 1,450-mile-long river, the 5th longest in the United States, drains an expansive, arid watershed that encompasses parts of seven U.S. states and two Mexican states. Names after the state in which it begins its journey, La Poudre Pass Lake a small lake located in the Rocky Mountains of northern Colorado, finishing in the Gulf of California also known as the Sea of Cortés.



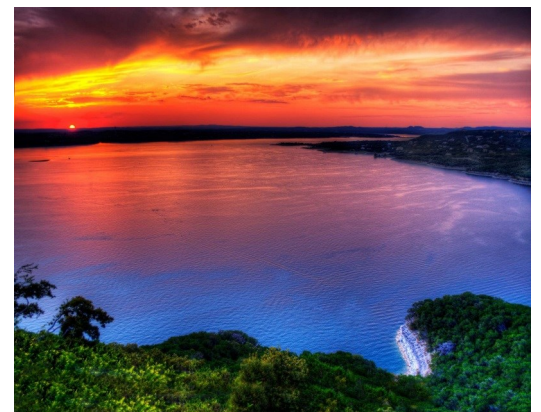
The second Colorado River is an approximately 862-mile-long river in the U.S. state of Texas. It is the 11th longest river in the United States and the longest river with its source, The Llano Estacado, sometimes translated into English as the Staked Plains, somewhat large as the source is 265 miles North West of the city of Llano before reaching the sea at Matagoda Bay between Galveston and Corpus Christie in the Gulf of Mexico.



So why are there two? It was just an accident of geography by unimaginative early Spanish explorers who didn't have (or make) accurate maps too well, and yes, some of them thought the two rivers named Colorado from Spanish meaning "Colour Red" referring to the rivers muddy colour. actually connected, but they don't and never did.

So, my article this issue is about the latter which is an important source of water for farming, cities, and electrical power production. Major man-made reservoirs, on the river include, Lake Travis, Lake Austin, and Lady Bird Lake in Austin. Collectively, these lakes are known as the Highland Lakes, all in the Austin area

Lake Travis named in honour of William B. Travis. Serving principally as a flood-control reservoir, its historical minimum to maximum water height change is nearly 100 feet. Uses also for



recreation with two well-known public areas.



The first of these is Windy Point a fun destination campground, camping is primitive—you can set up anywhere you want in the grass, trees, or waterfront—yet the groomed lawn and abundant shade trees help make it feel civilized with other facilities provided. A great place for families to spend time and play games Fishing is allowed for Largemouth bass, Grass carp, Bluegill, Blue catfish and White crappie.

Windy Point Park is also one of the top diving “hot spots” in Central Texas. Scuba instructors, recreation divers, and underwater freedivers enjoy the multiple entries and relaxed atmosphere.



Boats can be hired at various other sites and next to Windy Point is Bob Wentz Park, Dog-friendly gathering spot for swimming & picnics, with BBQs & a ramp for non-motorized boats.

Next to Bob Wentz Park is a wire fence separating it from Hippie Hollow the only legally recognized clothing-optional public park in the State of Texas. Hippie Hollow Park has been used as a nude swimming spot for years, because the area was along a particularly remote section of the shoreline of Lake Travis. The area became more popular in the 1960s due to the cultural changes of that era and, after Woodstock, the nickname 'Hippie Hollow' was born, with park usage restricted to those over 18. There is ranger cabin in the car park and the area is patrolled by rangers any wrong doers are swiftly removed.



As with the other areas, Hippie Hollow has washroom facilities and recycle bins situated at various points in addition there are nature trails.



I also where I saw my first road runner, and garter snake. And as with other areas is totally relaxed and friendly, a great place to get away from it all. It is not as open as Windy Point, a service road runs through it with numbered stepways leading down to the lake.

In the next issue we go to another tourist attraction on Lake Travis and a look at another lake.